Emotional functioning of patients before during and after radiotherapy treatment for cancer

by

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Chapter 1

Introduction

We are not ourselves

When nature, being oppressed, commands the mind

to suffer with the body[1]

Cancer is a major cause of death throughout the world with approximately nine million new cases diagnosed annually and five million deaths per year (Koroltchouk 1994). Statistically, more than a quarter of a million people in the UK are diagnosed with cancer each year. It is estimated than one in three people will develop cancer during their lifetime and the incidence of cancer increases with age, with 70% of all new cancers being diagnosed at ages over sixty (Cancer Stats. 1995).

Cancer is more quickly detected, more treatable and is more openly discussed than ever before. However the word 'cancer' is still associated with dying, pain and loss of hope. Today a cancer diagnosis does not automatically mean a death sentence but it can inflict an emotional burden on patients which for some results in psychological illness. "Psychological Factors in Illness and Recovery" is the title of a paper by Clarke (1998) in which epidemiological factors show the interaction of psychology and physical disease. These are reviewed together with the cost to the health services. This article explains how psychological factors do significantly affect outcome and the author calls for more research into this area. If time is taken in assessing patients for psychological distress, the length of time in hospital is shortened and recovery is quicker.

How do people cope with the news that they have cancer? Initially patients go through a period of distress in which they experience many emotions. These feelings can include both emotional and cognitive processing as to what cancer means to them, (Moorey, 1990). Cancer care has now incorporated these constructs and has moved from the strictly biomedical model into a much broader format incorporating psycho-social aspects.

The most common psychological responses of cancer patients are anxiety and depression (These will be further discussed in Chapters 2 and 3). Depression is the classic response to loss as is anxiety to danger (Hughes 1991). These are normal responses provided that they are

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[1] Shakespeare, William, King Lear, 11, iv,105-107

not unduly severe or prolonged. However, if anxiety and or depression are abnormally high, they can interfere with patients' quality of life, decision-making and compliance and, accordingly, can affect survival (Massie & Holland, 1990).

Treatments for cancer can cure or prolong life substantially. However, they too can cause a number of physical and psychosocial problems. Radiotherapy is one of the treatments for cancer. It can be used alone or in conjunction with surgery and or chemotherapy. It is used both radically to cure, and, palliatively, to alleviate symptoms.

Approximately 50-60% of all cancer patients receive radiotherapy (Crosson 1984). The principle aim of radiotherapy is to stop the spread of cancerous cells to the surrounding tissue or to treat where the tumour is inaccessible. Radiation alters body cells so that they are either destroyed or cannot reproduce. Cancer cells tend to be more radiosensitive than normal tissue. This sensitivity, however, depends on the origin of cancer as each cell type varies.

Radiation treatments vary considerably. A number of different factors need to be considered when assessing the patient for treatment. Is the treatment radical or palliative? What is the age and physical condition of the patient? What is the histology report on the tumour and where is this tumour situated?

With radical patients, treatment is spread out over weeks to allow normal tissue repair and also to try and prevent, or rather minimise, permanent physical injury. For palliative patients, treatment can be a single treatment or multiple treatments over weeks. Radiotherapy involves a careful balance so that the cancer cells are killed while the normal cells remain relatively intact.

Radiation does, however, affect both healthy and malignant cells so that it can cause a number of unpleasant side-effects. These include skin irritation, hair loss, lack of appetite, nausea and vomiting, sterility, reduced bone marrow function and extreme tiredness. For some patients, these side-effects are disturbing and anxiety can further rise (Andersen et al, 1984). However, not all the medical profession acknowledge this problem. Neither are the patients always educated in what to expect during their treatment and after it has finished.

Just the thought that one is experiencing radiotherapy can cause nausea and vomiting as exhibited in what would be considered an unethical experiment today, carried out by Parson et al (1961). They found that 75% of patients receiving 'sham' radiotherapy experienced fatigue and nausea. This study highlights how the mind and body can interact.

What are the long-term effects of radiotherapy treatment, how long do patients suffer from these side-effects and how do patients feel during and after treatment? These aspects

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will be analysed in more depth in Chapter 2. Very few studies have looked at patients for more than two years, even though they may still be suffering from side-effects of radiotherapy. With regard to how patients feel after their treatment little has been done and without this information, it is impossible to assess how to organise help. The survivors in a Canadian study reported that psychological and social effects of cancer were of more importance than physical effects (Belec 1992). Can psychological distress be predicted post treatment on the basis of patients' scores prior to actual radiotherapy treatment?

Interventions to relieve distress have taken place and helped patients. Interventions can take many forms both psychologically and physically. Meyer & Mark (1995) showed the efficacy of a wide range of psychological interventions. Evans & Connis (1995) found that both cognitive behavioural therapy and social support therapy brought about a reduction of distress symptoms for patients undergoing radiotherapy treatment. The social support group, in particular, was still effective in reducing distress six months post treatment. Similarly adjuvant therapy has also been shown to be effective (Greer & Moorey 1997). Other studies have shown that survival can be extended. Faller et al (1999) found that

> "both coping and emotional distress had a statistically independent effect on survival among patients with lung cancer"
> (Faller et al 1999)

This sample size of one hundred and three was not big and the survivors numbered only eleven. Sheard and Maguire (1999) undertook meta-analyses on the psychological components of anxiety and depression to see if psychological interventions were effective. They found that

> "Group therapy was as effective as individual therapy and that anxiety was lowered more than depression. For those patients at risk or suffering from significant clinical distress, interventions had strong clinical effects".
> (Sheard &Maguire 1999)

Ross-Petersen et al (1998) studied the literature on psychosocial interventions and survival and found that psychosocial intervention had a real effect immediately after the intervention. They felt that there could be long-term benefits however all the studies had methodological flaws.

It is apparent that patients' psychological state needs to be ascertained so that appropriate interventions, if needed, can be arranged. How can this be done economically in the current atmosphere of cutbacks in the health service? One possible answer is by the use of reliable well-validated questionnaires that are cheap, easy to administer, use and mark.

Aims

The aims of this study were

- To observe, using questionnaires, the emotional functioning of patients attending a radiotherapy clinic before, during and five years after treatment has finished.
- To ascertain the times of greatest distress for patients.
- To identify factors that could indicate which patients are the most vulnerable to psychological morbidity.
- To find out what and how patients feel and need during this period
- To see if predictions can be made on the basis of psychological tests at simulation.
- To see if there are indicators for survival.

Accordingly, the results of this study will give a 'snapshot' view of the emotional distress incurred by patients before, during and after their radiotherapy treatment. It is hoped that guidelines to radiotherapy departments can be suggested, either in the form of further research in specific areas or in positive recommendations, so that the patient's quality of life can be improved during this stressful period.

Why?

All patients attending the radiotherapy clinic at Mount Vernon Hospital during the month of October 1993 were asked to participate.

Why a longitudinal study? To assess where patients' needs are. For example, Johnston (1980) in her study on anxiety found that patients did not generally peak in anxiety levels just before an operation but earlier. Patients needed, and thus gave themselves time, to adjust mentally to the anxiety of the operation. Therefore when do patients having treatment that lasts for weeks feel distressed? Does the distress occur when the treatment has finished and they are left unsupported having attended the hospital regularly for weeks or is it when they first attend for planning of their treatment. Do men and women react differently to their distress? Is age a factor? Breast patients tend to have more counselling available, so will this show in the results?

Why ask all patients?

It is known that radiotherapy can cause distress in patients (Holland et al 1979). Mount Vernon was in the process of opening a centre – the Lynda Jackson Macmillan Centre. One

of its aims was to alleviate distress in patients. With limited resources it is difficult to know which patients are in most need so that they can be treated in the most appropriate way.

A radiotherapy unit consists of radiotherapists, radiographers, nurses and other hospital staff who attend patients suffering from cancer and who need radiotherapy treatment. Staff involved in treating patients are not restricted to one particular cancer site – although breast patients predominate: neither are they restricted by age, gender or social class. The patients entering for treatment are a mixed cohort. The aim of this study was to look at this heterogeneous population being treated for radiotherapy during one specific calendar month by the same team of professionals. It would have been more satisfactory to continue the study for another month or more but financial constraints restricted this. The patients were regularly tested over a five-year span. Anxiety could change over time for the cancer patient. For example, those who have been hospitalised for a lengthy time and then return home or to work could be subject to higher anxiety levels. As already mentioned, radiotherapy can effect anxiety and depression. There are very few longitudinal studies to show how long these feelings continue. Similarly, there is a dearth of material about what patients think or want. Health carers tend to make assumptions about what they think the patient requires. This study should help a little in addressing these issues and ascertaining the needs of the patients.

Questionnaires were given instead of interviews to assess how patients feel. Some questions were based on answers from the last questionnaire given or patient led. Others were based on interviews with survivors or were suggested by the Lynda Jackson team. This was combined with psychological questionnaires. The psychological questionnaires given were all well validated.

Finally, it is also hoped that this longitudinal study may be able to assess indicators of survivorship.

Chapter 2
Literature Review

The literature review is divided into five sections: the first being research pertaining to anxiety and cancer; the second to anxiety and radiotherapy; the third to depression, cancer and radiotherapy, the fourth to gender and age differences, and the fifth to the side-effects of radiotherapy especially fatigue.

The primary search engines used were Medline (1966-2002), Psychlit (to 2002), Cancerlit (to 2002) and Web of Science (1982-2002). In general studies were excluded which did not focus on adult cancer patients. Keywords used were radiotherapy, anxiety, depression, gender and psychological distress.

Anxiety and Cancer

Anxiety is a normal reaction to cancer with levels of anxiety varying from patient to patient. Anxiety if prolonged and left untreated can interfere with patients' and their family's quality of life (Davis-Ali et al 1993, Payne 1992). Some doctors may not recognize the symptoms of anxiety or may think that these are 'normal' feelings for patients with a diagnosis of cancer. Patients similarly feel their anxiety is understandable even if it persists for some considerable time and therefore do not seek medical advice. If symptoms of anxiousness persist beyond a seven to ten day period, advice should be sought (Massie 1990) as there is a clear distinction between what is considered normal fear/anxiety and a reaction that becomes more intensive and prolonged. It is then referred to as a psychiatric illness, which under DSM111 is called an adjustment disorder. This is confirmed by Massie (1990), who stated that the most frequently encountered type of anxiety, is reactive anxiety (situational), which would be expected to be high in a newly diagnosed cancer patient, but which should adapt. Thus these anxious symptoms can be transient. Only if these feelings become prolonged and or out of control can the anxiety be categorised under DSM111.

Most patients with adjustment disorder have no previous history of other psychiatric disorders. Severe nervousness, worry, jitteriness, inability to function properly, maladaptive behaviour and/or moods in response to cancer can be classified 'adjustment disorder'. This requires intervention. Interventions can take a variety of forms: relaxation technique, reassurance, low doses of quick acting benzodiazepines, support and education (Maissie

1990). When the anxiety is caused by such variants as pain or a hormone-secreting tumour, prompt treatment can lead to immediate lowering of anxiety levels (Briebart 1995). Often depression can co-exist with anxiety in cancer patients. Maguire (1992) and Greer (1994) found that approximately 25-30% of cancer patients during the first two years of diagnosis develop clinically significant anxiety or depression. Anxiety can seriously affect patients' quality of life. It can increase with pain (Glover et al 1995, Velicova et al 1995), cause sleep disturbance, affect appetite and it has even been shown that it can lead to premature death if left untreated (Sirois 1993).

Some specific cancers, for instance pancreatic cancer, are particularly prone to produce symptoms that are similar to anxiety-related psychiatric illness. Lung metastasis and/or lung cancer, which can cause shortness of breath, can sometimes lead to extreme anxiety and panic attacks if not controlled.

Some patients are more at risk of developing anxiety disorders. Those patients who have previously suffered from an anxiety disorder are at greater risk of relapse when suffering from cancer. Patients who suffer from psychological problems such as phobias often feel ashamed of their condition and fail to mention it to their oncologist and their anxiety can accelerate.

Other factors that can affect anxiety are lack of support, lack of communication by the patient to friends and family and the advancement of the disease especially if it is accompanied with severe pain (Breibart 1995). Similarly, anxiety can increase if the patients have experienced someone dying from cancer.

Age and gender can be contributing factors towards increased anxiety. Women and those who have cancer at a young age have been shown to be at more risk (Friedmann et al 1994).

A number of studies have looked at the prevalence of anxiety in cancer patients. Studies have shown that 44% of patients with cancer report some anxiety, with 23% reporting significant anxiety (Schag et al 1989). For most patients, this is short lived. Information seeking, support and adjustment usually control anxiety to normal levels.

One of the most frequently cited studies is Derogatis et al (1983), which found that one hundred and one patients from a total of two hundred and fifteen were assigned a psychiatric diagnosis. That is a prevalence rate of 47% for DSM 111-defined psychiatric disorders in a cancer patient population. To put this into perspective, what would be the expected number in a normal population and in a medical patient population? Hoeper et al (1979), found cancer patient rates for psychiatric illness three times higher than the general population (at 15%) and twice as high as a medical patient population. Jenkins et al (1998) reports on the prevalence

of anxiety disorders in the general population as between 3-16%. In Derogatis's study, a total of 32% suffered from adjustment disorder, 12% depressed mood, 13% mixed emotional features, 6% anxious mood and 1% emotion and conduct. Major affective disorders accounted for 13% and anxiety disorders 2%. It should also be noted that, in the Derogatis study, all the patients were new admissions to the cancer unit. Therefore the largest percentage of these psychological cases is patients trying to adjust to their cancer. Only a very small percentage of these patients had a history of previous psychiatric illness. Farber et al (1984) found lower levels of anxiety when one hundred and forty one cancer patients were tested. Of this population, 13% had high levels of anxiety and 14% intermediate levels of anxiety. In contrast to the other studies, however, 60% were in remission and 33% were not receiving treatment. A study carried out by Massie & Holland (1987), assessed reasons for referral to a psychiatrist. The largest group, (54%), suffered from reactive distress, which consisted of anxiety, depression or mixed mood.

From a long-term perspective, Maguire et al (1978), found medium to severe anxiety in 21% of breast patients, which continued for up to four months after their mastectomy and, in 19% of patients, for up to one year. They also found, unsurprisingly, a significant difference between mastectomy patients and those with benign breast disease.

However, it should be noted that this study was carried out in 1978, before mastectomy counselling was introduced. Indeed, in the 70s and 80s, little or no counselling or psychiatric referrals took place with cancer patients. It was mainly in the mid 80s that professionals started to respond to articles written by Derogatis and his colleagues. This gradually began to have an affect in making health professionals more aware of their patients' feelings and anxieties.

Payne et al (1999) in a more recent study studied ambulatory breast patients attending two cancer clinics and still found significant psychological distress in this population. Fallowfield et al (1994) with a sample of breast cancer patients over a three year period found anxiety levels of between 17-23%.

How long do patients feel anxious after their diagnosis and treatment? A total of one hundred and ninety seven patients were studied in a cancer follow-up clinic. Most patients reported no or mild anxiety in relationship to their visit. However, one-fifth had moderate or severe anxiety. Of this cohort, 46% were worried about recurrence. Those patients who were in remission following treatment reported more distress than patients whose treatment had finished two or more years before (Lampic et al 1994). The study could be questioned in that

the test given for anxiety was a visual analogue test only and was not used in conjunction with any other well-validated questionnaire. Also the patients were tested three weeks after the follow-up clinic and anxiety was higher at this time point. Three weeks post clinic was suggested in order to get a 'normal' reading. However many patients could still be waiting the results of tests performed at the follow-up clinic at this time. A more appropriate time testing time could be six weeks after their hospital appointment when test results have arrived.

Loge et al (1997) carried out a survey of four hundred and fifty nine survivors of Hodgkin's disease. They found that those whom had survived seven to ten years were significantly more anxious than those who had survived three to six years. Predictors of anxiety were chemotherapy and radiotherapy combined, (radiotherapy treatment only reached near significance), low educational status and psychiatric symptoms before or during treatment. However, this was a survey not a longitudinal study and no psychological tests had been previously performed on the patients. Therefore no comparisons can be made. The question 'do patients generally feel more anxious after a cancer diagnosis and for how long?'- remains largely to be answered.

According to Nordin & Glimelius (1997), who tested for psychological distress in gastrointestinal patients, although the average levels of anxiety were low, some patients had high levels of either anxiety or depression or both and this continued over time. This study indicates the importance of testing to identify patients so that appropriate treatment can be given.

From a slightly different viewpoint Pasacreta & Massie (1990) conducted a survey on nurses who have more direct contact with in-patients. Their study involved four hundred and seventy five subjects. They specifically wanted to know how many patients:

- "exhibited psychiatric symptoms,
- had a psychiatric history,
- were being seen by psychiatric consultants,
- required psychopharmacological treatment,
- required special nursing observation for suicidal thinking or agitated behaviour
- and had psychiatric symptoms related to acuity of illness"
  (Pasacreta & Maissie 1990).

Patients were grouped into two groups: high (N=277) and low (N=160) acuity. Acuity referred to the extent of disease or hospitalisation of a patient in critical care. In the low group, 26% suffered from anxiety, depression or both. In the high group, the figure was 51%.

Although a total of 55% of the patients was recorded as having psychiatric symptoms, only 13% were receiving psychiatric help in any form. A small proportion of patients, 11%, reported having a history of psychiatric problems prior to admission. Only 5% of these were being followed up. Therefore more than half of the patients were considered to be 'at risk', but were receiving no psychological help during this distressing time. The findings of this study have major implications for patient cancer care. Houts et al (1986) in their study of six hundred and twenty nine cancer patients, recommended a more effective screening for psycho-social problems and a better referral service.

An American study highlighted the fact that 50% of terminally ill patients in hospital have moderate to severe pain and 25% die with untreated anxiety and depression, Foley K. (2000), and Hospice Association of America (1999).

At what time in the 'cancer journey' do patients require assistance to help them with their anxiety? Diagnosis is an obvious time, but treatments also can raise anxiety levels. What effect does radiotherapy have on patients psychologically? Does this further increase their distress and for how long? This will be discussed further in the literature review on radiotherapy.

Anxiety And Radiotherapy

Various treatments given to cancer patients such as radiotherapy can further increase anxiety. Fears and misconceptions about the aims of radiotherapy treatment and how it works cause patients to become worried and anxious. This has been confirmed by several studies (Greenberg 1998, Roach et al 1996). In a study carried out by Peck & Bolland (1977), on fifty patients, two-thirds of the patients remained anxious throughout their treatment. The most feared side-effects were burns (72%), scars (54%) and pain (54%). Gyllenskold (1982), cites 'being radioactive' and 'worries about damage to healthy tissue' and 'permanent genetic damage' as being high sources of anxiety.

Radiation cannot be seen; neither can it be felt nor smelt. Therefore to some patients the whole experience can be extremely threatening. In addition, some patients have to wear perspex masks which are clamped to the treatment bed. Others have to lie immobilised in uncomfortable positions. All patients have to be left alone during their treatment, although they can be seen on video screens and can talk with and be heard by staff.

Some patients believe that radiotherapy is only given to palliate symptoms and therefore their surgery must have been unsuccessful. Others believe that their cancer

must be inoperable. Some experience additional fears concerning the equipment and the possible administration of incorrect doses. In recent years, there has been much publicity about the effect of ultra violet radiation on the skin and how it is a contributor to the increase in skin cancer. For patients this is an anomaly - how can something which causes cancer, cure cancer?

Radiotherapy Departments can look rather bleak and depressing. Patients often have to wait for considerable lengths of time, frequently in the company of obviously sick and dying patients, and this can be a factor in increasing anxiety levels. In this environment, it is very difficult to sustain denial (Fallowfield et al 1986). Mitchell & Glickman, (1977), studied patients having radiotherapy treatment and found that 80% would not discuss their emotional problems with their referring doctor or their radiotherapist. Is this because patients feel that doctors, especially radiotherapists, are highly trained 'technical experts' and they do not want to 'waste' their valuable time on their emotional problems? Or is it because they feel inhibited?

Fallowfield et al, (1986), in their study on mastectomy patients, asked patients

'Looking back over this past year, can you pick out one period that was worse than any other?'

Most women stated:

'between finding the lump and hearing the diagnoses, closely followed by their experiences during radiotherapy'.

Can information help the radiotherapy patient? Patients want information and evidence shows that they cope better with their diagnosis and treatment if they are given good honest information in a sensitive format (Cohen et al 1979).

Cassileth et al (1980), stated that radiotherapy patients felt poorly informed and desired more information, especially from their radiotherapist. Holland et al (1979) carried out a study in which women patients were randomly assigned to two groups, an intervention group or non-intervention group. The intervention group had a tour of the department, which included talks by the staff who would be treating them on the procedures involved, followed by a question and answer session. The women were found to be less anxious on their first visit. This is a time consuming operation and it would be difficult to organise in a busy department. A less disruptive method of giving patients information could be by video presentations. Rainey (1985), divided patients into low and high-information groups. The low information group only received a booklet, whereas the high-information group was

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shown a video with information about the staff, treatment, common misconceptions etc. Staff was present to answer any problems. Those in the high information group had less anxiety and less mood disturbance when they arrived at the radiotherapy department and this continued through to the end of their treatment. Thomas et al (2000) found that both anxiety and depression were significantly lower in the group that had been given a video to take home. They felt that well designed video programmes were very useful sources of accurate information.

An orientation programme given to patients on their initial visit can help anxiety depression and distress. McQuellon et al (1998) in their study found that their programme of orientation could help patients at the time of their diagnosis. Not only did it help in reducing psychological distress but also their overall knowledge on treatments was greater as was patients' satisfaction with the care given.

The role of information in patients' adaptation to radiotherapy was highlighted in an Article by Ream and Richardson (1996). They found in the studies they reviewed that the role of information was restricted to topics such as self-care strategies and their effectiveness. They recommended that other factors be taken into consideration so that information can be tailored to patients' needs, for example, anxiety be measured, socio-demographic details and medical state noted. Whether the treatment is palliative or radical should also be a factor in this equation.

What is lacking therefore is a broader concept of patient satisfaction. Has the information supplied by the hospital covered all the salient points? Do departments ask for feedback from their patients on what their requirements are and if the information was satisfactory for their needs? In this way the needs of the patients could be dealt with. This could have an effect in reducing anxiety and depression. Montgomery et al (1999) undertook a study combining satisfaction with information and levels of anxiety and depression. A total of 28% were not happy with the information given, 30% were probable subjects of adjustment disorder and 13% were suffering from depression. Significance was reached between high scorers on the HADS and dissatisfaction with the information. This study only reviewed patients before and at completion of their treatment. Nothing was given post treatment.

If patients are anxious, their recall is low and thus they may not be registering the information given to them. Similarly, patients could also be using avoidance techniques and deliberately not reading the information. Denial is another method of coping. When and how the information is given are important factors.

Johnson et al (1997) took a sample of two hundred and twenty six patients and divided them into two groups, a control group and an experimental one. The control group was given the standard nursing care. The other group was given, at four different times, theory-based interventions. The experimental group were not only found to be less pessimistic about their outcome but also experienced less disruption in their usual life style both during and after their radiotherapy treatment.

High levels of anticipatory anxiety are common reactions, before, during and after treatments. Andersen & Tewfik (1985) state that

> "...in threatening situations, the level of fear can potentially determine the adequacy of adaptation." (Andersen & Tewfik 1985)

In a Norwegian study by Kaasa et al (1993), two hundred and seventy seven palliative radiotherapy patients were tested before their radiotherapy treatment. They found that those patients in the most pain with poor performance status were the ones identified as being the most distressed. A total of 69% of the two hundred and forty seven patients who agreed to participate in the study reported a high level of psychological distress. This is approximately five to eight times higher than in a normal population. The psychometric tests used were:

- Impact of Event Scale, involving 15-item self-report scale and
- The 20-item version of the General Health Questionnaire.

Pain was assessed on a five point Likert scale and the doctor involved completed the Karnofsky performance status scale. The tests used in this study are all very time consuming to fill in and score.

Rahn et al (1998) studied breast patients at the beginning and at the end of their radiotherapy treatment. At the beginning, 40% were anxious and 54% expected side-effects. By the end of their treatment, anxiety had dropped. This study was too short. Anxiety was still present in patients, how long did it continue? Depression was not measured. Holland et al (1979) found that anxiety was at its highest at the onset of treatment. By the end of treatment, patients were more depressed, angry and less hopeful.

Jane Graydon, (1988), with a sample of seventy nine patients, found that those patients who were anxious and tense at simulation tended to have poor functioning following their treatment. However, Graydon's sample size was small and, although it assessed patients twice, once in the first week of treatment and the other time four to thirteen weeks after radiotherapy had finished, it did not follow patients through treatment and only did one testing post treatment and this was not at a consistent time.

As treatments for cancer become more aggressive for the cancer patient, so anxiety can be further heightened. Acute anxiety can also be indicative of a change in metabolic state. Sepsis and or electrolytic abnormalities can cause raised anxiety levels. Patients with metastatic disease can display high degrees of anxiety. This is usually due to uncontrolled pain, with high anxiety and agitation, isolation, abandonment and dependency (Hackett et al 1987). Similarly, drugs such as corticosteroids can cause motor restlessness and agitation as well as depression and suicidal thoughts. For those patients who are in active treatment, and who have dependency problems with nicotine, alcohol or drugs, anxiety could be raised by their having to comply with hospital rules and regulations.

What emerges from this literature review on anxiety and radiotherapy is that hospitals need to find out firstly what is the psychological state of the patients undergoing radiotherapy and secondly at what specific times does anxiety occur in order to give appropriate information, advice and support. Do the majority of patients adjust to their treatment as emphasized in the literature or do they get more anxious when they return home? Do side-effects make patients more anxious? Do patients carry the burden of their cancer diagnosis for years or do they forget and get on with their lives?

Cancer, Depression And Radiotherapy

Much was written on anxiety but until recent years little was written on depression with cancer patients. Approximately 6% of the general population suffer from depression (Angst 1992, Lépine et al 1997). Depression is frequently seen in cancer patients and is the most frequent psychiatric complication. However it still remains largely undiagnosed and untreated. It can include such symptoms as lack of sleep, loss of interest in life, irritation, suicidal thoughts, fatigue, changes in sexual desire and anxiety. Each of these symptoms can lead to a poor quality of life. Patients who are suffering from depression can also be less compliant with their treatments, have longer stays in hospital and have higher mortality rates (Spiegel 1996, Bottomley 1998). Faller et al (1999) looked at survival time in lung cancer patients and found that emotional distress, depression and depressive coping were associated with shorter survival. Similarly Watson et al (1999) found that a high depression score in breast cancer patients was linked to a significantly lower chance of survival.

A diagnosis of depression can be confusing for the physician as symptoms of cancer can replicate depressive symptoms. If one looks at the criteria for classification of depression DSM-1V it says

"At least five of the following symptoms to be present during the same two-week period and represent a change from previous functioning: at least one of the symptoms is either (1) or (2).
Depressed mood most of the day, nearly every day.
Markedly diminished interest or pleasure in all or almost all activities most of the day, nearly every day.
Significant weight loss of gain
Insomnia or hypersomnia nearly every day
Psychomotor agitation or retardation nearly every day
Fatigue or loss of energy nearly every day
Feelings of worthlessness or excessive or inappropriate guilt nearly every day
Diminished ability to think or concentrate, or indecisiveness nearly every day.
Recurrent thoughts of death, recurrent suicidal ideation or suicide attempt" (*American Psychiatric Association 1994*)

Weight loss, a decrease in activity and fatigue are common side effects of cancer and its treatments, which can confuse the diagnosis for depression.

It is estimated that 20-25% of cancer patients suffer from untreated long-term depression. However, a lower figure was found in a 1998 study by Berard et al (1998). Their prevalence rate was 14%. From this cohort, only 14% had been previously identified. Serious depression was estimated by Sellick & Crooks (1999) as being between 6-15% of the cancer patient population. This highlights the need for routine screening in oncology departments.

The most common form of depression in cancer patients is adjustment disorder with depressed mood. This can be characterised by dysphoric mood and an inability to perform normal functions such as not getting up in the morning or not going to work. If these symptoms persist for more than two weeks then treatment should be sought. Newport & Nemeroff (1998) point out that:

'neurovegative symptoms which may be due to secondaries can sometimes cloud the picture'.

If depression is alleviated, quality of life improves as does immune function and length of survival time (Mcdaniel et al 1995). It should be noted that approximately 50% of patients do adapt naturally. Patients are then able to assess the information given to them, prepare for treatment, adjust to family lifestyles around their treatments and maintain a positive attitude to their illness (Massie & Shakin 1993). It has also been shown that the presence of anxiety or depression in patients can cause an increase in emotional problems in a partner, which can reflect into the family (Harrison et al 1995). This reinforces the importance of assessing patients for psychological distress.

Depression is particularly prevalent in a palliative care setting. Indeed, Kuuppelomaki and Lauri (1998) interviewed thirty two incurable cancer patients. The most common psychological suffering was caused by depression. When they were in pain, tired or in bad shape, they felt depressed. This in turn brought about feelings of giving up and wanting to die. One third of the patients in this study had experience of wanting to die.

Breibart (2000) in a paper, 'Depression and Hopelessness Predict Desire for Early Death Among Terminally Ill' found that those patients who were suffering from a major depressive disorder were four times more likely to want an early death. They also found that scores for depression were moderately high in all the assessed patients. Their paper concludes that psychiatric and psychosocial care are both essential in the quality of palliative patient care. Hopwood & Stephens (2000) in their study of palliative lung patients found that of the nine hundred and eighty seven patients studied, a third suffered from depression and another third suffered from borderline depression. A total of 34% had high levels of anxiety and 21% suffered from both anxiety and depression. They suggest that, as the incidence is so high, perhaps all patients suffering from late stage lung cancer should be assessed. The self-assessment questionnaire used was the HADS. Jenkins et al (1998) looking specifically at radiotherapy patients found one third were suffering from clinically significant depression. Again, self-report scores were used. This was the Inventory of Depressive Symptomatology - Self Report (IDS-SR). Relevant factors, which they found could be helpful in a diagnosis of depression, were

> "a personal or family history of depression and or a positive endorsement of one of the following three statements: thoughts of suicide or death, feeling restless, or diminished mood response to good events".

Uchitomi et al (2000) found that patients who were not satisfied with their confidante were significantly more likely to suffering from depression three months after surgery. Indeed, the importance of social support and communication has been shown by other studies (Akechi et al 1998, Neuling & Winefield 1983).

Depression can be treated pharmacologically or psychologically or by a combination of both methods. The effects of antidepressants on cancer patients require more trials. However, they do appear to be safe and effective in the treatment of depression and depressive symptoms. Unfortunately, they also appear to be under prescribed. Berney et al (2000) wrote

"While there has been considerable progress in the pharmaceutical development of new drugs, antidepressant are still under utilised in patients with advanced disease. A variety of

factors, such as lack of effective communication, uncertainties surrounding psychosocial aspects of disease, and the lack of clearly established diagnostic and therapeutic procedures may be responsible for this unsatisfactory situation".

It is interesting to note that with tricyclic antidepressants (TCAs), cancer patients need much less dose than healthy psychiatric patients. The reason for this is not yet known. However, Aapro & Cull ., (1999) recommend that TCAs should be prescribed with caution. Instead they recommend selective serotonin reuptake inhibitors (SRRIs), as they have fewer side-effects especially anticholinergic effects including dry mouth, constipation, tachycardia, blurred vision, urinary retention and delirium (Jenner 1992). SRRIs can also bring about sleep without causing day-time drowsiness. Drugs, such as fluoxetine, which is an SRRI, can also reduce pain. However, this is contra indicated if the patient is anxious or under weight as they can also be appetite suppressors (Cooper 1988), both common problems with cancer patients. Therefore the choice of the antidepressant depends very largely on symptoms, medical problems and side-effects. For example, patients with stomatitis after radiotherapy need an antidepressant with low anticholinergic side-effects such as bupropion. Benzodiazepines can be used if anxiety is associated with the depression. Unsurprisingly, high pain scores were correlated with high depressive scores in a study by Pimenta et al (1997). Does pain cause depression or does depression cause pain? Spiegel et al (1994) studied two groups, one with high pain and one with low. The group with high pain had significantly more depressive problems even though the low pain group had a significantly higher history of depressive disorders.

A meta-analysis of fifty eight studies after 1980 was undertaken by van't Spijker et al (1997) on the psychological consequences of cancer diagnosis. They found that anxiety and general psychological distress did not differ significantly from that in the general population. However, cancer patients did exhibit increased depression. Compared with other medical patients, they found that cancer patients were significantly less anxious. These findings contrast with previous reports and emphasize the need for more research.

In a more recent article by Sanson-Fisher et al (2000), they found the highest area of need of cancer patients undergoing treatment was in the psychological domain.

In 1981, Petty and Noyes stated that etiological factors associated with cancer are primarily responsible for patients experiencing depression. However, factors such as radiotherapy can also contribute to depression.

Looking at long-term effects, Buccheri (1998) found a relationship between depression and prognosis in lung patients, the more depressed, the shorter the survival. One

could question which comes first. Depression is also considered to be a contributing factor with fatigue in patients. Depression could be a cause but it could also be a consequence of permanently feeling tired.

How is depression recognised? Are oncologists successful at recognizing the symptoms of depressed patients? Passik et al (1998) found

> "that oncologists frequently assessed their patients' levels of depressive symptoms inaccurately. Although physician and patient ratings were moderately (and significantly) correlated, most of the actual agreement in physician and patient ratings were on the none or mild end of the continuum. Physicians accurately classified only 20 of 159 moderately to severely depressed patients and rated 78 of these patients as having essentially no depressive symptoms. We also found that physicians' ratings were most highly correlated with patients' endorsements of more obvious symptoms, such as sadness, tearfulness and irritability, while they were less strongly associated with more subtle symptoms such as concentration difficulties, anhedonia and somatic symptoms" (Passik et al 1998)

In this study, 36% of 1,109 patients had clinically significant depression, yet less that 3% of those patients were currently seeing a mental health professional.

These are frightening statistics for cancer patients but they are indicative of a problem, which needs attention. This was confirmed by Newell et al (1998) who wrote that:

> "medical oncologists do not accurately reflect their patients' reported levels of anxiety, depression, perceived needs or many physical symptoms"

Fallowfield et al 2001, wrote

> "psychological morbidity is still common and that much of it goes unrecognised and is not therefore treated".

What about other health professionals? McDonald et al (1999) studied nurses' assessments of depression in their patients. The results were similar to oncologists. The nurses under estimated depression in those who were severely depressed. They again were most influenced by overt feelings such as crying. Both these studies emphasize the need for more education in depressive symptomology and in a good easy to administer diagnostic tool for measuring depression in a cancer patient population.

Penninx et al (1998) found that when a person suffers from chronic depression for at least six years, there is a correlation with a generalized increase in the risk of cancer. Indeed, could one hypothesize that those patients already depressed could be at a higher risk of spread?

Little research has been done in this area. Controlled trials of available pharmacological and non-pharmacological treatments are urgently needed.

Bottomley in his literature review on depression writes

"It is now important that health care professionals routinely assess and offer treatment for depression in cancer patients" (Bottomley, 1998).

According to Maguire et al (1978), 80% of clinically depressed mastectomy patients are not seen as such by their surgeons. Symptoms such as worry, tension, dread, irritability and an inability to relax can be present permanently or can manifest themselves in different forms such as unnecessary fear of recurrence, dying and of attending for treatment (Hughes 1991).

Depression is largely undiagnosed and untreated for cancer patients. Studies have shown that about a quarter of people with cancer develop depression. In contrast two percent of cancer patients in one study (Stiefel et al 1990) were receiving medication for this serious complaint, which may impact on the course of the disease, affect participation in treatment and thus affect quality of life and survival.

Gender and Age
Gender

Gender is a huge subject and was the topic of the American Psychiatric Association meeting in 1999. At this meeting Leibenluft (1999) stated that depression was two to three times more common in women than men. Nopoulos (1999) showed, through neuroimaging, gender differences in emotion as women show more use of their limbic system when sad than men. This can be extended to external factors. Kendler et al (1999) found that women display more emotions than men.

Mood disorder has also been shown to have a strong causal relation to stress. Young (1999) found a difference in stress levels in men and women. Stress is mediated by the hypothalamic-pituitary-adrenal axis. Cortisol is increased with stress. Normal women appear to have a stronger HPA response to stress than do normal men. In women, ovarian steroids modulate the stress response. At puberty, after birth and during menopause this axis can be de-stabilised. This could be one of the reasons for the increase in anxiety disorders in women. In fact, depressed women show more hypothalamic pituitary axis deregulation than depressed men and this seems to be in part regulated by the sex hormones. This difference is continued in response to drugs. Women respond better to SSRIs (selective serotonin reuptake inhibitors) than men. Women experience more side-effects with the tricyclics. However, this difference appears to change in menopausal women. Schatzberg (1999) further states that "exogenous estrogens may speed antidepressant effects in women". Depression is not gender specific. However depression in women is twice as common as men (National Comobidity

Survey, 1994) though men are more likely to die from suicide (Horton 1995). Wearn et al (2002) found that malignant disease was associated with an increase risk for suicide. This was gender specific for men.

A difference has also been noted in how health professionals see men and women. Men are perceived as being less ill and women as exaggerating their illness (Macintyre 1993). Surveys have shown higher morbidity for women and higher mortality for men (Waldron 1983; Wingo et al 1995). Men are reported as having better health. However their life expectancy is about 7 years lower than women's. In a study on gender differences in cancer patients Greimel et al (1998) found that men had significantly less social resources than women, more cancer-related problems and more restrictions in daily living.

Should gender be a consideration when treating patients with radiotherapy? Studies have been mixed. Cella et al (1987) found that women experienced more distress. This was confirmed by Nordin et al (1996). They showed that women exhibited more anxiety than men. These patients were all gastrointestinal cancer patients attending follow-up clinic. Similarly, Brandberg et al (1995) found a gender difference with female melanoma patients being more depressed than men. In contrast, Pettingale et al (1988), found men were more distressed and that their lives had been far more upset by cancer than the women.

Stefanek et al (1987) found no gender difference. Similarly, Irwin et al (1986) found no sex differences in how men and women coped with cancer and radiotherapy treatment. They found that both depression and anxiety fell after treatment.

Depression studies in cancer patients were examined by DeFlorio and Massie (1995). They looked specifically at gender differences. From the forty nine studies reviewed, twenty nine included gender. However, from the twenty nine studies, six did not stipulate any differences or did not look for a difference. From the remaining twenty three studies, nineteen were specifically looking at one sex. The remaining studies found no significant difference at the 0.05 level. The only study mentioned with radiotherapy patients was Peck & Bolland (1972) and gender difference was not cited. Craig & Abeloff (1974) found that, while gender differences were not significant, they found a tendency for white females of higher social class to have more psychological symptoms. Plumb & Holland (1977) found that more men than women were suffering from depression. However, both Craig & Abeloff and Plumb & Holland were studying palliative patients and these studies are nearly thirty years old. In a more recent study, Holland et al (1986) found that the men's depression and distress scores were equal or slightly higher than the women's, though significance was not

reached. These patients were all palliative pancreatic or gastric patients. In contrast, Lloyd et al (1984) found that women had significantly higher psychiatric morbidity. This was a study testing newly diagnosed cancer patients.

In a paper on the Unmet Needs of Cancer Patients, Sanson-Fisher et al (2000) identified age and gender as factors, with women reporting higher levels of unmet needs than men. Being female is associated with increased anxiety in medical situations according to Friedman et al (1994). Härter et al (2001) found gender differences. Anxiety disorders were more common with women who had cancer. The risk of mental disorder was double for women with cancer over their lifespan in comparison with men patients.

Gender differences were studied in patients undergoing chemotherapy. Women's distress could primarily be explained by physical impairment such as old age. In comparison men's distress was closely related to their psychological state (Keller & Henrich, 1999).

Leigh et al (1987) in a longitudinal study found a gender difference and suggested that men coped by denial and that women's coping was more realistic. Men and women were re-tested three years after the initial testing. The women who failed to survive had a more realistic view of their illness in contrast to the men who rated their illness as only 'somewhat serious'. Is it that men take longer to adjust and come to terms with their illness or do they as Leigh et al suggest, cope by denial?

Psychological distress can be a product of a life threatening illness. Patients undergoing radiotherapy treatment will be in a vulnerable position. Dysphoric mood is more common in women (Weismann & Klerman 1977). Similarly, depression has been shown to reach its peak in women between the ages of 25-45 and decreases in subsequent years and with an increasing trend in men with age (Schwatz & Blazer 1986). Will this be the case throughout treatment? This needs to be tested. More research is required in this area especially with radiotherapy patients.

Age

Age is another major factor that has not been extensively studied in connection with anxiety and depression in cancer patients. Compas et al (1999) found that younger women around the time of diagnosis exhibit more distress and have less means of coping. At six months after diagnosis, these patients displayed no significant difference compared with the older patients. Similarly, Sanson-Fisher et al (2000) found that patients within the age range of 31-60 consistently had more unmet needs that those aged 70 and over. Other research has confirmed this (Mor et al 1992). However, this could reflect a change in attitude. Young people could be more forward in their needs and more willing to voice their needs in contrast to older age people who tend to be more stoic.

In a Swedish study with breast patients receiving radiotherapy after surgery, Marasate et al, (1991), found that from one hundred and thirty three patients, eighteen (14%) had morbid anxiety. In particular, they found a significant correlation between morbid anxiety and women aged 50-59 who had a mastectomy. This they felt indicated that menopausal women are more at risk of emotional disorder not all of which is specifically linked to cancer and radiotherapy. These factors could include hormonal imbalance, children leaving home, plus the natural aging process. When these facts are added to the natural anxiety of mutilating surgery, emotional distress is heightened. There were only thirty three women in this category, so that ideally it should be repeated using a larger number of women to verify the statistics that menopausal women need more emotional support. In this study, a score of 8 was used to show borderline anxiety on the HADS (Hospital and Anxiety and Depression Scale) and 10 to indicate high anxiety. No other tests were used. This anxiety could have been short lived, a longitudinal study would have indicated anxiety over time and whether it was repeatedly high for menopausal women.

Other studies have highlighted the higher levels of psychological morbidity among young cancer patients (Jarrett et al 1991, Edlund & Sneed 1989). Harrison and Maguire (1995) confirmed that younger patients were subject to greater distress when coping with emotional issues but older patients were subject to more limitations imposed by treatment and the disease.

How do elderly patients cope with radiotherapy treatment which is arduous and time-consuming? According to an article by Lindsey et al (1994) they found that the only side-effects patients suffered from were a decrease in weight and activity. This study was

longitudinal over radiotherapy treatment and three months post. However it would have been more interesting if it had been coupled with a measurement for depression. The loss of weight could be due to a lower calorie intake and this could have been related to feelings of depression.

These studies indicate the importance of studying for differences in gender and in age coupled with psychological distress with radiotherapy patients.

Side-effects of Radiotherapy

Radiotherapy can cause long-term effects. Non-malignant, healthy cells can be damaged by the radiation if they are in the pathway of the area to be treated. Thus previous symptoms can be aggravated and new symptoms can develop, such as diarrhoea, frequency, pain, skin reactions, nausea and fatigue. The major ongoing symptom of radiotherapy appears to be fatigue. This could be caused by or related to cell injury (Aanno et al 1989). In lung patients, for example, fatigue could result from fibrosis caused by the treatment, which in turn causes shortness of breathe and/or pain, with results in tiredness. Certainly Smets et al (1998) found that lung cancer patients had the highest mean fatigue scores of the patients in their study. Immobilisation resulting from prolonged bed rest can result in fatigue following resumption of normal activity (Sharpe & Bass 1992). Other factors explaining fatigue include pain, nausea or sleep disturbance (Irvine et al 1994). Smets et al (1998) found a relationship between fatigue and psychological distress, in particular depression. They suggest that fatigue is a result of acute physical and psychological stress that is associated with both the cancer and its treatment and suggest that interventions to reduce psychological distress may reduce fatigue

Monga et al (1999) in their prospective study with prostate patients found that, at commencement of treatment, 8% felt tired. On completion, this rose to 25%. Fatigue is often associated with depression. However, this was not the case with these patients. Before treatment, eight patients indicated depression. By the end of the treatment seven were depressed, with no new cases reported. Indeed Monga et al (1997) thought that subjective fatigue is related to a fall in neuromuscular efficiency due to radiotherapy treatment.

A number of studies have put the incidence of fatigue as a common side-effect of radiotherapy treatment between 65%-100%, Peck & Bolland (1977), Kubricht (1984), King et al (1985), Greenberg et al (1992).

Holmes (1991) studied two cancer patient populations, one group of radiotherapy patients and the other chemotherapy patients. Both cohorts were found to have similar levels of symptom distress. Tiredness was the most common symptom. Variations did occur. The radiotherapy patients reported more significant distress due to pain, altered appearance, constipation and appetite change whereas the chemotherapy patients found their inability to concentrate, mood changes and alterations in their appearance distressful. However, Berglund et al (1991) studying a similar cohort of chemotherapy and radiotherapy patients found the radiotherapy patients reported decreased stamina (75%) when compared with the chemotherapy patients (61%). It must be noted that this study looked at the late effects of treatment and was carried out two to ten years after the patients' treatment had finished, hence the difference in the findings.

Fatigue was also reported to be the most distressing symptom by Oberst et al (1991) in their study that assessed self-care, stress and mood in seventy two patients who had undergone radiotherapy treatment for an average of four weeks. They found that coming for treatment was the most demanding aspect.

Fatigue can also accelerate physical helplessness and dependency (Charmaz 1983). Can patients be helped to combat fatigue? Mock et al (1997) studied forty six women undergoing six weeks of radiotherapy treatment for early stage breast cancer. Patients were tested pre and post treatment and divided into a control group and an exercise group. The exercise involved a self-paced home-based walking programme. Significant differences occurred in the groups. The 'walkers' suffered less from fatigue, anxiety and sleeping problems. Depression was not assessed.

Faithfull's (1995) article describes the debilitating symptoms experienced by patients both during and after radiotherapy treatment to the pelvis. Men can receive damage to the bowels, the rectum and the testes. However, many of the patients felt that the symptoms suffered were inevitable in the curing process. Information on side-effects did alleviate anxiety, but did not help patients in managing their symptoms – in this case urinary problems. The side effects of leakage and incontinence are associated with old age. These side effects caused embarrassment, and made the patients feel stigmatized. Similarly, the fear and anxiety for women undergoing pelvic radiation is described in an article by Whales, (1991). These patients can have damage to the vagina and the ovaries because of the treatment for their cancer.

Head and neck or pelvic- treated patients appear to be particularly susceptible to problems following treatment. Regular support in the form of information and follow-up care should assist patients in their adaptation to cancer and its treatments. Wells (1998) undertook a study on head and neck patients after their treatment had finished and found that patients had a reluctance to ask for help even though this cohort underwent severe physical and psychological trauma. This article highlights the need for more care both during and after treatment, especially with regard to information and communication. In head and neck patients, permanent damage to the salivary glands affecting taste and salivary production can result. The worst time for head and neck patients was during and just after finishing treatment (Hammerlid et al 1997).

Patients seemed satisfied with the clinical care they have received (Suomminen 1992, Wiggers et al 1990), but were not satisfied with other aspects of their care including information about the disease, its treatments, the side-effects of radiotherapy treatment and their control. Furthermore patients and their families felt a lack of support.

In a study in 1999 (Mose et al) carried out in Germany on breast patients receiving radiotherapy post surgery, 92% felt they were well informed about the treatment. However 83% still wanted further information. All the patients (100%) stated that the treatment was tolerated because of good communication with the staff. Montgomery et al (1999) found that some patients (22%) could not remember signing a consent form. Those who did remember signing did not understand fully what they had signed for. Patients were told of side-effects but one fourth of patients could not remember being told. Over a quarter of the patients were not satisfied with the information given to them. Of this cohort, 30% scored so high on the HADS that they could be considered to be suffering from an adjustment disorder. Anxiety inhibits recall and, therefore, when giving patients important information on their treatment, anxiety levels should be noted. Montgomery et al also found a significant correlation between the high scorers on the HADS and dissatisfaction with information given. This limited recall could also be the patients' method of coping with the treatment. Similarly, those patients with high initial anxiety could be the patients who adapt the quickest to their treatment. This needs to be further investigated. Patients can be given information but the content and time of giving it needs to be assessed.

As time evolves, more side-effects can occur. Johansson et al, (2000) studied seventy one patients who had received treatment in 1963-1965 for cancer of the breast. Survival was almost 50%. Late effects started from about five to thirty four years post treatment. 92% of

these survivors had paralysis of their arm, 5% suffered from paralysis of their vocal cords. This had developed nineteen years after treatment. Indeed, the development of neuropathy is slow with an average time of 4.2 years. Over time the neurological problems increase with Grade 4 damage obviously taking longer time to emerge, approximately ten years. 61% of the patients developed skin fibrosis, with a mean time for developing it of 1.8 years, with one patient developing it eleven years after treatment.

Chapter 3
Specific Longitudinal Studies

The following five studies were carefully selected. The first study is longitudinal and looks specifically at emotional distress over time. This corresponds with the second aim of the present study to ascertain the times of greatest distress. The population of bone marrow transplant patients have a high attrition rate and are undergoing unpleasant treatment and could be compared with cancer patients undergoing radiotherapy treatment.

The second study is also longitudinal and measures psychological distress using the HADS. The population consisted of both radical and palliative patients. Both factors are used in the current study. The subjects are either having radiotherapy or brachytherapy.

The third study looked at predictions made on the basis of tests at diagnosis, using the HADS questionnaire. Both radical and palliative patients were included in the study. The fifth aim of the current study was to see if predictions can be made on the basis of psychological tests at simulation.

The fourth study was chosen because it looked at psychological predictors of survival in radiotherapy patients. This is the last aim of the current study. The STAI state and trait questionnaire was used and are also used in the current study.

The fifth study is a longitudinal study of head and neck patients undergoing radiotherapy treatment. The HADS is used to assess patients' anxiety and depression. However here calandrical points are used. This is common in cancer studies, rather than specifically important times that are used in the current study.

First Detailed Study

Longitudinal Study of Adaptation to the Stress of Bone Marrow Transplant
Authors: Fife B., Huster G., Cornetto K., Kennedy V N., Akard L P., Brown E
Journal: Journal of Clinical Oncology Vol 18, No 7 (April) 2000 pp 1539-1549

This longitudinal study looked at emotional distress. Although bone marrow transplant (BMT) is not radiotherapy, both treatments are aggressive therapies and both can cause physical, psychological, social and emotional distress for patients and their families.

This study assessed patients before, during and after transplant.
1. before hospitalisation
2. 1/2 days before infusion
3. 7 days after infusion

4. 14 days after infusion
5. 1 month post
6. 3 months post
7. 1 year post

The testing points, one to six, are all valid. However, the break from three months to one year needs to be questioned. Most problems occur in the first year post transplant. Similarly, the study was only for one year post transplant. Is this sufficient time for adaptation? The authors' reasoning was that previous studies have looked at the long-term problems. However, data from a prospective longitudinal study with all the same patients and lasting for more than one year would have given a more complete overview of patient adaptation in this particular cohort.

The study addressed three points.

Firstly: "At what specific time points in the BMT process do individuals experience the greatest distress?"

Secondly "what factors are associated with this distress as well as with the individual's ability to cope and adapt successfully?"

Thirdly "what variables demonstrate the potential to serve as clinical indicators of those individuals in greatest need of intervention if the development of psychological emotional and social problems secondary to the transplant are to be minimised or prevented?"

Nine questionnaires were used which were all self-report questionnaires, namely:

- BiPolar Profile of Mood States where each variable is on a continuum giving negative and positive emotions.
- Social Support was measured by the modified versions of
- Perceived Family,
- Perceived Friends Support Scales and
- Perceived Health Care Provider Support Scale.
- Stress was measured using the Ways of Coping Checklist, which was modified for people with life threatening illness. It consists of forty items. Patients are asked to show on a scale of 'never' to 'very often' how often they used a certain strategy.
- Next a Mastery Scale was given, whose aim is to show, if the patients feel they have some control over their lives.
- Followed by a body image scale, which was developed for this research. – seven items with a Likert-type format.

- Then patients completed a questionnaire adapted for bone marrow transplant patients for cognitive response/meaning, which was labelled a Meaning of illness Scale.

- Finally, patients had a questionnaire on the symptoms – the Impact of symptomology – checklist developed by the team, which ranged from physical, psychological and social. This was arranged as sixteen items on a Likert scale.

These nine questionnaires seem rather excessive for a sick population to fill in and not surprisingly the results indicated a lot of missing data. The authors, however, did not subject the patients to all the tests at every point. Only the POMS, the symptomology checklist and the Mastery Scale were repeatedly used.

Patients completed all nine questionnaires at three different points only; before hospitalisation (baseline), after three months and one year post transplant. Surprisingly, at one month after treatment, the body image questionnaire, the social support questionnaire and the coping strategies were left out. This is the first testing since leaving the care of the hospital and support and coping should have been included.

With regard to the validity of these questionnaires, only Bipolar Profile of Mood States (POMS) has been the subject of debate and is a robust well-validated tool for use with medical patients. The other questionnaires were formed or adapted for use with patients on this study.

One of the biggest problems in this study was missing data due to sickness, death and non-compliance. The attrition rate was not included in the result section. Missing data was replaced by data from previous time point, if the patient was known to be alive, but was a non-participant. However, this was only done if results had been obtained from three different time points. This can be questioned. There were also the problems of self-selection with the healthy replying. The decision was made to analysis the data as two separate studies and to test for differences between them. The first group consisted of only the information sent by patients, the second group consisted of a much bigger group where data was inserted on missing variables.

The results using T-tests between the two groups showed little difference with few significant results. Those significant differences, which did occur, were not recorded in the paper, though the authors covered themselves by stating that none of the differences were significant for more than one testing.

The authors therefore used the bigger group to analyse the data as a single sample using repeated measure analysis of variance, correlations and regression.

The analyses were carried out looking at specific time points and repeated measures analysis of variance used to see the changes over time for each variable. If significance was attained, the Duncan multiple range test was used to protect against Type 1 error. This showed that the period in hospital before the transplant was the most stressful for patients. Both depression and anxiety levels fell one week after the transplant.

To understand what factors were associated with distress, emotional responses over time and other factors such as social support, symptoms and self-image were correlated. Fife et al found that, one year after BMT, the more symptoms that the patient was suffering from, the higher the emotional distress levels. Unfortunately this was where the study ended. Extending this study for another year would have given valuable information on symptoms and emotional functioning.

Significant correlations were also found in patients who were distressed before treatment. They continued to be significantly more distressed after treatment. Personal control was significantly correlated with lower anxiety levels.

In the area of social support, family support was the strongest. An association was found between decrease in depression and support from health carers.

Using multiple regression analysis, the authors found that emotional distress and personal control were the two most important factors in predicting those patients in greatest need of intervention. The more avoidance coping, the higher the anxiety. Similarly, the more cognitive coping, the less the anger. Personal control was associated with lower anxiety and depression.

Although there were flaws in this study with problems in attrition and in the questionnaires used, this study has given thought as to how to cope with analysis in a longitudinal study with patients who are at risk of dying. Complete data sets were impossible with this particular cohort. However the data analysed from this study does give an accurate picture of what actually happens with bone marrow patients with the results biased towards the more healthy individuals.

The highest anxiety, depression, anger and uncertainty levels were measured when patients were hospitalised after intensive chemotherapy and before the bone marrow transplant. It will be of interest to see if the present study produces similar crucial time points. This study showed the importance of, firstly, personal control and, secondly, the importance of the health carers in this crucial time in reducing psychological and emotional

distress which all help in the adaptation process. A more complete picture would have emerged if the study had been carried out for longer.

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Second Detailed Study

A prospective Quality of Life Study of Patients with Oral or Pharyngeal Carcinoma Treated
with External Beam Irradiation with or without Brachytherapy
Authors: Hammerlid E., Mercke C., Sullivan M., Westin T.
Journal: Oral Oncology Vol 33 No3 189-196, 1997

This is a prospective longitudinal study carried out over one year. Patients were oral and pharyngeal cancer patients and were divided into two groups according to treatment. One group consisted of radiotherapy treatment only and the other group received radiotherapy and brachytherapy. Brachytherapy is an increased localised dose by irradium implant. It gives a high dose of radiation to a specific tumour volume at very close range, with a rapid fall-off in dose to adjacent normal tissues (Dow & Hilderley, 1992)

The aim of the study was to gain a better understanding of the quality of life of pharyngeal/oral cavity cancer patients and to see what symptoms and what side-effects distressed patients the most. Finally, the study wanted to assess if there was a difference in patients' quality of lives dependant on the type of treatment.

Patients were tested at 6 points:-

1.   At time of diagnosis

2.   1 month after treatment started

3.   2 months after treatment started

4.   3 months after treatment started

5.   6 months after treatment started

6.   1 year after treatment started.

The questionnaires used in the study were:-

The European Organisation of Research and Treatment of Cancer Quality of Life Questionnaire Core 30 (EORTC QLQ-C30) to measure patients' quality of life.
Psychological distress was measured using the HADS.

A head and neck questionnaire was used on the first twenty one patients and the next eighty four patients answered a more complete but preliminary version of the EORTC designed for head and neck patients the EORTC H&N-37. The head and neck component had questions that related to the position of the tumour and its treatment. To counteract any problems, data was analysed only using questions that appeared in both the head and neck module and the EORTC-H&N-37.

A Sociodemographic and clinical questionnaire contained eight self report questions that related to family, education and work, plus smoking.

Only the questionnaires given at diagnosis were completed in the hospital – all others were by mail.

The sample size consisted of one hundred and five radical and palliative patients. Women formed one third of the sample and ages ranged from 20-85.

The two groups were not strictly evenly distributed. The radiotherapy group consisted of more palliative patients of an older age and were smaller as a group, fifty as opposed to fifty five in the combined radiotherapy and brachytherapy group. There was a compliance rate of 74%. Sixteen of the patients died in this period and ten became non-participants. The cumulative response rate was 89%.

Head and neck patients are cited in the literature as being at more risk of distress and this was verified in this study. Probable psychiatric cases were continuously high over the time of the study. Anxiety peaked at diagnosis for both groups. In comparison depression was at its lowest at diagnosis and peaked at three months for both groups. Depression registered lower than anxiety only at diagnosis. The radiotherapy plus brachytherapy group had continuously lower scores than the radiotherapy group. After one year, depression was higher than at diagnosis for the radiotherapy group. This could be because this group consisted of more palliative patients. Seven was used as the cut off point for the HADS as a possible case and 10 as a probable case. The number of people who scored 7 and over on a scale (anxiety or depression scale) were highest at three months post treatment with 44% scoring 7 and over and lowest at one year with 24%. A more detailed breakdown of anxiety and depression was needed.

Pain was highest at two to three months but side-effects such as dry mouth were worse at one year. With side effects still evident one year was not long enough for this kind of study. One third of patients were still having pain and weight problems. The brachytherapy and radiotherapy group had lower levels of symptomology. This could be because their tumours were not so advanced and the patients were not as old and thus more able to cope with the unpleasant side-effects. The radiotherapy and brachytherapy group seemed in better shape and weighed more.

In order to better compare the two groups statistically, the authors used only those patients who had cancer of the floor of the mouth. This made the sample size even more different with 47/24. The radiotherapy and brachytherapy group had significantly better physical functioning at the time of diagnosis and this continued.

This study could have produced more complicated statistics with the data available such as, correlations and regression analysis. This would have given a better picture of the problems involved and the variables associated with them.

The aim of this study was to look at quality of life in both groups of patients and from this study it does appear that patients' quality of life is not affected by the combined treatment of brachytherapy and radiotherapy.

However, the patients were not randomised into these groups. The decision as to which group to put the patients into was informed. Many of the patients who have these tumours are frail. However, to make an accurate statistical test, both groups need to be randomised or at least to be of equal numbers in each group. The radiotherapy group did have the smaller, weaker, older, and more advanced diseased patients and this showed in the difference from diagnosis point onwards. The radiotherapy and brachytherapy group did not appear to have more problems except at two month period, in fact, by one year, it had statistically less. As the group was a mixed cohort of men and women, it would have been interesting to see if gender and treatment intent were factors associated with psychological distress and quality of life symptoms.

Finally, this was the first time the EORTC H&N-37 had been used.

Third Detailed Study

Predicting delayed anxiety and depression in patients with gastrointestinal cancer
Authors: Nordin, K., Glimelius B.
Journal: British Journal of Cancer; 79(3-4):525-9, 1999

This study was designed to see if psychological distress could be predicted on the basis of tests at diagnosis on anxiety, depression and coping.

Patients were tested twice.

Firstly:- After the biopsy (this was not a set time but was within twelve weeks with a mean of three weeks). There is a large variation in time here. The reason given was that it was dependent on their physical status. A specific time should have been given to see if and when psychological adaptation occurs. It could have happened before physical adaptation with these patients.

Secondly:- At three months and six months for palliative patients and at six months only for radical patients after diagnosis/surgery.

Why were all the patients not tested at three and six months?

Three questionnaires were used

• The Mental Adjustment to Cancer (MAC),

• The Impact of Event Scale (IES)

• The HADS.

The sample consisted of one hundred and fifty nine gastrointestinal patients of mixed gender with ages ranging from 23-89.

The authors used scores of between 8-10 on the HADS to classify 'doubtful' cases, and 11 and over and was considered a 'case'.

Analysis was carried out using stepwise regression with scores from the HADS, MAC and IES questionnaires together with repeated measures anova for changes over time and two-tailed unpaired T test to see the difference in observed frequencies.

A total of ninety eight patients were tested at six months. This gives an attrition rate of 38% in six months. The mean scores at diagnosis were low, with 4 for anxiety and 4.4 for depression. Those who died during the study had significantly higher scores at diagnosis than those who survived. There was a significant decrease for both scales of the HADS over the period of the study.

Using stepwise regression analysis, anxiety and depression at diagnosis could account for 35% of the variance of anxiety and depression at six months, thus showing that the levels of

anxiety and depression at diagnosis are predictive. The MAC and IES questionnaires did not really help in predicting distress. The HADS was a more useful tool with appropriate cut off points to suggest cases

There were flaws in this study. The authors did not state what treatments patients were receiving. Two patients who scored less than 8 at diagnosis, subsequently became 'cases'. No further information was given about these subjects. Were they borderline at diagnosis? What was their gender? Were these palliative patients? Did they become doubtful cases or true cases? Were they receiving social support? A record was made of gender intent and treatment intent but no statistical analysis was carried out in this paper using these groups.

The authors divided the HADS scores into 'doubtful cases' and 'cases'. In the analysis, the two groups were combined. What proportion of patients who were 'cases' subsequently became 'non cases' or 'probable cases' at six months?

A more substantial database of information would have been to have a baseline before surgery, then a set time after diagnosis plus testing at three and six months.

Fourth Detailed Study

Psychological Predictors of Survival in Cancer Patients Undergoing Radiation Therapy
Authors: Leigh, H., Percarpio B., Opsahl C., Ungerer, J.
Journal: Psychotherapy Psychosomatic 47: 65-73 , 1987

This is a prospective study assessing patients who have had radiotherapy treatment. The aim of this study was to address psychological factors affecting survival.

The study assessed patients during one of their visits to the radiotherapy department for treatment.   After three years patients' notes were reviewed to assess 3-year survival in conjunction with the psychological variables.

However, the authors do not specifically say at what point in their treatment were the questionnaires given. They say:-

"During one of their daily visits, subjects received a questionnaire"

This needed to be more specific as treatments can last one day or can continue for six weeks. Similarly, the patients were only tested once. As we do not know when the patients were tested, we do not therefore know if adaptation had already started. By multiple testing, we can ascertain when and how adaptation/coping occurs.

The study addressed three points:-

- The assessment of anxiety and depression in radiotherapy patients

- The assessment of how psychological coping mechanisms relate to survival.

- The assessment of gender differences in psychological predictors of long-versus short-term survivors.

All three points have relevance to this thesis.

Questionnaires used were:

- STAI State

- STAI Trait

- Beck Depression Inventory

- Health Awareness Questionnaire

- A General information Questionnaire was also included.   This was designed to ascertain demographic data, knowledge of diagnosis, procedures and number of people living with the patient.

The STAI State and Trait together with the Beck Depression Inventory are well-validated reliable tests.

Tests for significance using correlation coefficients were carried out on the non-survivors and the survivors with firstly State anxiety and survival time, secondly with Trait anxiety and survival time and thirdly with depression and survival time.

The variables of depression and anxiety were then correlated with factors such as pain, how ill the patients felt, prognosis, nausea, other complications and weight status.

The results showed that significance was reached with Trait anxiety, the higher the Trait anxiety, the higher the chance of survival. Neither State anxiety nor depression reached a point of significance. Patients' ratings on how ill they felt were significantly related to survival time. The survivors' anxiety and depression scores were significantly related to how ill they felt. With the non-survivors, increased anxiety coupled with increased depression was predictive of a shorter survival time. No significant difference in anxiety and depression was found between radical and palliative patients based on their five year survival prognosis. This is surprising. A significant difference was, however, found between radical patients who survived and radical patients who did not.

A difference was also found with gender. In men, the number of people living with the patients correlated positively with their depression scores. Women non-survivors thought their condition was more serious than the men non-survivors. The seriousness of the women's condition correlated with both State and Trait anxiety.

The findings of the study enhance the point that the patients' medical condition is predictive of their survival. However they found that increased distress is associated both with survival and non-survival, rather like a horseshoe effect. The author's explanation is that increased anxiety is adaptive in cancer patients. They hypothesized that as the disease shows signs of advanced progression, the psychological defence mechanism breaks down, resulting in patients feeling both anxious and depressed. In contrast the survivors had high anxiety levels because they were more realistic about their disease.

If the anxiety levels are adaptive then there has to be more than the one test. The anxiety tests must be repeated over time to see the adaptation trend.

The study suggests that the difference in gender is due to coping mechanisms. Women appear to be more realistic in their attitude, whilst the men appear to cope by denial.

This study has flaws. A specified time should have been given to test patients, such as at the commencement of radiotherapy treatment. If the study is looking at survival and patients' coping/adaptation, these tests need to be repeated over time, both during treatment and after treatment has finished. The difference in gender could have been initial and men may need

more time to adapt to a diagnosis of cancer. Measurements over time would have been able to show how, when and if men adapt and cope with their diagnosis and treatment of cancer.

Fifth Detailed Study

A Prospective Multicentre Study in Sweden and Norway of Mental Distress and Psychiatric Morbidity in Head and Neck Cancer Patients.

Authors: Hammerlid, E., Ahiner-Elmqvist M., Bjordal K., Biörklund A., Evensen J., Boysen M., Jannert M., Kaasa S., Sullivan M., Westin T.

Journal: British Journal of Cancer 1999, May; 80(5-6):766-774

This is an interesting longitudinal study the aim of which was to evaluate prospectively psychological distress in a heterogeneous population of newly diagnosed head and neck cancer patients.

A total number of three hundred and fifty seven patients were assessed with ages ranging from 18-88. The majority of patients (72%) were male. Patients were tested six times in all,

1. At the time of diagnosis,

2. One month post treatment

3. Two months post treatment

4. Three months post treatment

5. Six months post treatment and

6. One year post treatment.

All questionnaires were mailed, apart from the testing point at diagnosis, when patients completed the forms at the hospital. The questionnaires used consisted of

- The HADS,

- The EORTC (not analysed in this paper)

- A study-specific questionnaire relating to social, educational and vocational matters plus smoking habits plus clinical data and

- The Karnofsky Performance Status.

The cut-off point for the HADS was over 7 indicated a 'possible' case and over 10 made it a 'probable' case.

The authors state that:

"the majority of patients had combined treatment, most of them external radiotherapy".

The numbers for radiotherapy are 88%, surgery 37% and chemotherapy 19%. However, analysis is not done on the basis of treatment. Futhermore Hammerlid et al did not say or take into account treatments. The measurements started from diagnosis and sometime during that year in which patients were treated. What is required is a specific time frame incorporating treatments.

This study does present data according to gender and age and treatment intent. The authors do acknowledge that compliance rates are lower for those with active disease at one year post diagnosis and that therefore this study has underestimated the psychological problem. The non-participant rate with a mail out questionnaire was low at 18% over the year.

The mean score for the HADS at diagnosis was 4.74, very similar to the previous study, and 3.8 for depression. Patients who could be classified as a possible or probable 'case' on the anxiety scale was highest at diagnosis, 32%. The table in this study clearly makes the distinction between possible and probable cases.

The authors did find that the patterns of anxiety and depression varied over time. Anxiety was highest at diagnosis. However, the number of possible cases was highest at three months. In comparison, depression peaked during treatment at the two month mark. Palliative patients could have finished treatment by two months and this is not clear. However, depression was lowest at diagnosis (17%) and at the one year point. It would have been more informative if the authors had presented the figures for treatment intent.

The authors divided patients up according to scores, 0-7 (no case), 8-10 (possible case) and 11 plus (probable case). They then selected three time spots; at diagnosis, at three months, which they assessed was at the end of treatment, effectively an arbitrary point, and follow-up at one year. They found that some patients shifted from a non-case to a possible or probable case at both the three month and twelve month points. This was particularly prevalent with the depression scale, especially at the three month point. Anxiety showed a marked improvement from diagnosis to three months. They suggest that the HADS be repeated during the first year in order to identify patients in need.

With regard to gender, women were significantly more anxious than men at diagnosis and at the one year mark. No differences were found with respect to depression. It is interesting to note that on the graphs supplied by the authors, at the two month, three month and one year post diagnosis points, the number of men as possible/probable cases on the depression scale is larger than the women. However, the authors do not discuss this. In contrast, anxiety is consistently higher for the women. It would have been interesting to see if this pattern continued.

With regard to age, patients who had retired were significantly less anxious than those who had not, both at diagnosis and at one year. The 'younger' patients were consistently more anxious than the older patients for all six testing points. However, the pattern for

depression was different. There was a peak at the two month point when the older patients out numbered the younger patients and this was repeated at the one year point.

At one year with the depression component of the HADS using the variable of age and gender, the pattern changes and the study ends at this point. The study should have been continued.

Treatment intent was further analysed by combining stages 1 and 11 (radicals) – and stages 111 and 1V (palliative). Anxiety was consistently higher for the Stage 111 and 1V group, except at the one year point when the combined stages 1 and 11 had more possible cases. With the depression component, the patients with more advanced disease were more depressed over time for all testing points with the number of cases higher for the patients with advanced disease at the one year mark than at diagnosis.

A logistic regression analysis was carried out using the variables of age, sex, tumour site, KPS, living alone or not, and the HADS. The one predictor for psychological distress was probable and or possible anxiety or depression at diagnosis. Social support and treatment intent should have been included in the analysis.

In conclusion, this is a good study and the division of the HADS into possible and probable cases is clear. However, rather than specific times according to the calendar, patients should have been tested at specific threatening periods. When the authors write "at diagnosis" what does this mean? Is it immediately after they have been given their diagnosis of cancer, or is it at some other time point? Similarly, why were patients not tested when they first arrived for treatment, in the middle of treatment and at the end of treatment. These time points then become more relevant. The gender component in this study is heavily biased towards men. The authors do not say if this cancer specifically affects more men than women, but with a proportion of 72% men to 28% women, the numbers are an issue. Finally, with changes occurring specifically with the depression component at the one year point, the study should have continued.

From the review of these specific longitudinal studies several points are repeatedly emphasised. The variables of gender, social class and treatment intent need to be incorporated into further studies. The timings of the questionnaires need to be specific and accurate. Patients need to complete the questionnaires under similar conditions. In this way a clear picture of the pattern of anxiety and depression before, during and after treatment can be assessed.

Chapter 4

Measuring Anxiety And Depression Using A Questionnaire Format, Namely Hospital Anxiety And Depression Scale (HADS) and Spielberger's State Trait Inventory (STAI)

Questionnaires have been used with patients to register anxiety and depression. How successful are they when used with cancer patients?

Hospital Anxiety And Depression Scale (HADS)

A number of studies has been carried out using the HAD Scale to measure anxiety and depression in a cancer patient population. The HAD Scale was designed by Zigmond & Snaith, (1983). It has two separate components, anxiety and depression. Their aim was to design a psychiatric questionnaire that would not be affected by a patient's physical state. It could thus be used to screen patients for psychiatric disorder amongst a medical population. Therefore in order to differentiate between different mood disorders, the items relating to emotional and physical disorder were removed.

"The eight items composing the depression subscale were largely based on the anhedonic state since this is probably the central psychopathological feature of that form of depression which responds well to antidepressant drug treatment (Klein 1974) and therefore provides the most useful information for the clinician. The eight items composing the anxiety subscale were chosen from a study of the appropriate section of the Present State Examination (Wing et al 1982) and also from personal research (Snaith et al 1982) into the psychic manifestations of anxiety neurosis" (Zigmond & Snaith 1983).

The HADS questionnaire is laid out in an easy to read format. Patients are required to tick their appropriate response in relationship to how they have been feeling in the past week. If the questionnaire asked patients how they feel now, it might be interpreted too literally.

Moorey et al, (1991), carried out an exploratory factor analysis of the HAD Scale on five hundred and sixty eight cancer patients. They found not only did it have high internal consistency, but the questionnaire also has a reliable, robust factor structure. They were able to confirm its usefulness for measuring anxiety and depression in cancer patients. They looked at the construct validation of the HADS with not only breast cancer patients but also with stroke and myocardial infarction patients. The high levels of internal consistency were confirmed. This has been validated by other studies (Dagnan et al 2000, Lisspers et al 1997, Spinhoven et al 1997, White et al 1999).

Greer et al, (1991), demonstrated that the HADS is an effective tool for cases of anxiety and depression in clinically referred cancer patients. It was successfully used by them to assess anxiety and depression during treatment of adjuvant psychotherapy. They carried out a follow up of this study using not only the HADS but also the Rotterdam Symptom Checklist and Mental Adjustment to Cancer and found HADS showed similar sensitivity to changes in anxiety levels.

In a prospective longitudinal study with head and neck cancer patients in Sweden the feasibility of the HADS and EORTC was assessed (Hammerlid et al 1997). The questionnaires were given six times in one year. Distress was high immediately after treatment with an estimated 21% probable cases of psychiatric morbidity. Both questionnaires showed similar patterns.

Studies do confirm that the HADS is not only a useful tool in assessing anxiety and depression levels, but it is also effective in assessing changes in emotional distress.

With regard to the use of the HADS depression component, Hosaka and Aoki (1996) found that the depression scale on the HADS split the depressed from the normal. The items contained in it were not related to physically ill conditions. However, they did not test it against or in conjunction with the golden standard of the psychiatric interview. They suggested a cut-off point of 8. Montazeri et al, (1998) used the HADS in a quality of life study with lung cancer patients and found that three months after diagnosis nearly one quarter (22%) were depressed.

Ibbotson et al (1994) in their paper 'Screening for anxiety and depression' found that the HADS worked well with patients currently in treatment. They suggest that side-effects do not contaminate the results, as there are no somatic items present in the questionnaire.

The HADS was designed for patients in hospital and may not be suitable for using in comparisons with the general population. Groenvold et al (1999) did not find a significant difference in "cases" of psychological distress between a group of breast cancer patients and women randomly selected. They question the suitability of the HADS for a normal population. But the HADS was not designed for a 'normal' population, it was designed for patients in a hospital setting and the questions reflect this.

Hall et al in a paper written in 1999, six years after this study was started, questions the use of the HADS. They used it in conjunction with a shortened version of the Present State Examination (PSE). They found that if a cut-off point of 11 was used, that sensitivity was low with anxiety at 24.2% and depression 14.1%. With a cut off point of 7, sensitivity was

improved on the anxiety scale to 72%, but the depression scale was still low at 37.4%. Using the combined scores, they found that even reducing the cut-off point to 12, the sensitivity was only 42.7%. This study needs to be questioned. The patients were interviewed in their own homes. The HADS was left for them to complete and return in a sealed envelope. The timescale is not necessarily the same nor are the circumstances and this should have been taken into account. It would have been better to ask them to fill in the forms at the same time as their interview. Their breast patients could have been at various stages of radiotherapy or chemotherapy treatment in this three month period. The PSE is designed to measure how patients felt within the last four weeks, the HADS is designed to see how patients are feeling within the last week. These different time frames could allow for inconsistencies in the accuracy of the emotional functioning recorded if the patients answer the PSE and HADS correctly, especially if they are about to undergo treatment or have just started treatment. Stark et al (2002) in a paper just published used the HADS, STAI State and Trait and PSE to assess anxiety disorders in cancer patients. They found that the questionnaires were useful tools. The HADS and the STAI State were assessed as the most accurate questionnaires, but they did not recognise abnormal anxiety adequately enough. As with Hall et al the time frame was inconsistent. The HADS was given on touch screen monitors, in out patient clinics. The STAI State and Trait and PSE was given within three weeks in patients own homes or in the consulting room, as the patients preferred. Neither the environment nor the time scale is the same for the questionnaires used in this study. The PSE, which is given within three weeks of the HADS is the closest on time. It measures how patients feel within the last four weeks. The HADS measures how patients feel in the last week, there will be a time difference here. In contrast the STAI State measures how patients are feeling 'at that moment in time'. It should not accurately correlate with the PSE given at the same time. The STAI Trait measures how patients 'generally feel' and could therefore be better equated to the PSE than the State questionnaire in this specific study.

Hammerlid et al (1999) emphasized the stability on the HAD scale. They found it had a high internal consistency – Cronbach's α was 0.89 for anxiety, and 0.82 for depression. One question could be considered as having a dual slot of either anxiety or depression – 'I can sit at ease and feel relaxed'. They also found the psychometric performance of the HADS were consistent over time.

Johnston et al (2000) attempted to validate the HADS, and found that the HADS performed satisfactory, and had high internal consistency. This was further confirmed in a

very recent paper by Smith et al (2002). They studied 1474 cancer patients and found stability in the factor structure for different variables such as gender, age and different metastatic cancers.

In a discussion document, Depression and Anxiety in Oncology (2001) Jones, Berard, Nutt and Davidson all confirm the usefulness of the HADS. With respect to depression:

"In terms of a compromise of time, specificity and sensitivity, it seems the best we have.....we have compared it with a structured interview and the Beck Depression Inventory and found it a very useful and robust tool"

The HADS has been translated and used successfully in Europe, for example in Italy (Costantino et al 1999). It has also been used successfully in Japan (Kugaya et al 1998). Therefore, it does seem to be a particularly robust questionnaire, as it can be used effectively cross-culturally.

From this literature review, the HADS does appear to be able to measure both anxiety and depression in patients who are undergoing treatment such as radiotherapy. In a study by Pinder, Ramirez et al, (1993) using the HADS questionnaire, they found that patients in lower socio-economic class were at higher risk for psychiatric disturbance. This could be due to a number of reasons. Members of this social group tend to be less financially secure, have less education, and are frightened of asking the 'professionals' questions. They also tend to have more frequent stressful life events. These factors could lead them to feel more anxious. This increased anxiety could inhibit their recall which in turn reduces the absorption of the information given. This highlights why other factors such as social class and treatment intent need to be incorporated in this study.

Spielberger's State-Trait Inventory (STAI)

This has been a frequently used tool both in research and in a clinical setting. It consists of two questionnaires; the State component investigates how 'one' is feeling at this moment, whilst the Trait part looks at how 'one' generally feels in order to identify levels of neurotic anxiety. The idea of State and Trait anxiety began in the 1960s with Catell & Scheier (1961). Catell further expanded this idea in 1966. Spielberger elaborated on this theory and his ideas were incorporated into a single scale, which had different instructions to measure either State or Trait (Spielberger 1966). The STAI was first used with the two separate components of State and Trait in 1970 (Spielberger et al 1970) and further expanded during the 70s. The current format has been used since the 1980s (Spielberger et al 1980). The STAI has now been used extensively and has been shown to be reliable and well validated in medical and psychiatric trials. Indeed, over 2000 studies have been listed (Spielberger 1983).

Marie Johnston, (1980), used the STAI to measure anxiety in patients before and after surgery. She found that patients experienced high anxiety at various times, before admission, between admission and after surgery. Only a small percentage 'peaked' on the morning of their surgery. Williams et al, (1972), felt high anxiety increased risks in surgical patients. Those with high anxiety required more anaesthetic, which, in turn, increases the risks in surgery.

A number of studies with cancer patients have used the STAI. Cassileth et al, (1986), used the STAI with three hundred and seventy eight cancer patients and three hundred and seventy nine matched relatives. Those patients who were palliative had significantly higher scores than radical patients. A correlation between the State and Trait scores was carried out on the palliative patients and was so high that Cassileth suggest that State and Trait become 'fused' as death approaches. Female patients gave significantly higher scores on the Trait Scale. Similarly, relatives of palliative care patients exhibited significantly higher scores, showing the need for more supportive intervention in the family.

Andersen & Tewfik, (1985), used the STAI to measure anxiety in 45 patients receiving radiotherapy. They investigated the pre and post-treatment anxiety scores for State and Trait. They found significant changes in State anxiety and no change in Trait anxiety levels. Those who registered high anxiety at the pre-treatment stage were still the highest group at the end, but their scores did fall from their original values. Those with moderate anxiety remained

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static and those with low initial anxiety showed an increase. This could be indicative of patients' coping strategies.

In a study on the emotional impact of cancer on patients and their families the Stait Trait Inventory was used to assess anxiety. In contrast to expectation, no difference was found between the adolescent patients and a control group. However this was only three weeks after diagnosis and follow-up data was not included (Allen et al 1997).

Jacobsen, Bovbjerg & Redd, (1993), used the STAI to measure levels of anxiety of seventy seven women who were to have chemotherapy infusions. An association was found between Trait anxiety and anticipatory anxiety on the first and second infusion. They also found that young women suffered from more severe pre-treatment anxiety. They suggest that patients at risk of having high anxiety could be identified in the first instance by their Trait anxiety levels.

Millar et al (1995) used both the HADS and STAI together with a visual analogue scale (VAS) to assess anxiety in patients awaiting surgery for breast cancer. They found a strong correlation between the HADS, STAI and VAS, with an 89% agreement in anxiety scores between the HADS and the STAI. The strongest relationship was with the STAI and the HADS, the weakest was with the STAI and the VAS. Patients were only tested the once and at a particularly anxious time.

Morris et al (1981) evaluated patients prior to their breast biopsy using the STAI and found that the patients who had cancer were more stressed than the patients with benign disease. They also found that age was a variable in that young patients had a tendency to suppress feelings of anger more than their age-matched control group.

Very few longitudinal studies have been undertaken. Leigh et al (1987) looked at anxiety and depression scores over three years and compared the survivors to the non-survivors. This study involved testing only twice, once at the beginning of treatment and after the three years. They found that higher Trait anxiety was significantly associated with survivors. They suggest that realistic anxiety may be adaptive in cancer patients. With only two readings of the anxiety levels, it is difficult to get a total picture. Also 'five' years is considered to be survival in cancer terms. Therefore this study is lacking in both time and number of assessments.

The drawback of the STAI is that it consists of a total of forty questions, twenty State and twenty Trait.

In 1992, Marteau & Bekker compiled a short-form of the STAI State, which consisted of six items. They found that this shortened form produced similar scores to the long-form of the STAI. Therefore coupled with the long Trait test, the overall questions are now reduced to twenty six, which is a more manageable number for an anxious population waiting in a radiotherapy department. This short-form STAI State has been used successfully with a number of different populations but it has not been used in oncology.

Throughout the literature studies, there is an emphasis on psychological distress, particularly on first diagnosis and when having treatment, especially, radiotherapy. To improve the quality of patient care, patients 'at risk' have to be identified. To man a team of psychologists to assess patients would be far too expensive. Accordingly a cheaper but still effective means of screening needs to be put into operation.

From the literature reviewed, the Hospital Anxiety and Depression Scale seems an appropriate tool for a radiotherapy population. Similarly, the STAI State and Trait has been used by previous studies to assess distress in a cancer patient population. The STAI is a well-validated tool as far as the Trait component is concerned, but it is the first time this shortened version of the State component has been used with a radiotherapy patient population.

These questionnaires will therefore be used to assess patients both prior to, and during radiotherapy treatment and for five years after.

Main Issues from the literature review

Anxiety has been shown to differ wildly from 17-50% (Derogatis et al 1984, Fallowfield et al 1994). What causes these differing values? One of the main problems appears to be the differing time frame and context the patients were tested in. Leigh et al (1987) says 'during one of their visits subjects received a questionnaire'. In a treatment, which can span between one day or six weeks this is lacking an accurate time frame. Some studies mention 'diagnosis' (Hammerlid et al 1997). Specificity is also lacking in this statement. Were they tested at the exact time the diagnosis was given, when patients are normally in shock or was it pre or post? Other Studies mention testing in an out patient clinic (Derogatis et al 1984), but with no other information. Anxiety and depression can vary according to disease progression but in many studies patients are grouped together with no selection into specialised cohorts such as gender or treatment intent.

The literature review also shows a dearth of longitudinal studies especially in the field of radiotherapy. In 1977 Peck and Bolland found two third of patients remained anxious throughout their treatment. Have these levels now changed with a more 'open' society and more cancer information given to the patients.

The literature review has also highlighted the conflicting information on gender studies (Holland et al 1986, Lloyd et al 1984). Rahn et al (1998) studied breast patients at the beginning and end of treatment. Anxiety had dropped at the end, but patients were still anxious. How long did this continue? Do other cancer sites cause similar results or is this related to women who are known to be at more risk of anxiety than men (Friedman et al 1994)? Side effects exist with radiotherapy patients. These can affect patient's emotional state (Andersen et al 1984). How long do these side effects continue?

Depression and anxiety affect up to 25% of cancer patients. These are serious conditions, which can be treated. Patient's quality of life and or survival can thus be improved. However their needs tend to go unrecognised. Feelings of sadness and anxiety are expected with a cancer diagnosis and are therefore not recognised by medical staff or family. Screening needs to be implemented. It is therefore necessary to see what specific times are considered 'peak' times for distress, and which population is at most risk. Therefore gender, age, site of tumour, social class, and treatment intent are all confounding variables which need to be addressed. The HADS and STAI have been chosen as well validated psychological screening questionnaires. The HADS measures anxiety and depression in the last week. The STAI

State measures anxiety at this moment, and the STAI Trait measures anxiety generally. Will this difference be apparent in the patient's scores?

In the light of this review the following aims and objectives were proposed.

AIMS

- To observe, using questionnaires, the emotional functioning of patients attending a radiotherapy clinic before treatment, during and five years after treatment had finished.

- To ascertain the times of greatest distress for patients.

- To identify factors that could indicate which patients are the most vulnerable to psychological morbidity.

- To find out what and how patients feel and need during this time.

- To see if predictions be made on the basis of psychological tests at simulation?

- To see if there are indicators for survival.

OBJECTIVES

- To suggest guidelines to radiotherapy departments so that patients' quality of life can be improved during this stressful period

- To identify areas of further research

- To make positive recommendations, for example to health workers so that patients' quality of life can be improved after treatment at the hospital

Chapter 5

Methodology

The Radiotherapy Centre

The radiotherapy department at Mount Vernon Hospital in Middlesex is a large regional centre catering for an approximate area of 1300 square miles. Nine clinical oncologists work in the department, which gave over 4,600 courses of radiotherapy in 1993. The department is supplied with four linear accelerators and one superficial machine. These are manned by twenty seven radiographers.

The Lynda Jackson Macmillan Centre was opened in 1993 at Mount Vernon Hospital to cater for the psychosocial needs of the cancer patient. This study was carried out in collaboration with this centre.

A surgeon or an oncologist transfers patients to the radiotherapy department for further treatment of their cancer. The patient's first appointment in the radiotherapy department is for assessment and very careful planning. This planning is referred to as simulation and is extremely important. The consultant radiotherapist together with a physicist and radiographer make an informed decision on the amount of radiation the patient will require. This depends on a number of factors; whether the patient is being treated radically or palliatively; the position of the tumour, whether it is close to vital organs, the age and general medical condition of the patient; the type and grade of tumour. When the overall dosage is agreed, it is then divided into a daily treatment dose. This is referred to as a fraction. The patient might require further tests and scans before planning can be done. The radiotherapy treatment can vary in length from one day to six weeks.

Instruments

Two anxiety questionnaires were consistently used, the Hospital Anxiety and Depression Scales (HADS) and Spielberger's State-Trait anxiety inventory (STAI). Both these questionnaires require patients to rate their emotional state. Familiar verbal statements are used in a category rating scale. A further in-house Research Questionnaire was added to get feedback from the patients at the end of treatment and for five years after.

The Hospital Anxiety and Depression Scale (HADS) – (See Appendix 1)

Controversy still exists as to the cut-off point of both the anxiety and depression component of the HADS. Furthermore, should this questionnaire score of two components be combined for an overall level of distress or should they be considered separately?

Razavi et al (1990), in their study with two hundred and twenty six cancer in-patients used the total score of 13 as the low cut-off point for adjustment disorder, as they found that this gave them 75% sensitivity and 75% specificity and only 25% false +ve rate. Sensitivity refers to the correct proportion of identified cases. That is the number of true cases (true positives) divided by the number of true cases plus number of false cases. Specificity refers to the proportion of correctly identified non-cases (number of non-cases [true negatives] divided by the number of non-cases plus number of false cases). A high cut-off point of 19 detected major depressive disorder, which gave them 70% sensitivity and 75% specificity. They used the HADS in conjunction with a psychiatric interview, which lasted 45 minutes. The HADS scores varied significantly. Similarly, the psychiatrist interviewing the patients found a comparable difference in his psychological assessment. They ascertained that, in screening for adjustment disorders and major depressive disorders, the incidence of a high score of 15 correlating with a case was 90% and, in the case of low scorers, 74%. It is also important to note that all patients were interviewed and tested by the questionnaires under similar conditions in hospital.

Thus their study was able to validate the HADS as a good tool to be used with hospitalised cancer in-patients with appropriate cut-off points to indicate psychological distress.

Moorey et al (1991) used a cut-off point of 8 for each subscale and recorded clinical anxiety levels of 27% and depression levels of 9%. This patient sample was newly diagnosed patients, within three months of their initial diagnosis, and they were nearly all outpatients. Gender and treatment intent were not included in the variables. Furthermore, Moorey did not use a psychiatric interview for verification of their results.

Is the HADS a suitable instrument to use with a palliative care population to assess anxiety and depression and what cut-off point should be used? Hopwood et al (1991) undertook a study using the HAD Scale looking at eighty one women with advanced breast cancer. They used the Rotterdam Symptom Checklist in combination with the HADS. Patients who achieved high scores on either questionnaire, were further interviewed by a

psychiatrist, who had no knowledge of the questionnaire results. In this study the cut-off point of 11 was used on the individual scales. Some low scorers were further randomised to an interview assessment too. Using the HADS total score with a cut-off at 19 for major depressive disorders, the scores were very similar to Razavi et al (1990), though they found their cut-off point of 18 to be more accurate with sensitivity further improved to 81%. When the two subsets are used with a cut-off point of 11, they found the anxiety scale to be more effective than the depression.

A study by Pinder et al (1993) used 11 as the cut-off point on the separate scales. Their patient population was one hundred and thirty nine women with advanced breast cancer. A total of 19% had scores of 11 and above on the anxiety subscale and 12% depression, with an overall percentage of 35. Other studies have shown a similar rating with approximately 25-50% of patients suffering from clinically significant anxiety and depression (Plumb & Holland 1981).

Carroll et al, (1993), screened for anxiety and depression in a total of eight hundred and nine in and outpatients with cancer. They used both the low cut-off (8) and high cut-off (11) for both subscales. Previously only fourteen patients had been referred by the doctor for psychological screening. With the low cut-off point, 47.6% of this population needed further psychiatric intervention. This is remarkably similar to Derogatis' (1983) figure. With the higher cut-off point of 11, a total of 23% fell into this high score category. The depression subscale of 11 was found more frequently in inpatients, though there was no significant difference in anxiety levels between in and outpatients. A total of 89% of the subjects had active disease, but again their scores showed that there was no significant difference in their anxiety or depression scores. However, the HADS was the only instrument used in this study. It was not specified if patients were having treatment or not. Neither did they specify if any patients were receiving anxiolytic drugs or if they had any previous psychiatric history.

Ibbotson et al (1994) stated that:

"at a score of over 15, the sensitivity was 85% specificity 71% and positive predictive value of 47%"

Using a cut-off point of 19 they found it was effective in patients whose cancer was in remission

'sensitivity was 92%, specificity was 95% and the positive predictive value 72%.'

That is ¾ of the high scorers would be cases. For those patients with stable disease they suggest a cut-off point of 15

"with sensitivity of 85% and specificity of 77% and positive predictive value of 47%"

Aass et al (1997) using the HADS found a prevalence rate of 13% for anxiety and 9% for depression in a radiotherapy hospital, with female patients exhibiting significantly more anxiety than their male counterparts. The HADS was used with a cut-off point of 11 for cases. In a comparison with other malignancies, gynaecological patients were the most anxious cohort. This was not a longitudinal study.

Kygaya et al (1998) found that the HADS was sensitive and specific for Japanese cancer patients. Using both psychiatric interviews and the HADS, they found that the optimal cut-off point was 10/11 for adjustment disorders. This gave a high sensitivity of 91.5% and specificity of 65.4%. For depressive disorders a 19/20 cut-off point was needed. This gave an 82.4% sensitivity and 96.3% specificity.

The HADS has also been used successfully on older cancer patients. A cut-off point of 15 was used by Roth et al (1998) on elderly prostate patients.

Young and Maher (1992) in their study showed that the HADS identified 75% of patients to be in need of extra support, when compared with a trained counsellor's assessment. They ascertained that 44% of radiotherapy patients had high anxiety levels. Young & Maher used the separate subscales of the HADS score, with the low cut-off point of 8 and considered 10 as high. According to Murphy et al (1987), a high sensitivity cut-off point should be utilised where the prevalence rate is high. Therefore, in a radiotherapy department where the stress levels are high, a higher cut-off level is needed to screen more accurately.

From the review of the cut-off points of the HADS it appears that both the separate and unitary scales should be used. Patient's scores will, therefore, be assessed at the 8 cut-off point to indicate a 'possible' case and at the 11 cut-off point to indicate a 'probable' case, for the separate subscales of anxiety and depression. Using the combined scores, the cut-off points of 13 and 18 will be used, which suggest adjustment disorder and major depressive disorder respectively. These points were used successfully in previous studies in conjunction with a psychiatric interview.

The HADS was given to patients on twelve separate occasions. The HADS asks patients to tick the response "which comes closest to how you have been feeling in the past week".

Spielberger's State-Trait Anxiety Inventory

This is a self-report questionnaire (see Appendix 2 & 3), which has two components that measure two different aspects of anxiety, Trait and State. The Trait was given only at simulation, but the State STAI was given all twelve times.

The Trait anxiety refers to an individual's proneness to anxiety generally. In contrast State anxiety refers to the individual's response to stress at that moment in time. Each item on the scale is scored one to four.

The STAI Trait has been used to identify people with neurotic anxiety. It is a self-evaluation questionnaire. No time limit is imposed, however, each component should take five minutes to answer. Instructions are written on the forms. The Trait form consists of twenty questions. Scores range from 20 to 80. If one or two items are missing, the mean for the questions answered is taken and multiplied by twenty and then rounded to the following highest number. The form is discarded if three items are missing. The average Trait score for patients without psychiatric complications was 41.33 (Spielberger 1983) and this was used as the cut-off point for Trait anxiety.

The State form was given first and then the Trait. The State form of the STAI consisted of six items only. Marteau and Bekker 1992, modified the twenty item test to six. The reliability coefficient for this six item STAI State test was $\alpha = 0.82$. and for the 20 item STAI was $\alpha = 0.91$. Furthermore Marteau & Becker found no difference in the mean scores between the three sets of subjects whom were tested with both questionnaires. Therefore as patients were already having one anxiety questionnaire (HADS) and the State component unlike the Trait was being repeated over time, this shortened version was thought to be an appropriate tool with sick patients who had a number of forms to fill in. It was further hoped that this shortened version would maximize the response rates and reduce the number of response errors and unanswered items, which in turn would improve the validity of the findings.

The mean given for general medical and surgical patients without psychiatric complications by Spielberger was 42.6 and this were used as the cut-off point to indicate a possible anxiety 'case'. A score of 46 was used as the cut-off point to indicate a probable anxiety 'case'. Normal scores range between 32 and 39.5 depending on the sex and age of the person, with women showing a slightly higher score than men on average. However, women aged between 25 and 29 have the highest scores and women aged between 55 and 59 have the lowest score overall.

In-House Research Questionnaire

A number of other questions need to be asked when assessing cancer patients during and after radiotherapy. This is predominately in the area of patients' needs. It is only through

direct contact with patients and asking relevant questions that assessment on patients' requirements can be made. What staff think patients' needs are and what patients feel their needs are could be very different.

One of the aims of the current study is to identify factors to improve patients' quality of life. In order to do this, patients' wants and needs have to be assessed. The in-house Research Questionnaire (See Appendix 7,10,12,14,18,20,22,24) was specifically planned. It was designed from feedback from patients and staff. Some questions were patient-led on their experience of radiotherapy treatment, others were introduced from interviewing past sufferers at the Lynda Jackson Macmillan Centre. To obtain some feedback on the Lynda Jackson Macmillan Centre staff suggested other questions. The centre had only recently opened and information was needed to ascertain which areas were being satisfactorily addressed or not. Specific questions related to specific areas were considered to be more appropriate.

The questions for the in-house research questionnaire were designed into four principal sections namely; psychological well-being, information seeking, social support, and physical well-being.

Psychological Well being:

Sanson-Fisher et al (2000) in a large study in Australia of one thousand four hundred and ninety two cancer patients tried to assess some of cancer patients' unmet needs. The area of highest need was in psychological support. Patients still had many fears concerning the cancer spreading or returning and general uncertainty about the future with regard to themselves and their families.

With regard to this study, it is important to know if patients feel more anxious and depressed when their treatment finishes, or at weekends when they do not have contact with the hospital staff. Do patients feel frightened during their treatment and why. Once a need is found that issue should be addressed. Questions therefore might follow on to see how patients feel that their needs can be addressed.

Information Seeking:

Sanson-Fisher et al (2000) stated that the next area of need was in information. Patients want to be given accurate information about the cancer so that informed choices could be made and a sense of control regained. The staff at the Lynda Jackson Macmillan Centre wanted to know if the patients had enough information on their cancer. Literature was given to patients and feedback was required. It is a difficult balance and it is easy to swamp a patient with information. Also information needs alter and this should be assessed continuously.

Patients were finally asked in the Sanson-Fisher study for a perceived need with regard to services or resources. The overwhelming response was for 'Easy car parking at the hospital or clinic'. This was followed by 'monetary allowance for travel and library of books and videos about cancer and related issues. Brochures about services and benefits followed. The next item was a 24-hour telephone support and cancer advisory centre. All these requests are needs which patients felt would improve their quality of life. These items could be labelled as 'information services' in the current study.

Social Support

It is important to know if patients have a confidante, as the literature shows that patients are less depressed if they have someone to confide in. This information will therefore be analysed with the results of the HADS. Did patients get enough support while undergoing radiotherapy? Other areas such as counselling, relaxation classes, home support and support groups would be discussed.

Physical Well Being

Side-effects especially fatigue are a problem with radiotherapy patients and these were included in the physical well-being section. How long did patients suffered from their side effects? Did they start immediately at the time of treatment or sometime after? How debilitating was the side effect? Did it affect their psychological state? It was hoped from this information obtained from patients that literature on these effects could be given to patients prior to treatment or at the end of their treatment. This would explain the risks of side effects, how long they last and how patients can be helped. Specific sites could be at more risk of side effects and specialised literature should be made available for these specific sites.

This should, in turn, help patients' psychological state. Patients should feel more informed and have more control of their situation.

The Research Questionnaire also asked general questions on how patients felt and their health. We needed to know if patients had received anxiolytic or depressive drugs from their GPs , so a question on medicines was inserted. Space was given on the form for patients to write how they felt their treatment could have made less stressful.

Some questions were repeated at each posting, other questions were new. The in-house Research Questionnaire was given eight times in all, starting from the time of the last treatment for five years. At the end of five years it was important to know how patients felt looking back, being assured that no more questionnaires would follow!

Materials and Method

Ethical approval was obtained in two stages for this study. It was first given by the Hillingdon District Ethics Committee in July 1993 to study distress in patients receiving radiotherapy treatment. A new second application was then submitted to the committee and passed in April 1994. This enabled the study to be further extended from six months post treatment to five years after the radiotherapy treatment ended.

Various points were made in the application. As patients' notes were to be used, assurance was given on patient confidentiality. All completed forms would be kept in a locked cabinet. Care would be taken to insure that bereaved relatives would not be upset. Steps would be implemented to ascertain if the patient had died before the postal questionnaire was sent out. In the event of a death, a sympathy letter would be sent out. All patients, who were eligible for the study, had to give their consent in writing. As ethical approval was in two stages, patients' consent had to be given twice, firstly, when they arrived in the radiotherapy department and secondly, before the six month postal questionnaires.

This study commenced in September 1993 and was in conjunction with the Lynda Jackson Macmillan Centre, which had just opened. During one calendar month, all patients arriving in the radiotherapy department for simulation, were interviewed, provided they were not too sick or sedated. A simulator is a diagnostic x-ray machine that can replicate the treatment conditions, but which is linked to a closed TV circuit. This enables the staff to accurately pin-point the tumour. Appropriate markers are put on the body so that accuracy is repeated throughout treatment.

An explanation was given of the Centre and its purpose and the patients were given literature (see Appendix 4) with timetables. For example, Benefits Advice was 11am to 3.30pm on a Monday. They were told they could visit the centre at anytime during the day. A pamphlet was also given called 'Coping with your cancer – A Self Help Guide'. It was then explained that, in order to increase the quality of patients care, feedback was needed from the patients. An explanation of the study was given. A letter was then handed to the patients (see Appendix 4 - Consent Letter), which explained the study and why and how this would help the quality of patient care. All patients were also assured that, if they did not wish to participate, their treatment would not be affected in anyway. The letter also explained that permission was needed to check details of treatment given in their notes.

Once the patient had signed the forms, he/she was further interviewed for demographic details which were entered onto an index card. The patient's address, telephone number, GP

and date of birth were verified. A number of other factors was noted (see Appendix 5 – List 1) including gender, marital status, occupation and social class[2]. The patient was then given an identity number and this was used on all the forms to insure confidentiality The researcher was the only person to know any personal details. At this point, some patients took the opportunity of talking about the department and their treatment.

Each patient was then given a pen, clipboard and a booklet of questionnaires, which he/she was asked to complete while waiting to be called in for the planning of their radiotherapy treatment.

Other information was secured from the patient's notes. This included treatment intent, type and site and stage of tumour. The number of fractions the patient was to receive, plus the treatment area and if the patient had secondaries present. Note was also made if the patient was receiving anxiolytic or depressive drugs. Other treatments such as surgery, chemotherapy, previous radiotherapy, hormone treatment were noted on the index card, identified by the identity number. The dates of the current radiotherapy treatment were also included so that it could be assessed when the follow-up questionnaires should be given.

The booklet of questionnaires contained the HADS (see Appendix 1) and STAI. At simulation, the STAI consisted of both the State (See Appendix 2) and Trait components (See Appendix 3). The Trait questionnaire consisted of the normal twenty questions, whereas the State component consisted of a shortened form of six questions only.

When the questionnaire booklet was given at the end of treatment and with all subsequent postings, it also contained the research questionnaire, which was specifically written for that posting. Each patient was also sent an individual letter (See Appendix 11,13,17,19,21,23). At first, the purpose of these letters was to remind patients of the study and to personally thank them for participating. However, as the study progressed, feedback about the study began to be incorporated into the letter. For example, after-care booklets were added or changed and given to patients, maps to the department were redone and patients were informed of these changes in the letter. These changes were brought about from the feedback obtained from the patients.

At the time of the six month postal questionnaires, a leaflet on the Lynda Jackson Macmillan Centre was included giving patients further information should they need it (See Appendix 9) and this was repeated in the first year postal questionnaires. At the eighteen

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[2] The Market Research Society, 'Occupation Groupings A Job Dictionary' 3rd Ed.(1991) Pub. Twentieth Century Press Limited.

months postal questionnaires, a booklet 'Coping now that your radiotherapy treatment is finishing' and a sheet about the booklet and requesting feedback was included (Appendix 15). In this way patients were able to feel that their comments initiated positive action.

In the first phase, that of testing prior to and during treatment, the number of times the patients were tested depended on the number of fractions they were to receive. If a patient was only having a single fraction, which is used primarily to alleviate pain, they were referred to as the SF group (single fraction). This group of patients would only receive questionnaires at simulation and four weeks post treatment. Their maximum number of questionnaires during treatment therefore was two. These were all palliative patients.

Graph 1: Timings of the Questionnaires
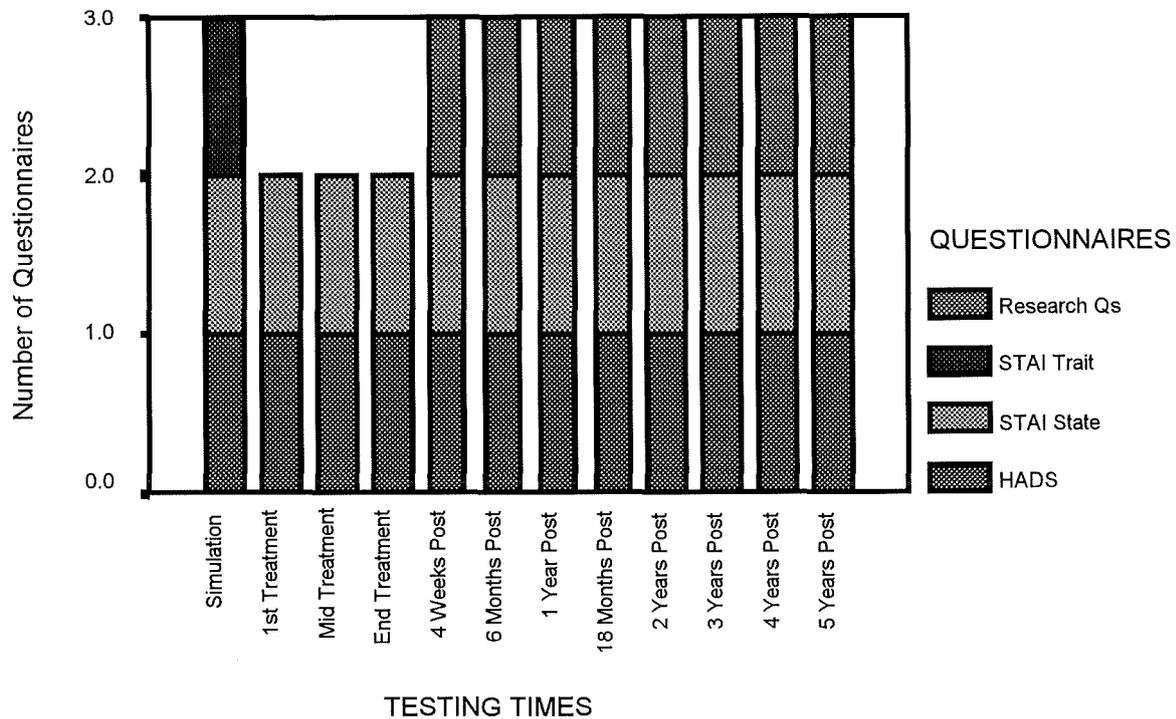
Patients who were having two to five treatments filled in the questionnaires three times; at simulation, at end of treatment and four weeks post treatment. This group was referred to as short multi fractions (SMF). These were all palliative patients

Patients, who had more than five fractions, were referred to as long-multi fractions (LMF). This included both radical and palliative patients and this group was the largest cohort. They completed the questionnaires on five separate occasions during treatment; namely, at simulation, before the first treatment, mid-treatment, end of treatment and four weeks post treatment. Therefore all patients completed the forms at simulation and post treatment.

In the first phase of the study, the patients were given the questionnaires to do while they waited for treatment. If they had any problems, staff was on site to assist. Patients' notes were perused to see if there was any change to treatment or drugs. Before the four week postal questionnaires, all patients' notes were checked to see if the patients were still alive before the questionnaires were sent out. If the forms were returned saying the patient had died, a letter of condolence was immediately sent out. All the demographic details plus

medical records were entered onto an index card (See Appendix 25) so that they could be data processed for the computer.

Six months after treatment, written informed consent from all patients was sought according to the Ethical Permission, to see if they would be willing to continue with the study. Patients were required to sign a letter (see Appendix 9) if they now longer wished to participate and return it in a stamped addressed envelope. Those who agreed to participate were then tested at six months, one year, eighteen months, two, three, four and five years after treatment. This added up to a maximum of twelve times for the Long Multi-Fraction group. Each time before sending out the postal questionnaires, the patients' notes were checked to see if they were still alive and changes in treatment noted. In the event of missing notes, the GP was contacted to make sure the patient was alive or not. This was to insure that the forms arriving did not upset the relatives. Each time that the postal questionnaires were sent out, a personal letter (see Appendix 11) was included which also gave the patients some feed back..

The problem of incomplete forms was easily rectified when the patient was on site. With the postal questionnaires, it was a problem. Once the forms were returned, they were checked and if any questionnaire was missed in error, they were sent back to the patients with an accompanying letter. If the patients had inadvertently missed data out, this was also returned. However, if it was only one item in the questionnaires, then an average was taken, as recommended by Zigmond and Snaith (1983) and Spielberger (1983). In the case of two patients, the forms were not returned as it was obvious from the research questionnaire that they were at the terminal stage of the disease and this was inappropriate. That questionnaire was excluded from the analysis. All data from the questionnaires were entered into the computer and all were double-checked.

Method of analysis

Analysis was carried out using SPSS. Differences in the variables were computed by univariate analysis of variance, Tukey Post Hoc tests were used. Independent Ttests for unpaired data were undertaken provided the distribution was normal (tested by Levine's test for equality of variances) and General Linear Models (GLM) construed. Correlations were undertaken. Stepwise multiple regression analysis was used. For all analysis, P equal to or less that 0.05 was considered to indicate significance. All data analyses were conducted using SPSS 8 and 10.00 for Windows statistical software, 2001.

Chapter 6

Results – Analysis of Questionnaires through Treatment

Because of the complexity of this longitudinal study the data will be analysed in three separate stages. Part 1 will consist of the analysis of patients through treatment and four weeks post treatment. This marks the boundary of the first ethical permission. Part 2 will show the analysis from six months to five years after treatment. Part 3 will analyse those patients who completed all questionnaires for all time points. This is a very much smaller cohort, as some patients who survived missed a questionnaire due to illness, holidays or the postal system. It will look at the differences between those who did not respond to all the questionnaires over treatment and those who did.

Part 1 – Results through radiotherapy treatment

All patients attending the radiotherapy department during one calendar month for radiotherapy treatment were asked to participate.

A total of three hundred and forty six patients were interviewed in the radiotherapy department when they first arrived for simulation - the planning of their treatment.

A total of two hundred and sixty nine patients (79%) agreed to participate. Non-participants were perceived as too ill (36), language problems (4), got missed (11), had a physical disability (4), were confused and/or highly anxious (9) and forgot to bring their glasses (6). There were seven refusals.

The cohort of two hundred and sixty nine patients who agreed to participate was divided into groups. The assignment to a group was dependent on the number of fractions – (treatments) they were to receive. The Single Fraction group was those patients who received only one treatment. These totalled thirty one (12%). The Short-Multi-Fractions group received 2 - 5 fractions. These totalled fifty two (19%). The Long Multi-Fractions group received over 5 fractions. These totalled one hundred and eighty six (69%).

Table 1: Demographic And Medical Characteristics

DEMOGRAPHIC	Nos	%	MEDICAL	Nos	%
Gender			**Sites**		
Female	157	59.0	Breast*	106	39.0
Male	112	41.0	Lung	39	14.0
			Prostate	25	9.0
Social Class			Skin**	24	9.0
			Other***	18	7.0
Class A	13	5.0	Gastro-int	14	5.0
Class B	41	15.0	Bladder	14	5.0
Class C1	84	31.0	Head & Neck	12	4.0
Class C2	70	26.0	Gynae	10	4.0
Class D	49	19.0	NHL	4	1.0
Unclassified	12	4.0	Unknown	3	1.0
Marital Status			**Treatment Intent**		
Married	178	66.0	Radical	173	64.0
Widowed	45	17.0	Palliative	96	36.0
Divorced	18	7.0	**Ages**		
Single	17	6.5	18-25	3	1.0
Separated	6	2.0	26-50	44	16.0
Unknown	1	0.5	50-65	86	33.0
Partner	6	2.0	65+	136	50.0

*   Includes one male breast patient
**   Includes only superficial tumours, melanoma is included in 'others'.
***   Includes glioblastoma, sarcoma, mesothelioma, Hodgkin's Disease, melanoma.

Table 1 summarises the patients' demographic and medical characteristics. Ages ranged from 20-89 with a mean age of 63.

Tables 2,3,4 and 5 are in the appendix No 28, 29, 30, 31 respectively. These analyse the demographic data at first treatment, mid treatment, end of treatment and four weeks after their treatment has finished.

In this study, anxiety and depression were analysed first as separate components and then as a combined score indicating psychological distress. Each separate component has a range of scores from a minimum of 0 to a maximum of 21.

The patterns of anxiety and depression as scored by the HADS exhibit very different patterns over the course of radiotherapy treatment. Anxiety shows a decrease from a peak at simulation to 4 weeks after treatment. Depression scores are lower, with mid treatment the lowest point with an increase in scores from the end of treatment. Anxiety and depression also appear to peak at different times, anxiety at simulation and depression at 4 weeks post treatment.

Graph 2. Mean Anxiety and Depression Scores through treatment as measured by the HADS

Times Questionnaires were Given
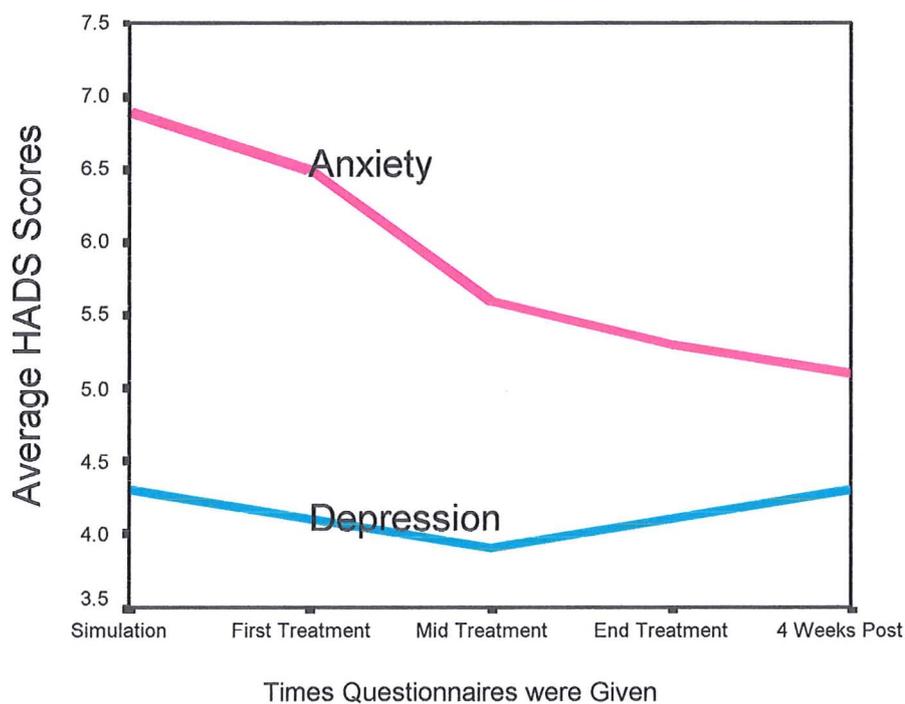
Anxiety

Graph 3 shows the distribution of anxiety scores' according to the variables of gender and treatment intent. All patients initially show a downward trend from simulation. From mid treatment onwards two contrasting trends are apparent. Women and radical patients continue a downward trend. In contrast men and palliative patients showed an upward trend.

Graph 3. Mean HADS Anxiety Scores from Simulation to Four Weeks Post Treatment
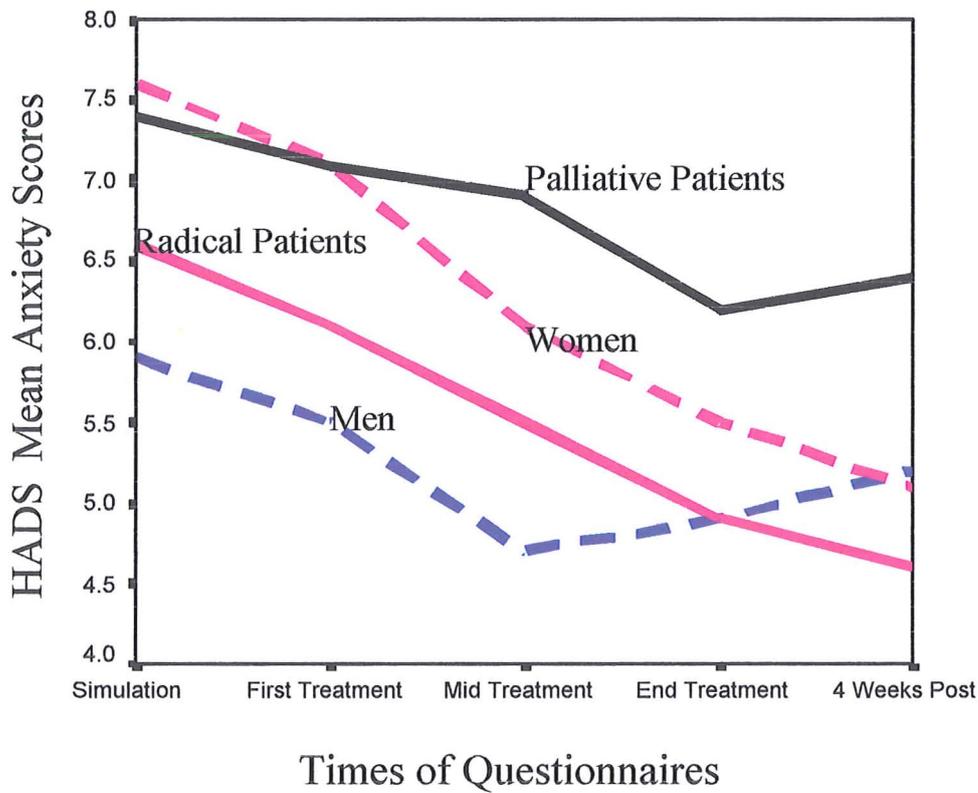
Table 6 gives the mean HADS anxiety scores of the different patient groups as they go through treatment. Palliative patients had significantly higher anxiety scores than radical patients at each time point throughout the treatment time. Women had significantly higher anxiety scores than men at simulation, first treatment and at the end of treatment.

Table 6: Mean HADS Anxiety Scores of Patients from Simulation to Four Weeks Post Treatment

Times of Questionnaires	All Mean (sd)	Radical Mean (sd)	Palliative Mean (sd)	Females Mean (sd)	Males Mean (sd)
Simulation	6.93	6.6*	7.4*	7.6**	5.9**
	(4.2)	(4.1)	(4.3)	(3.9)	(4.3)
Numbers	269	173	96	157	112
First Treatment	6.47	6.11*	7.11*	7.18**	5.52**
	(4.19)	(4.09)	(4.31)	(4.16)	(4.05)
Numbers	257	166	91	147	110
Mid-Treatment	5.65	5.46*	6.91*	6.08	4.75
	(3.91)	(3.9)	(3.8)	(4.07)	(3.40)
Numbers	168	145	23	115	53
End Treatment	5.27	4.93*	6.25*	5.53**	4.87**
	(3.94)	(3.81)	(4.18)	(3.95)	(3.90)
Numbers	215	160	55	131	84
4 Weeks Post	5.15	4.66*	6.37*	5.13	5.19
	(3.85)	(3.68)	(4.01)	(3.76)	(4.02)
Numbers	217	155	62	133	84

* Significant difference in treatment intent, $F(1,265)=7.016$, $p=0.009$

**Significant difference in gender, $F(1,265)=15.885$, $p=0.001$

* Significant difference in treatment intent $F(1,253)=8.404$, $p=0.004$

**Significant difference in gender $F(1,253)=13.738$, $p=0.001$

* Significant difference in treatment intent $(F1,164)$, $p=0.05$

* Significant difference in treatment intent $F(1,211)=6.705$, $p=0.001$

**Significant difference in gender $F(1,211)=4$, $p=0.04$

* Significant difference in treatment intent, $F(1,216)=9.38$, $p=0.002$

Palliative patients were significantly more anxious throughout treatment and 4 weeks post than the radical patients. Women were more anxious than men at simulation, 1st treatment and end of treatment.

During treatment the variables age, use of complementary medicine, previous radiotherapy, social class, marital status were non significant except for site of tumour. Site was significant for both the HADS and STAI State at simulation. A posteriori Tukey-HSD test showed that the mean anxiety for skin patients was significantly lower than those patients being treated for cancer of the lung, $F(10,258)=2.12, p=0.028$. At first treatment a significant difference was found in anxiety on the HAD Scale between the site of the tumours, $F(10,246)=1.96, p=0.038$. A posteriori Tukey-HSD test showed that this difference occurred between patients who had a head and neck tumour (Mean=9.750) and patients with Non-Hodgkin's Lymphoma (Mean=7). However, as none of the group sizes is equal, Type 1 error is not guaranteed.

Analysis using cut-off points to indicate psychological problems

HADS

In this study, anxiety and depression were analysed separately using an initial cut-off point of 8, as recommended by Zigmond and Snaith (1983) to show borderline anxiety and depression cases. A further cut-off point of 11 was used as verified by Zigmond and Snaith and Hopwood et al (1991) to indicate 'cases' of anxiety and depression.

Graph 4 shows the percentage of patients through treatment who were either a 'non case' with scores of less than 8, a 'possible case' with scores of between 8 and 10 and a 'probable case, with scores of 11 and over in each subscale.

Graph 4: Possible/Probable or Non Cases of Anxiety and Depression through Treatment
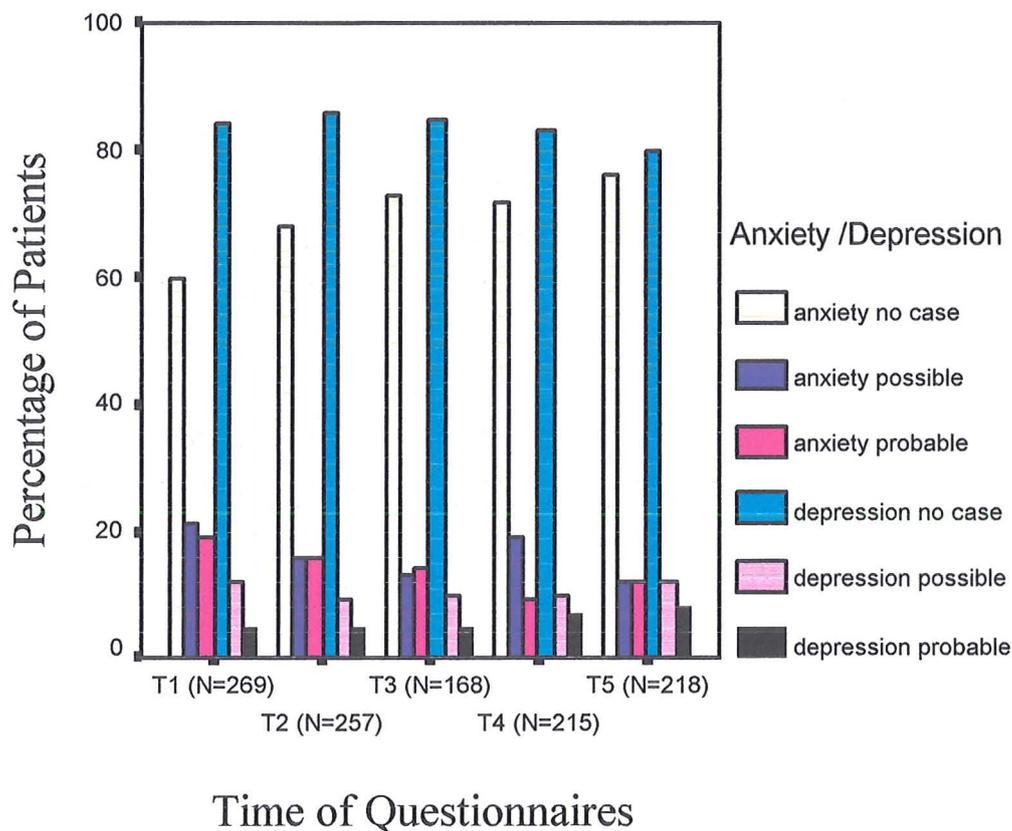
[T1= Simulation, T2= 1st Treatment, T3= End Treatment, T4= End Treatment, T5= 4 Weeks Post Treatment]

Anxiety HADS

The peak number of 'cases' for anxiety is at simulation with 40% of patients indicating anxiety. At four weeks post treatment this dropped to 24%. These are all the patients scoring 8 and over on the anxiety subscale of the HADS. A large percentage of patients according to gender are indicating anxiety over the course of their radiotherapy treatment as shown in Table 7. Women show a decrease in the percentage of cases over treatment. Men show a decrease until mid treatment and then the numbers rise. By the post treatment point men are indicating one more case than the women.

Table 7: Percentage of men and women with anxiety levels of 8 and over

	T1	T2	T3	T4	T5
Women	45 (N=157)	37 (N=157)	30 (N=115)	30 (N=131)	23 (N=133)
Men	33 (N=110)	25 (N=110)	17 (N=53)	24 (N=84)	26 (N=84

[T1 = Simulation, T2 = 1ˢᵗ Treatment, T3 = End Treatment, T4 = End Treatment, T5 = 4 Weeks Post Treatment]

Graph 5 shows the HADS anxiety scores being further broken down into two groups of possible anxiety, scoring between 8-10 and probable scoring 11 and over for men and women patients undergoing a course of radiotherapy treatment. Overall the percentage of patients as possible/probable cases for men and women fell from a high at simulation over the course of treatment. A higher percentage of women, 45% are indicating anxiety than men 33%. Over the course of treatment the number of 'cases' for women drop to 23%. Men's 'cases' falls at first and mid treatment, but then rises. At the four weeks post point the percentage of 'cases' for men is higher than for women.

At the end of treatment the number of 'possible' cases for women rose, but 'probable' cases fell. After treatment the number of 'probable' cases for men and women rose.

Graph 5: Possible/Probable Cases of Anxiety through Treatment with variable of Gender
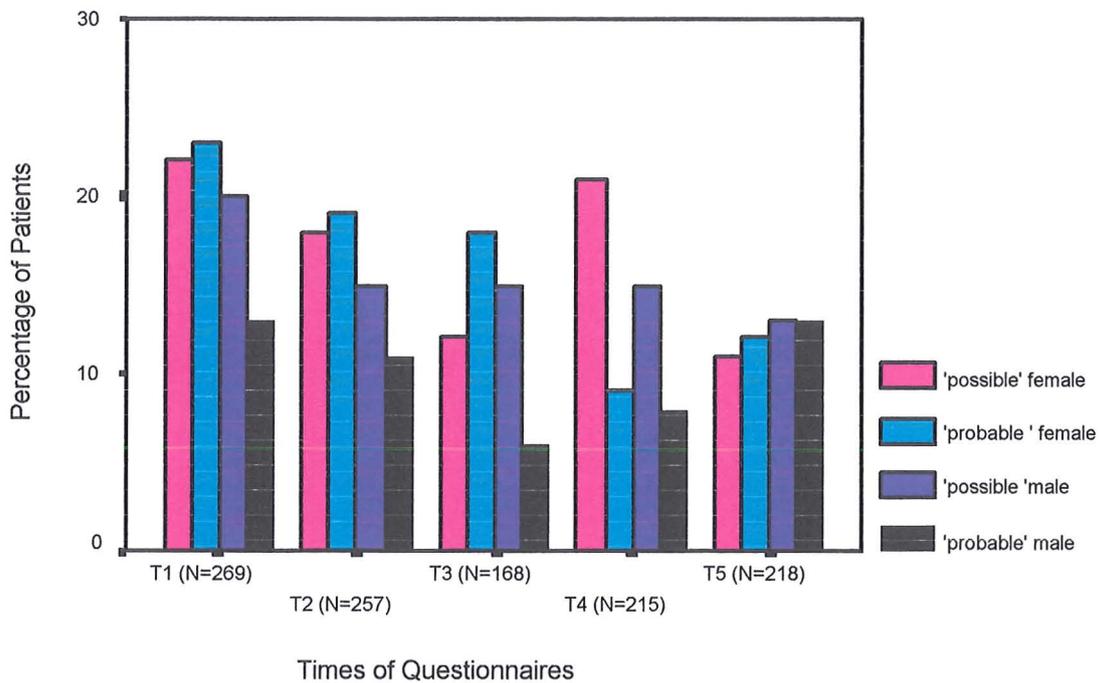
[T1= Simulation, T2= 1ˢᵗ Treatment, T3= End Treatment, T4= End Treatment, T5= 4 Weeks Post Treatment]

The division by treatment intent using the cut-off point of 8 shows the degree of anxiety which palliative patients especially are experiencing. This is illustrated in Table 8. Radical patients show a decline in cases over treatment. Palliative patients exhibit a decline until mid treatment. The number of cases then rises. Simulation has the highest number of 'cases' for both radical and palliative patients, 38% and 44% respectively.

Table 8: Percentage of radical and palliative patients with anxiety levels of 8 and over

	T1	T2	T3	T4	T5
Radical Patients	38 (N=173)	29 (N=166)	25 (N=144)	25 (N=160)	19 (N=155)
Palliative Patients	44 (N=96)	37 (N=91)	33 (N=24)	36 (N=55)	37 (N=62)

[T1= Simulation, T2= 1ˢᵗ Treatment, T3= End Treatment, T4= End Treatment, T5= 4 Weeks Post Treatment]

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Graph 6 shows this data being further analysed into 'possible' and 'probable' anxiety cases. The number of cases throughout treatment is very high for the palliative patients. The number of cases for the radical patients is consistently lower. Simulation has the highest number of 'possible' cases. At four weeks post treatment the number of 'possible' cases has fallen but 'probable' cases has risen for both radical and palliative patients. The number of 'probable' cases for palliative patients throughout treatment remains high.

Graph 6: Possible and Probable 'cases' of Anxiety for palliative and radical patients over treatment
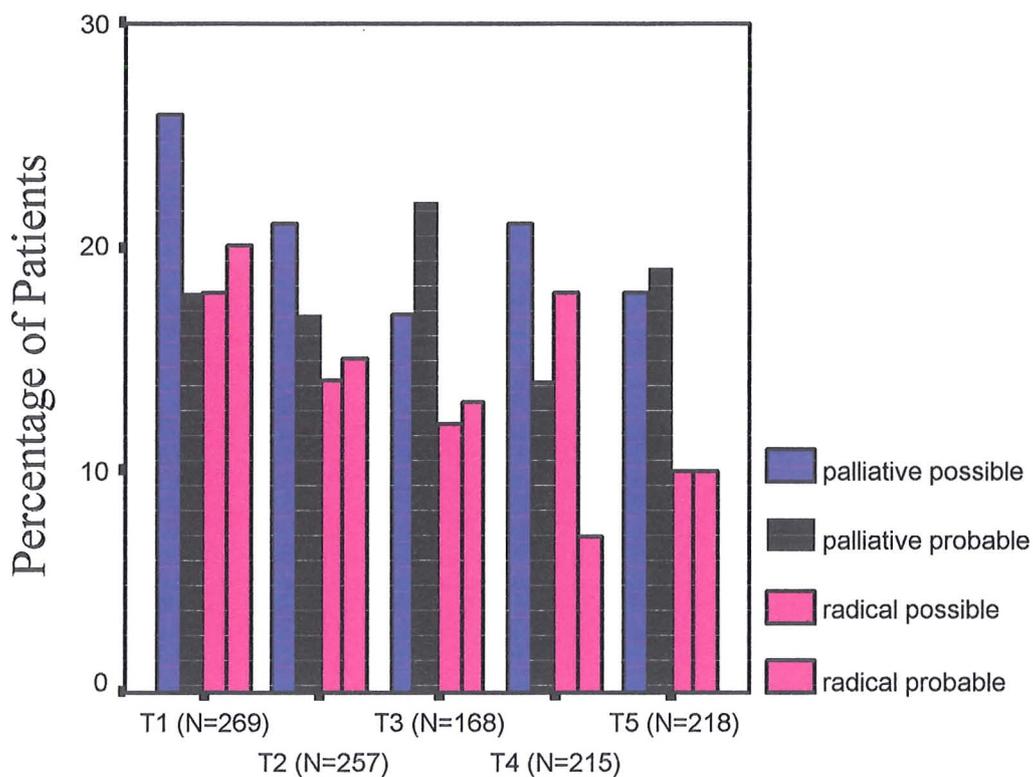
[T1 = Simulation, T2 = 1st Treatment, T3 = End Treatment, T4 = End Treatment, T5 = 4 Weeks Post Treatment]

Repeated measures analysis of variance was used to see the effects of gender and treatment intent on anxiety over the course of treatment. Mid treatment was left out of this analysis, as only 15 palliative patients were included at that testing. There was a significant effect for anxiety over time, $F(3,570)=15.180$, $p=0.001$. There was also a significant effect

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for treatment intent, palliative patients (Mean 6.955), radical patients (Mean 5.178), $F(1,190)=7.809$, $p=0.006$. However, gender did not reach significance, men (Mean 5.487), women (Mean 6.646), $F(1,190)=3.316$, $p=0.070$.

STAI State

The STAI State anxiety questionnaire showed the same similar patient trends as the HADS. Graph 6 shows the different patterns for the various patient groups.

Graph 7: Mean STAI Anxiety Scores During Treatment

Time of Questionnaires

T1=simulation, T2=1ˢᵗ treatment, T3=mid-treatment, T4=end treatment, T5=4 weeks post treatment

The STAI State indicated that the time of greatest anxiety was at simulation for all patient groups except the palliative patients, who peaked at mid treatment. Women, men and radical patients all show a decline in anxiety through treatment. At the end of treatment men and palliative patients, show a trend upwards, with anxiety four weeks post treatment higher than at simulation. Radical patients and women have scores at the four week post treatment lower than at simulation. This is also confirmed by the HADS anxiety questionnaire. Men had the lowest score at simulation, by 4 weeks post they have the second highest score after the palliative patients who have the highest scores. In contrast women and radical patients had the highest scores at simulation. Both the HADS and the STAI State registered this same peak in anxiety scores at mid-treatment for the palliative patients. The HADS registered

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simulation as being the highest anxiety for the palliative patients. The STAI State shows that mid-treatment is the 'peak' point of anxiety for the palliative patients.

Table 9: Mean STAI State Anxiety Scores of Patients from Simulation to Four Weeks Post Treatment

Anxiety	All Mean (sd)	Radical Mean (sd)	Palliative Mean (sd)	Females Mean (sd)	Males Mean (sd)
TraitAnxiety Simulation	37.76	36.97	39.20	38.17	37.19
	(9.5)	(9.3)	(9.7)	(9.32)	(9.13)
Numbers	269	173	96	157	112
State Anxiety Simulation	41.89	42.06	41.60	44.12*	38.73*
	(14.22)	(14.79)	(12.93)	(14.26)	(13.01)
Numbers	261	167	94	156	108
First Treatment	40.48	40.40	40.64	42.94*	37.10*
	(13.16)	(13.66)	(12.69)	(13.16)	(12.80)
Numbers	259	169	90	150	109
Mid-Treatment	37.34	36.34*	43.62*	37.94	36.03
	(12.11)	(11.86)	(11.97)	(12.11)	(12.10)
Numbers	168	145	23	115	53
End Treatment	35.05	34.86	37.42	35.50	35.51
	(11.64)	(11.61)	(11.63)	(11.80)	(11.46)
Numbers	212	160	53	131	81
4 Weeks Post	36.62	35.03*	40.46*	36.11	37.46
	(12.20)	(11.65)	(12.71)	(11.93)	(12.65)
Numbers	218	154	64	135	83

* Significant difference in gender $F(1,257)=8.25$, $p=0.004$

* Significant difference in gender $F(1,256)$, $=12.15$, $p=0.001$

* Significant difference in treatment intent $F(1,163)=9.19$, $p=0.003$

* Significant difference in treatment intent $F(1,217)=8.43$, $p=0.004$

Palliative patients had higher anxiety than radical patients at all testings except simulation. Significance was only reached at mid-treatment and 4 weeks post treatment. Anxiety was higher for women than men at the four first testing points. A significant difference was found only at simulation and 1st treatment.

At 1st treatment Social Class A had significantly lower State anxiety scores than the other classes, $F(4,244)=2.78$, $p=0.027$. Similarly after treatment Social Class A was significantly less anxious than the other social classes, $F(4,204)=3.242$, $p=0.013$. A Post Hoc Tukey test also showed a significant difference after treatment in marital status. The married

patients (Mean 37.1) were significantly more anxious than the separated patients (mean 26.1). $F(6,211)=1.186$, $p=0.007$. However, the numbers in the groups were not even.

STAI State – *cut-off points*

State anxiety refers to the individual's response to stress <u>at that moment in time</u>. Normal anxiety levels for men and women range from 32-36, depending on age and sex on the State component. Spielberger, (1983), found that General Medical and Surgical (GMS) patients had a mean anxiety of 42.8 with a standard deviation of 13.76. This number of 42.8 has, therefore, been used in this study to indicate abnormally high levels, as this should be a comparable figure to the HADS with a cut-off point of 8. Scores above this indicate anxiety. A cut-off point of 46 has been used to indicate high anxiety, equivalent to a HADS 'probable' case.

The anxiety 'non' case pattern is similar to that of the HADS. The number of 'possible' cases with the STAI State lowers over treatment, with a peak at 1st treatment. 'Possible' cases gradually lower from a peak at simulation over the course of treatment, but 4 weeks post are indicating a rise.

Graph 8: Percentage of Patients using STAI State indicating a 'non' case, 'possible' case or 'probable' case over treatment
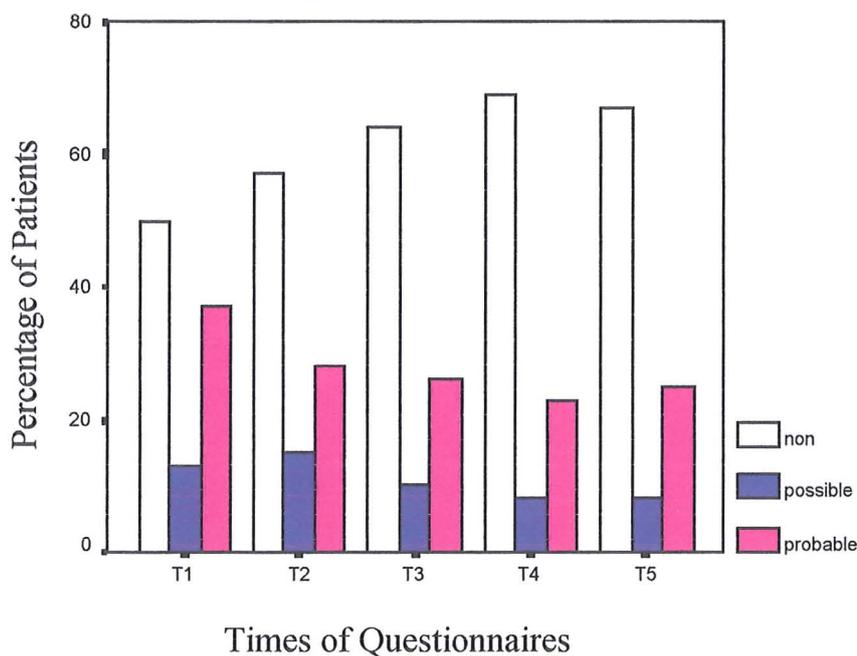
T1=simulation, T2=1st treatment, T3=mid-treatment, T4=end treatment, T5=4 weeks post treatment

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The following table shows the further breakdown according to gender of patients with anxiety of 42.8 and over indicating a 'possible' case. At simulation the percentage of women scoring over 42.8 is higher than the men at 54% and 44% respectively. However from the end of treatment onward the men have a higher percentage of cases. This was confirmed by the HADS but the percentages are higher with the STAI State.

Table 10: Percentage of men and women with anxiety levels of 42.8 and over on the STAI State Anxiety Scale

	T1	T2	T3	T4	T5
Women	54 (N=153)	49 (N=150)	37 (N=115)	29 (N=131)	32 (N=135)
Men	44 (N=108)	35 (N=109)	34 (N=52)	33 (N=81)	35 (N=83)

[T1= Simulation, T2= 1ˢᵗ Treatment, T3= End Treatment, T4= End Treatment, T5= 4 Weeks Post Treatment]

Graph 9 looks at anxiety according to gender and divides the anxiety into 'possible' cases, that is scores above 42.8 to 46 and 'probable' cases with scores of over 46.

Graph 9: Percentage of Men and Women Patients as 'Possible' and 'Probable' Cases with STAI State Anxiety Scale
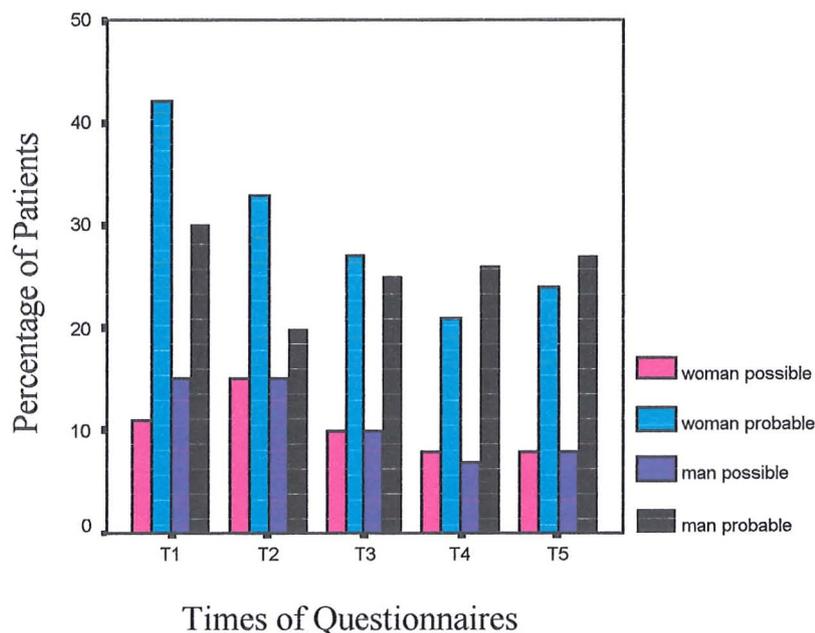
[T1= Simulation, T2= 1ˢᵗ Treatment, T3= End Treatment, T4= End Treatment, T5= 4 Weeks Post Treatment]

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The number of 'probable cases for women is very high at simulation. This gradually drops over radiotherapy treatment to a quarter, which is still high. The percentage of 'probable' cases for men is lower at simulation than for women. After treatment the percentage of 'probable' cases is higher for men than that those of the women.

Table 11: Percentage of radical and palliative patients with anxiety levels of 42.8 and over on the STAI State Scale through treatment

	T1	T2	T3	T4	T5
Radical Patients	48	39	33	28	29
	(N=167)	(N=169)	(N=144)	(N=159)	(N=154)
Palliative Patients	53	49	53	38	45
	(N=94)	(N=90)	(N=23)	(N=53)	(N=64)

[T1 = Simulation, T2 = 1st Treatment, T3 = End Treatment, T4 = End Treatment, T5 = 4 Weeks Post Treatment]

Table 11 shows the high percentage of patients recording high anxiety throughout their radiotherapy treatment as measured by the STAI State. At simulation 53% of the palliative patients are recording levels of over 42.8 and 45% are still registering high anxiety at four weeks post treatment. A smaller percentage of radical patients have scores of over 42.8 but it is still high with 48% registering at the 42.8 mark at simulation and 29% four weeks post treatment.

Graph 10: Possible and Probable Number of Cases for Radical and Palliative Patients with STAI State Anxiety Scale Through Treatment
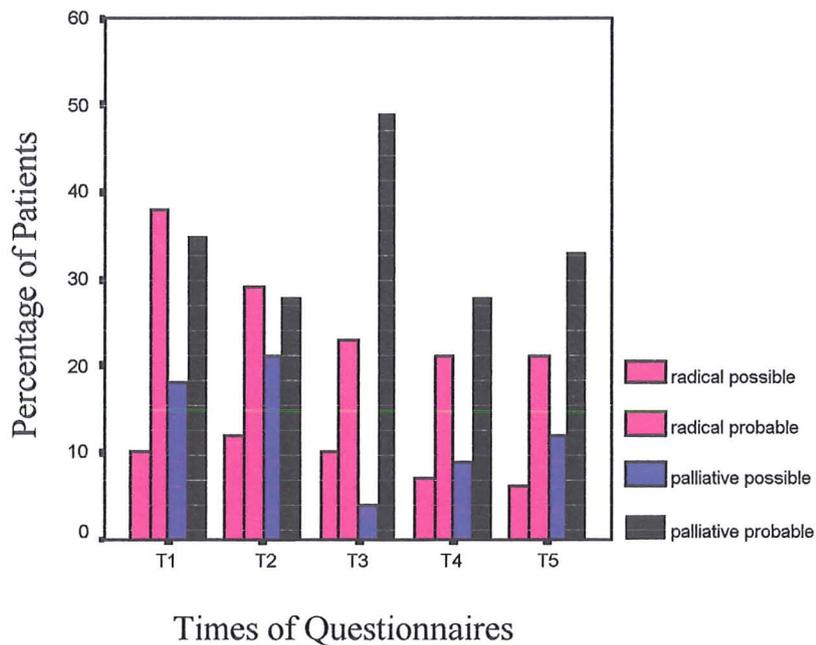
Times of Questionnaires

[T1 = Simulation, T2 = 1ˢᵗ Treatment, T3 = End Treatment, T4 = End Treatment, T5 = 4 Weeks Post Treatment]

At simulation there are more radical 'probable' cases than palliative 'probable' cases even though there are more palliative patients registering at the 42.8 level. Over half the palliative patients at mid treatment could be considered as 'probable' cases. The radical patients show a linear decline, the palliative patients show a more erratic pattern, with a peak at mid-treatment.

STAI Trait

The STAI Trait was only given once to patients, at simulation. The palliative group had the highest mean of all patient groups with respect to their Trait scores and this difference was significant, $F(1,265)=4.76$, $p=0.003$. Gender was not significant. The cut-off point for Trait Anxiety was 41.33 as recommended by Spielberger (1983).

Table 12: Showing the Statistical Breakdown of the STAI Trait Scores by Treatment and Gender

Patient Group	Anxiety Over 41.33	Mean Anxiety + (std dev)
All (269)	32% (85)	37.76 (9.5)
Palliative (96)	37% (36)	39.20 (9.7)
Radical (173)	28% (49)	36.97 (9.3)
Females (157)	32% (51)	38.17 (9.32)
Males (112)	31% (34)	37.19 (9.31)
Male Palliative (58)	38% (22)	38.59 (10.28)
Male Radical (53)	23% (12)	35.69 (9.09)
Female Palliative (12)	37% (14)	35.69 (8.83)
Female Radical (103)	31% (37)	37.5 (9.4)

Table 12 shows trait anxiety levels at simulation. It points to the small difference in Trait anxiety according to gender. Palliative patients have the highest percentage of patients scoring over the cut-off point of 41.33. Although there is a small difference between men and women on their mean scores, there is a much lower percentage of male radical patients 23%, than female radical patients 31%.

Table 13 shows a large difference between the Trait and State anxiety levels for women. The men have very similar trait/state scores, as do the palliative patients

Table 13: Results of The STAI State/Trait Anxiety According to Patient Groups at Simulation

Patient group	Trait Mean Anxiety	State Mean Anxiety
Females	38.180	44.12
Males	37.180	38.73
Palliatives	39.200	41.60
Radicals	36.971	42.06

The women and the radical patients show state scores as registering much higher than their trait scores. The trait and state scores of the males are very similar.

Depression Results

The score of the HADS depression component similarly ranges from 0-21. Graph 10 shows the various results according to treatment intent and gender. Palliative patients have the highest depression scores with mid treatment time the peak. Men scores are higher than women's at all testing points. Two contrasting patterns are apparent by the end of treatment. The palliative patients and the women show an increase in depression scores. The men and radical patients show a fractional trend downward.

Graph 11: Mean HADS Depression Scores through treatment
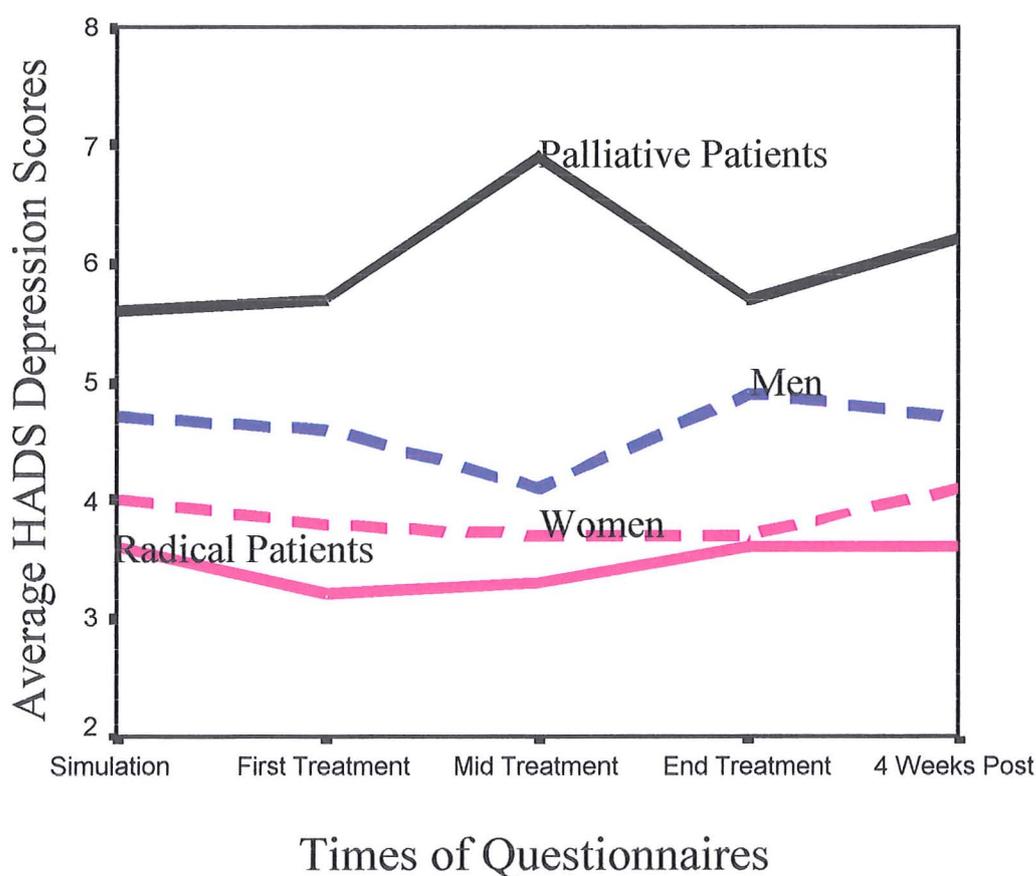
[T1= Simulation, T2= 1st Treatment, T3= End Treatment, T4= End Treatment, T5= 4 Weeks Post Treatment]

At simulation patients who had participated in complementary medicines were significantly less depressed than patients who had not, t(227)=-1.962, *p*=0.05. At mid

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treatment widowed patients were significantly more depressed than separated patients, $F_{(5,162)}=2.35$, $p=0.04$.

At first treatment patients who had participated in radiotherapy before were significantly less depressed $t_{(216)}=1.8$, $p=0.04$.

Table 14: Mean Depression Scores of Patients by Gender and Treatment Intent from Simulation to Four Weeks Post Treatment

Depression HADS	All Mean (sd)	Radical Mean (sd)	Palliative Mean (sd)	Females Mean (sd)	Males Mean (sd)
At Simulation	4.30	3.62*	5.60*	4.04	4.71
	(3.30)	(3.12)	(3.26)	(3.08)	(3.18)
Numbers	269	173	96	157	112
First Treatment	4.13	3.25*	5.73*	3.80	4.57
	(3.33)	(3.03)	(3.29)	(3.38)	(3.20)
Numbers	257	166	91	147	110
Mid-Treatment	3.86	3.35*	6.92*	3.75	4.12
	(3.39)	(3.08)	(3.61)	(3.52)	(3.08)
Numbers	168	145	23	115	53
End Treatment	4.14	3.60*	5.72*	3.68	4.87
	(3.76)	(3.60)	(3.79)	(3.53)	(4.00)
Numbers	215	160	55	131	84
4 Weeks Post	4.33	3.59*	6.177*	4.09	4.71
	(3.79)		(4.03)	(3.87)	(3.66)
Numbers	217	(3.43)	62	133	84
		155			

* Significant difference in treatment intent, $F_{(1,265)}=21.9$, $p=0.001$

* Significant difference in treatment intent, $F_{(1,253)}=32.7$, $p=0.001$

* Significant difference in treatment intent, $F_{(1,164)}=24.3$, $p=0.001$

* Significant difference in treatment intent, $F_{(1,211)}=10.8$, $p=0.001$

* Significant difference in treatment intent, $F_{(1,217)}=20.9$, $p=0.001$

Palliative patients were significantly more depressed than the radical patients at all testing points. Gender did not reach significance.

At mid-treatment widowed patients were significantly more depressed than separated patients $F_{(5,162)}=2.35$, $p=0.043$.

By the end of treatment a posteriori Tukey-HSD test showed that head and neck patients were significantly more depressed than patients with cancer of the breast,

$F(10,204)=2.161$, $p=0.022$. However the sample sizes were not even therefore type 1 errors are not guaranteed.

Analysis using cut-off points to indicate psychological problems

The HADS depression Scores are similarly divided into 3 sections.

- 0-7 indicates that there is not a problem.

- 8-10 indicates a possible case, and

- Finally 11 and over which indicates a probable case.

The percentage of depression cases is lower than for anxiety from 16% at simulation to 20% at 4 weeks post treatment. Simulation marks the lowest number of cases (26) according to gender. This rises over the course of treatment. Men have a peak at mid treatment with 24% indicating a 'case'. The number of 'cases' of depression for women was at its highest 4 weeks post treatment. Men have consistently more 'cases' of depression than women, apart from 4 weeks post treatment.

Table 15: Percentage of men and women patients with depression levels of 8 and over through treatment

	T1	T2	T3	T4	T5
Women Patients	12 (N=157)	12 (N=157)	12 (N=115)	16 (N=131)	20 (N=133)
Men Patients	14 (N=112)	17 (N=110)	24 (N=53)	19 (N=84)	19 (84)

[T1= Simulation, T2= 1ˢᵗ Treatment, T3= End Treatment, T4= End Treatment, T5= 4 Weeks Post Treatment]

Graph 12 demonstrates the percentage of men and women, which are 'possible' and 'probable' depression cases. The percentage of male 'possible' cases is consistently higher than the women's over the course of radiotherapy treatment. The peak number of 'cases' for men is at mid-treatment. In contrast the peak number of 'cases' for women is 4 weeks post treatment. The number of 'cases' for women increases over the course of treatment.

Graph 12: Possible and Probable Depression Cases for Males and Females through Radiotherapy Treatment
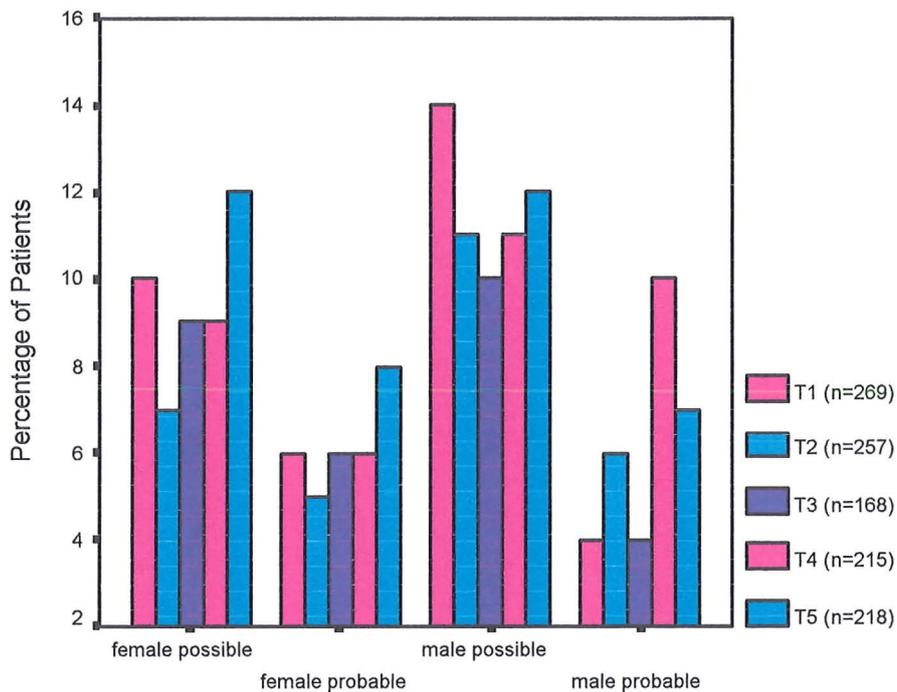
[T1= Simulation, T2= 1st Treatment, T3= End Treatment, T4= End Treatment, T5= 4 Weeks Post Treatment]

The number of 'possible' cases for men is at its highest at simulation, however the number of 'probable' cases peaks at the end of treatment. The number of 'possible' and 'probable' cases for women peak at four weeks post treatment.

Table 16 demonstrates the percentage of radical and palliative patients with depression levels of 8 and over during radiotherapy treatment. The numbers increase for palliative patients with a peak at mid-treatment, 42% indicating a 'case' in comparison with 14% of the radical patients. Overall the number of 'cases' for palliative patients is high. By 4 weeks post treatment 32% of palliative patients and 15% of radical patients are indicating a 'case'. This table also indicates the rise in the number of cases of depression over treatment.

Table 16: Percentage of radical and palliative patients with depression levels of 8 and over through treatment

	T1	T2	T3	T4	T5
Radical Patients	11 (N=173)	13 (N=166)	14 (N=144)	14 (N=160)	15 (N=155)
Palliative Patients	25 (N=96)	26 (N=91)	42 (N=24)	29 (N=55)	32 (N=62)

[T1= Simulation, T2= 1st Treatment, T3= End Treatment, T4= End Treatment, T5= 4 Weeks Post Treatment]

Graph 13 shows the breakdown of depression into 'possible' and 'probable' cases. It indicates that the palliative patients at the mid treatment point consisted of 29% 'possible' cases. At four weeks post treatment there is an increase from simulation for both radical and palliative 'probable' cases. Radical patients 'probable' cases reaches a peak at the end of treatment. 'Possible' cases reach a peak after treatment.

Graph 13: Possible and Probable Depression 'Cases' According to Treatment Intent over radiotherapy treatment
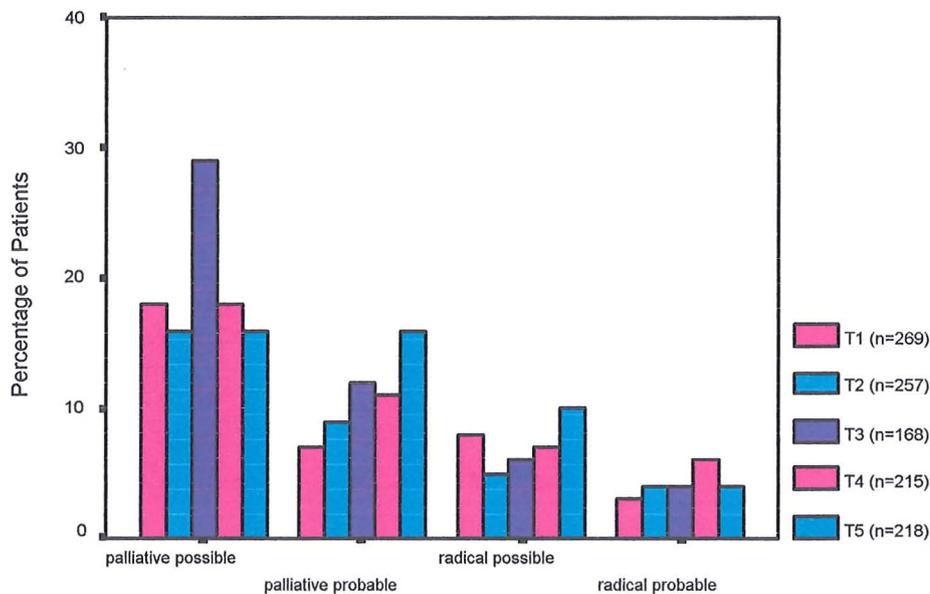
[T1= Simulation, T2= 1st Treatment, T3= End Treatment, T4= End Treatment, T5= 4 Weeks Post Treatment]

Repeated measures analysis of variance for depression over the course of the treatment with the variables of gender and treatment intent, (minus the mid-point) showed a significant

time effect for depression $F(3,570)=2.981$, $p=0.031$ and for treatment intent $F(1,190)=15.815$, $p=0.001$. Gender was not significant $F(1,190)=0.629$, $p=0.429$.

Psychological Distress

A combined unitary score of the HADS was used to indicate psychological distress. From the total HADS scores, a cut-off point of 13 is used, which suggest adjustment disorder and scores of 18 and over to indicate major depressive illness, as confirmed by Razavi et al (1990).

The time of greatest distress appears to be at simulation with 40% of the patients having scores of 13 and over.

Assessing distress with the variable of gender shows that women are most distressed at simulation and men by the end of treatment. Graph 14 shows an unusual graph with mirror images of distress, with the midpoint at mid treatment.

Graph 14: Mean Combined Scores of HADS to Indicate Psychological Distress through Radiotherapy Treatment for Men and Women
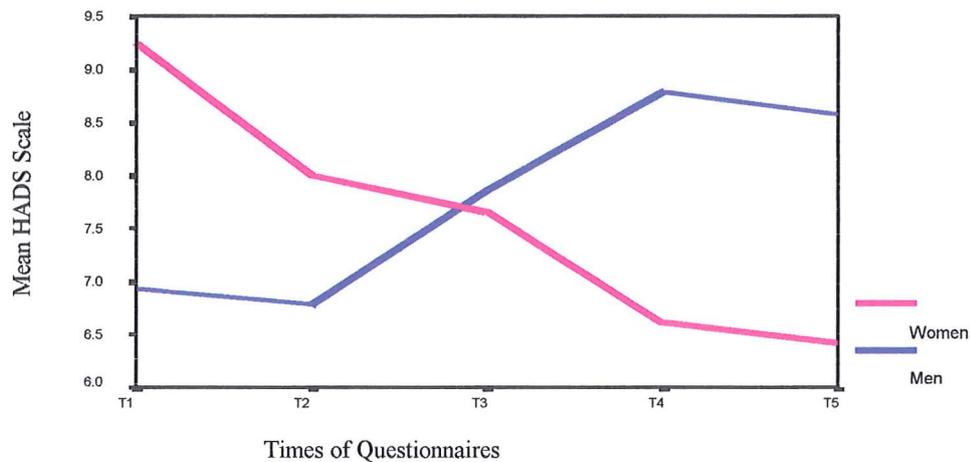
[T1 = Simulation, T2 = 1ˢᵗ Treatment, T3 = Mid Treatment, T4 = End Treatment, T5 = 4 Weeks Post Treatment]

Both male and female patients at four weeks post treatment indicate a downward trend in distress.

Using cut-off points of 13 and 18

Table 17 shows the percentage of 'cases' for men and women, that is patients having a score of 13 and over on the combined HADS score.

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Table 17: Percentage of men and women patients with distress levels of 13 and over during radiotherapy treatment

	T1	T2	T3	T4	T5
Women Patients	41 (N=157)	35 (N=147)	29 (N=115)	29 (N=131)	32 (N=133)
Men Patients	37 (N=112)	35 (N=111)	25 (N=52)	30 (N=84)	31 (N=84)

[T1= Simulation, T2= 1st Treatment, T3= End Treatment, T4= End Treatment, T5= 4 Weeks Post Treatment]

The overall distress levels over treatment is high, but falls during radiotherapy. The percentage of 'cases' fell for women from 41% at simulation to 32% at four weeks post treatment. 'Cases' levelled for women from mid treatment to the end of treatment and then rose 4 weeks post treatment. The percentage of 'cases' for men fell from 37% at simulation to 31% at the four weeks post treatment time with a dip at mid treatment.

Graph 15: Psychological Distress Possible and Probable Cases For Men and Women during radiotherapy treatment
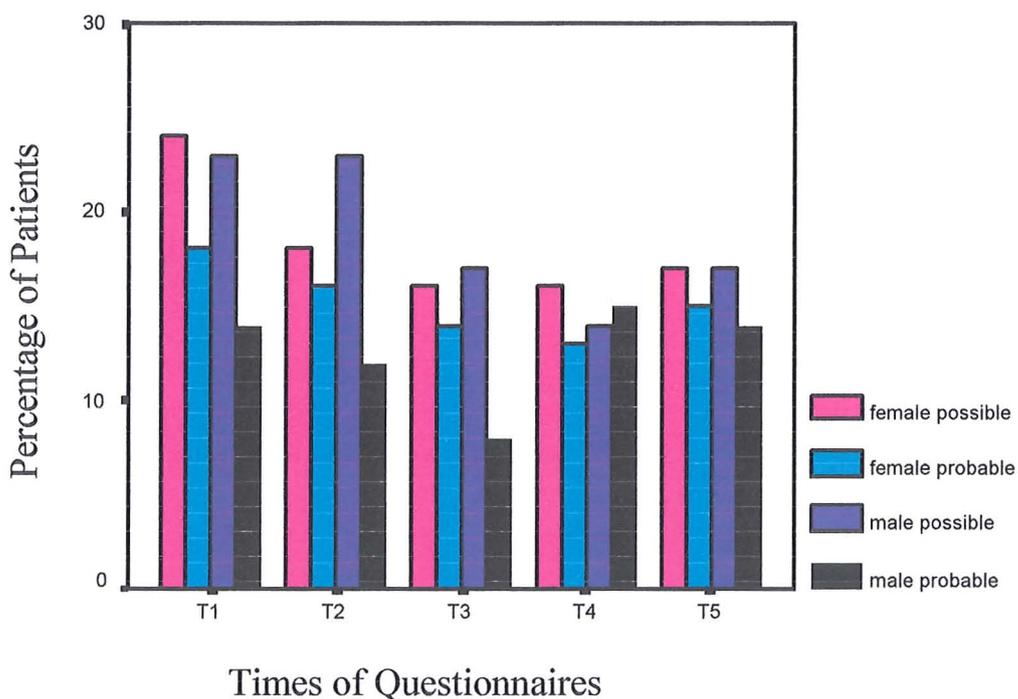
Times of Questionnaires

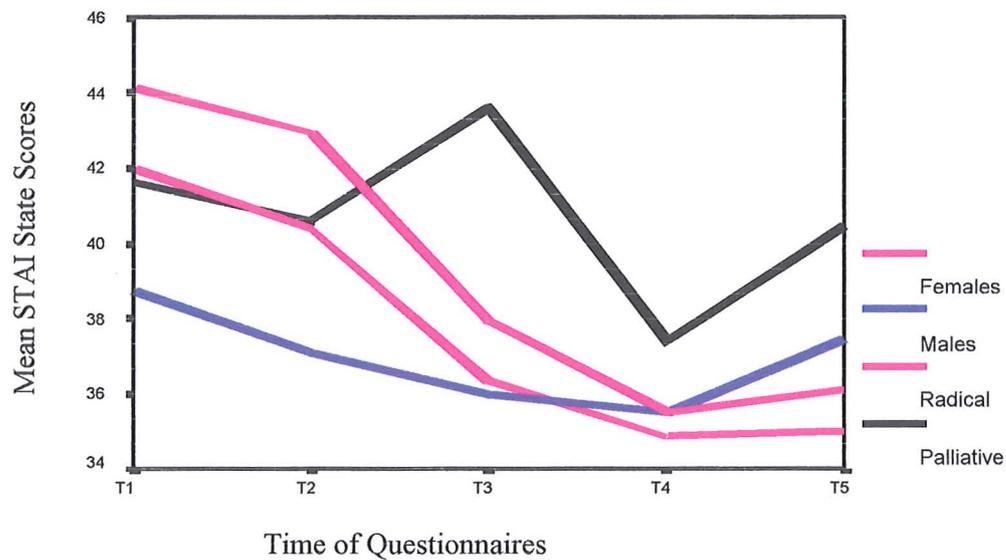*[T1= Simulation, T2= 1st Treatment, T3= End Treatment, T4= End Treatment, T5= 4 Weeks Post Treatment]*

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Graph 15 shows the breakdown into 'possible' and 'probable' cases for men and women. It shows that the number of male 'probable' cases is higher at the end of treatment and four weeks post treatment than at simulation or beginning of treatment. The number of male 'possible' cases fell during this period.

The overall distress levels are very high throughout treatment especially for the cohort of palliative patients with approximately 50% being distressed throughout their treatment and 4 weeks after treatment. The levels for both radical and palliative patients fall from simulation to 4 weeks post. However palliative patients have the highest number of 'cases' at mid-treatment.

Table 18: Percentage of radical and palliative patients with distress levels of 13 and over through treatment

	T1	T2	T3	T4	T5
Radical Patients	32 (N=173)	26 (N=166)	24 (N=144)	25 (N=160)	26 (N=155)
Palliative Patients	53 (N=96)	50 (N=92)	56 (N=23)	42 (N=55)	47 (N=62)

[T1= Simulation, T2= 1ˢᵗ Treatment, T3= End Treatment, T4= End Treatment, T5= 4 Weeks Post Treatment]

Graph 16 shows the further division into 'possible' and 'probable' cases. The palliative patients show an increase in the number of 'probable' cases at the end of treatment and after. The number of palliative patients who could be labelled as 'probable' at 4 weeks post treatment is nearly 30%. In contrast the number of 'probable' cases for the radical patients fell over the course of treatment.

Graph 16: Radical and Palliative Percentages of Psychological Distress Levels over Radiotherapy Treatment
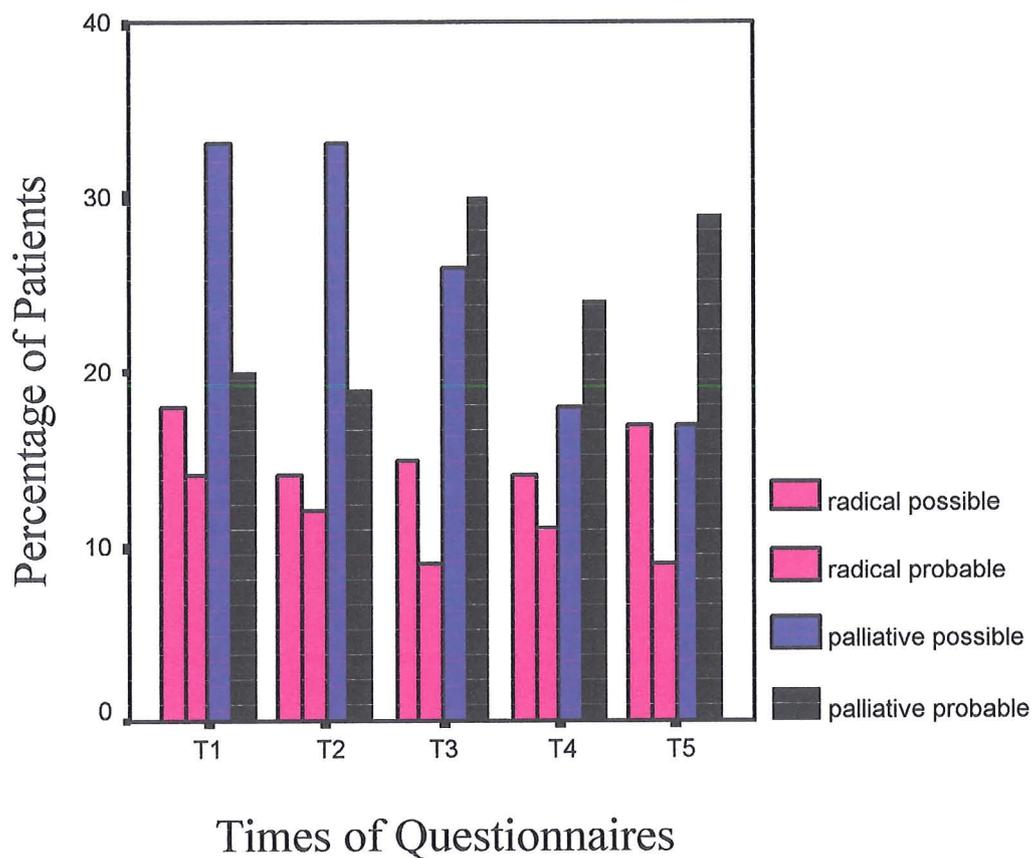
[T1 = Simulation, T2 = 1st Treatment, T3 = End Treatment, T4 = End Treatment, T5 = 4 Weeks Post Treatment]

Repeated measures analysis over the radiotherapy treatment (excluding the midpoint) showed a significant effect over time for distress, $F(3,570)=3.267$, $p=0.021$, gender was not significant $F(1,190)=0.074$, $p=0.492$, but treatment intent was, the mean of the palliative patients was 11.458 and that of the radical patients was 7.819, $F(1,190)=13.849$, $p=0.001$.

Was there a difference in anxiety and depression between those patients that completed all five questionnaires and those who did not?

Graph 17 Anxiety and Depression over Treatment of those who finished all five questionnaires and those who did not

Times of Questionnaires
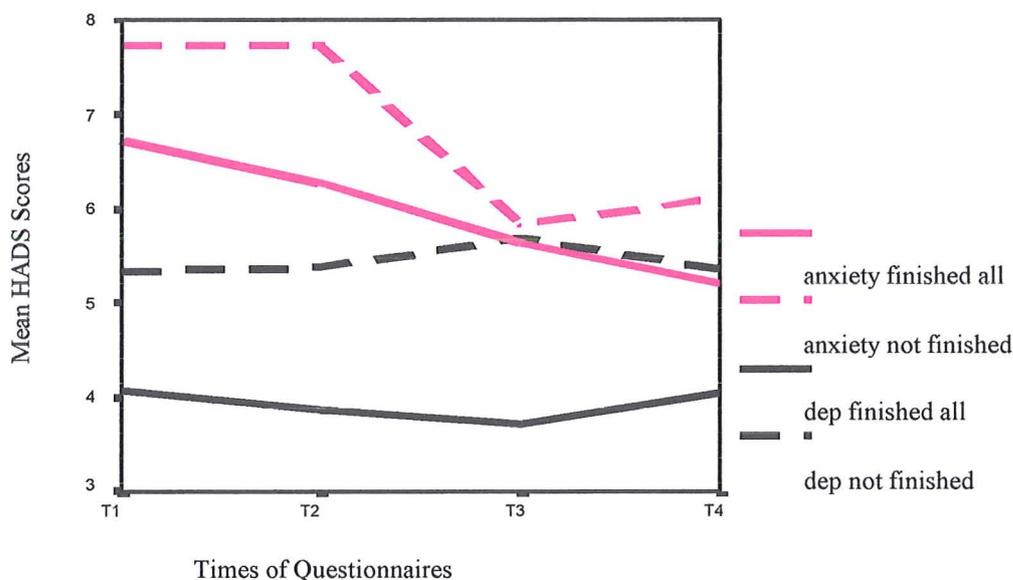
T1=simulation, T2=1st Treatment, T3=Mid-Treatment, T4=End Treatment

Anxiety for the patients who finished all questionnaires was lower than for those who did not. Similarly with the depression scores, those who finished had lower depression scores than those who did not.

Further analysis was carried out on this data. Four weeks post was not included in this analysis. There was no significant difference in anxiety between those who finished all five and those who did not. There was a significant difference in depression at simulation, $t(267)=2.512$, $p=0.013$, at first treatment, $t(255)=2.8$, $p=0.005$ and at mid treatment, $t(166)=2.046$, $p=0.042$.

Sites

Further analysis was undertaken on the variable site to eliminate a gender bias. Patients with cancer of the breast are analysed in more depth. The one male cancer patient is removed from this analysis so that it contains only women. Prostate patients are further analysed. They are compared with breast cancer patients and non-gender related cancers. The non-gender related cohort are divided into female non gender related and male non gender related so that these groups can be compared. The non gender related sites consist of the following cancers; lung, skin, gastrointestinal, bladder, head and neck, Hodgkins Disease, Non-Hodgkins Lymphoma and tumours of unknown origin.

Results

At simulation the breast Patient (n=104) cohort consists of 82 radical and 22 palliative patients. The non gender related sites (n=128) consisted of 85 males (radical n=42, palliative n=43) and 43 females (radical n=29, palliative n=14). The prostate patients (n=25) 11 radical and 14 palliative patients.

Breast Patients

There was no significant difference between the anxiety levels of the radical and palliative breast patients. However significance was reached at all the time points before, during and after treatment for depression with palliative patients showing significantly higher scores. This repeats the pattern shown for the larger cohort of mixed sites.

Table 19: Mean Depression of Radical and Palliative Patients over treatment for Breast Patients

Times of Questionnaire	Mean (sd)	Numbers	t-test result
At simulation Radical Palliative	7.20 (3.88) 8.09 (4.47	83 22	t(103)=-1.957 p=0.05
First Treatment Radical Palliative	6.81 (4.14) 7.65 (4.17)	81 20	t(99)=-3.463 p=0.001
Mid Treatment Radical Palliative	5.92 (3.93) 7.75 (4.09)	79 8	t(85)=-3.814 p=0.001
End Treatment Radical Palliative	5.00 (3.8) 7.00 (2.9)	78 11	t(87)=-3.099 p=0.003
4 Weeks Post Radical Palliative	4.81 (3.8) 5.75 (3.3)	76 16	t(90)=-3.466 p=0.001

Anxiety of both the radical and palliative patients fell over the course of radiotherapy treatment with the palliative patients subject to higher levels of anxiety throughout treatment. Similarly the depression levels were higher for palliative patients, with a peak of 8 at mid treatment. This fell to 5.5 at the end of treatment but showed an upward trend from that point.

Prostate Patients

There were no significant differences between radical and palliative patients on the anxiety scale. A significant difference was found with treatment intent on the depression component of the HADS at first treatment and mid treatment.

Table 20: Mean Depression of Radical and Palliative Patients over treatment for Prostate Patients

Times of Questionnaire	Mean (sd)	Numbers	t-test result
At simulation Radical Palliative	4.45 (4.1) 5.93 (4.41)	11 15	t(24)=1.732 p=0.096
First Treatment Radical Palliative	3.9 (2.98) 5.78 (4.54)	11 14	t(23)= 2.038 p=0.05
Mid Treatment Radical Palliative	5.10 (5.08) 10.00 (2.82)	10 2	t(9)=2.52 p=0.03
End Treatment Radical Palliative	3.72 (3.04) 5.71 (4.15)	11 7	t(16)=1.969 p=0.067
4 Weeks Post Radical Palliative	5.54 (4.32) 6.90 (3.69)	11 10	t(19)=1.31 p=0.206

Analysis was then carried out on breast and prostate patients. A significant difference was found in anxiety at simulation. The breast patients were significantly more anxious than the prostate patients, t(129)=2.35, p=0.02. Similarly at first treatment the breast patients were significantly more anxious t(124)=2.02, p=0.03. Depression was not significant at any of the

testing times. With the larger mixed cohort, a significant difference in gender was found at simulation, first treatment and end treatment. Similarly no difference in gender was found in depression on the analysis of the larger cohort.

Non gender related sites were divided by gender. Significance was found at all testings for anxiety. Women were repeatedly more anxious than the men. With the larger mixed cohort a difference was found at simulation, first treatment and end treatment.

Table 21: Mean Anxiety over treatment for
Non-Gender Related Male and Female Patients

Times of Questionnaire	Mean (sd)	Numbers	t-test result
At simulation Women Men	8.23 (4.1) 6.07 (4.34)	43 85	t(122)=2.775 p=0.006
First Treatment Women Men	7.89 (3.9) 5.65 (4.1)	37 84	t(115)=3.025 p=0.003
Mid Treatment Women Men	6.95 (4.76) 4.32 (2.7)	20 40	t(25)=2.284 p=0.03
End Treatment Women Men	7.0 (4.33) 4.93 (4.04)	33 65	t(93)=2.79 p=0.006
4 Weeks Post Women Men	6.22 (3.84) 4.75 (3.95)	32 62	t(89)=1.99 p=0.05

A significant effect due to gender was observed. Anxiety was higher for women (M=6.71) than men (M=4.8) over the course of treatment, and this difference was significant, $F(1,51)=4.68, p=0.03$.

Graph 18: Mean Anxiety Scores over Treatment for men and women with non-gender related cancers.
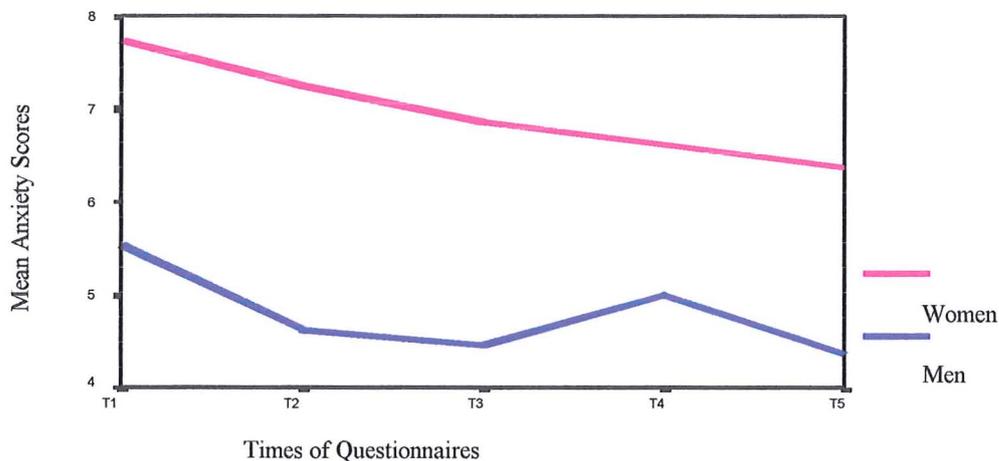
[T1= Simulation, T2= 1ˢᵗ Treatment, T3= End Treatment, T4= End Treatment, T5= 4 Weeks Post Treatment]

Did the breast cancer patients differ significantly from the other women with non gender related cancers? A significant difference was found only at the end of treatment when female non gender related cancers had significantly higher scores in anxiety than the breast women, $t(119)=2.208$, $p=0.03$.

No significant difference was found in depression for men and women who had non gender related sites. This replicated the findings of the bigger mixed cohort. Men, except for mid treatment, had consistently higher scores than women.

Graph19: Mean Depression Scores of Men and Women with Non Gender Related Cancers over Treatment
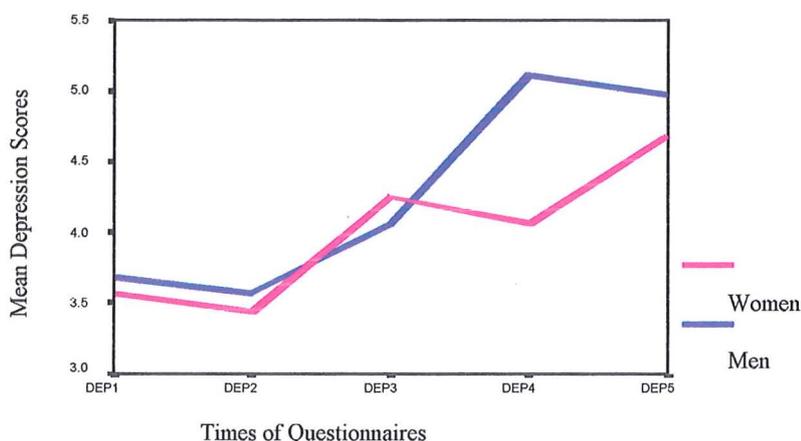
[T1= Simulation, T2= 1ˢᵗ Treatment, T3= End Treatment, T4= End Treatment, T5= 4 Weeks Post Treatment]

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At the end of treatment non gender related women had significantly higher depression scores than the breast patients, t(119)=2.5, p=0.014. Similarly post treatment, non gender related women had significantly higher depression scores, t(121)=2.144, p=0.03.

Was there a difference in anxiety and depression scores between the prostate patients and the non gender related male patients? No significant difference was found with either anxiety or depression.

Graph 20: Mean Anxiety Scores of Radical Breast, Prostate, and Non Gender Related Patients over Treatment
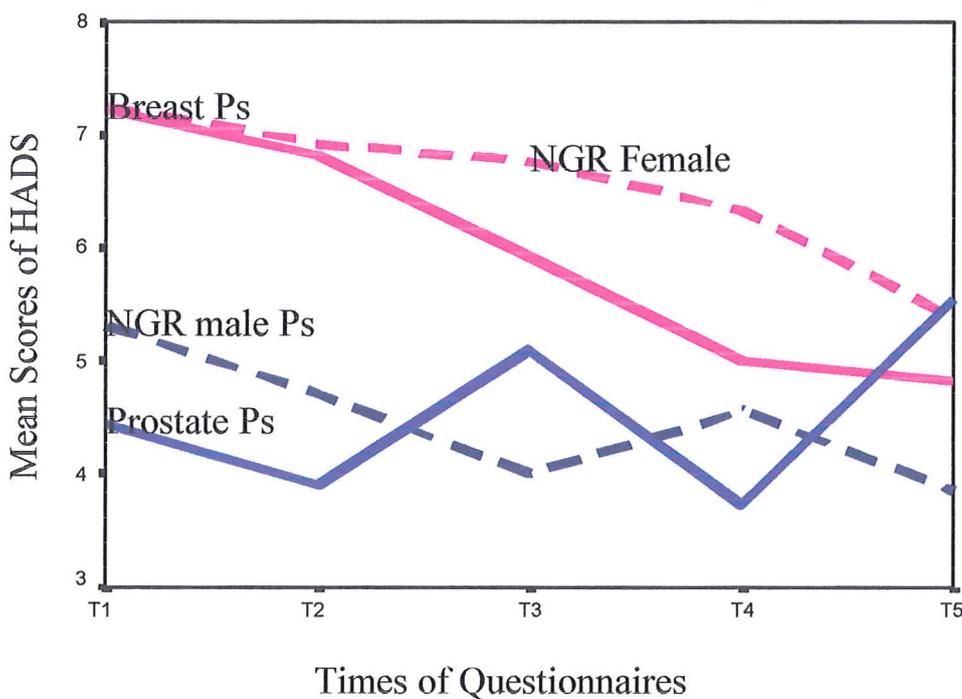
[T1= Simulation, T2= 1st Treatment, T3= End Treatment, T4= End Treatment, T5= 4 Weeks Post Treatment]
ngr=non gender related

Apart for a rise in anxiety at the end of treatment male and female non-gender related radical patients showed a similar pattern of anxiety. The men had consistently lower levels throughout. The breast patients displayed a gradual decrease in anxiety over the course of treatment. Both radical breast patients and radical non gender related female patients had the same levels of anxiety at simulation and first treatment. By the end of treatment and after, the breast patients showed lower levels of anxiety.

In contrast the prostate patients showed a more erratic pattern, which was not consistent with the non gender related male patients. Prostate patients were further analysed to see if

this increase in anxiety was due to symptoms, which they might be experiencing as a result of their treatment. Although patients who did have symptoms had higher anxiety scores (mean 7.6) as opposed to no symptoms (mean 4.9). This difference was non significant.

Graph 21: Mean Anxiety Scores of Palliative Prostate, Breast and Non Gender Related Sites through Treatment
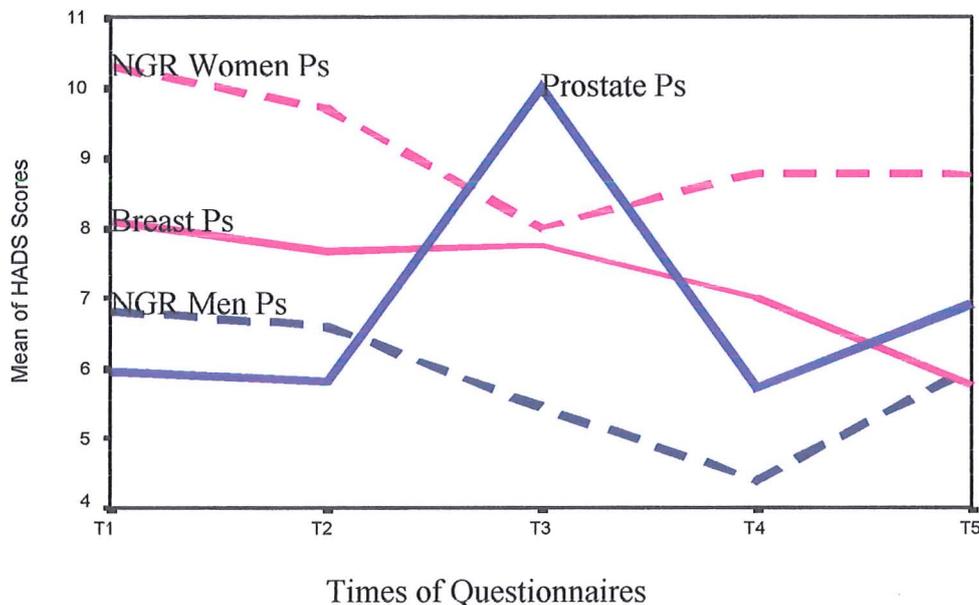
Times of Questionnaires

[T1= Simulation, T2= 1ˢᵗ Treatment, T3= End Treatment, T4= End Treatment, T5= 4 Weeks Post Treatment]

The non-gender related palliative women and the palliative breast patients exhibit similar patterns of anxiety with a decline from simulation. The level is high throughout for the palliative patients. Breast patients have consistently lower scores than the non-gender related patients. This is especially marked at the end of treatment and after.

The levels of anxiety for men are much lower. It appears that prostate patients at the mid treatment point go through a particularly anxious time. Further analysis revealed that there were only two palliative prostate patients tested at mid treatment.

However radical prostate patients also showed a peak at this time. At the end of treatment both radical and palliative prostate patients show an upward trend with anxiety after treatment being higher than before. The radical and palliative non-gender related males exhibit different patterns from the end of treatment. The palliative non-gender related patients show a rise, in contrast to the radical patients whose anxiety is at the lowest point.

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In contrast the radical depression scores of both non-gender related women and men with prostate and breast patients showed little similarities. The non-gender related women had the highest scores over the treatment period. It reached a peak at the end of treatment and showed a downward slope from that point. Depression was higher after treatment for this group. In contrast breast patients with the second highest scores at simulation displayed a fall in their mean depression score until the end of treatment with a rise from that point. Simulation was the peak depression point for these patients.

Both male groups started from a similar low point at simulation. After treatment men reached their highest depression scores.

Graph 22: Mean Depression Scores over Treatment for Radical Non Gender Related Males and Females, Prostate and Breast Patients
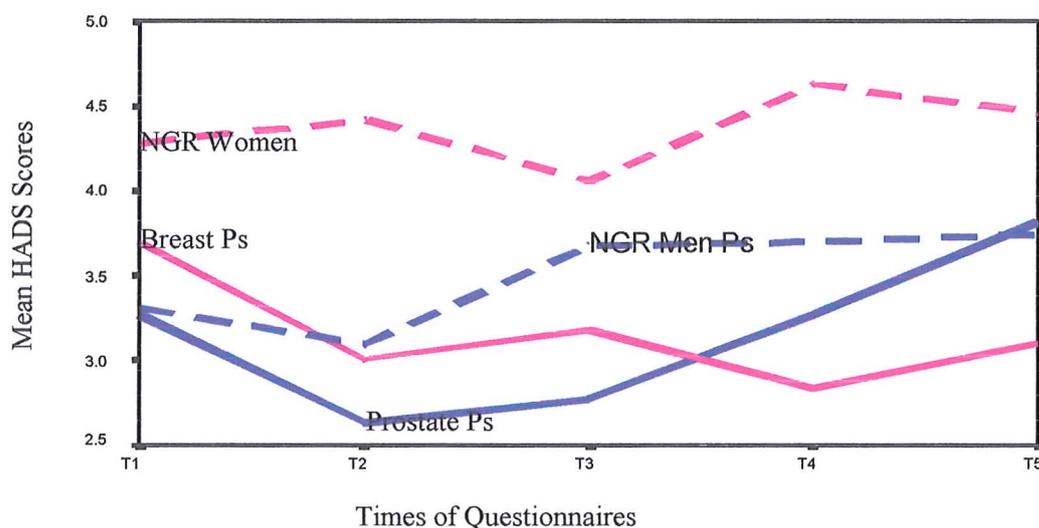
[T1= Simulation, T2= 1st Treatment, T3= End Treatment, T4= End Treatment, T5= 4 Weeks Post Treatment]
ngr=non-gender related

Graph 23 showed that regardless of site the palliative patients showed an increase in their depression scores at mid treatment. This was especially pronounced for the breast patients with a score of eight.

The women palliative groups showed very similar patterns of depression until the post treatment time when non-gender related patients showed a much steeper rise in contrast to the more gradual incline of the breast patients. The non-gender related patients start with the lowest scores and end with the highest.

The non-gender related men had the highest depression scores at simulation and end with the lowest, although there is a tendency to rise from the end of treatment. The prostate patients after a peak at the midpoint show a very slight decline from that point.

Graph 23: Mean Depression Scores of Palliative Breast, Prostate and Non Gender Related Sites through Treatment
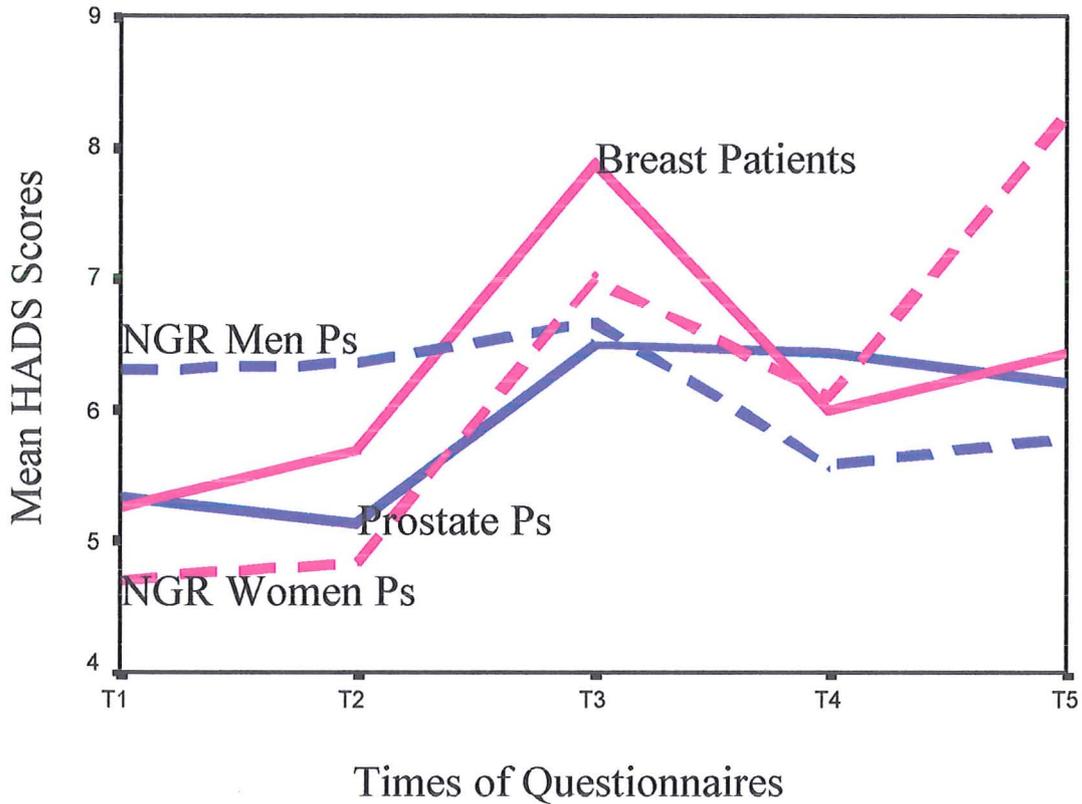
[T1 = Simulation, T2 = 1st Treatment, T3 = End Treatment, T4 = End Treatment, T5 = 4 Weeks Post Treatment]

Predictions

Anxiety, depression and distress at simulation are good predictors of psychological state at the end of radiotherapy treatment.

Anxiety

Anxiety at simulation was used together with gender, treatment intent, trait anxiety, age, and site in a stepwise regression analysis to see if anxiety could be predicted at the end of treatment. Anxiety levels at simulation explained 42% of the variance, trait anxiety 3% and palliative treatment a further 1% of the anxiety at the end of treatment

Table 22: Results of Stepwise Regression Analysis for Anxiety at End of Treatment using Dependant Variable as Anxiety at Four Weeks Post Treatment, and the Independent Variables of Trait Anxiety, Gender, Treatment Intent and Anxiety at Simulation.

Significant Variable	R square	B	Beta	T	Significance
Anxiety At Simulation	0.419	0.589	0.647	12.442	0.001
Anxiety At Simulation	0.450	0.429	0.471	6.591	0.001
+ Trait Anxiety		0.101	0.250	3.496	0.001
Anxiety At Simulation	0.466	0.426	0.468	6.627	0.001
+ Trait Anxiety		9.579E-02	0.237	3.352	0.001
+ Treatment Intent		1.089	0.128	2.540	0.014

As patients are significantly more anxious at simulation than at any other time, it could be better to use the anxiety levels at first treatment to assess predictions. In the Stepwise multiple regression analysis, with the variables of anxiety at first treatment, gender, treatment and Trait anxiety, anxiety at first treatment explained 42% of the variance in anxiety at the end of treatment, Trait anxiety a further 5% and treatment intent a further 1%.

Table 23: Results of Stepwise Regression Analysis using Dependant Variable as Anxiety at Four Weeks Post Treatment, and the Independent Variables of Trait Anxiety, Gender, Treatment Intent and Anxiety at First Treatment.

Variable	R square	B	Beta	T	Significance
Anxiety At First Treatment	0.419	0.593	0.647	12.338	0.001
Anxiety At First Treatment + Trait Anxiety	0.467	0.425 0.116	0.464 0.286	7.091 4.366	0.001 0.001
Anxiety At First Treatment + Trait Anxiety + Treatment Intent	0.483	0.424 0.110 1.054	0.463 0.272 0.124	7.157 4.180 2.468	0.001 0.001 0.014

Depression

Depression at simulation could explain 40% of the variance at the end of treatment and a further 2% were explained by palliative treatment.

Table 24: Results of Stepwise Regression Analysis for the Dependant Variable, which is Depression, at Four Weeks After Treatment, and the Independent Variables of Gender, Treatment Intent, Age, Site and Depression at Simulation

Significant Variable	R square	B	Beta	T	Significance
Depression At Simulation	0.401	0.722	0.633	12.002	0.001
Depression At Simulation + Treatment Intent	0.420	0.676 1.199	0.594 0.143	10.951 2.639	0.001 0.009

Depression at first treatment is used to see if it is a better predictor of depression after treatment.

Table 25: Results of Stepwise Regression Analysis with the Dependent Variable of Depression at Four Weeks After Treatment and the Independent Variables of Gender, Treatment Intent, Age, Site and Depression at First Treatment

Significant Variable	R square	B	Beta	T	Significance
Depression At First Treatment	0.493	0.793	0.702	14.324	0.001

The only predictor of depression at four weeks post treatment was depression at first treatment, and this explained 49% of the variance. This shows a higher predictive value than at simulation.

Distress

Using the combined scores to indicate psychological distress, the following table is generated with Stepwise regression analysis. Distress at simulation can explain 45% of the variance of the distress levels at the end of radiotherapy. A further 2% can be explained by treatment intent with palliative patients being significantly more distressed than radical patients.

Table 26: Results of Stepwise Regression Analysis Using the Dependant Variable of Distress at the End of Treatment, and the Independent Variables of Trait Anxiety, Gender, Treatment Intent, Age, Site and Distress at Simulation.

Significant Variable	R square	B	Beta	T	Significance
Distress At Simulation	0.455	0.682	0.702	14.324	0.001
Distress At Simulation	0.479	0.650	0.643	12.784	0.001
+ Treatment Intent		2.378	0.158	3.148	0.002

Changing the variable distress at simulation to distress at first treatment, the following table was generated.

Table 27: Results of Stepwise Regression Analysis Using the Dependant Variable of Distress at the End of Treatment, and the Independent Variables of Trait Anxiety, Gender, Treatment Intent, Age, Site and Distress at 1st Treatment.

Significant Variable	R square	B	Beta	T	Significance
Distress At First Treatment	0.474	0.694	0.488	4.015	0.001
Distress At First Treatment	0.492	0.663	0.658	13.077	0.001
+ Treatment Intent		2.092	0.140	2.772	0.006

Distress at first treatment seems a better predictor of distress at the end of treatment, with distress at first treatment explaining 47% of the distress at the end of treatment.

In-House Research Questionnaires

The questionnaires (See Appendix 7) were given to patients at the end of their treatment and four weeks after their treatment had finished. Questions pertained to information and control, social support, psychological well-being and to physical well-being. A total number of two hundred and eighteen patients responded to this questionnaire. The patients at the post treatment period were a different cohort from those patients responding to the end of treatment questionnaire. At the post treatment period single fraction patients were also included. The full analysis of the questionnaires for the end of treatment and four-week post treatment is in Appendix 32 and 33 respectively. A short précis of the results follows.

Information and Control:

Most patients (90%) thought the booklet given to them before radiotherapy treatment was adequate. Those patients who did not were significantly more anxious and depressed, $F_{(1,213)}=3.89$, $p=0.05$ and $F_{(1,213)}=5.798$, $p=0.017$ respectively.

Support

Most patients felt supported while undergoing treatment. A quarter did talk to a counsellor during this period.

Psychological Well Being

A third of patients would have preferred a visit to the department prior to their treatment. A total of 20% felt frightened during their treatment and these patients were significantly more anxious. Over half of this cohort would have liked to have discussed this with someone.

A total of 40% experienced anxiety after their treatment had finished and these patients were significantly more distressed, $F_{(1,213)}=4.9$, $p=0.027$, and anxious, $F_{(1,213)}=7.45$, $p=0.007$.

Physical Wellbeing

Some questions were repeated in all the questionnaires. Patients were asked how they felt and if they were still suffering from side effects in all eight questionnaires.

After treatment 52% were feeling better. Those who felt worse were significantly more anxious, $F_{(2,206)}=5.52$, $p-0.005$, depressed, $F_{(2.295)}=4.5$, $p=0.012$ and distressed, $F_{(2,206)}=12.648$, $p=000$.

Table 28 shows the difference in anxiety, depression and distress between those patients who had side-effects and those who did at the end of treatment and five weeks post treatment.

Table 28 :   Difference in Anxiety, Depression and Distress between those Patients who had Side-Effects and those who did at the End of Treatment and four weeks post

Treatment Times	Percentage of patients with side effects	Anxiety	Depression	Distress
End Treatment (215)	60% (127)	t(210)=1.142 p=0.255	t(210) = 1.46 p=0.146	t210)=1.4 p=0.157
Four Weeks Post Treatment (218)	49% (102)	t(207)=1.705 p=0.09	t(207)=3.17 p=0.002**	t(207)=2.7 p=0.007*

At the end of treatment 60% had side effects, but anxiety, depression and distress were not significant. Four weeks post treatment, 49% had side effects and anxiety, depression and distress were significant.

Chapter 7

Part 2 – Results from 6 months to five years after treatment has finished

Further ethical permission had to be sought before the next set of questionnaires was sent out. The breakdown of this mixed cohort agreeing to participate in this second ethical study is shown in Table 29

Table 29: Demographic And Medical Characteristics at 6 months post treatment

DEMOGRAPHIC	Nos	%	MEDICAL	Nos	%
Gender			**Sites**		
Female	97	64.0	Breast*	70	48.0
Male	49	36.0	Lung	13	9.0
			Prostate	12	8.0
Social Class			Skin**	13	10.0
			Other***	7	4.0
Class A	7	5.0	Gastro-int	6	4.0
Class B	22	16.0	Bladder	2	2.0
Class C1	50	35.0	Head & Neck	8	5.0
Class C2	37	26.0	Gynae	8	5.0
Class D	25	18.0	NHL	5	3.0
Unclassified	0	0.0	Unknown	2	2.0
Marital Status			**Treatment Intent**		
Married	99	69.0	Radical	124	85.0
Widowed	21	15.0	Palliative	22	15.0
Divorced	8	5.0	**Ages**		
Single	7	4.0	18-25	1	1.0
Separated	5	2.0	26-50	25	17.0
Unknown	0	0.0	50-65	55	38.0
Partner	2	1.0	65+	65	44.0

*   Includes one male breast patient
**   Includes only superficial tumours, melanoma is included in 'others'.
***   Includes glioblastoma, sarcoma, mesothelioma, Hodgkin's Disease, melanoma

The ethical permission required that all patients were written to individually and asked if they would like to continue in an extension of the study. This next part would last for five years after treatment. A negative response form was attached with a pre-stamped envelope. At this point, thirty five patients had died since the beginning of the study, leaving two hundred and thirty four patients, and these patients all received the letter. From this cohort, seventeen (8%) returned the forms saying they no longer wished to participate.

These questionnaires were sent to patients six months after the patient's treatment had finished in May 1994. Before the postal questionnaires were sent to patients, their status was checked again, another thirteen patients had died in the intervening period bringing the number of deaths to forty eight (18%) since the start of the study. Questionnaires were sent out to the remaining one hundred and seventy five patients. The questionnaires were sent out as a postal pack with stamp addressed envelopes for replies. A total of one hundred and forty six forms were returned duly completed. This is a response rate of 84% - twenty eight patients did not participate.

Analysing the patients who died six months after treatment reveals the numbers of single fractions (SF) was 13, 42% of this cohort. A total of seventeen (33%) was short multi-fractions (SMF) and eighteen, 10% of the long multi-fractions (LMF). This count contained three radical men and women.

The demographic details and medical characteristics of the patients at the other six testing points; from one year to five years - Table 30, one year – Table 31, eighteen months – Table 32, two years – Table 33, three years – Table 34, four years- Table 35 and five years –are numbered in the Appendix No 41, 42, 43, 44, 45 and 46 respectively.

The anxiety and depression scores as measured by the HADS continued to show different patterns in the period of 6 months post treatment to five years.

Graph 24: Mean Anxiety and Depression Scores from 6 months to five years
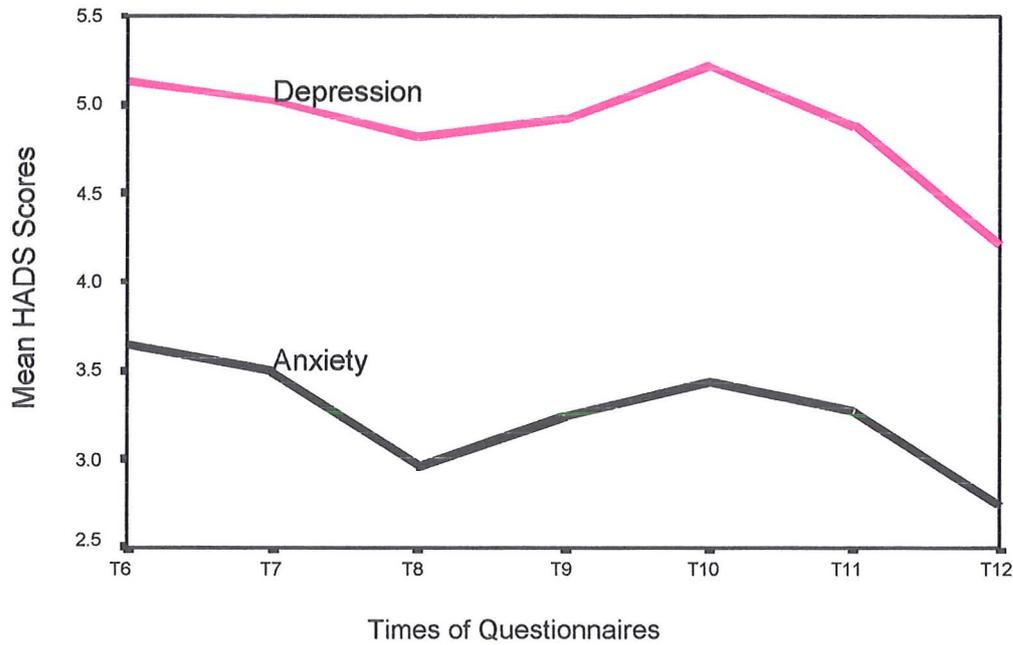
*T6= 6 months post treatment, T7= 1 year post, T8=18 months post, T9=2 years post, T10= 3 years post,
T11= 4 years post, T12=5 years post*

From 6 months post treatment to five years anxiety and depression follow very similar patterns. The anxiety scores are continuously higher than the depression scores. Both anxiety and depression are lower at the five year point than at the 6 month post treatment time.

Anxiety for men and women was approximately the same at the 6 months post treatment point. However from the 18 months point the men exhibited greater anxiety, and this continued for five years after treatment, apart from year 3.

Depression for women was continuously lower than the men's over this whole time period.

Graph 25: Mean Anxiety and Depression Scores from 6 months to 5 years post treatment for men and women

T6= 6 months post treatment, T7= 1 year post, T8=18 months post, T9=2 years post, T10= 3 years post, T11= 4 years post, T12=5 years post

Graph 26 shows the different patterns of the radical and palliative patients. The anxiety of the radical and palliative patients shows very similar patterns. However the palliative patients always have higher mean scores throughout than the radical patients. The number of palliative patients from one year post treatment point have rapidly diminished. At 18 months post treatment only 8 are still participating and this number falls to 5 at two years. Therefore the variable of treatment intent no longer applies for statistical purposes. At year five 4 palliative patients are still participating.

Graph 26: Mean Depression and Anxiety Scores of radical and palliative patients from 6 months to 5 years.
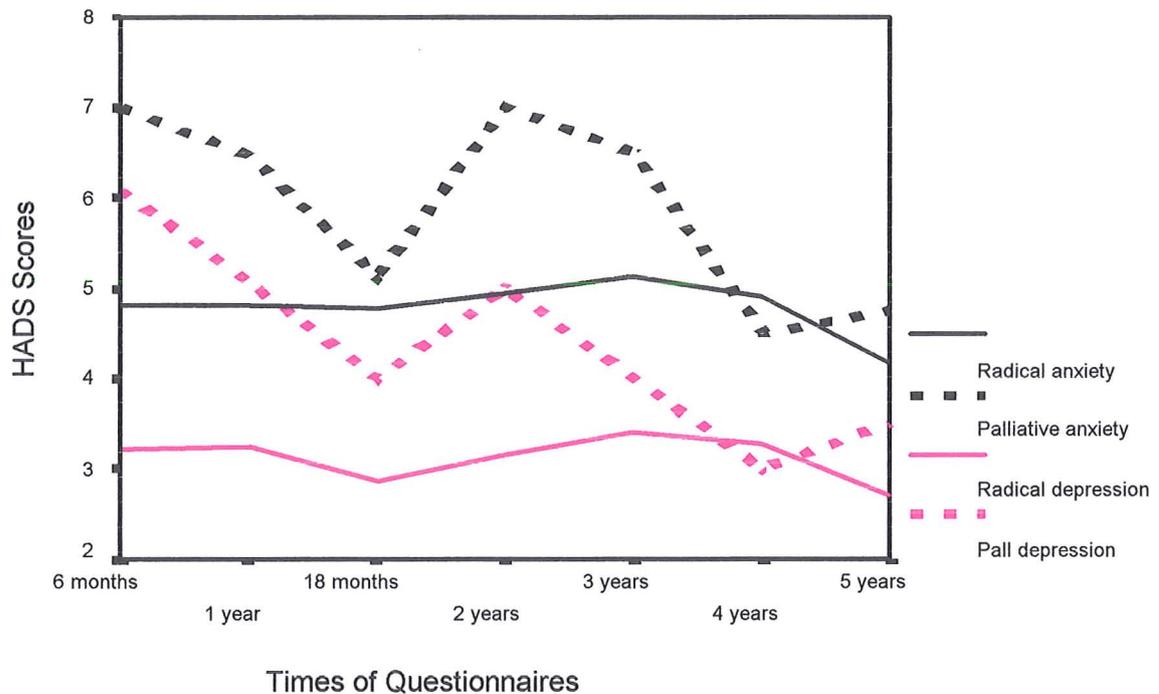
The levels for anxiety continued to fall except at the two year mark. The anxiety and depression of the radical and palliative patients follow remarkably similar patterns. The scores of the palliative patients are higher for depression and anxiety than the radical patients. In both cohorts depression rose at year 2 and dropped at years three and four. Anxiety for both groups was very stable.

The following table give the means and standard deviation for patient group from six month to five years post treatment, using the HADS anxiety subscale.

**Table 36: Mean HADS Anxiety Scores of Patients
from Six Months to Five Years Post Treatment**

Anxiety HADS	All Mean (sd)	Radical Mean (sd)	Palliative Mean (sd)	Females Mean (sd)	Males Mean (sd)
Six Months Post Treatment Numbers	5.14 (4.15) 146	4.81* (3.96) 124	7.00* (4.76) 22	5.14 (4.04) 97	5.12 (4.41) 49
One Year Post Treatment Numbers	5.03 (4.30) 113	4.81 (4.13) 98	6.47 (5.22) 15	5.01 (4.42) 80	5.06 (4.08) 33
Eighteen Months Post Treatment Numbers	4.81 (3.96) 101	4.78 (3.94) 93	5.13 (4.42) 8	4.77 (4.17) 69	4.90 (3.51) 32
Two Years Post Treatment Numbers	4.92 (3.91) 95	4.93 (3.83) 90	7.00 (5.20) 5	4.84 (4.11) 68	5.11 (3.41) 27
Three Years Post Treatment Numbers	5.22 (3.63) 92	5.13 (3.63) 86	6.50 (3.51) 6	5.34 (3.80) 68	4.88 (3.08) 24
Four Years Post Treatment Numbers	4.88 (3.96) 76	4.90 (3.98) 72	4.50 (4.12) 4	4.70 (3.97) 54	5.32 (3.98) 22
Five Years Post Treatment Numbers	4.21 (3.44) 78	4.18 (3.48) 74	4.75 (3.44) 4	3.96 (3.27) 56	4.82 (3.86) 22

*At 6 months a significance difference in anxiety was found in treatment intent, $F(1,145)=5.552$, $p=0.02$.

Palliative patients were significantly more anxious than radical patients at 6 months post treatment F(1,144.

At four years a post Hoc Tukey showed that the patients in the age groups 26-50 (Mean 7.23) were significantly more anxious than the patients in the group 50-65 (Mean 4.069), and the group 65 plus (Mean 4.33), $F(2,73)=4.329$, $p=0.018$. A similar difference was found at five years post treatment. No other variable was significant.

Analysis using cut-off points to indicate psychological problems

HADS Anxiety

For the following five years anxiety appears to exist in approximately 20% of this population. The percentage of anxiety 'cases' according to gender is shown in table 38.

Table 37: Percentage of Men and Women with Scores of 8 and over on the HADS Anxiety Scale from 6 Months to 5 Years Post Treatment

	T6 (Total Nos)	T7 (Total Nos)	T8 (Total Nos)	T9 (Total Nos)	T10 (Total Nos)	T11 (TotalNos)	T12 (TotalNos)
Women	25 (97)	23 (80)	24 (70)	22 (68)	28 (68)	22 (54)	12 (56)
Men	24 (49)	18 (33)	19 (31)	19 (27)	21 (24)	23 (22)	23 (22)

The further breakdown according to possible and probable 'cases' is displayed in graph 27.

Graph 27: Percentage of Possible/Probable Anxiety 'Cases' from 6 Months to 5 Years After Treatment
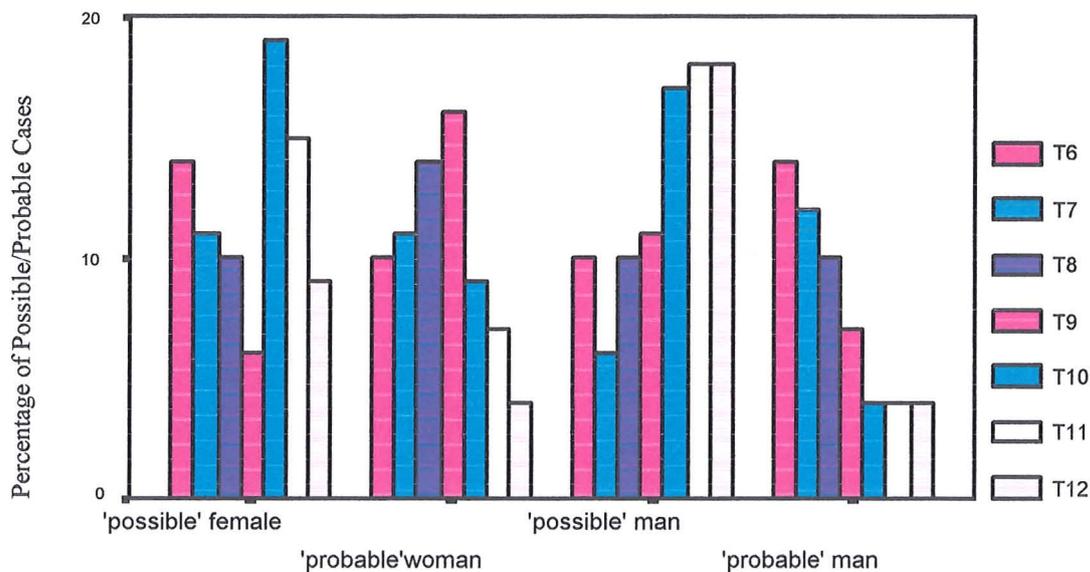
T6= 6 months post treatment, T7= 1 year post, T8=18 months post, T9=2 years post, T10= 3 years post, T11= 4 years post, T12=5 years post

The largest drop of possible or probable cases of anxiety is at year five, the end of the study, when, for the first time, the number of 'cases' drops to below 20%. The number of 'possible'

and 'probable' cases for men remains stable for years 3 to 5. The number of 'cases' for women falls in this period.

The palliative patient number dwindles from one year post treatment due to death and non-participation to only five at the five year mark. From one year onward, palliative patients numbers (N=14) are dramatically reduced. This was reduced to nine at eighteen months. During this period from one year to eighteen months post treatment, forty patients died. The absence of these terminally ill patients in the data could be responsible for the dip in anxiety levels.

With the high attrition rate in the palliative patients, treatment intent could not be used as a variable from one year post treatment. Repeated measure analysis was carried out on anxiety of all twelve testings with the variable of gender. There is no significant effect over time for either anxiety or gender. However, there was an anxiety * gender interaction, $F(11,594)=2.956, p=0.001$.

STAI State

The anxiety for the radical and palliative patients and men and women is shown on Graph 28. The numbers of the palliative patients from year one is 8 and therefore does not warrant further statistical analysis.

Graph 28: STAI State from 6 months to five years after treatment for radical and palliative patients
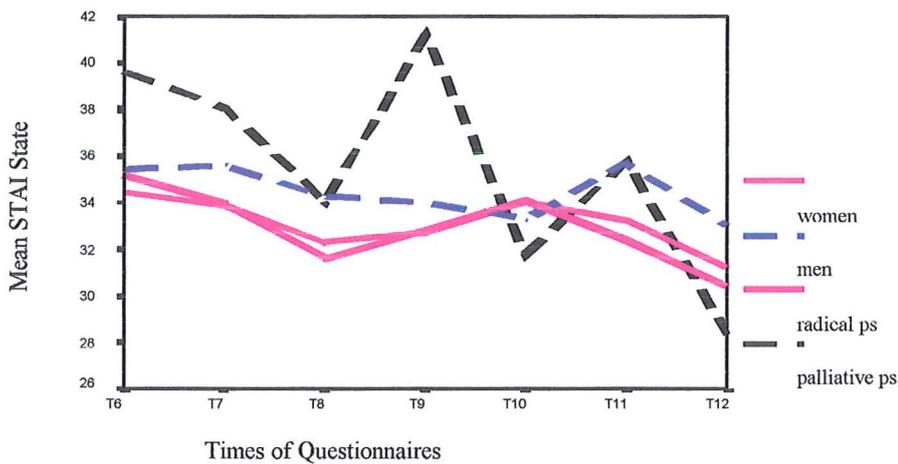
T6= 6 months post treatment, T7= 1 year post, T8=18 months post, T9=2 years post, T10= 3 years post, T11= 4 years post, T12=5 years post

The STAI State pattern is very similar to the HADS anxiety scale (Graph 25, 26). Both questionnaires show a similar increase in anxiety at year 3 for the palliative patients group.

From 6 months to year 2 the palliative patients and the men are exhibiting the highest levels of anxiety. The numbers of palliative patients in year 2, 3 and 4 is on average 5 and therefore statistical analysis is not possible. However the men throughout this post period continue to show higher anxiety than the women patients. The STAI State shows that men have higher levels of anxiety from 6 months. The HADS shows the men having higher levels of anxiety from 18 months onwards. From year 3 both radical patients and women show a downward trend. As before the men, women and radicals patients follow similar patterns. The palliative patients show a much more erratic pattern. All show a downward trend at year 5.

The exact numbers of patients participating, their STAI state mean and standard deviation is all shown in Table 35.

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**Table 38: Mean Anxiety Scores of Patients Using STAI
from Six Months to Five Years Post Treatment**

Anxiety	All Mean (sd)	Radical Mean (sd)	Palliative Mean (sd)	Females Mean (sd)	Males Mean (sd)
Six Months Post Treatment Numbers	35.27 (11.79) 146	34.46* (11.17) 124	39.64* (14.16) 22	35.20 (11.93) 97	35.42 (11.59) 49
One Year Post Treatment Numbers	34.45 (12.79) 113	33.87 (12.33) 98	38.06 (15.33) 15	33.94 (12.44) 80	35.58 (13.63) 33
Eighteen Months Post Treatment Numbers	32.47 (10.84) 101	32.29 (10.80) 93	34.50 (11.92) 8	31.62 (10.38) 69	34.28 (11.74) 32
Two Years Post Treatment Numbers	33.16 (11.23) 95	32.70 (11.00) 90	41.20 (13.66) 5	32.80 (10.75) 68	34.04 (12.51) 27
Three Years Post Treatment Numbers	33.91 (10.84) 92	34.04 (10.69) 86	31.80 (14.32) 6	34.14 (10.86) 68	33.29 (10.97) 24
Four Years Post Treatment Numbers	33.37 (12.32) 76	33.24 (12.45) 72	35.75 (10.87) 4	32.41 (12.76) 54	35.73 (11.08) 22
Five Years Post Treatment Numbers	31.12 (10.45) 78	31.23 (10.59) 74	28.33 (7.23) 4	30.40 (11.07) 56	33.00 (8.58) 22

At 6 months a significant difference $t(216)=3.050$, $p=0.003$.

As with the HADS anxiety scale the palliative patients were significantly more anxious at 6 months.

At six months post treatment a Post Hoc Tukey showed a significant difference between the State anxiety levels of the separated patients (mean 26.1) and the married patients (Mean 37.1), $F(4,204)=3.24$, $F(6,211) = 3.071 p=0.007$. Also a significant difference was found in anxiety according to social class. A Post Hoc Tukey showed that patients from Social Class A were significantly less anxious than patients from Social Class B ($p=0.039$) and C2, $F(4,204)=3.242$, $p=0.013$.

At five years a post Hoc Tukey showed that patients form Social Class A were significantly less anxious than patients from Social Class B and C, $F(4,69)=3.057$, $p=0.022$.

STAI using cut-off points to indicate a 'case'

Graph 29: Percentage of Possible Anxiety 'Cases' Using STAI State from 6 months to 5 years post treatment
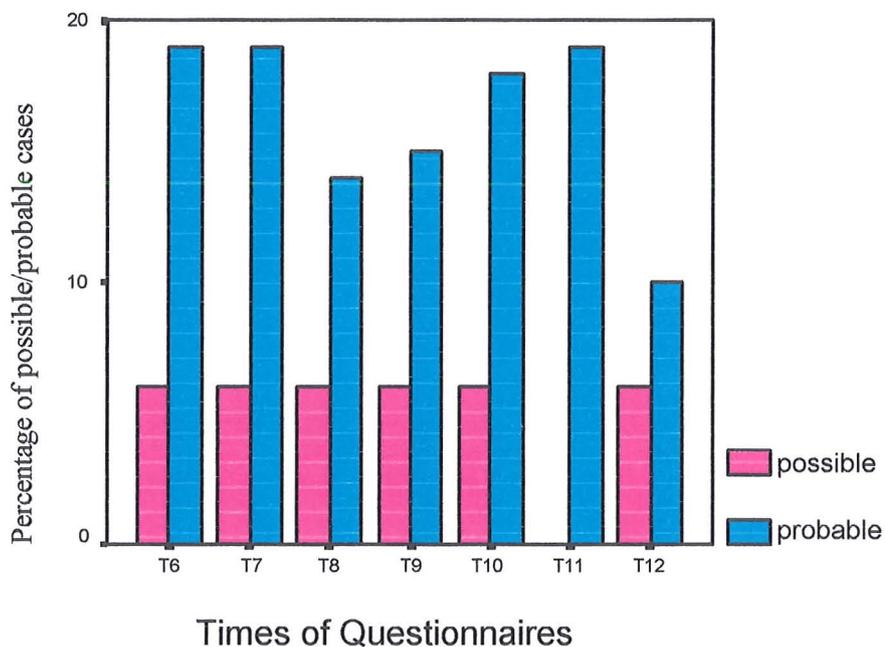
T6— 6 months post treatment, T7— 1 year post, T8—18 months post, T9—2 years post, T10— 3 years post, T11— 4 years post, T12—5 years post

The overall percentage of possible and probable cases from six months to five years remains fairly static at over 20% until year 5 when there is an overall drop in numbers.

The number of 'probable' cases for men is higher than for women throughout this period from 6 months to 5 years. The number of 'possible' cases is higher overall for the women than the men.

Table 39: Percentages of Men and Women Indicating Anxiety from 6 months to 5 years Post Treatment with STAI State

Gender	T6	T7	T8	T9	T10	T11	T12
Females	25%	22%	19%	18%	25%	19%	18%
(Numbers)	(93)	(80)	(69)	(66)	(63)	(53)	(55)
Males	21%	27%	21%	29%	21%	21%	19%
	(47)	(36)	(32)	(27)	(24)	(19)	(22)

T6= 6 months post treatment, T7= 1 year post, T8=18 months post, T9=2 years post, T10= 3 years post, T11= 4 years post, T12=5 years post

Looking at the levels of anxiety from one year men have a higher percentage of cases, except at 6 months and year 4.

Graph 30: Possible and Probable Anxiety Cases Using STAI State from 6 Months to 5 Years Post Treatment by Gender
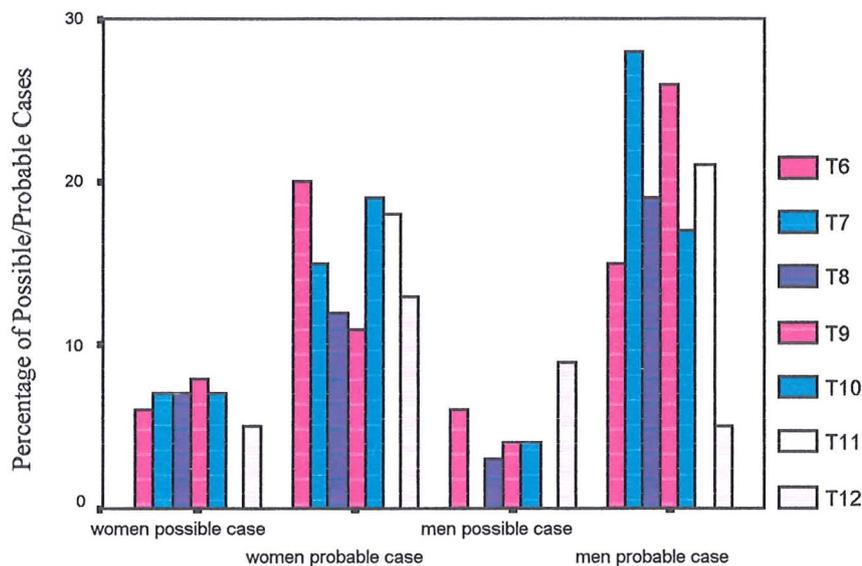
T6– 6 months post treatment, T7– 1 year post, T8–18 months post, T9–2 years post, T10– 3 years post, T11– 4 years post, T12=5 years post

The highest number of 'probable' cases for women is a 6 months post treatment. This drops until year 3. In contrast the number of 'possible' cases for men is at its lowest at 6 months (apart from year 5) and increases over the study. Palliative patients are statistically too small, however as with the HADS there are no cases from year 3.

Depression

Levels of depression overall fell from six months to eighteen months post treatment and then start rising again, with a fall at year five.

Table 40: Mean Depression Scores of Patients by Gender and Treatment Intent from Six Months to Five Years Post Treatment

Depression HADS	All Mean (sd)	Radical Mean (sd)	Palliative Mean (sd)	Females Mean (sd)	Males Mean (sd)
Six Months	3.64	3.20*	6.09*	3.21+	4.52+
Post Treatment	(3.39)	(3.13)	(3.79)	(3.28)	(3.48)
Numbers	146	124	22	97	49
One Year	3.49	3.25*	5.07*	2.90**	4.88**
Post Treatment	(3.27)	(3.15)	(3.69)	(3.1)	(3.13)
Numbers	113	98	(15)	80	33
Eighteen Months	2.96	2.87	4.00	2.45*	4.09*
Post Treatment	(2.92)	(2.89)	(3.34)	(2.71)	(3.09)
Numbers	101	93	8	69	32
Two Years	3.24	3.14	5.00	2.84	4.26
Post Treatment	(3.52)	(3.47)	(4.30)	(3.58)	(3.19)
Numbers	95	90	5	69	27
Three Years	3.43	3.41	4.00	2.98*	4.64*
Post Treatment	(3.50)	(3.52)	(3.46)	(3.34)	(3.69)
Numbers	92	86	6	68	24
Four Years	3.27	3.28	3.00	2.81	4.36
Post Treatment	(3.66)	(3.75)	(1.41)	(3.79)	(3.13)
Numbers	76	72	4	54	22
Five Years	2.74	2.70	3.50	2.27*	3.95*
Post Treatment	(3.19)	(3.24)	(2.08)	(3.07)	(3.24)
Numbers	78	74	4	56	22

*　　　Signifcant difference in treatment intent at 6 months $t(215)=4.753$, $p=0.001$
\+　　　Signficant difference in gender at 6 months $t(143)=2.227$, $p=0.027$
**　　Significant difference in gender at one year $t(112)=3.069$, $p=0.003$
*　　　Significant difference in treatment intent at one year in $t(112)=2.030$, $p=0.045$
*　　　Significant difference in gender at 18 months in $t(101)=2.721$, $p=0.008$
*　　　Significant difference in gender at three years $t(88)=2.052$, $p=0.043$
*　　　Significant difference in gender at five years in depression, $t(76)=2.151$, $p=0.035$

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Palliative patients were significantly more depressed than the radical patients at 6 months and 1 year. Men were more significantly depressed than the women at 6 months, 1 year, 18 months, 3 years and 5 years. At eighteen months A Post Hoc Tukey revealed those patients aged 65 plus were significantly more depressed than those patients aged between 50 and 65, $F(2,110)=4.44$, $p=0.014$.

At two years a significant difference in depression in marital status was found, $F(5,89)=2.759$, $p=0.023$.

At three years a significant difference was found in site, $F(10,79)=2.4$, $p=0.015$. A post Hoc Tukey showed that lung patients (Mean 12) were significantly more depressed than prostate patients (Mean 2.3).

At four years the patients in the 65 plus (Mean 4.33) group were significantly more depressed than the patients aged 50-65 (Mean 4.07), $F(2,72)$ $p=0.09$.

A similar difference was found at five years post treatment. A significant difference was found in relationship to depression and age. A Post Hoc Tukey showed that patients aged 65 plus were significantly more depressed than patients aged 50-65, $t(76)=2.151$, $p=0.035$

Depression – cut-off points

Analysis looking at the number of possible and probable 'cases' post treatment showed a big drop at five years with 8% indicating a 'case', however, before that time the percentage was fairly static at about 15% overall.

Table 41: Percentage of Men and Women with Scores of 8 and over on the HADS Depression Scale from 6 Months to 5 Years Post Treatment

	T6 (Total Nos)	T7 Total Nos)	T8 (Total Nos)	T9 (Total Nos)	T10 (Total Nos)	T11 (TotalNos)	T12 (TotalNos)
Women	12 (97)	10 (80)	8 (70)	10 (68)	13 (68)	15 (54)	5 (56)
Men	17 (49)	23 (34)	16 (31)	22 (27)	21 (24)	18 (22)	14 (22)

T6= 6 months post treatment, T7= 1 year post, T8=18 months post, T9=2 years post, T10= 3 years post, T11= 4 years post, T12=5 years post

A clear distinction can be seen in the distribution of depression 'cases according to gender. Men have consistently higher numbers of patients indicating 8 and over on the HADS depression scale.

Graph 31: Possible and Probable Depression 'Cases' by Gender from 6 Months to 5 Years Post Treatment
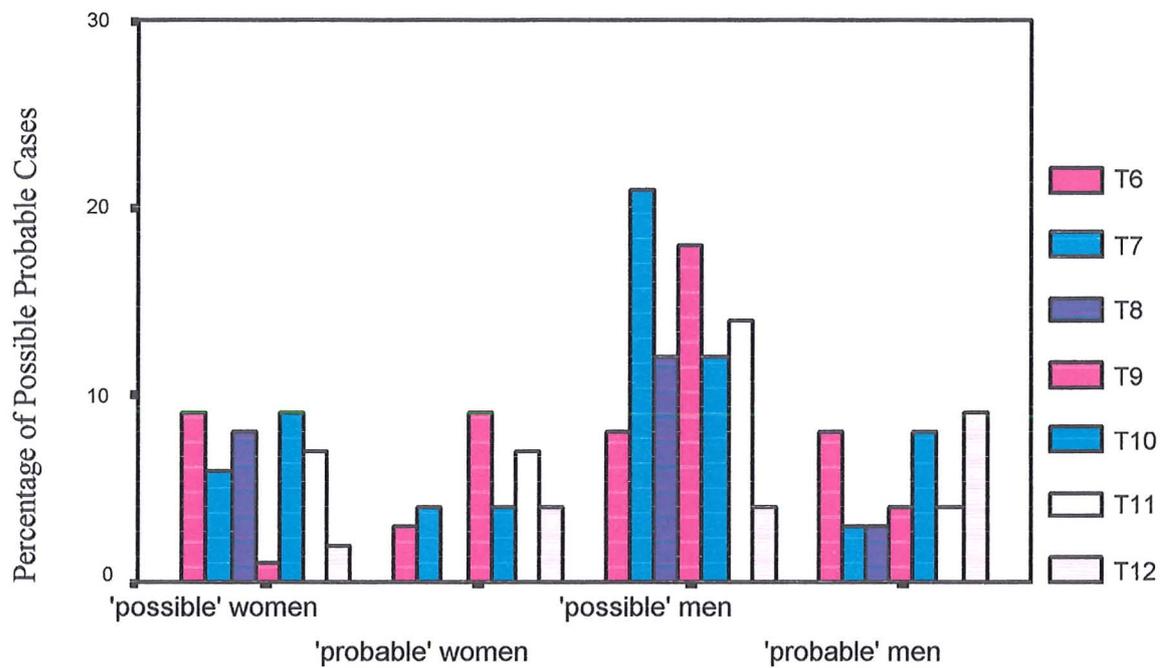
T6= 6 months post treatment, T7= 1 year post, T8=18 months post, T9=2 years post, T10= 3 years post, T11= 4 years post, T12=5 years post

None of the palliative patients left in the study showed signs of depression with the HADS from year three to the end of the study.

Although the number of 'cases' of depression is not so high as anxiety, at six months 14% are indicating a possible/probable case. This rises to 16% at years 3 and 4. The biggest drop is at year 5, the end of the study.

Analysis over the whole period, using repeated measures, with the variable of gender showed that depression and gender had a significant effect over the course of the study, depression $F(11,572)=2.366$, $p=0.007$, and gender $F(1,52)=8.532$, $p=0.005$. There was also a gender* depression interaction, $F(11,572)=2.665$, $p=0.002$.

Psychological Distress using 13 and 18 as cut-off points for unitary HADS scores.

Overall the levels from 6 months remained fairly consisted. Graph 32 indicates the level of distress still occurring in patients over this period. Men's psychological distress has risen and is higher than the women's. The number of men at the end of the study still participating was only 22 and women 56.

Graph 32: Psychological Distress as Measured by the Combined Scores of the HADS from 6 Months to 5 Years Post Treatment for Men and Women
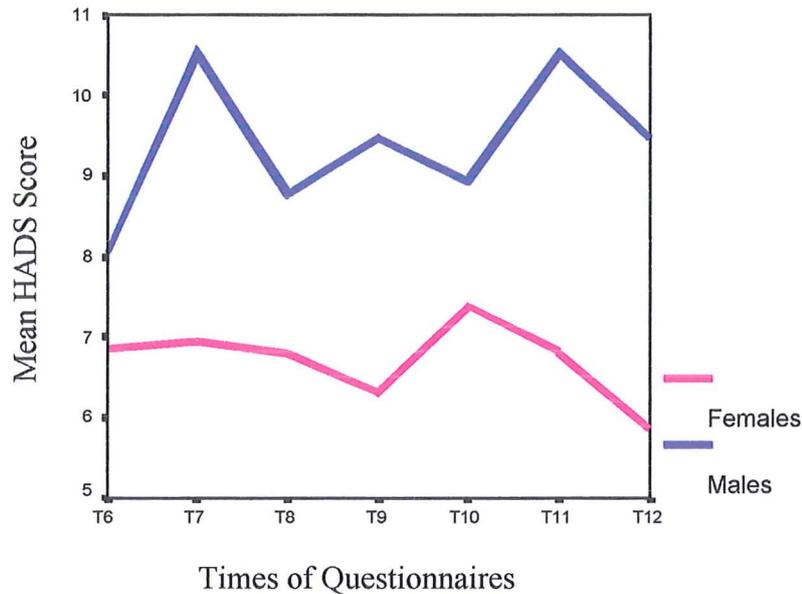
Times of Questionnaires

T6=6 months post, T7=1year post, T8=18 months post, T9=2 years post, T10=3 years post, T11=4 years post, T12=5 years post.

The women's score show a downward trend apart from year 4. The men's score is not only higher but more erratic. At 6 months 29% are indicating a 'case'. At year 4 the percentages rise to 41% and drop at year 5 to 32%.

Table 42: Percentage of Men and Women Patients with Combined HADS Scores of 13 and over from 6 Months to Five Year Post Treatment

	T6 (Total Nos)	T7 (Total Nos)	T8 (Total Nos)	T9 (Total Nos)	T10 (Total Nos)	T11 (Total Nos)	T12 (Total Nos)
Women	26 (97)	21 (80)	19 (70)	17 (68)	23 (66)	19 (54)	16 (56)
Men	29 (48)	27 (33)	26 (31)	26 (27)	29 (24)	41 (22)	32 (22)

T6=6 months post, T7=1year post, T8=18 months post, T9=2 years post, T10=3 years post, T11=4 years post, T12=5 years post.

A high percentage of the men were indicating 'possible' distress at three, four and five years post treatment. 'Probable' cases for men showed a decline from year two.

Apart from at the 6 month point, 'possible' cases were lower for women. 'Probable' cases for women for the first four years seem to be approximately 10% of this population.

Graph 33: Percentage of Cases Indicating Psychological Distress for Men and Women from 6 Months to 5 Years Post Treatment
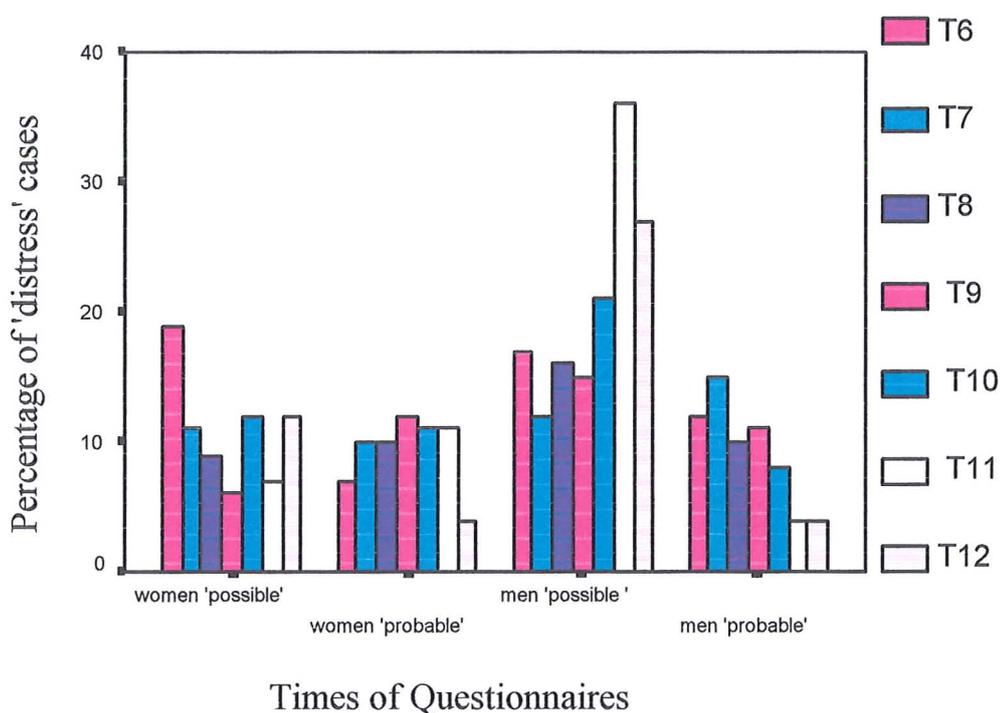
T6= 6 months post treatment, T7= 1 year post, T8=18 months post, T9=2 years post, T10= 3 years post, T11= 4 years post, T12=5 years post

Treatment intent is not really valid for this small cohort of palliative patients. The number of palliative patients in this period is very small. There are 22 at 6 months and this falls to 15 at year 1, 8 at year 2, 5 at year 3, and four thereafter. It is interesting to note however that none of the palliative patients are 'probable' cases from 3 years post treatment onwards.

From one year onward, the numbers of palliative patients declines with forty deaths in the second year of the study.

Analysis over time for the whole study showed that there was no significant effect for distress overtime and treatment intent, however, significance was reached with gender, men (Mean 13.244) women (Mean 6.034), $F(1,51)=5.8$, $p=0.019$.

The psychological problems, which patients suffer throughout their treatment and for years after, are high.

At 6 months post treatment breast patients numbered 70, prostate 12 and non-gender related 56. At the end of the five year period breast patients numbered 40, prostate 5 and non-gender related, 27.

Graph 34: Anxiety from 6 Months to Five Years Post Treatment for Prostate, Breast and Non Gender Related Cancers
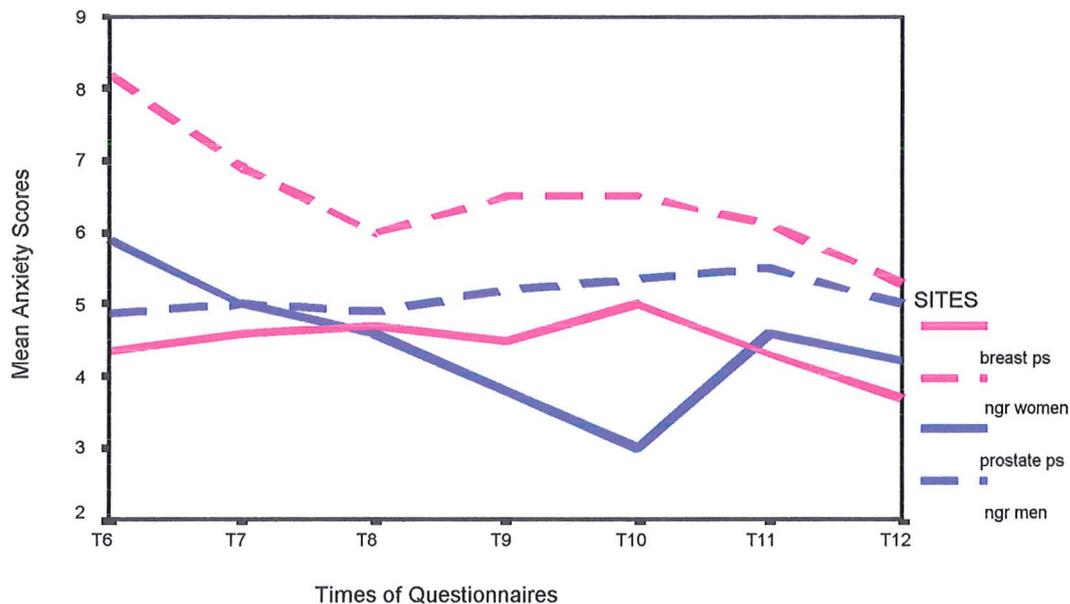
T6=6 months post, T7=1year post, T8=18 months post, T9=2 years post, T10=3 years post, T11=4 years post, T12=5 years post.

The non-gender related women have higher anxiety levels at simulation. This drops at years 1 and 18 months. The men and women then follow similar patterns, though the women have consistently higher anxiety.

The non-gender related male cancer patients had higher anxiety scores than the prostate patients from year 1 to year 4. The difference was not significant at any time point.

The non-gender related female cancer patients had higher anxiety scores throughout the five years than the breast patients. The difference was only significant at 6 months post treatment, $t(87)=4.003, p=0.001$

The non-gender related male and female scores were analysed. The females had significantly higher scores at 6 months, $t(53)=2.641, p=0.01$. Similar findings were found

with the larger male and female cohort not divided by site. At 6 months the larger cohort found no difference in anxiety scores. Similarly at year 4, the low anxiety of prostate patients pulled the average scores of the male population down. This explains (Graph 25) why the women's anxiety scores were higher than the men's at this time.

Depression

Graph 35 showing depression, displays a more erratic pattern than the anxiety graph. Non-gender related men have the highest scores throughout from 6 months to five years post treatment. Prostate patients show higher scores than the women except years three and four. Non-gender related site women have higher depression scores at year 3 and four. By year 5 all groups are showing a downward trend. Breast patients have consistently low levels of depression.

Graph 35: Depression from 6 Months to 5 Years Post Treatment for Prostate, Breast and Non-Gender Related Cancers
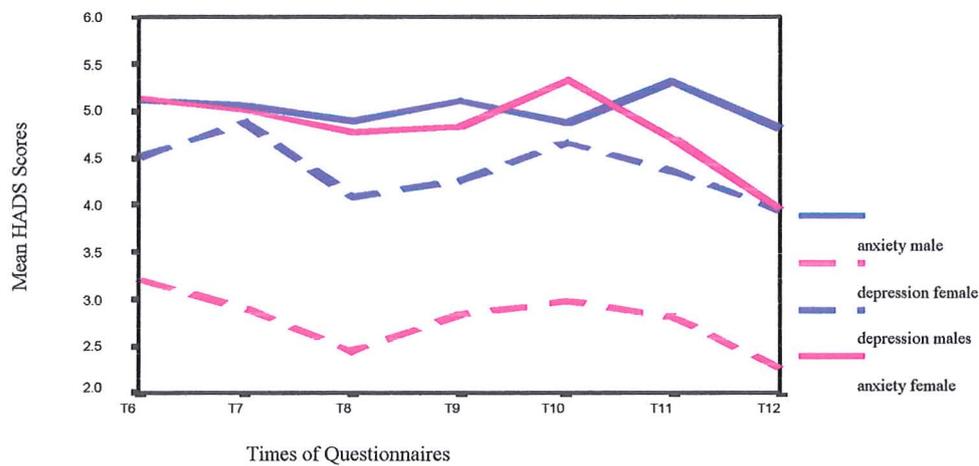

Times of Questionnaires
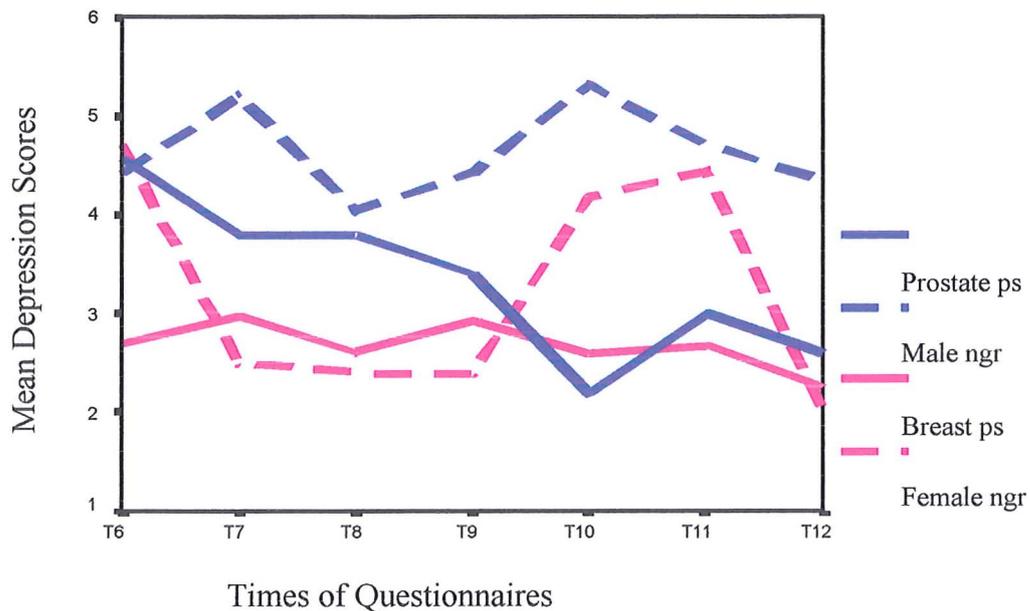
T6=6 months post, T7=1year post, T8=18 months post, T9=2 years post, T10=3 years post, T11=4 years post, T12=5 years post.

At year 3 there is a significant difference in the depression scores of non-gender related male and prostate patients. Non gender related patients are significantly more depressed, t(22)=2.6, *p*=0.019

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Analysis on the non-gender related males and females showed that the males had higher depression scores from one year to five. Significance was reached at year one, t(36)=2.578, *p*=0.014, at two years, t(30)=2.6, *p*=0.04 and five years, t(25)=2.02, *p*=0.05. These results are very similar to the larger mixed male and female cohort where significance was reached at six months, 1 year, 18 months, three years and five years.

The attrition rate was high in this study due to deaths, particularly as the cohort included palliative patients. It is important to assess the psychological state of those patients who died. The following table shows the anxiety and depression results of those patients who died after a specific testing point.

Table 43: Statistical Findings According to
Anxiety and Depression of Patients who Died by the End of the Study

Treatment Times	Anxiety	Depression
Simulation	0.296	0.001**
First Treatment	0.203	0.001**
Mid Treatment	0.372	0.001**
End Treatment	0.092	0.001**
Four Weeks Post Treatment	0.007*	0.001**
Six Months Post Treatment	0.031*	0.001**
One Year Post Treatment	0.663	0.084
Eighteen Months Post Treatment	0.515	0.50*
Two Years Post Treatment	0.103	0.010*
Three Years Post Treatment	0.009*	0.113
Four Years Post Treatment	0.633	0.736
Five Years Post Treatment	N/A	N/A

*   <0.05
**   <0.005

At each testing, the patients who had died had higher mean scores in the previous data sets than those who were still alive. For the first eight testing points depression was significantly higher for those who had died (except for year 1). As the timescale got larger between testings, when it was extended from 6 month to one year, the timescale then became too long for accurate data analysis on deaths post testing.

Predictions

Can anxiety at either simulation or first treatment predict anxiety five years after treatment has finished?

With the dependant variable of anxiety after five years after treatment, the stepwise regression results are shown in the following table

Anxiety at simulation can explain 15% of the variance of anxiety five years later.

Table 44: Stepwise Regression Analysis Using Anxiety at the End of Five Years as the Dependant, and the Independent Variables of Trait Anxiety, Gender, Treatment Intent and Anxiety at Simulation.

Significant Variable	R square	B	Beta	T	Significance
Anxiety At Simulation	0.150	0.352	0.387	3.658	0.001

Would a better predictor be anxiety at first treatment?

Table 45: Results of Stepwise Regression Analysis Using the dependant variable of anxiety at the end of five years, and the Independent Variables of Trait Anxiety, Gender, Treatment Intent and Anxiety at 1st Treatment.

Significant Variable	R square	B	Beta	T	Significance
Anxiety At First Treatment	0.232	0.459	0.481	4.754	0.001

Using anxiety at the first treatment gives a higher predictive rate than at simulation, from 15% to 23%. Is this also the case with depression?

Depression

If depression at five years post treatment is used at the dependant variable, then depression at simulation explains 14% of the variance and a further 5% by male gender.

Table 46: Stepwise Regression Analysis Using the Dependant Variable of Depression at the End of Five years, and the Independent Variables of Trait Anxiety, Gender, Treatment Intent and Depression at Simulation.

Significant Variable	R square	B	Beta	T	Significance
Depression At Simulation	0.137	0.416	0.370	3.470	0.001
Depression At Simulation + Treatment Intent + Gender	0.197	0.420 1.732	0.374 0.246	3.615 2.377	0.001 0.020

A total of 14% of the variance can be attributed to depression at first treatment and a further 6% to gender, with men being significantly more depressed than women.

Depression at first treatment could be a better predictor of depression after five years.

Table 47: Stepwise Regression Analysis Using the Dependant Variable of Depression at the End of Five Years, and the Independent Variables of Trait Anxiety, Gender, Treatment Intent and Depression at 1st Treatment.

Significant Variable	R square	B	Beta	T	Significance
Depression At First Treatment	0.235	0.650	0.485	4.802	0.001
Depression at 4 weeks post treatment	0.384	0.646	0.619	6.6	0.001

Using the depression at simulation gave a 14% variance of depression five years after treatment. Using depression scores at the first treatment increased the variance to 23%. Using depression at the 4 weeks post time explained 38% of the variance 5 years later.

Psychological Distress

Looking at the distress scores from simulation to the end of the study, distress at simulation explained 15% of the variance of the distress five years later and gender another 5%, with male patients being more distressed than females.

Table 48: Stepwise Regression Analysis Using the Dependant Variable of Distress at the End of Five years, and the Independent Variables of Trait Anxiety, Gender, Treatment Intent, Age, Site and Distress at Simulation.

Significant Variable	R square	B	Beta	T	Significance
Distress At Simulation	0.149	0.390	0.386	3.644	0.001
Distress At Simulation + Gender	0.208	0.420 3.199	0.415 0.245	12.784 3.148	0.001 0.021
Distress at 4 weeks post treatment	0.417	0.657	0.645	7.07	0.001

Similar findings were also attained with distress at first treatment.

A total of 26% of the distress five years post treatment being explained by the distress at first treatment. The predictive value has thus increased from 15% to 26%, when the variable of distress at first treatment is used as opposed to distress at simulation.

A better predictor of distress at five years is distress at 4 weeks post treatment. Forty-two percent of distress at five years can be explained by distress at 4 weeks post treatment.

Table 49: Stepwise Regression Analysis Using the Dependant Variable of Distress at the End of Five years, and the Independent Variables of Trait Anxiety, Gender, Treatment Intent, Age, Site and Distress at 1st Treatment.

Significant Variable	R square	B	Beta	T	Significance
Distress At First Treatment	0.263	0.555	0.513	5.175	0.001
Distress At First Treatment + Treatment Intent	0.313	0.572 2.916	0.529 0.225	5.477 2.325	0.001 0.023

In-House Research Questionnaire

Full analysis of the research questionnaires is in the appendix. (Appendix 34- RQ at 6 months, Appendix 35- RQ at 1 year, Appendix 36- RQ at 18 months, Appendix 37- RQ at 2 years, Appendix 38- RQ at 3 years, Appendix 39- RQ at 4 years, Appendix 40- RQ at 5 years.

A short précis of their findings follows:

Information and Control

At the end of treatment 91% of patients thought the information given was adequate. By six months post treatment 25% did not think it was adequate and 40% wanted more information. At one year post treatment 19% wanted more information. At 18 months patients were sent a booklet 'Coping now your radiotherapy treatment has finished'. By the third year only 12% needed more information.

Cancer had an affect on patients' lives and they appeared to be exerting more control. A total of 82% were eating more healthily, 14% had changed their diet, 22% had changed their smoking habits.

Support

In the six months post treatment questionnaire patients were asked if they would have found a telephone call helpful during the period directly after treatment. Nearly half, 43% stated they would. Some already had contact with breast care nurse and district nurse. Even after one year patients were still feeling insecure and although 80% felt they had enough emotional support, 23% would have liked some more emotional support from staff. By five years only 9% felt they needed more support.

Psychological Well Being

Looking back on their treatment, over 50% found it made them anxious, 20% frightening, 62% caring, 53% reassuring, 18% depressing, 22% sore and painful, 12% distressing and 15% powerless.

By year 2, 91% felt cancer had affected their lives in a positive manner. Only 6% felt fearful, 22% uncertain but 61% were thankful and 47% happy. Life had changed for 37%.

By the end of the study 22% were participating in positive self help, exercise, support groups, diet and 9% had started complementary medicines.

When the study had finished patients were asked how they felt about taking part.

A total of 91% of patients found it helpful to participate in something that would help other patients.

Only seven (9%) found it helpful as it reminded them of their cancer. The seven included four patients being treated for breast cancer, two had skin cancer and one head and neck patient.

A total of 41% thought that the study helped them to come to terms with their illness, twenty women and thirteen men.

One third of the patients thought the study had made them more confident to talk with their doctor. Over half (52%) thought that the study made them realize that their reactions were normal and only five (6%) felt worried by the study.

Patients were also asked to make comments about the treatment. The following are quotes from patients and are divided into the following sections,

1. Their feelings.

2. The questionnaires.

3. Support issues.

4. Positive attitudes in coping with cancer.

5. The altruistic aspect of this study

6. Their physical condition

7. Positive responses to the staff.

1. Their Feelings

'Taking part in this series of questionnaires actually helped me to think about and admit what I was feeling about my treatment. I am not very good at admitting how I feel about things, but just being able to circle or tick something which affected me helped me to face the way I was feeling at the time'

'I could not discuss my feelings with anyone and even now only a few people know so that the questionnaires dealt with my deep mind'

'It made me feel lucky that I had not many problems and came to term with my illness'

'This study seemed to sum up how I was feeling and this made me realize my feelings were "normal".

'This is not something I like doing too frequently'

'I am glad I took part in the research, I knew that there were a lot of other people taking part in it and it made me feel I was not alone in my illness'.

2.   The Questionnaires

'I found the to-ing and fro-ing of the questions a bit dizzying. The "strongly disagree", "agree" gets me cross-eyed. I never knew if I put what I intended'.

'Sometimes how I answered the questions depended upon how I felt at the time which may not have any bearing on the cancer, e.g. answering questionnaire following a heavy cold or a difficult time at work. Some questions felt repetitive some I had mixed feelings about which made them difficult to answer'

'A bit laborious but OK as it is only once a year'

'When you believe yourself to be cured it is rather irritating to keep answering the same questions. The same questions put another way is also very annoying. I understand however why the information is useful. The questions are rather black and white and one cannot qualify. The questions make one realize what it would be like if incurable cancer was ever one's diagnosis'

'Questions about my physical and mental state were quite easy and straight forward'

'Occasionally I felt confused when answering the questions because I wasn't sure whether problems I experienced were attributable to my cancer or not. Also self-evaluation – are we supposed to evaluate our moods/state of mind in general terms or only as relating to our cancer'.

'I sometimes found it difficult with the negative questions I find it easier with the positive questions. I have also found it difficult with degrees of answer e.g. as in disagree- strongly, moderately, slightly'.

3.   Support Issues

''I found the chemotherapy very frightening and would have given up after three months if I had not had the support of my husband'

'Yes, Macmillan nurses seem to take an interest when diagnosed with cancer and then they never seem to be there anymore. Anyhow I'm really well and getting on with my life'

'Normally at the 5 year mark appointments are gradually trailed off – She wants to keep me, still once a year. It is extremely reassuring to have this support'.

4.   Positive Attitudes in Coping with Cancer

'I would like to say that one has to be positive and each day/year is a bonus'

'Although I wanted to help I didn't like being reminded. Being a positive person I don't like looking backwards'

'I found being positive about having cancer helped me to cope with it'

'Having a positive mental attitude throughout I believe has helped me through it along with a little help from my friend'

5.   The Altruistic Aspect of this Study

'I think if more people's reactions were asked for and collated and expressed by the medical profession cancer wouldn't appear so scaring. This is why it is important for patients to help other it may apply to'.

'I hope the responses you have received will help fellow sufferers'

'The study has been helpful to me in respect I felt in some small way helping future sufferers and that I wasn't just forgotten about after treatment. The trouble was radiotherapy didn't kill off all the cancer cells so I am told'

'Taking part in the survey made me realize that there are many more people who are going through the same traumas as me and knowing that the survey may help others has helped me

6.   Their Physical Condition

'Drugs I need to take would appear to have adverse result i.e. blood pressure, heart, gout, water retention, diabetes, thyroid'

'I do not think my trouble was too serious (skin patient), I would not have been too concerned if I had to have further treatment'

'The Zoladex injections I have once a month in the surgery have reduced the cancer level and I am extremely grateful for this'.

7.   Positive Response to the Staff

'To thank staff for their kindness and help in taking worry away'.

'I was treated very well indeed and everyone so very kind and helpful'

'Thank you for all you do'

'It's good to know that you and others care'

'It's nice to know that somewhere somebody cares. At 76 years of age, it's more unusual. Thank you'

'I found everybody so kind right from start to finish'

'The treatment from surgeon to doctors and nurses at the hospitals both MV and Watford G were so wonderful, they helped me through the whole time. There is always an exception to

this and that was a nurse who was supposed to be a cancer patient support – But she was soon sorted – so for all forgotten'

'To express my gratitude for immediate and effective treatment received which has extended my life by 5 years so far'

'Thanks to all the people at MV who helped me to reach where I am now. A very successful businesswoman in the cleaning business called Supermaids'

Finally, two miscellaneous comments

'I now would like to be left alone to get on with my life and try to forget the past as much as possible'

'My sense of humour helps when I feel a bit down in the mouth'.

Physical Wellbeing

Side effects

The number of patients with side effects from their radiotherapy treatment fell from 60% at the end of treatment to 28% at five years post treatment. However, at two years post treatment, only 20% had any side effects and therefore some side effects develop later. Having side-effects did not appear to affect patients' anxiety and depression. Patients, who had side effects at 2 years were significantly more anxious, $p=0.03$

Table showing if there is a difference in anxiety, depression and distress between those patients who had side-effects and those who did from the end of treatment to 5 years post treatment

Table 50: Percentage of Patients with Side Effects from 6 Months to 5 Years Post Treatment

Treatment Times	Percent/Nos. of patients with side effects
Six Months Post Treatment	33% (41)
One Year Post Treatment	29% (29)
Eighteen Months Post Treatment	41% (42)
Two Years Post Treatment	20% (18)
Three Years Post Treatment	29% (26)
Four Years Post Treatment	23% (17)
Five Years Post Treatment	28% (22)

The following is a series of comments from the patients on the side effects they were suffering from.

Breast patients wrote:

'Excess heat and numbness in upper arm. Also some swelling of the wrist'

'Lymphodaema'

'Weakness in left arm'

'I find movement in my left arm on the side I had radiotherapy quite painful at time'

'Very occasional pain the hollow of neck. Ditto breast pain'

'Scarring of the tissues'

'Displaced implant following surgery and radiotherapy'

'When tired feel sick in area of radiotherapy – more like nausea'.

Three of the five remaining cancer of the prostate patients had problems:

'Sex'

'Still have little energy'

'Nocturnal bathroom visits, continued flatulence'

Patients suffering from cancer of the cervix made the following comments:

'Regular diarrhoea and appearances of blood in my urine from time to time'

'Greater frequency on passing water'

A colon patient wrote

'Wind and bowel irregularities – side-effects from HRT'

A skin patient wrote

'Itchy at times'

Non Hodgkins Lymphoma patients wrote:

'Tightness of the skin'

'Bad arm/shoulder, swollen ankle'

Patients who had tumours of the head and neck immediately after treatment suffered quite badly. On the present survey, only one patient made a comment:

'Very dry mouth'

and the only surviving lung patient wrote

'Sore chest'

A patient being treated for Hodgkin's Disease wrote:

'Knackered circulation – especially in cold weather and increased tiredness as a result',

and the one patient suffering from a tumour of unknown origin wrote:

'Neck and right shoulder pain'.

Fatigue

Fatigue is a common side-effect of radiotherapy treatment. How long do patients continue to feel tired and is their psychological state affected? The question on tiredness was only included from questionnaire 8, given at eighteen months. Nearly half the patients five years post treatment felt tired. Those patients who felt tired were significantly more anxious, depressed and distressed than those who did not. At eighteen months 48% felt tired. This dropped to 32% at two years but increased to 45% at five years post treatment.

Table 51: Showing the statistical difference for those patients who still feel tired after their radiotherapy and those who do not, provided they completed all the 12 questionnaires

Treatment Times	Nos/Percentages of patients feeling tired	Anxiety	Depression	Distress
Eighteen Months Post Treatment	48% (35)	0.012*	0.024*	0.007*
Two Years Post Treatment	32% (21)	0.001**	0.002**	0.001**
Three Years Post Treatment	47% (35)	0.001**	0.002**	0.001**
Four Years Post Treatment	40% (28)	0.001**	0.001**	0.001**
Five Years Post Treatment	45% (34)	0.042*	0.018*	0.014*

*   <0.05
**   <0.005

At the end of the study 50% of the patients were experiencing sleeping problems and these patients were significantly more anxious and depressed, $p=0.01$

Chapter 8

Part 3 – Results of Patients with Complete Data Sets

The final part of the results section consists of those patients who answered every questionnaire. A number of patients who responded to the final questionnaire had missed a questionnaire out through the vagaries of the postal system, holidays, or sickness. These were excluded from this final analysis.

Table 52: Demographic And Medical Characteristics of Patients with Complete Data Sets

DEMOGRAPHIC	Nos	%	MEDICAL	Nos	%
Gender			**Sites**		
Female	41	73.0	Breast	30	54
Male	15	27.0	Lung	1	2.0
			Prostate	4	7.0
Social Class			Skin	2	7.0
			Hodgkin Disease	2	4.0
Class A	3	5.0	Gastro-int	2	4.0
Class B	15	27.0	Bladder	2	4.0
Class C1	19	34.0	Head & Neck	2	4.0
Class C2	9	16.0	Gynae	5	9.0
Class D	10	18.0	NHL	4	7.0
			Unknown	1	2.0
Marital Status			**Treatment Intent**		
Married	41	73.0	Radical	53	95.0
Widowed	5	9.0	Palliative	3	5.0
Divorced	2	4.0	**Ages**		
Single	5	9.0	26-50	13	23.0
Separated	2	4.0	50-65	22	40.0
Partner	6	2.0	65+	21	37.0

Results of HADS

The graph depicting the anxiety and depression of the 56 survivors looks very similar to that of the larger mixed cohort. The anxiety is consistently higher than depression throughout treatment and for the five years after. Anxiety is at its peak at simulation, falls during treatment and has two small peaks at year 1 and year 3. From year four anxiety and depression both show a decline.

Depression throughout the five years is more uniform. During treatment the highest point is at the end of treatment, with another small peak at one year and four years post treatment.

Graph 36: Anxiety and Depression of survivors from simulation to five years post treatment
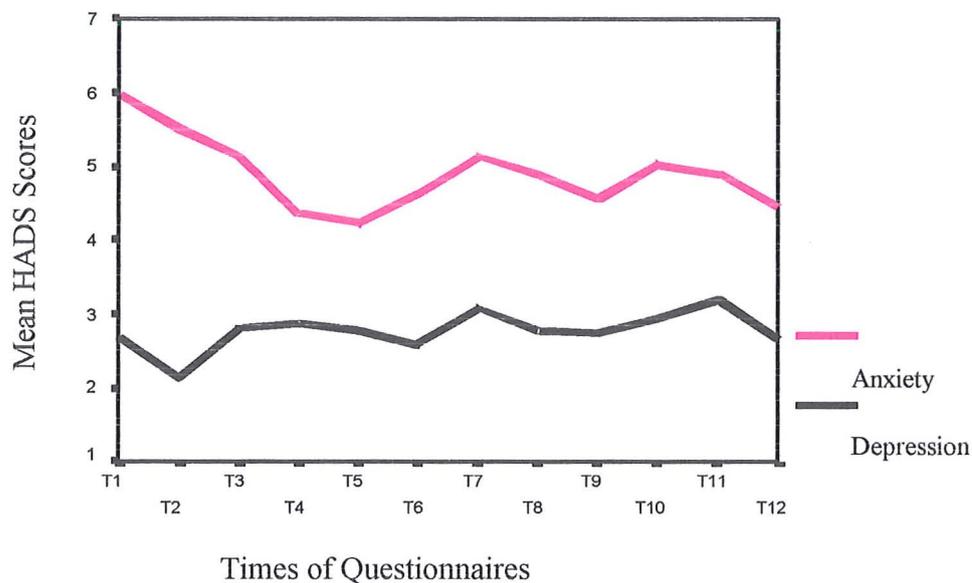
T1=simulation, T2= 1ˢᵗ treatment, T3=mid treatment, T4=end treatment, T5=4 weeks post, T6=6 months post, T7=1year post, T8=18 months post, T9=2 years post, T10=3 years post, T11=4 years post, T12=5 years post.

As with the larger mixed cohort, the anxiety of women was much higher at simulation and falling over the course of treatment (graph 37). In contrast the anxiety of the men, which was low at simulation, rose over treatment. As with the larger cohort this rise was seen at the mid treatment point. However the rise is steeper with the survivors. After treatment the pattern again is similar for the sexes, with men's anxiety being nearly always at a higher level than the women's.

Significance was reached with the survivors at simulation, with women having significantly higher anxiety, $t(54)=2.179$, $p=0.03$, similarly at first treatment $t(54)=2.014$,

p=0.049. These findings occurred with the original cohort. Significance was also found at the end of treatment but this did not occur with the 56 in the complete data cohort.

Graph 37: Mean Anxiety of Men and Women with Complete Data Sets over the Study

T1=simulation, T2= 1st treatment, T3=mid treatment, T4=end treatment, T5=4 weeks post, T6=6 months post, T7=1year post, T8=18 months post, T9=2 years post, T10=3 years post, T11=4 years post, T12=5 years post.

The survivors consisted of only 3 palliative patients, therefore further statistical analysis is not relevant. However it is interesting to note that the pattern of these three patients during treatment and after reflects the anxiety that the larger cohort of palliative patients indicated. Anxiety fell over treatment, but showed an increase at the end of treatment. Throughout the first four years of the study anxiety is consistently higher for the palliative patients.

Graph 38: Mean Anxiety for Radical and Palliative Patients through the Study for Patients with Complete Data Sets
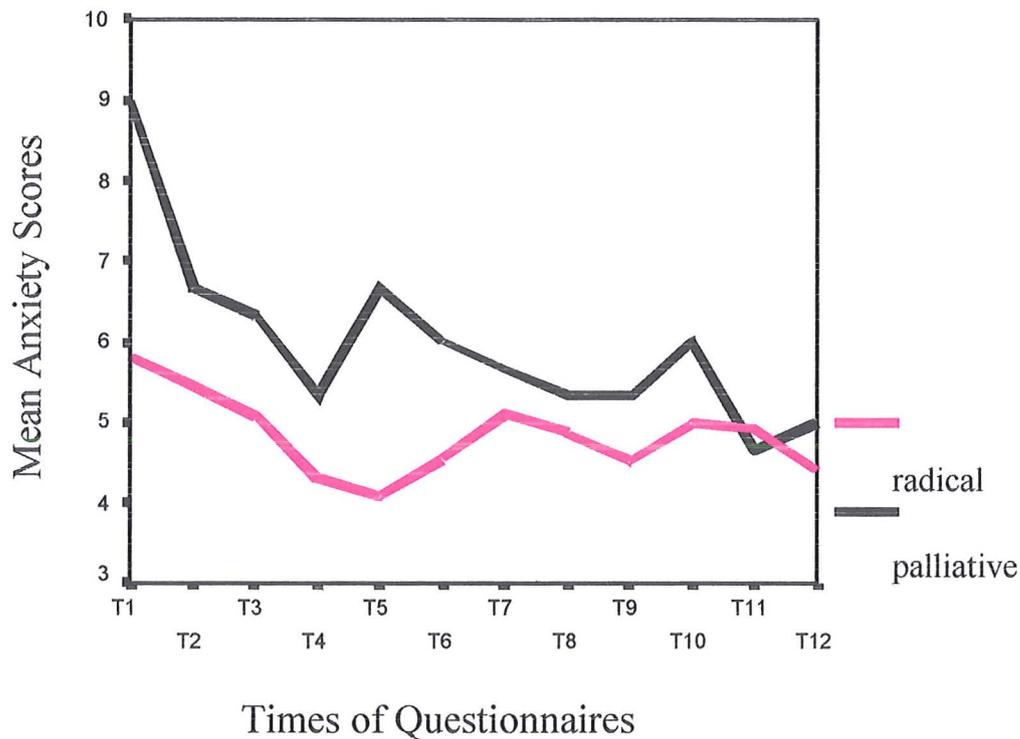
Times of Questionnaires

T1=simulation, T2= 1ˢᵗ treatment, T3=mid treatment, T4=end treatment, T5=4 weeks post, T6=6 months post, T7=1year post, T8=18 months post, T9=2 years post, T10=3 years post, T11=4 years post, T12=5 years post.

HADS – using the cut-off points to indicate psychological problems

Anxiety

The basic pattern of the larger group appears to be the same with this smaller cohort. The overall number of cases registering at the 8 and over level on the HADS anxiety scale fell from 29% at simulation to 20% at five years.

Table 53 shows the number of men and women with anxiety 8 and over for the whole five years of the study.

Table 53: Percentage of Anxiety Cases According to Gender Over the Whole Study for Patients with Complete Data Sets.

	T1	T2	T3	T4	T5	T6	T7	T8	T9	T10	T11	T12
Women	34	24	22	22	17	17	19	19	17	22	19	15
Men	13	7	13	27	13	27	27	20	13	27	27	33

T1=simulation, T2= 1st treatment, T3=mid treatment, T4=end treatment, T5=4 weeks post, T6=6 months post, T7=1year post, T8−18 months post, T9−2 years post, T10−3 years post, T11−4 years post, T12−5 years post.

Table 53 highlights the change of anxiety between the sexes. At simulation, through treatment and after women had more 'possible' and 'probable' cases of anxiety. Simulation and 1st treatment especially were anxious times for the women of this 'completers' cohort

With only 56 patients split between 41 women and 15 men it is a small uneven sample to split into 'possible' and 'probable' cases. The females have more 'possible' and 'probable' cases at simulation and at first treatment. However at the end of treatment the number of 'probable' cases for men is higher than for women. By the end of the study both 'possible' and 'probable' cases for men are higher than for women.

Graph 39: Percentage of Possible and Probable Anxiety Cases According to Gender Through the Study.
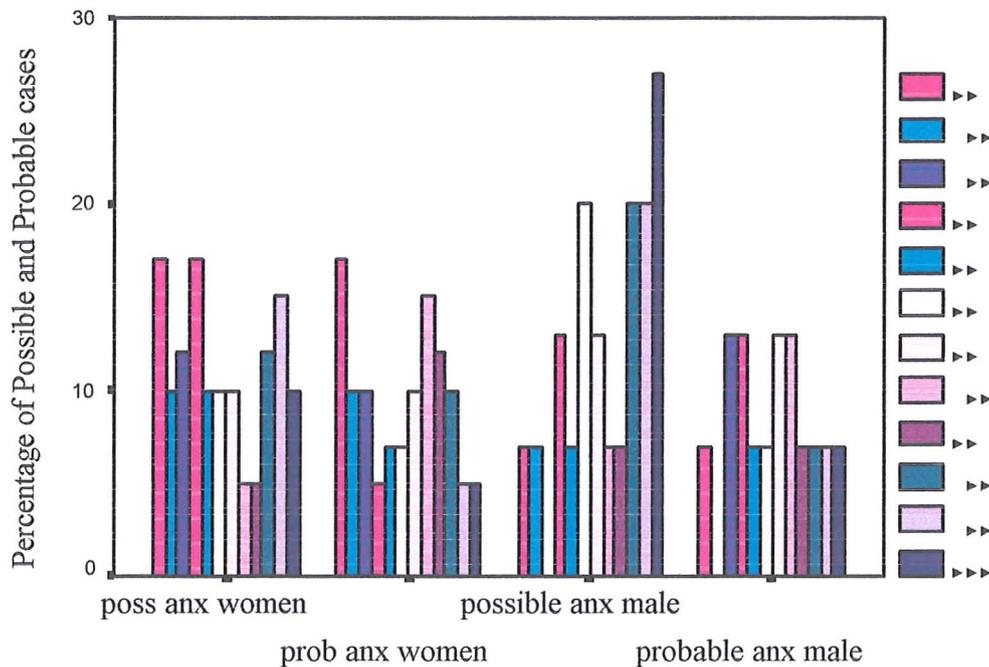
T1=simulation, T2= 1st treatment, T3=mid treatment, T4=end treatment, T5=4 weeks post, T6=6 months post, T7=1year post, T8=18 months post, T9=2 years post, T10=3 years post, T11=4 years post, T12=5 years post.

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Repeated measures analysis of variance for anxiety with the variable of gender over the study showed no significant effect for anxiety or gender.

STAI State

The anxiety scores when measured with the STAI achieved similar results to the HADS. They replicated the findings that anxiety over the course of treatment fell from a high at simulation. Two small peaks occurred at 18 months and year 4 and were measured by both anxiety instruments.

Graph 40: Mean STAI State Scores According to Gender for Patients with Complete Data Sets throughout the Study
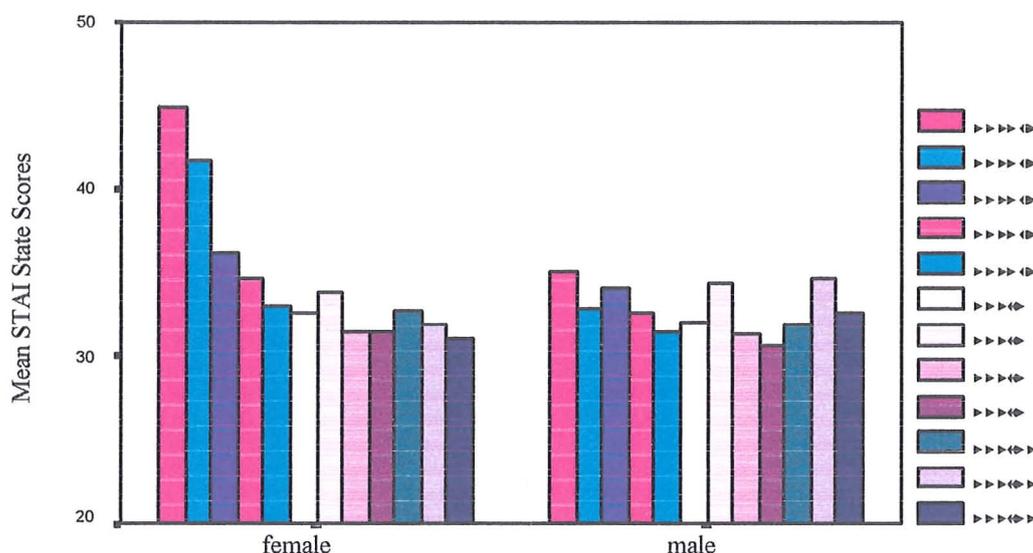
State1=simulation, State2= 1ˢᵗ treatment, State3=mid treatment, State4=end treatment, State5=4 weeks post, State6=6 months post, State7=1year post, State8=18 months post, State9=2 years post, State10=3 years post, State11=4 years post, State12=5 years post.

Women were more anxious than men at simulation, and through treatment. After treatment the anxiety levels of the men were higher than the women. Significance was reached at first treatment, $t(54)=1.98$, $p=0.05$.

Repeated measures analysis of variance for anxiety showed a significant effect for anxiety but not for the variable of gender, $F(11,528)=3.9$, $p=0.001$.

Analysis using the cut-off points

The following graph shows the decline in the number of 'possible' and 'probable' cases of anxiety from simulation. The number of 'probable' cases at 45% at simulation is very high. The number of 'possible' cases was at its highest at first treatment and mid-treatment.

Graph 41: Percentage of Possible and Probable Cases Measured by STAI State for Complete Data Sets through Radiotherapy Treatment.
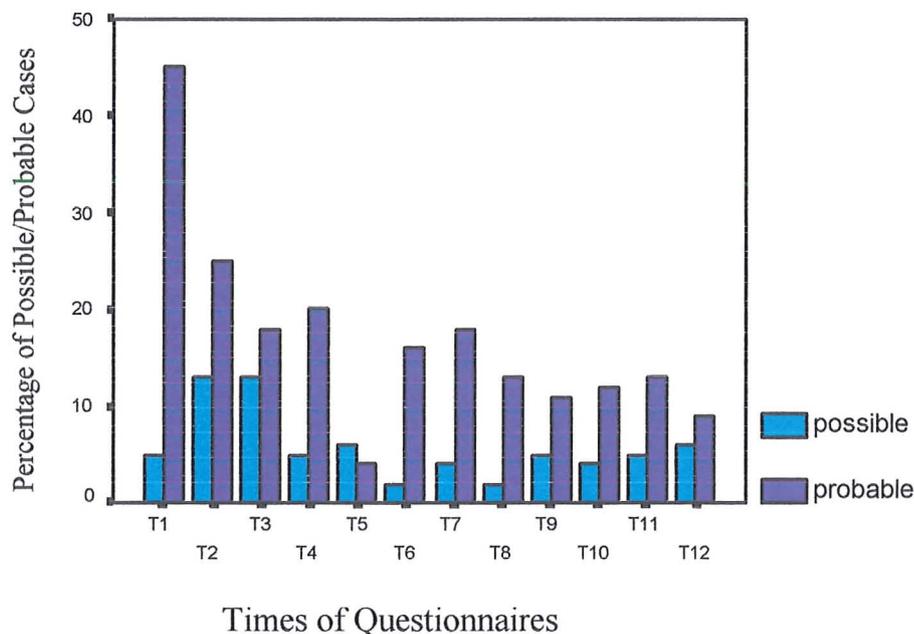
T1=simulation, T2= 1ˢᵗ treatment, T3=mid treatment, T4=end treatment, T5=4 weeks post, T6=6 months post, T7=1year post, T8=18 months post, T9=2 years post, T10=3 years post, T11=4 years post, T12=5 years post.

Gender findings were similar to the larger cohort. Women (n=41) had a higher number of 'probable' cases at simulation. This number was extremely high at 49%. With the original cohort of 157 women, 54% had anxiety over 42.8, with 42% registering as 'probable' cases. Men (n=15) had 29% of 'probable' cases at simulation. With the original cohort of 112 men, 30% were 'probable' cases.

The number of 'possible' and 'probable' cases for men at mid treatment was high and this was the peak anxiety point for men. This should be further investigated with larger numbers. The original cohort of men patients did not show this peak at mid treatment. Anxiety was higher than at first treatment, but not as high as simulation.

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Table 54: Percentage of Patients with Complete Data Sets with Scores over 42.8 on the STAI State through treatment

	T1	T2	T3	T4	T5
Women (41)	56	46	27	27	17
Men (15)	33	13	42	20	27

T1=simulation, T2=first treatment, T3=mid treatment, T4=end treatment, T5=4 weeks post

The percentage of patients indicating anxiety in the five years following treatment is just under 20%. Men, apart from year 5, are exhibiting a higher percentage of 'cases'.

Table 55: Percentage of Patients with Complete Data Sets with Scores over 42.8 on the STAI State from 6 Months to Five Year Post Treatment

	T6	T7	T8	T9	T10	T11	T12
Women (41)	17	20	14	14	14	17	17
Men (15)	20	27	13	20	20	20	7

T6=6 months post, T7=1year post, T8=18 months post, T9=2 years post, T10=3 years post, T11=4 years post, T12−5 years post.

It is apparent that the number of cases of anxiety regardless of sex, falls from 18 months post treatment onwards. However, apart from year 5, anxiety of between 14-20% is evident in these patients from 18months.

Graph 42: STAI State Anxiety of Men and Women with Complete Data Sets
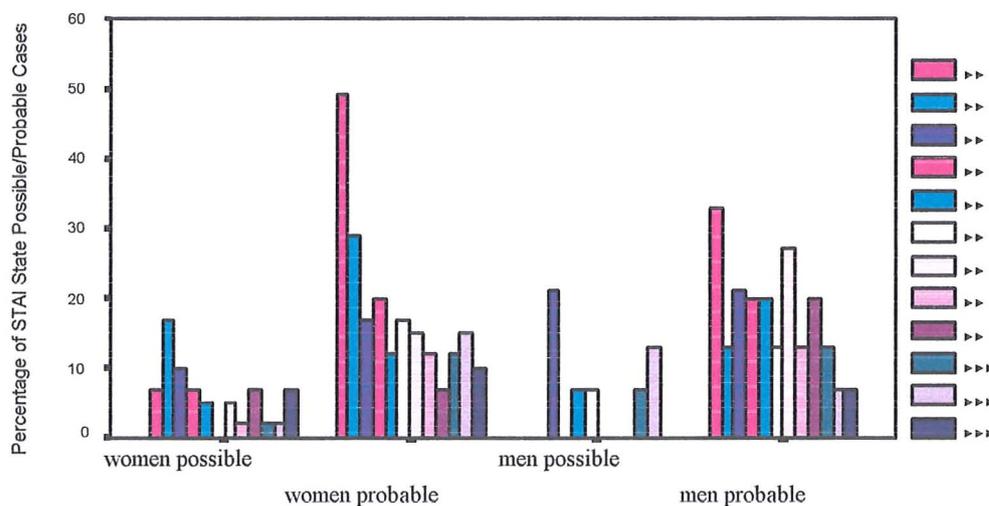
T1=simulation, T2= 1st treatment, T3=mid treatment, T4=end treatment, T5=4 weeks post, T6=6 months post, T7=1year post, T8=18 months post, T9=2 years post, T10=3 years post, T11=4 years post, T12=5 years post.

What was the STAI Trait scores for this group of completers at simulation? The overall mean for this cohort was 34.73 (sd 7.27). This is low. The one palliative male patient had a mean trait anxiety level of 53, the radical men 33.43 (sd 6.28), 2 palliative women 36.50 (sd 6.3) and the radical women 34.64 (sd 7.23). Ten patients had anxiety over the cut-off point of 41.33, 7 women and 3 men. The palliative patients also showed very high STAI State and HADS scores at simulation.

HADS - Depression

The depression scores for the 'completers' were low at simulation. The overall pattern of depression showed a gradual rise. Levels were consistently lower than anxiety scores.

In the larger original cohort men had consistently higher scores than the women through treatment. This pattern is repeated with this smaller group of survivors. This same pattern is continued after treatment for the full five years for both cohorts.

Graph 43: Complete Data Set – Mean Depression Scores of men and women throughout the Study
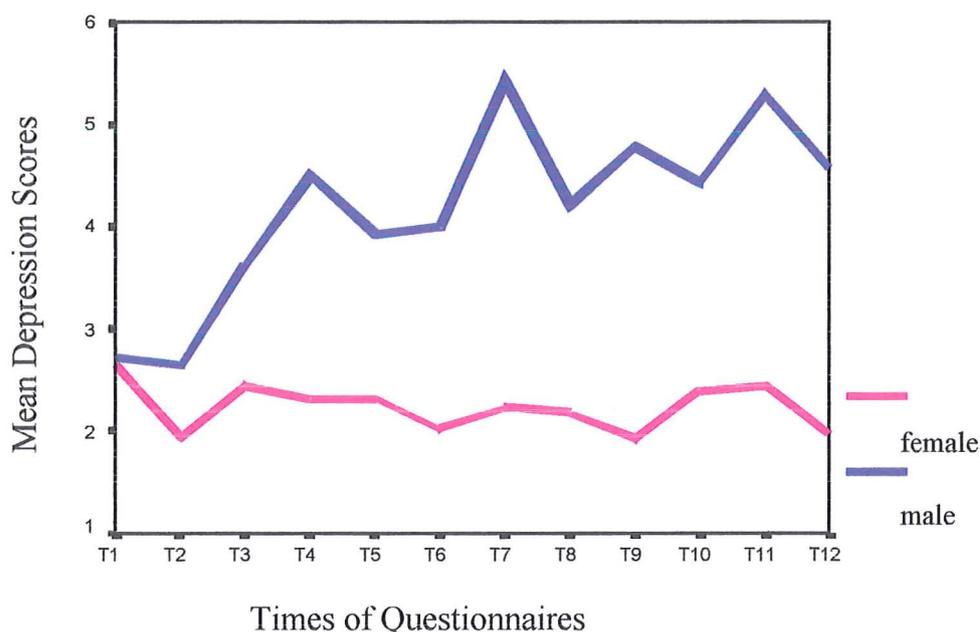
T1=simulation, T2= 1ˢᵗ treatment, T3=mid treatment, T4=end treatment, T5=4 weeks post, T6=6 months post, T7=1year post, T8=18 months post, T9=2 years post, T10=3 years post, T11=4 years post, T12=5 years post.

The pattern of depression for men and women was different. The women's average scores over the whole study remained remarkably stable. In contrast the men's scores show a steady increase.

Table 56: T-tests between Men and Women on Depression Scores Through Treatment on the 56 Patients with Full Data Sets

	T1 (Mean +sd)	T2 (Mean +sd)	T3 (Mean+sd)	T4 (Mean +sd)	T5 (Mean +sd)
Women 41 Men 15	$t(54)=0.208$ $p=0.836$ (2.66 + 2.29) (2.80 + 2.18)	$t(54)=1.107$ $p=0.273$ (1.98 +1.71) (2.60+ 2.26)	$t(54)=1.44$ $p=0.155$ (2.51 +2.37) (3.64 +2.98)	$t(54)=2.38$ $p=0.021$ (2.32 + 3.2) (4.47+4.36)	$t(54)=1.74$ $p=0.068$ (2.34 +3.20) (4.0+2.98)

T1=simulation, T2= 1ˢᵗ treatment, T3=mid treatment, T4=end treatment, T5=4 weeks post

The average depression score was not high at the beginning of treatment. Throughout radiotherapy the depression scores for women remained low. From the mid-point onwards the depression scores for the men began to rise, with a significant difference in the scores between the men and women at the end of treatment.

Table 57: T-tests between Men and Women on their Depression Scores Post Treatment on the 56 Patients with Full Data Sets

	T6 (Mean+sd)	T7 (Mean+sd)	T8 (Mean+sd)	T9 (Mean+sd)	T10 (Mean+sd)	T11 (Mean+sd)	T12 (Mean+sd)
Women Men	$t(54)=2.82$ $p=0.007$ (2.05+2.21) (4.07+2.76)	$t(54)=3.9$ $p=0.001$ (2.22+2.60) (5.47+3.16)	$t(54)=2.72$ $p=0.009$ (2.17+2.55) (4.40+3.14)	$t(54)=3.53$ $p=0.001$ 1.93+2.69) (5.0+3.38)	$t(54)=2.236$ $p=0.03$ (2.41+2.89) (4.40+3.09)	$t(54)=2.79$ $p=0.008$ (2.45+3.3) (5.20+3.19)	$t(54)=3.051$ $p=0.004$ (2.0+2.33) (4.47+3.48)

T6=6 months post, T7=1year post, T8=18 months post, T9=2 years post, T10=3 years post, T11=4 years post, T12=5 years post.

Depression was significantly higher for men than women at all testing points from 6 months post treatment to the five year post treatment point. The numbers of the men are considerable smaller than the women. However this pattern was repeated with the larger cohort, but significance was only reached at 1 year, 18 months, 3 years and 5 years. The men in the larger cohort had consistently higher depression scores than the women.

Using the cut-off points of the HADS to indicate a 'possible' or 'probable' depression case, the following data is produced. The number of 'cases' is far less than the anxiety component. However the pattern is very different. The number of 'cases' fell over the course of the study for the anxiety component of the HADS. In comparison, apart from year 5, the number of 'cases' rose with depression. At simulation only 2% could be considered a 'case', by year 4 this had risen to 16%.

Table 58: Indicating the Percentage of Depression 'Cases' through Treatment for Patients with Complete Data Sets

	T1	T2	T3	T4	T5
Women (41)	1	0	2	5	7
Men (15)	0	0	14	7	13

T1=simulation, T2= 1ˢᵗ treatment, T3=mid treatment, T4=end treatment, T5=4 weeks post

The numbers of men scoring above 8 is higher for the men than the women through treatment.

Table 59: Percentage of Patients with Complete Data Sets with Scores over 8 on the Depression Scale from 6 Months to Five Year Post Treatment

	T6	T7	T8	T9	T10	T11	T12
Women (41)	2	5	5	5	10	12	2
Men (15)	7	33	20	27	20	27	20

T6=6 months post, T7=1year post, T8=18 months post, T9=2 years post, T10=3 years post, T11=4 years post, T12=5 years post.

At every testing point after treatment is finished the men patients have more depression 'cases' than the women.

Graph 44: Percentage of Possible and Probable Depression Cases According to Gender For Patients with Complete Data Sets
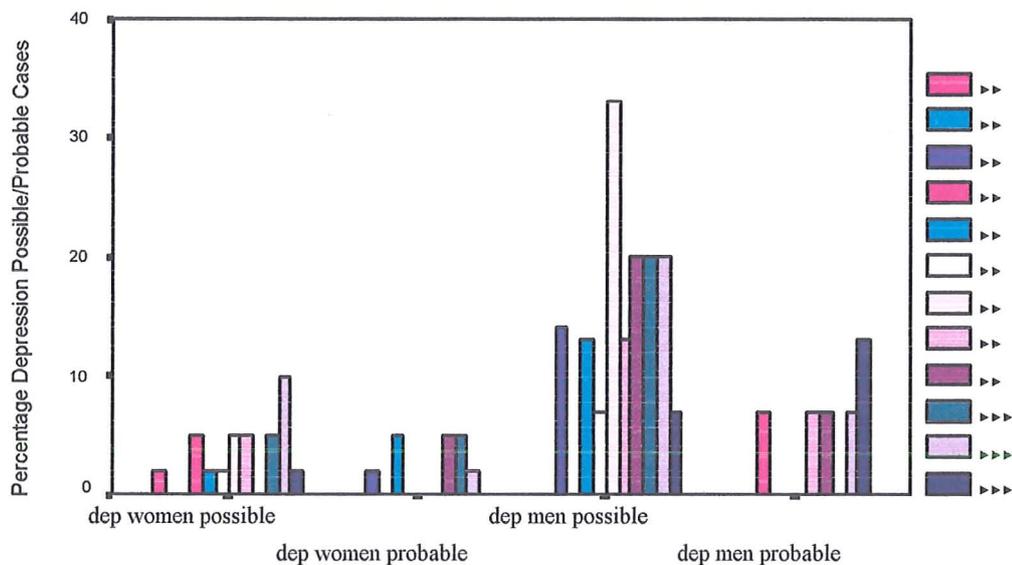
T1=simulation, T2= 1ˢᵗ treatment, T3=mid treatment, T4=end treatment, T5=4 weeks post, T6=6 months post, T7=1year post, T8=18 months post, T9=2 years post, T10=3 years post, T11=4 years post, T12=5 years post.

Repeated measures analysis of variance for depression over the course of the study with the variable of gender showed a significant effect for depression $F(11,572)=2.36$, $p=0.03$. and for gender $F(1,52)=8.5$, $p=0.005$.

Using the combined scores to indicate psychological distress

Distress levels of 23% occurred at simulation. This dropped to 20% at the end of treatment. Post treatment it fell further to 18%. From 6 months to five years post treatment distress remained at approximately 20% for this population overall. However the distribution according to gender was not even.

Gender

At the beginning of the study psychological distress was higher for the women cohort. This changed from the end of treatment onwards. Men had higher scores than women from the end of treatment to the end of the study. Significance was reached at year 1, (Men mean=11.4, women mean=7.07), $t(1,54)=2.19$, $p=0.03$, at year 3 (Men mean=10.13, women mean=6.29), $t(1,54)=2.14$, $p=0.03$, year 4 (Men mean=11.4, women mean=6.95) $t(1,54)=2.27$, $p=0.02$ and year 5, (Men mean=10.6, women mean = 6.02) $t(1,54)=2.37$, $p=0.02$.

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Graph 45: Psychological Distress as Measured by the Combined Scores of the HADS for Patients with Complete Data Sets over the Course of the Study
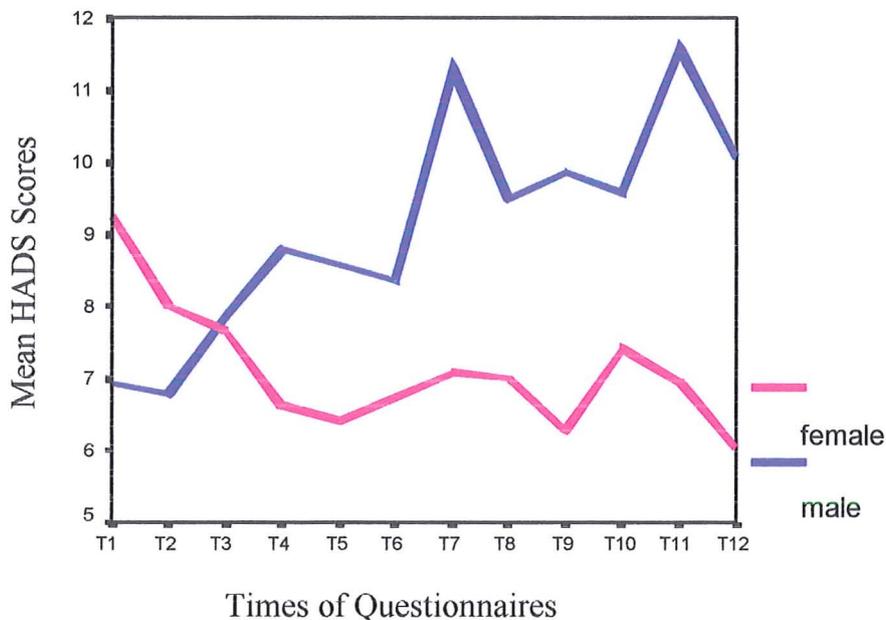
Times of Questionnaires

T1=simulation, T2= 1ˢᵗ treatment, T3=mid treatment, T4=end treatment, T5=4 weeks post, T6=6 months post, T7=1year post, T8=18 months post, T9=2 years post, T10=3 years post, T11=4 years post, T12=5 years post.

Repeated measures analysis over the whole study period with the variable of gender showed no significant effects.

Using the cut-off points of the combined scores to indicate a 'case'

At simulation women displayed twice as many patients 'cases' at the cut-off point of 13 as men. From mid treatment onward this changes, and by the 4 weeks post treatment point the pattern has reversed with nearly twice as many men indicating 'caseness' as women.

Table 60: Percentage of Men and Women with Mean Combined Scores 13 and over through Treatment for Patients with Complete Data Sets

	T1	T2	T3	T4	T5
Women	27	19	14	19	15
Men	13	7	21	20	27

T1=simulation, T2= 1ˢᵗ treatment, T3=mid treatment, T4=end treatment, T5=4 weeks post,

From 6 months onward the number of 'cases' for men is considerably more than for women, especially in the last three years of the study.

Table 61: Percentage of Men and Women with Combined Scores 13 and over on the HADS Post Treatment for 5 Years with Complete Data Sets

	T6	T7	T8	T9	T10	T11	T12
Women(41)	19	19	17	10	12	15	17
Men (15)	27	47	27	33	40	53	47

T6=6 months post, T7=1year post, T8=18 months post, T9=2 years post, T10=3 years post, T11=4 years post, T12=5 years post.

The number of men indicating a 'case' during this five year period is high. Year one and year four seem particularly bad years. Even in year five when a lowering of anxiety and depression for all patients occurs, distress although lower than year four is still high with 47% of men patients having scores above 13 and over on the unitary scale of the HADS.

Graph 46: Percentages of Probable and Possible 'Cases' for Patients with Complete Data Sets through the Study with 13 and 18 Cut-off Points to Indicate a 'Case'.
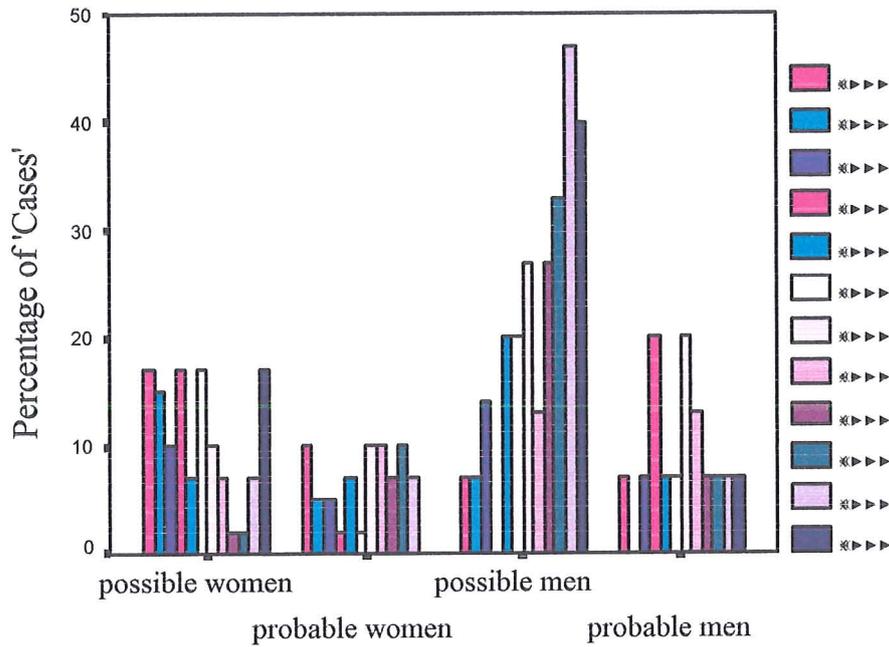
T1=simulation, T2= 1st treatment, T3=mid treatment, T4=end treatment, T5=4 weeks post, T6=6 months post, T7=1year post, T8=18 months post, T9=2 years post, T10=3 years post, T11=4 years post, T12=5 years post.

Site

With this small cohort it is difficult to further analysis the data into the variable of site. Breast patients consist of 30 of this cohort, non-gender related women patients make up 6, prostate patients 4 and non-gender related men 11.

Graph 47: Mean Anxiety Scores of Breast, Non-Gender Related Males and Females and Prostate Patients with Complete Data Sets
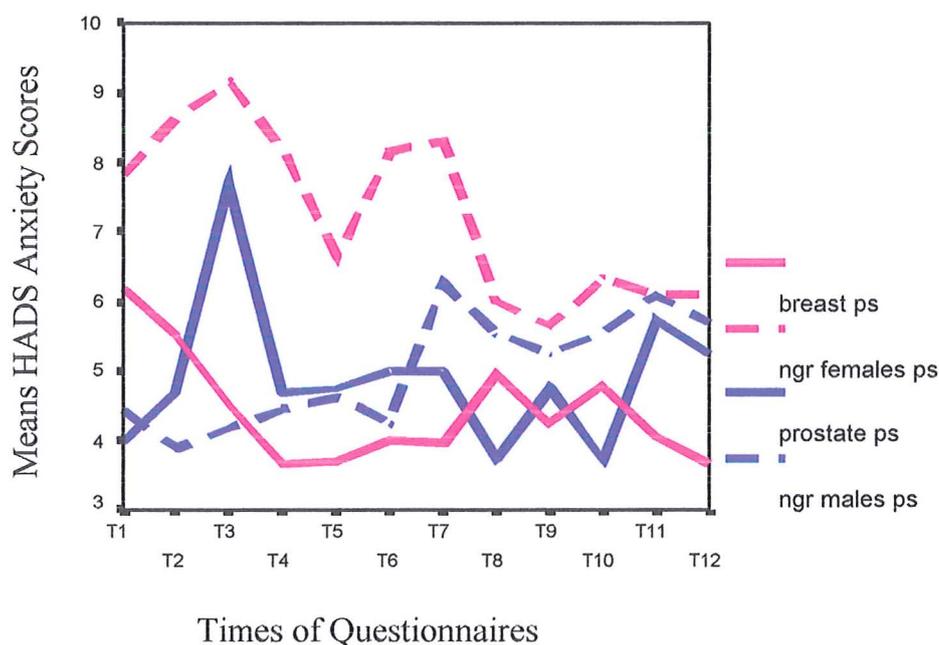
T1=simulation, T2= 1ˢᵗ treatment, T3=mid treatment, T4=end treatment, T5=4 weeks post, T6=6 months post, T7=1year post, T8=18 months post, T9=2 years post, T10=3 years post, T11=4 years post, T12=5 years post. Ngr=non-gender related site

The non-gender related females have consistently higher scores over the study. However they only number 6. Mid treatment was the most anxious point for this cohort. The breast patients have consistently lower scores after a peak at simulation. The overall pattern is very similar to the pattern of the larger cohort of survivors and non-survivors. Prostate patients peaked at mid-treatment and dipped at year 4. The non-gender related men had consistently higher scores than the prostate patients. This cohort had the lowest anxiety at simulation. Anxiety rose to a peak at mid-treatment and fell at the end of treatment, with two further dips in anxiety at 18 months and 3 years.

A significant difference in anxiety was found in the non-gender related females (Mean= 8.66, sd 3.0) having significantly higher scores than the non-gender related males at first treatment (Mean=4.75 sd1.5), t(15)=3.110, p=0.007 and at mid treatment, women's anxiety (Mean=9.1 sd4.8) was significantly higher than the men's (Mean 4.7 s.d.3.5) t(15)=2.5, p=0.02. No difference was found with the prostate and non-gender related male patients. However a significant difference was found between the non-gender related female patients and the breast patients.

At first treatment non-gender related females anxiety scores (Mean=8.66 s.d.3.0) were significantly higher than the breast patients (Mean= 5.5 s.d.3.2), t(34)=2.27,p=0.003.

Similarly at mid treatment, non-gender related females (Mean=9.166 s.d 4.8) were significantly higher than the breast patients (Mean 4,5 s.d. 3.18), t(34)=2.996, p=0.005.

At end of treatment, non-gender related females (Mean=8.16 s.d.2.0) had significantly higher scores than the breast patients (Mean=3.66 s.d.3.0), t(34)=3.425, p=0.002

At four weeks post treatment, the non-gender related patients continued to have higher scores but significance was not reached.

At six months post treatment, non=gender related females (Mean=8.16 s.d.5.7) had significantly higher scores than the breast patients (Mean 4.0 s.d.3.3), t(34)=2.428, p=0.02.

This was repeated at the first year, Breast patients (Mean=3.9 s.d.3.5) was significantly lower than the non-gender related females (Mean=8.1 s.d.5.7), t(34)=2.428, p=0.019.

Anxiety continued to be higher for the non-gender related females than the breast patients for the next four years but significance was not reached. Depression for these sites showed a different pattern.

Graph 48: Mean Depression Scores for Patients with Complete Data Sets and Sites, Breast, Non-Gender Related Male and Female and Prostate.
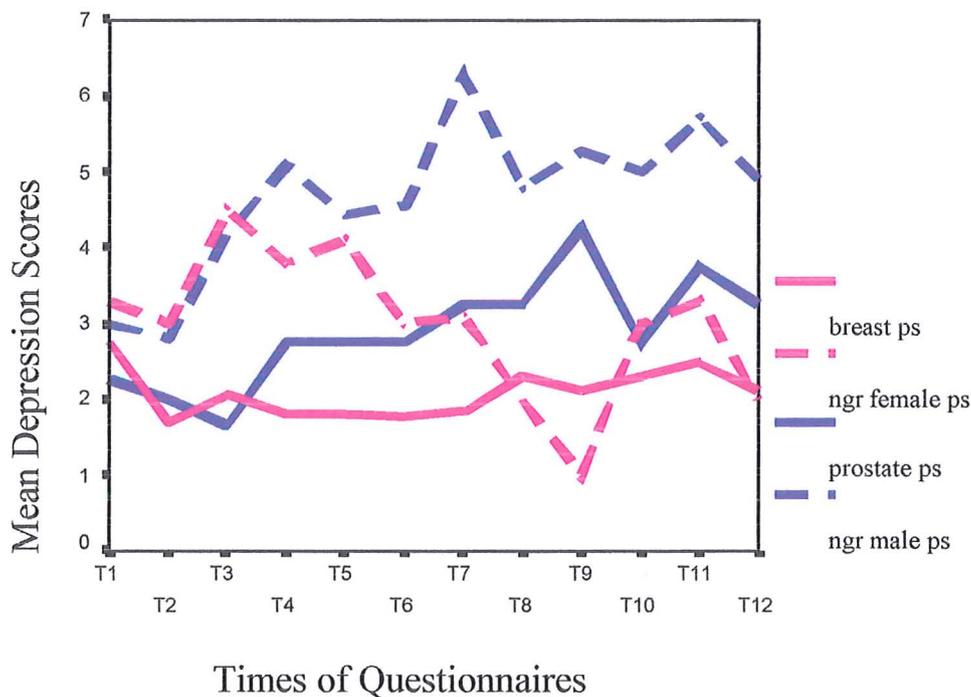
Times of Questionnaires

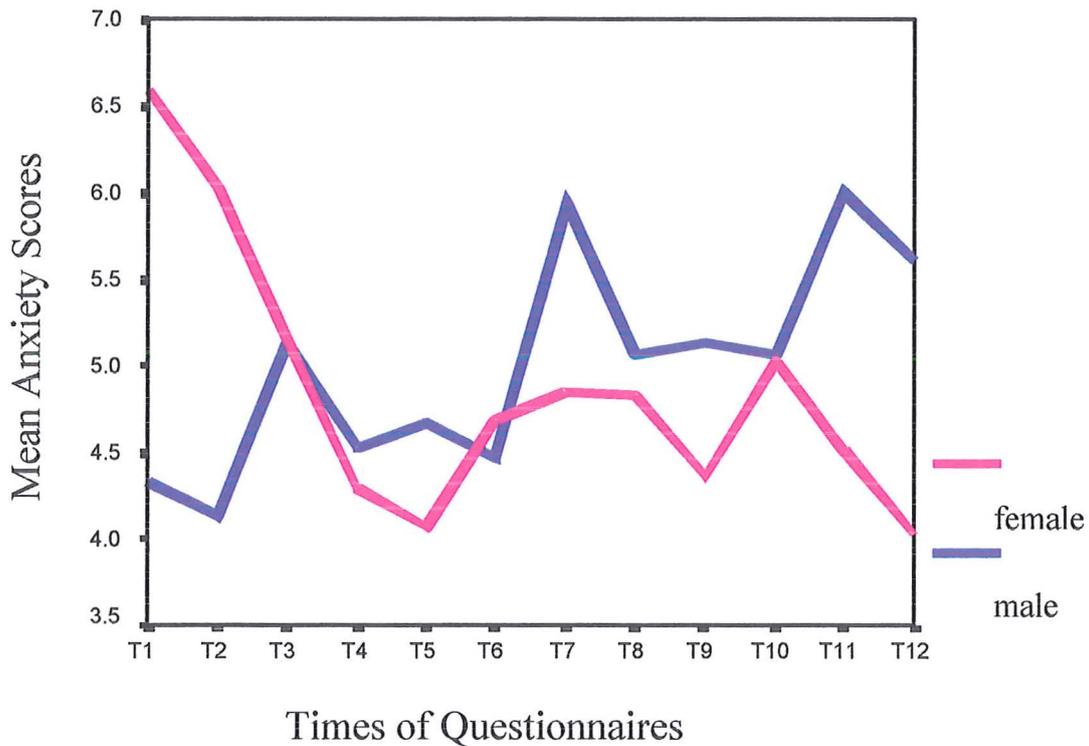*T1=simulation, T2= 1st treatment, T3=mid treatment, T4=end treatment, T5=4 weeks post, T6=6 months post, T7=1year post, T8=18 months post, T9=2 years post, T10=3 years post, T11=4 years post, T12=5 years post. Ngr=non-gender related site*

The depression scores for the men show a gradual upward trend. Through treatment both the non-gender related male and female patients have the highest depression scores. From year one the non-gender related males and the prostate patients have the highest mean scores. There is no significant difference between the male patient sites of non-gender related and prostate.

The breast patients show a continuous low level of scores from first treatment onwards. Apart from year 3, the scores are lower than the non-gender related patients. The breast patients have significantly lower scores on two occasions, at mid treatment, breast patients(Mean=2.06 s.d 1.9) score is significantly lower than the non-gender related patients (Mean 4.5 s.d. 3.7), $t(34)=2.396$, $p=0.002$. Similarly at the end of treatment, Breast patients (Mean1.8 s.d.2.1) is significantly lower than the non-gender related patients, (Mean=3.88 s.d.2.3), $t(34)=2.00$, $p=0.05$.

At simulation and first treatment women non-gender related patients have just higher scores than the men non-gender related sites. From the mid treatment point men have continuously higher depression scores for the five years of the study. Significance is reached

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only at year 3, Men (Mean 5.27 s.d.3.5) is higher than the women (Mean=1, s.d 1),t(15)=2.98, p=0.009.

With respect to the combined scores to indicate psychological distress, the women non-gender related patients have higher scores than the men through treatment. From six months onwards this changes and the men had continuously higher scores for the post five years of the study.

Graph 49: Combined Scores of the HADS to Indicate Psychological Distress for Patients with Complete Data Sets with sites of Breast, Non-Gender Related Males and Females and Prostate
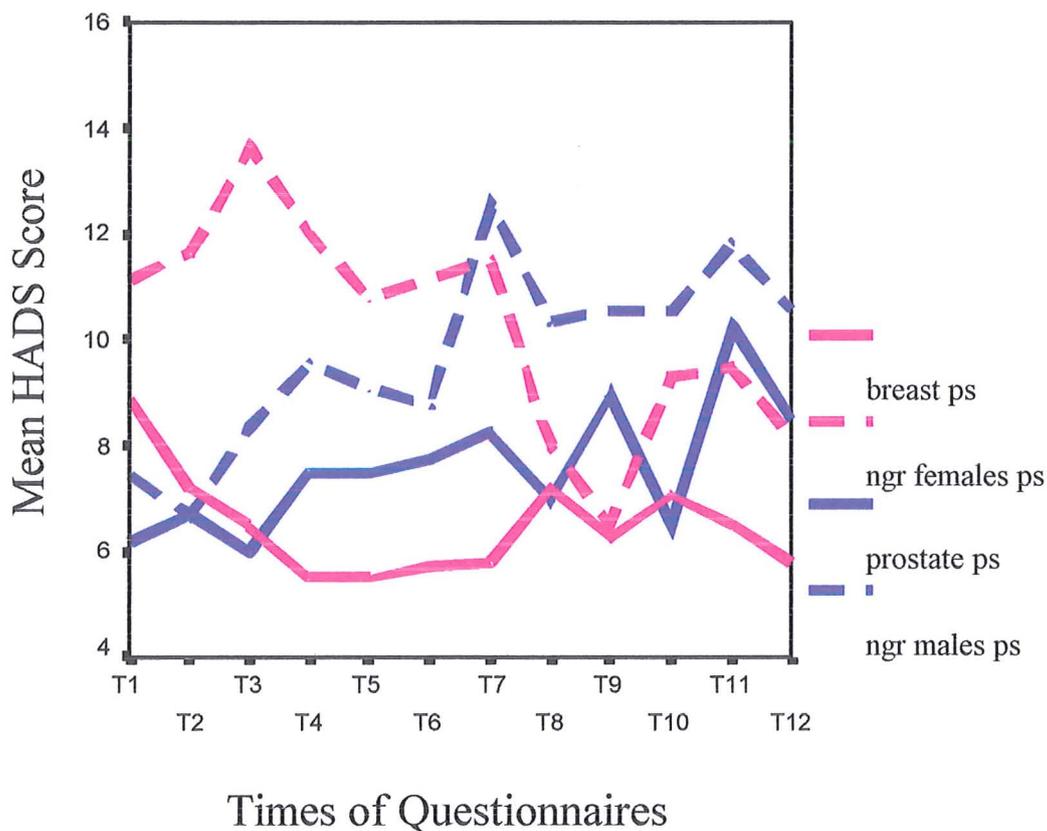
Times of Questionnaires

T1−simulation, T2− 1ˢᵗ treatment, T3−mid treatment, T4−end treatment, T5−4 weeks post, T6−6 months post, T7−1year post, T8−18 months post, T9=2 years post, T10=3 years post, T11=4 years post, T12=5 years post. Ngr=non-gender related site

Significance was only found with the breast and non −gender related patients at:

1ˢᵗ treatment Breast ean=7.266 sd4,2), Non-gender related (Mean 11.16 s.d.5.4), t(34)=2.245, p=0.03

Mid treatment, breast (Mean=6.5, s.d 4.3), non-gender related (Mean=13.66 s.d.8.2), t(34)=3.105, p=0.004.

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End of treatment breast (Mean=5.5 s.d 4.7), non-gender related (Mean=12 s.d 4.0), t(34)=3.109, p=0.004

Six months post treatment, breast (Mean=5.7 s.d4.7), non-gender related (Mean=11.16 s.d.8.7), t(34)=2.17,p= 0.037

At one year post treatment, breast (mean=5.8 s.d 5.35), non-gender related (Mean=11.5 s.d 9.0), t(34)=2.109, p=0.03

Non-gender related female patients had higher distress scores throughout the study than the breast patients.

Predictions

Can anxiety after five years be predicted?

The variables of anxiety at simulation, anxiety at first treatment, gender, treatment intent, age, social class and STAI Trait were analysed in a stepwise multiple regression analysis.

Table 62: Results of Stepwise Regression Analysis using the Dependant Variable – Depression after five years and the Independent Variables of Anxiety at Simulation, 1St Treatment, Gender, Treatment Intent, STAI Trait and Age.

Significant variable	R square	B	Beta	T	Significance
Anxiety at 1st treatment	0.296	0.618	0.544	4.76	0.001
Anxiety at 1st Treatment	0.419	0.727	0.640	2.199	0.001
+Gender		2.950	0.363	3.346	0.001

Using anxiety at 1st treatment gave a 30% variance of anxiety five years post treatment. When this is coupled with gender it increases the variance to 41%.

Can depression after five years be predicted?

Table 63: Results of Stepwise Regression Analysis with Dependant Variable Depression at the end of Study and Independent Variables Gender, Treatment Intent, Age, Depression at simulation, 1st treatment, Mid Treatment, End Treatment and 4 Weeks Post Treatment.

Significant variable	R square	B	Beta	t	Significance
Depression 4 weeks post treatment	0.312	0.503	0.558	4.89	0.005
Depression 4 weeks post Treatment	0.387	0.497	0.497	4.469	0.001
+Gender		0.282	0.282	2.535	0.014

Depression at 4 weeks post treatment explained 31% of the variance of depression at the end of the study. Depression at four weeks after treatment plus gender accounted for 39% of the depression at the end of the study.

Psychological distress at the end of study was used as the dependant variable in a stepwise regression analysis.

Table 64: Results of Stepwise Regression Analysis using the Dependant Variable distress at the End of the Study and the Independent Variables gender, Treatment Intent, Age, Distress at Simulation, Distress at 1st Treatment and Distress at Mid Treatment, Distress at the end of Treatment and Depression at 4 weeks post Treatment.

Significant variable	R square	B	Beta	t	Significance
Distress at end of treatment	0.402	0.622	0.634	5.97	0.001

Psychological distress at the end of treatment explains 40% of the variance at the end of five years.

Survivors

Was there a difference in anxiety, depression and distress when patients were having their radiotherapy treatment between the 56 'completers' and the rest of the cohort? Table 65 shows the analysis of these two groups.

Table 65: Anxiety, Depression and Psychological Distress t-tests Results of the Original Cohort of Patients and the 56 Completers through Treatment

	T1 (Mean sd) {Numbers}	T2 (Mean sd) {Numbers}	T3 (Mean sd) {Numbers}	T4 (Mean sd) {Numbers}	T5 (Mean sd) {Numbers}
Anxiety did not finish all Qs	(7.17 sd 4.3) {213}	(6.73 sd 4.3) {201}	(5.9 sd 3.88) {112}	(5.59 sd 4.0) {159}	(5.47 sd 3.9) {161}
56 Completers	(5.9 sd 3.5) {56} $t(265)=1.9$ $p=0.058$	(5.5 sd 3.19) {56} $t(119)=2.3$ $p=0.023$	(5.14 sd 3.9) {56} $t(166)=1.202$ $p=0.231$	(4.35 sd 3.6) {56} $t(213)=2.03$ $p=0.04$	(4.2 sd 3.5) {56} $t(215)=2.09$ $p=0.038$
Depression did not finish all Qs	(4.7 sd 3.4) {213}	(4.68 sd 3.4) {201}	(4.3 sd3.6) {113}	(4.58 sd 3.8) {159}	(4.86 sd 3.8) {161}
56 Completers	(2.69 sd 2.2) {56} $t(130)=5.4$ $p=0.001$	(2.1 sd 1.8) {56} $t(166)=7.27$ $p=0.001$	(2.8 sd 2.5) {56} $t(166)=2.9$ $p=0.004$	(2.89 sd3.1) {56} $t(213)=2.9$ $p=0.004$	(2.78 sd 3.2) {56} $t(215)=3.6$ $p=0.001$
Distress did not finish all Qs	(11.9 sd 6.6) {213}	11.3 sd 6.8 {202}	(10.25 sd 6.6) {112}	(10.18 sd6.9) {159}	(10.34 sd 6.6) {161}
56 Completers	8.67 sd 5.09 {56} $t(267)=3.3$ $p=0.001$	(7.6 sd 4.5) {56} $t(256)=3.7$ $p=0.001$	(7.7 sd 5.4) {56} $t(165)=2.47$ $p=0.014$	(7.2 sd 6.0) {56} $t(213)=2.8$ $p=0.005$	(7.0 sd 6.1) {56} $t(215)=3.2$ $p=0.001$

The anxiety, depression and distress was significantly higher for the patients who did not complete all the questionnaires. The cohort who did not complete all the questionnaires during treatment consisted of all the patients who had originally agreed to participate in the study. Some were allotted to the Single Fraction and Short Multi-Fractions groups who only had one to four treatments and therefore did not return to the radiotherapy department for any period. They would not have received the mid-treatment questionnaires and therefore would have been included in 'did not finish all questionnaires' group. This group would have also

included those patients who died during treatment, and those patients who no longer wanted to participate.

Analysing the patients from the 2nd ethical permission, the patients who responded to the first questionnaires given 6 months post treatment (N=146) were put into two groups. The first group consisted of those who replied to some of the questionnaires, 90 (62%). Some of this cohort died, others became non-participants. The other group consisted of the 56 patients who responded to all 12 questionnaires.

Table 66: Anxiety and Depression t-tests Results of the Original Cohort of Patients who agreed to participate in the 2nd Ethical Permission. This cohort are divided into those who did not answer all the questionnaires and the 56 Completers

	T6 (Mean sd) {Numbers}	T7 (Mean sd) {Numbers}	T8 (Mean sd) {Numbers}	T9 (Mean sd) {Numbers}	T10 (Mean sd) {Numbers}	T11 (Mean sd) {Numbers}	T12 (Mean sd) {Numbers}
1.Anxiety did not finish post Qs	(5.4 sd 4.3) {90}	(4.89 sd4.3) {56}	(4.58 sd 3.8) {43}	(5.27 sd 4.2) {37}	(5.4 sd4.1) {34}	(4.6 sd 4.4) {18}	(3.5sd3.0) {20}
56 Completers	(4.6 sd3.7) {56}	(5.1 sd 4.3) {56}	(4.89 sd 4.1) {56}	(4.57 sd 3.7) {56}	(5.0 sd3.3) {56}	(4.9 sd 3.8) {56}	(4.4sd3.6) {56}
	t(144)=1.17 p=0.241	t(110)=0.305 p=0.76	t(97)=0.385 p=0.7	t(91)=0.839 p=0.403	t(88)=0.5 p=0.6	t(72)=0.224 p=0.823	t(74)=1.0 p=0.3
Depression did not finish all Qs	(4.3 sd 3.7) {90}	(3.85sd3.4) {56}	(3.1sd2.9) {43}	(4.0 sd4.0) {37}	(4.1 sd4.1) {34}	(3.5 sd 4.3) (18)	(2.9 s4.0) {20}
56 Completers	(2.5 sd 2.5) {56}	(3.08 sd3.1) {56}	(2.8 sd 2.8) {56}	(2.7 sd 3.1) {56}	(2.9 sd 3.0) {56}	(3.2 sd3.5) {56}	(2.6 s2.8) {56}
	t(142)=3.04 p=0.001*	t(111)=1.25 p=0.214	t(99)=0.588 p=0.558	t(91)=1.6 p=0.14	t((87)=1.58 p=0.117	t(71)=0.297 p=0.3	t(74)=0.28 p=0.77

*Levene's test for equality of variance reached significance p>0.001therefore equal variance not assumed

Further analysis on those patients who responded to all questionnaires (N=56) and those who did not (N=90) revealed no significant difference in anxiety, depression or distress. That is a statistical difference between patients participating in Part 2 of the analysis and patients participating in Part 3 of the analysis was not found apart from depression at 6 months post treatment, those patients who did not finish all questionnaires were significantly more depressed than the 'completers'. How do the anxiety scores of the patients with complete data sets compare with those who died and with those with non complete sets?

Graph 50: Mean HADS Anxiety Scores of Dead, Incomplete Data Set, and Complete Data Set Patients over 4 Years of the Study
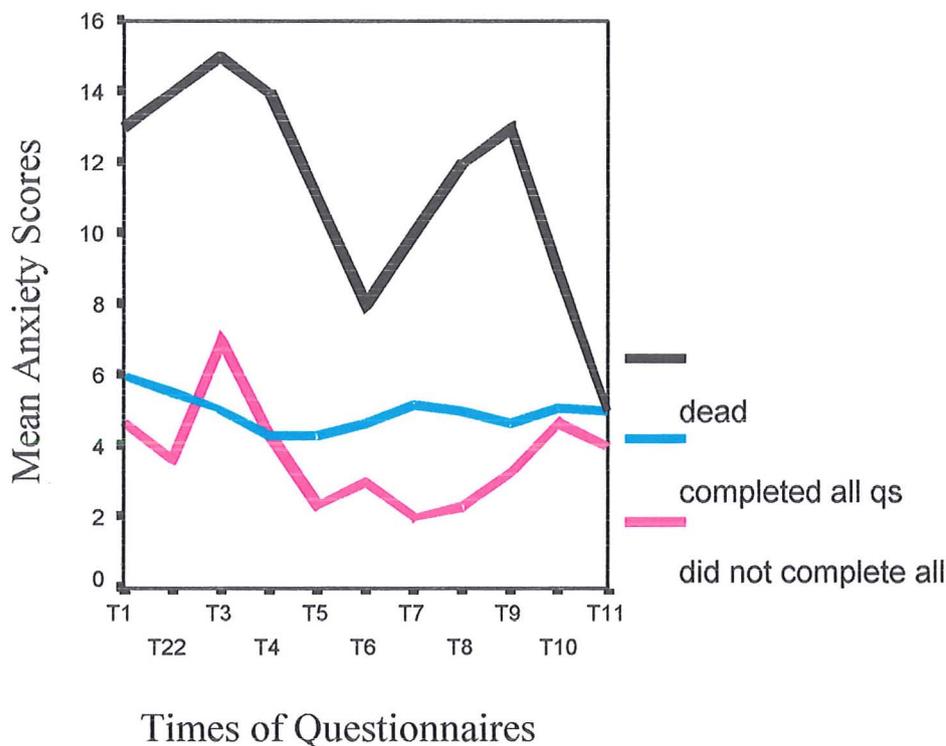
Times of Questionnaires

T1=simulation, T2= 1ˢᵗ treatment, T3=mid treatment, T4=end treatment, T5=4 weeks post, T6=6 months post, T7=1year post, T8=18 months post, T9=2 years post, T10=3 years post, T11=4 years post.

Graph 50 illustrates the high anxiety scores of those patients who died in comparison with the patients who remained in the study, whether they completed all 12 questionnaires of not. The patients who died show much higher mean anxiety scores. Apart from mid treatment and year 1, there is little difference in anxiety between those patients who had complete data sets and those patients with incomplete sets. Anxiety levels were on average lower for the 'non-completers'. The 'completers' showing much more uniform scores throughout.

A similar pattern follows with depression. Graph 51 illustrates the difference in the data sets of those who died, those with complete data sets and those who did not complete all the questionnaires in Part 2 of the analysis.

Graph 51: Depression Scores of those who finished all 12, those who died and those who did not have complete data set.
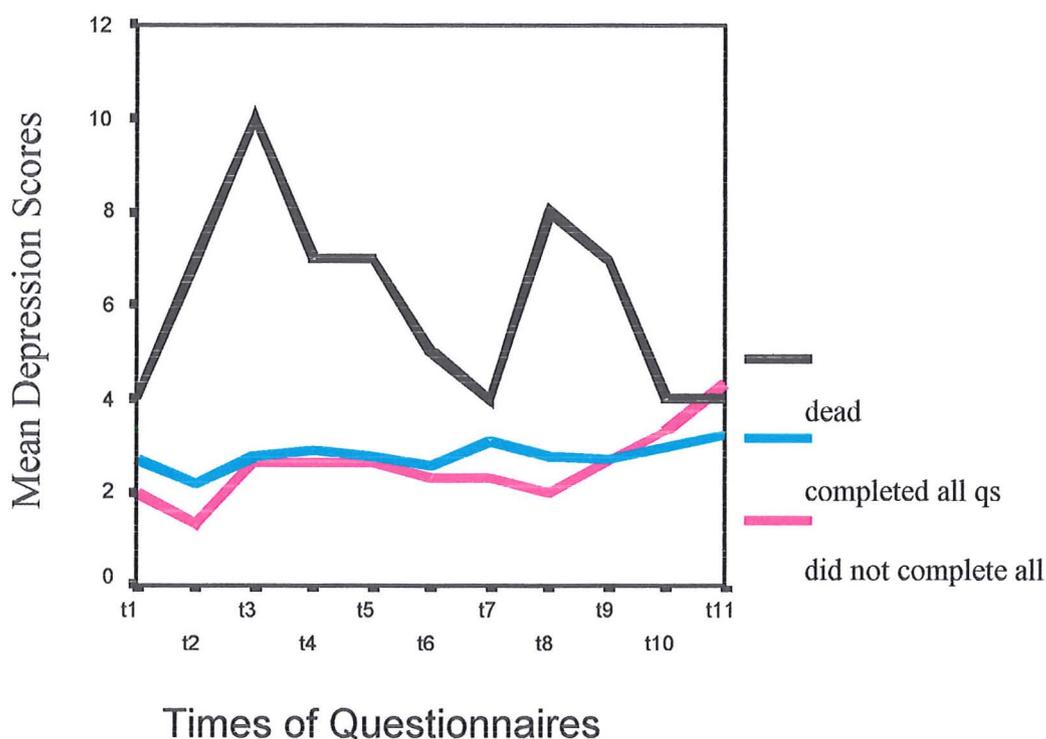
Times of Questionnaires

t1=simulation, t2= 1st treatment, t3=mid treatment, t4=end treatment, t5=4 weeks post, t6=6 months post, t7=1year post, t8=18 months post, t9=2 years post, t10=3 years post, t11=4 years post.

The patients who had complete data set had significantly lower depression scores than those who died and those with incomplete data, $F(2,265)=10.85$, $p=0.001$ (Post Hoc Tukey). From first treatment to 6 months post, the dead patients had significantly higher scores than the complete or incomplete data set patients.

Table 66 shows no significant differences between the cohort of 'completers' and the patients answering the questionnaires from one year onwards. Therefore analyse was undertaken on the patients who responded to the last questionnaire, namely the survivors (n=76). This is a larger cohort than the 56 completers. This excludes the number of non-participants (n=67). Table 70 shows t-test results of survivors (n=79) with the non survivors (n=119) using their scores at simulation to see if there are any indicators of survival.

**Table 67: Showing the Results of t-test plus Means and
SD of State/Trait Anxiety and Depression Scores of Survivors and Non-Survivors
with Respect to their Scores at Simulation.**

Questionnaires	Survivors [79] Mean (s.d.)	Non-Survivors [119] Mean (s.d.)	Test for significance
Trait Anxiety	35.78 (8.17)	38.49 (9.9)	t(196)=2.09 p=0.038*
State Anxiety	43.01 (14.24)	40.14 (13.020)	T(195)=1.5 p=0.135
Depression	3.09 (2.82)	5.12 (3.05)	T(196)=4.7 p=0.001**

The trait anxiety scores of the survivors and the non-survivors are significantly different. The trait anxiety score of the non-survivors is more similar to the State anxiety. This is not the case with the survivors. There is no significant difference with the State anxiety. There is a significant difference with depression. The non-survivors are significantly more depressed than the survivors.

Leigh et al (1987) hypothesized that high levels of State anxiety were indicative of long or short survival. This study therefore analysed the number of 'cases' of anxiety and depression at simulation according to gender to see if this hypothesis could be substantiated and developed.

Table 68: Possible and Probable Cases
of Anxiety 'Cases' at Five Years in Relation to Anxiety and Depression at Simulation

Case at simulation	Non-survivor female (48)	Survivor Female (68)	Non survivor Male (61)	Survivor Male (24)
AnxietyHADS possible	14	10	12	2
AnxietyHADS Probable	12	10	9	3
STAI Possible	8	5	10	1
STAI Probable	19	26	17	9
Depression Possible	8	3	10	2
Depression probable	2	2	4	0

This data shows that men and women appear to respond differently. The women who had high anxiety at simulation were approximately split 50:50 as to whether they survived or not using both HADS and STAI questionnaires. From the 15 'cases' of depression only 5 survived.

However the men exhibiting high anxiety mostly died. From the 26 HADS 'cases' only five survived. From the 38 STAI 'cases' 10 survived. From the 16 'cases' of depression for the men, 2 survived.

Chapter 9

Discussion

This is a long and complicated multivariable study in which the population has a high attrition rate. Screening patients with questionnaires was used to attempt to identify psychiatric morbidity. The result section was based on the psychometric properties of the HADS. The discussion will thus focus on the specific areas of anxiety, depression and psychological distress. The discussion starts with a summary of the findings. It then discusses the findings of the current study with relationship to those studies that were specifically set out in chapter 3. Anxiety, depression and distress are then discussed in relationship to the three different analyses given in part 1, 2 and 3 of the results section.

The aims of this study were

- To observe the emotional functioning in a cohort of patients attending a radiotherapy clinic before, during and five years after treatment has finished, using questionnaires.
- To ascertain the times of greatest distress for patients.
- To identify factors that could indicate which patients are the most vulnerable to psychological morbidity.
- To find out what patients need and how they feel during this time.
- To see if predictions can be made on the basis of psychological tests at simulation.
- To see if there are indicators for survival.

Summary of Main Findings

1. The main outcome of this study is that anxiety and depression are mobile factors which change over time. This may account for the varied range of levels of anxiety and depression listed in the literature review.

2. Anxiety and depression peak at different times in the course of treatment. Highest anxiety scores occur at simulation. The peak number of depression cases occur mostly at the end of radiotherapy treatment or four weeks after it has finished.

3. The psychological effects of radiotherapy treatment manifest themselves at different times for men and women regardless of site.

4. Palliative patients and men are at high risk of psychological distress.

5. Accurate measurements of anxiety can depend on the wording of the questionnaire.

6. Some patients have side effects from the radiotherapy treatment five years after treatment. In particular high rates of fatigue are found in patients five years after treatment for cancer has finished. Those patients who were tired were significantly more depressed, anxious and distressed.

7. Predictions using data generated at simulation can be made. Anxiety at first treatment can be predictive of anxiety at five years. Similarly depression at the end of treatment can predict a large percentage of depression five years later.

8. Indicators of survival: - High state anxiety, coupled with lower trait and low depression scores could be indicative of a higher survival rate. This requires more research.

This summary of findings will now be discussed in more depth. It will begin with a discussion of the findings in relationship to the specific studies in chapter four. It will then discuss anxiety, depression and distress in relationship to the three different cohorts analysed in the specific sections of Part 1, 2 and 3.

Integration of Findings with Previous Research

One of the aims of the present study was to find the time of greatest distress for patients. Following on from the detailed studies in Chapter 4, Fife et al (2000) in their prospective longitudinal study with bone marrow patients found that the period of greatest emotional distress was after admission and before transplant. Both anxiety and depression peaked at this time. This finding is understandable as patients are in isolation, which can cause severe depression. They also receive high dose chemotherapy and sometimes have irradiation prior to their bone marrow transplant. These treatments prior to the bone marrow transplant could result in high anxiety.

The findings of the current study are different. The greatest period of overall distress for all patients was at simulation, the planning of their treatment. At this time patients are positioned for treatment. X rays are obtained, the tumour is accurately localized, the treatment fields are planned together with the dose distribution and the treatment regime is verified. Patients' bodies are marked with felt tip pens so that the exact area can be treated

each day. Some patients need specialized set-ups to avoid vital organs. Head and neck patients for example need masks, which are then clamped onto the bed to insure accuracy of treatment.

The present study used the psychometric properties of the HADS, namely anxiety and depression. Looking specifically at anxiety, it peaked at simulation prior to the patient's radiotherapy treatment. Forty per cent of the patients at simulation had anxiety levels of 8 and over on the HADS, indicating a possible anxiety case, and 20% scored 11 and over indicating a probable case, with a mean of 6.9. This was the time of highest anxiety for the patients, with levels subsequently lowering. These findings were confirmed by a similar pattern in the responses to the STAI State questionnaire, but with a higher percentage, 50%, indicating anxiety and 37% indicating extreme anxiety. This anxiety could largely be adaptive as it could be in response to danger – the unknown radiotherapy treatment.

These results were not repeated with the depression component. The results of the analysis of depression showed a plateau-effect, with a peak at four weeks post treatment (Mean 4.3 sd 3.7).

Using Fife et al's study as a model, the differences over time can be observed for the bone marrow patients and the radiotherapy patients.

Table 69: Means Over Time: Repeated Measures Fife et al study compared with Current Study's Results

Dependant Variable	T1 (Nos)	T2 (Nos)	T3 (Nos)	T4 (Nos)	T5 (Nos)	T6 (Nos)	T7 (Nos)	F	P
Anxiety of BMT Patients BiPolar Profile of Mood*	21.07	17.89	20.87	21.27	23.71	25.93	25.35	14.29	0.001
Anxiety of RT Patients HADS**	6.92	6.47	5.65	5.27	5.15	5.14	5.03	7.47	0.001
Depression BMT patients BiPolar Profile of Mood***	22.40	19.10	21.29	22.81	24.65	26.79	25.18	11.47	0.001
Depression of RT Patients HADS****	4.30	4.13	3.86	4.14	4.33	3.64	3.49	0.9	0.492

[T1= Simulation, T2= 1st Treatment, T3= End Treatment, T4= End Treatment, T5= 4 Weeks Post Treatment, T6=6 months T7=1year]

* The lower the score the higher the anxiety
** The higher the score the higher the anxiety
*** The lower the score the higher the depression
**** The higher the score the higher the depression

Both studies show a significant difference in anxiety over time. However depression in the bone marrow transplant patients was significant, but was not significant in the radiotherapy patients. With the bone marrow patients the depression at T2 was probably due to the isolation they were experiencing. In contrast the radiotherapy patients peaked at the four weeks post treatment time point. This could be due to the impact of side effects and absence of hospital staff for support, resulting in similar feelings of isolation.

Fife et al in their analysis did not breakdown their anxiety and depression scores according to gender, neither did the POMS questionnaire allow this study to identify high scorers. Fife et al specifically looked at coping/adaptation in their article. They measured coping and also made a note of gender, but no reference to gender was given in this paper and this must be queried.

Gender is an important issue. At the time of simulation, in the current study, women are significantly more anxious than men. Forty five percent of the women had anxiety scores over 8 and 23% had scores over 11. In contrast, a third of the men had anxiety scores over 8 and 13% over 11. The number of women high anxiety scorers fell during treatment, and four weeks after treatment has finished 23% have scores over 8 and 13% have scores over 11.

Men's scores fell for the first three testings during treatment, however, at the end of treatment the number of cases rise with both cut-off points. At four weeks post treatment the proportion of men being a possible or probable case is greater than the women.

The different patterns of anxiety and depression exhibited by men and women are important. Historically women are considered to be more prone to mental disorder than men. However, Jenkins (1985) in her article on sex differences questions this historical assumption. In her study she found no difference between men and women. This was also confirmed by Wilhelm and Parker (1989). They found no sex differences for major and minor depressive episodes. It would have been interesting if Fife et al in their study had found similar patterns to those found in the current study.

Fife et al's study lasted one year. This was not long enough, as both anxiety and depression had increased in their bone marrow patients in the period of three months to one year. Was this just a small peak or did it indicate a change of pattern? In the current study anxiety continued to drop at the one-year mark, but rose at 18 months. This rise in anxiety appears to be related to an increase in side effects. At one year, only 28% of patients had side-effects. At eighteen months this had risen to 41%. Half of the patients felt tired and these patients were significantly more anxious than those who did not feel tired. The current study therefore shows that 18 months post treatment is an important time to focus on patient's side effects in order to lower their anxiety, maybe by appropriate information in the Out-Patient Clinic.

The number of patients who could be 'possible' depression cases remained static between six months and one year but fell at 18 months. This drop could be due to the number of palliative patients who died in the intervening six months. However it also occurred with the 'completers', therefore the reason for this lowering of depression scores remains unknown.

The second study to be assessed in depth was Hammerlid et al's longitudinal study of 1997. They assessed distress in head and neck cancer patients in order to gain a better understanding of the quality of these patients' lives and to see if there was a difference between those treated by radiotherapy and those treated by radiotherapy and brachytherapy. The HADS was used to measure psychological distress. Hammerlid's study tested patients at diagnosis and then at monthly intervals. The reader however was not informed if this was before or after diagnosis. Anxiety was highest for patients at this point with 37% scoring above 7 on the anxiety scale. The current study shows that the highest point of anxiety reached for radiotherapy patients was prior to the planning of their treatment with 40% of the

patients scoring 8 and over on the HADS. Therefore these two studies have approximately the same percentage of anxiety 'cases' at the start of their study.

The next testing point Hammerlid et al used was one month after treatment started. There is no comparable testing point during the treatment section of the current study. However their testing point three months after treatment started could be comparable to the current study's four weeks post treatment, taking into account that treatment for head and neck patients can last six weeks. Hammerlid et al found that depression peaked at this point and was higher than at diagnosis with 44% having depression of 7 and over. The result compares favourably with the current findings that depression for radiotherapy patients peaked at four weeks post treatment but the percentage was lower at 20%. The female to male ratio was biased towards men in Hammerlid's study and towards women in the present study. This could have been the cause of the higher percentage of depression in Hammerlid et als study. The men in the current study were more depressed than the women, but the women to male ratio was 2:1 in favour of women. The percentage of male patients with depression at the 4 weeks post treatment was 20% in the current study, a much smaller percentage than Hammerlid et al. No further statistical analysis was carried out on gender by Hammerlid et al.

Hammerlid's study contained a mixed cohort of radical and palliative patients totalling 105. Again, no detailed analyses were given on the differences between the cohorts. The current study shows how palliative patients are significantly more anxious and depressed than the radical patients. This could also account for Hammerlid et als higher depression numbers.

The third study which was reviewed in depth was Nordin and Glimelius (1999). Nordin and Glimelius had previously used the HADS in combination with other questionnaires to see if psychological distress could be predicted using analysis at diagnosis. Nordin and Glimelius found that depression and anxiety at diagnosis could account for 35% of the variance of anxiety and depression at six months.

One of the aims of the present study was to see similarly if psychological distress could be predicted. The current study, using similar statistical stepwise regression analyses to Nordin and Glimelius, found that anxiety at simulation could account for 42% of the anxiety at the four weeks post treatment point. Similarly depression at simulation could predict 40% of the depression at. four weeks post treatment. However a higher predictive rate was found by using data from the 1st treatment testing. In the present study, because the timings of the first two set of questionnaires were close, one at planning and one just before the first treatment, the author was able to show that a better predictive time of anxiety four weeks post

treatment was by using anxiety at 1st treatment rather than simulation.. Similarly depression at four weeks post treatment could be predictive of 39% of depression at end of the study. With respect to the five year study, the 'completers showed that distress at the end of treatment could predict 40% of the distress 5 years later.

Anxiety and depression are mobile factors during radiotherapy treatment and after. The current study shows that anxiety, depression and distress could all be predicted five years later using data at first treatment for anxiety. Depression and distress are better predicted by data generated at the end of treatment.

In the Nordin and Glomelius study patients (n=151) scored a mean of 4 on the HADS anxiety scale (sd 4.2), in contrast to 6.93 (sd 4.2) for patients prior to simulation in the present study. Therefore the anxiety at diagnosis is very much lower than for patients in the current study. The depression rates of the current study 4.30 (sd 3.3) were more similar to Nordin and Glimelius's study of 4.4 (sd 3.9). However, the current study did find the depression levels were more level throughout treatment. Nordin and Glimelius also used cut-off points to distinguish between possible and probable cases and found 24% of patients came into these categories. This was lower than the present study, in which levels at both simulation and first treatment were 40% and 37% for anxiety respectively, and 16% and 14% for depression.

The discrepancy in the anxiety levels appears to be caused by the randomness of the timing of the testings in Nordin and Glimelius's study. The patients were all tested sometime after the biopsy, when the patients were physically able. This timing varied with a median of three weeks and was not specific enough in comparison with the strict timing of the present study. Nordin and Glimelius's patients could have had time to adapt. Indeed the current study shows the importance of specificity in timings of questionnaires given to patients, the anxiety component especially showed large fluctuations over the treatment time. The patients in the current study were all tested at specific times before their simulation or treatment under similar conditions. A better estimate of anxiety for Nordin and Glimelius's study would have been prior to surgery and one week post surgery.

Patients were tested only twice in the Nordin and Glimelius study with the second time at six months. Both studies found a significant decrease in both scales over the period of the study. However with regard to depression the current study shows a gradual lowering of levels until the end of treatment when depression increased, a very different pattern from that displayed by anxiety. As the fluctuations in depression were not high in comparison to the

anxiety component, the levels of depression in the Nordin and Glimelius study and the current study are very similar.

In the Nordin and Glimelius study the threat of surgery is over. However treatments are not mentioned in the paper, neither is gender and the current study shows the importance of these two variables.

The fourth discussed study was Leigh et al (1987) who also looked at psychological predictors by comparing survivors to non-survivors in a group of radiotherapy patients. The site of the cancer was varied, as in the current study, with breast cancer dominant.

The subjects consisted of 101 consecutive outpatients receiving radiotherapy during the period July 1979 to June 1980. The author of the current study interviewed 346 patients in one month, so that 101 in eleven months seems a small number. There is no mention of refusals in Leigh et al's study.

At three years 38% were dead. Survivors therefore numbered 62%, which is high for a three year cancer study. However, in Leigh et al's study patients were only interviewed once. They were not re-tested at the three year point. Information was accessed through the patients' notes and no further testing of the patients occurred. Consequently there are no non-participants over that three year span. In contrast, known deaths in the current study were similar at 40% in year three. In Leigh et al's study, anxiety and depression were measured only once, namely:

"During one of their daily visits as they reported for radiation therapy"
Thus no accurate specificity in timing was given. This could have affected their results. In the present study survivors at five years are compared with the non-survivors.

Table 70:   T-Test plus Means and
SD of Trait Scores of Survivors and Non-Survivors
with Respect to their Scores at Simulation.

	Survivors [No] Mean (s.d.)	Non-Survivors [No] Mean (s.d.)	Test for significance
4 Weeks Post Treatment	[218] 37.2 (9.4)	[15] 38.93 (8.9)	t(231)=0.689 p=0.492
6 Months Post Treatment	[146] 36.32 (9.18)	[48] 40.35 (9.12)	t(192)=2.64 p=0.009*
1 Year Post Treatment	[144] 36.45 (9.2)	[59] 39.27 (9.7)	t(201)=1.94 p=0.054*
18 Months Post Treatment	[102] 35.94 (8.5)	[86] 38.88 (9.6)	t(186)=2.213 p=0.028*
2 Years Post Treatment	[95] 36.55 (9.21)	[99] 38.58 (10.01)	t(192)=1.46 P=0.144
3 Years Post Treatment	[92] 36.89 (9.6)	[109] 38.16 (9.9)	t(199)=0.931 p=0.353
4 Years Post Treatment	[76] 36.8 (9.69)	[116] 38.22 (9.90)	t(190)=0.981 p=0.328
5 Years Post Treatment	[78] 35.78 (8.17)	[119] 38.49 (9.9)	t(196)=2.09 p=0.038*

Table 70 shows Trait anxiety scores taken at simulation and compares them at each of the post treatment testing points.   The number of survivors decrease (n=218 to 78) and non survivors increase (n=15-119) during the five years.   The patients who survived the 5 years had significantly lower Trait scores than the non-survivors.

Therefore in contrast with Leigh et al the survivors in the current study did not have significantly higher trait anxiety.   In the present study the survivors had significantly lower Trait anxiety.   Cassileth (1986) hypothesized that State and Trait become fused as death approaches and this study confirm their findings.   At four weeks post treatment, the non-survivors Trait score was 38.93 and their State score was 38.57 indicating this fusion effect. At six months post treatment the Trait is 40.35 and State is 40.81 and this fusing of scores continues for the whole five years.   This is in sharp contrast to the survivors (n= 78) who at simulation have Trait scores of 37.2 and State scores of 41.9.   This pattern, too, is repeated for five years, with Trait lowering and State scores rising.   The STAI State score was 43.6 for the survivors at simulation.   This is a very high mean score taking into account that the cut-off point used to indicate a 'possible' case on the State questionnaire was 42.8.   If we further examine the 56 'completers' the Trait score mean is 34.73 (sd 7.2) whilst the STAI State is 41.95 (sd 12.58), thus re-enforcing the difference in these two questionnaires and the difference in their scores.

Leigh et al hypothesized that increased levels of anxiety and depression may be predictive of survival so that high or low levels of distress could indicate either a short or long survival level. This is an interesting hypothesis. Janis & Mann (1982) had previously shown that very high or very low levels of distress in response to a fearful stimulus can be indicative of survival with patients with extreme anxiety either living longer or dying quickly. They suggest that there is an 'inverted-U'-shaped relationship between anxiety and adaptation. In the current study the non-survivors had significantly lower state anxiety (Mean 39.2 sd 12.0) in comparison with the survivors (Mean 43.6 sd 14.47). However in the further analysis using cut-off points, the number of 'cases' at simulation of palliative and radical patients using the STAI State was 52% and 48% respectively, indicating that approximately half of the patients in each group were highly anxious.

All patients in the study have not only been given a diagnosis of a life-threatening disease but are entering a strange department for the first time, meeting new staff and are having their treatment planned with hi-tech equipment and possibly hi-tech talk. Under the circumstances moderate to high anxiety would be considered a normal response to the threat. It could be hypothesized that the survivors who responded to the threat of unknown treatment with anxiety are exhibiting a healthy psychological reaction and therefore adapt better and have a longer life expectancy. To show little or no anxiety could be considered as a maladaptive response or an avoidance coping mechanism. It is therefore surprising to find that at simulation 5% of the women scored between 0 and 2 on the HADS anxiety scale and 26% of the men. In the current study at simulation depression was significantly lower this was coupled with State anxiety scores which were significantly higher in the survivors.

With respect to gender, it has already been stated that more women than men were participating in the study. Analysing those who had died (n=15) at four weeks post treatment, more men (n=11) had died than women (n=4). It was found that three of the four women could be considered a 'case'. With regard to men, eleven died, one was a possible case and one a probable case. For the men therefore 2 out of eleven had anxiety scores of 8 and over in comparison with 3 out of 4 of the women. The men who had died in the time between simulation and four weeks post treatment appeared to exhibit less anxiety than the women.

These results appear to indicate that men and women manifest anxiety differently. Leigh et al suggested that the women who died had rated their condition as more serious than women survivors. This is in contrast to the men. They suggest that men cope with cancer with denial whilst women could be realistic about their situation. This could be the case.

However from the current results it appears than men and women come to terms with their cancer diagnosis and the threat of death at different times. From analysing the data through treatment the anxiety levels in women drop steadily through treatment and after. Women are significantly more anxious than men at simulation, 1st treatment and mid-treatment. However from the end of treatment onwards the number of anxiety cases for men increases and by four weeks post treatment a shift is now apparent with men having higher anxiety levels than the women. This is further confirmed by analysing the 'completers'. The women are significantly more anxious than the men at simulation and 1st treatment. Their anxiety is higher than the men until 6 months post treatment. The anxiety levels of the men are then higher than the women's for the next five years. It could therefore be hypothesized than men at first cope with their diagnosis by denial, take longer to register the threat and then react to the stimulus. It is difficult to sustain denial if one is attending a radiotherapy department every day, especially if that department freely uses the word cancer. This defensive failure could be a tactical coping skill so that they need not recognize their continuously deteriorating medical condition. Leigh et al (1987) hypothesized that:

> 'patients with high anxiety and depression in the non-survivor group had a massive defensive failure, while those who had high anxiety in the survivor group had been more realistic about their disease'.

With respect to depression, those patients who died in the current study were significantly more depressed. Table 69 shows that looking at the scores at simulation, the survivors were significantly less depressed. This table examines the depression scores at simulation and compares the survivors to the non-survivors from 4 weeks post treatment through the five years. The numbers of survivors decreases and the non-survivors increases in number.

**Table 71: Results of T-Test plus Means and
SD of Depression Scores of Survivors and Non-Survivors
with Respect to their Scores at Simulation.**

	Survivors [No] Mean (s.d.)	Non-Survivors [No] Mean (s.d.)	Test for significance
4 Weeks Post Treatment	[218] 4.11 (3.3)	[15] 7.4 (2.9)	t(231)=-3.715 p=0.001**
6 Months Post Treatment	[146] 3.59 (3.09)	[48] 6.46 (2.9)	t(192)=5.627 p=0.001**
1 Year Post Treatment	[144] 3.59 (3.09)	[59] 5.9 (3.04)	t(201)=4.90 p=0.001**
18 Months Post Treatment	[102] 3.25 (2.8)	[86] 5.69 (2.95)	t(186)=5.719 p=0.001**
2 Years Post Treatment	[95] 3.4 (3.2)	[99] 5.44 (3.07)	t(192)=4.52 P=0.001**
3 Years Post Treatment	[92] 3.6 (3.5)	[109] 5.16 (2.9)	t(198)=3.312 p=0.001**
4 Years Post Treatment	[76] 3.17 (3.00)	[116] 5.14 (3.09)	t(190)=4.38 p=0.001**
5 Years Post Treatment	[79] 3.09 (2.82)	[119] 5.12 (3.05)	t(196)=4.7 p=0.001**

The men who died were more depressed than the women.

Leigh et al's survivors had higher state and depression scores, but significance was not reached. The 56 'completers' in the current study also had high state anxiety, with 56% of the women and 33% of the men indicating a 'case' at simulation. The current study shows that at simulation and 1st treatment the 56 'completers' had no 'case' of depression for men and 1for women and that only at simulation. This did increase over the course of the study with men displaying more 'cases' than women from mid- treatment onwards. This again emphasises the importance in the specificity of the timings of the testings.

From the cohort of high scorers at simulation, that is the number of patients scoring 8 and over, 45% of them survived 5 years. The number of men who survived from these high scorers was lower than the number of women survivors, 37% and 53% respectively.

The anxiety levels for patients overall were far higher than the depression scores at simulation. One third of the patients who had died by four weeks post treatment had high anxiety, 40% had depression and 52% had psychological distress. Thus two thirds of the patients who died were not anxious even though they were in the terminal stages of their cancer. This could be that patients are no longer fearful, uncertain and worried about the outcome. They now know that the outcome will be death and they have come to terms with that so there is no point in being anxious. Alternatively it could be a maladaptive response to

the fear or denial. Eleven men in this small cohort of 15 died and only two indicated anxiety, this could confirm the hypothesis of Leigh et al than men cope with cancer by denial. Patients who did not survive had significantly higher depression scores (7.4 sd 2.9) than the patients who did survive (Mean 4.11 sd 3.3). Indeed in the current study men had significantly higher depression scores than the women throughout the study. It should also be noted that the HADS is not such a good predictor of depression as anxiety and the number of depression cases is likely to be higher.

The psychological effect of depression is different. Depression levels rose after treatment. From the research questionnaire patients who felt worse were significantly more depressed. Treatments have been given and now some patients are left with the feeling that nothing more can be done to change the outcome. This could result in a feeling of helplessness and hopelessness and lack of control.

The current study could therefore expand Leigh et al's hypothesis. This study shows that the predictors of survival in cancer patients who have undergone radiotherapy treatment have high State and lower Trait scores, coupled with low depression scores. The high State could indicate a healthy response to the threat of treatment, the lower Trait could indicate that generally they were not so highly anxious and the low depression could indicate a sense of control and emotional support. This is an hypothesis requiring more research.

The current study with its changes over time emphasizes the importance of respondents being tested at specific time points during treatment and post treatment in order to get accurate readings of distress. As simulation is such an anxiety provoking time for patients, the best time for testing would be at first treatment. Depression in this study reached its peak at the end of treatment and this would be the best time for testing for that variable.

The fifth study by Hammerlid et al (1999) was a longitudinal study of head and neck patients. The HADS was used to assess the levels of distress. Most of the patients, 88%, received radiotherapy treatment. Patients were tested six times, at diagnosis and then at monthly intervals.

The levels of anxiety and depression at diagnosis were lower than in the current study. Hammerlid et al's patients scored 4.74 on the anxiety component of the HADS with 32% of these patients classified as possible or probable cases. The patients in the current study had a higher mean of 6.93 and 40% of the patients were classified as 'cases'. What is causing the difference in the mean? Firstly Hammerlid's study only contained head and neck patients. It was not the mixed cohort of the current study. Secondly the current study tested patients

specifically after registration and before being called for simulation. Hammerlid et al patients were tested at the time of diagnosis. Does this refer to immediately after they were given their diagnosis? If this is the case, many patients would have been in shock and unfit to answer questionnaires. If it referred to a time after diagnosis, then this should have been stated. Thirdly Hammerlid et al's patients were primarily men, (72%). The current study shows that before and during treatment men had significantly lower anxiety scores than the women. The scores of the men were 5.9 at simulation. This dropped to 5.52 and 4.75 at first and mid treatment respectively indicating the importance of the specificity of the timing of the questionnaires.

Hammerlid et al further tested patients on a monthly basis and not at specific times of stress such as the start of treatment. Although they stated that most of the patients received radiotherapy (88%), surgery (33%) and chemotherapy (19%), the article did not state when patients received treatment. If they had surgery first, treatment could have been in the second month and this could have altered the statistics. They did consider diagnosis to be pre-treatment and three months as post treatment points in their analysis.

Depression scores in Hammerlid's study were also lower than in the current study. The number of 'cases' of depression in the current study was the same as at the first testing, 17%. The depression scores throughout the study were not subjected to the same fluctuations as the anxiety scores.

The current study found similar patterns in the scores of the anxiety and depression questionnaires to Hammerlid et al thus emphasising the current study's findings that anxiety and depression are transient for the cancer patient. Anxiety was at its highest at diagnosis and then lower in the first month, with a slight increase in possible anxiety cases at three months. This is equivalent to the rise of cases at the end of treatment in the current study. Radiotherapy treatment occurs every day for these patients with a potentially life-threatening disease. Suddenly, after six weeks of continuously travelling to the hospital for treatment and being supported by the hospital staff, patients leave with an appointment to see the physician in six weeks. This could be an explanation for the rise in anxiety at 4 weeks post treatment.

Hammerlid et al found that women were more anxious initially at diagnosis but this was not repeated over time. The current study confirms and elaborates on Hammerlid et al's study in that women were more anxious than the men at simulation until the end of treatment. However at that point a change occurred and by four weeks post treatment men have higher

anxiety scores than women. It is generally accepted that women are more anxious than men (Ware & Snow 1993) and this finding is therefore surprising.

Similarly the current study found that the number of depression 'cases' peaked at four weeks post treatment. Hammerlid's study found that depression cases peaked during treatment. However, their measuring points are months and not specific points before, during and post treatment. Consequently, we are unable to ascertain at what particular time in their treatment this monthly point is. The second month testing point, however, could be equivalent to four weeks post treatment time, depending on the number of fractions given to these patients.

At simulation the current study, with the larger original cohort, had a higher percentage of men than women as depression 'cases'. Women are normally perceived as suffering from more depression than men and this finding is different from the norm. Hammerlid et al found more women than men were cases at diagnosis. However no further statistics on gender were included in their study. The analysis on the 'completers' showed no cases of depression among the small male cohort at simulation and 1st treatment. The females had one depression case at simulation only. This again highlights the importance of the timings of the questionnaires and the mobility of the variables of anxiety and depression.

Hammerlid et al also found that patients with more advanced disease suffered from more depression. The current study found that palliative patients were significantly more depressed than radical patients throughout treatment. Age was also considered in the current study, but no significance was found except at five years when those patients over 65 plus were significantly more depressed. Hammerlid found that patients who had retired were less anxious than those not retired. The current study cannot confirm this finding. In contrast the current study showed that in the analysis of the survivors men and those aged over 65 were significantly more depressed from six months post treatment until the end of the study.

Hammerlid et al felt that the HADS needed to be repeated during treatment to identify new possible/probable cases that arise. The author would agree with this statement and would suggest testing at first treatment and at the end of treatment with appropriate questionnaires to identify those patients at risk.

Anxiety

Radiotherapy is usually given to patients after their diagnosis has been confirmed and quite often following surgery. Therefore a certain degree of adaptation to their cancer diagnosis has occurred by the time they arrive at the radiotherapy department. However treatments, especially radiotherapy, can heighten anxiety. Patients endure their radiotherapy treatment because they understand that it will help eradicate/control their cancer. Many do not understand how it works and feel very frightened when they arrive for the planning of their treatment. Patients, especially men, further confirmed in this study that after diagnosis and test results, radiotherapy was their worst experience.

This feeling of acute anxiety is a very understandable reaction to the threat of treatment and in this study anxiety reached its peak before simulation. Anxiety is the classic response to danger in this case the radiation treatment. This fear can manifest itself in a variety of ways, in the form of inattention, racing pulse, sweating, short-term memory loss and numbness. This is reactive situational anxiety. Philip Snaith (1991) wrote

> "Situational anxiety occurs when the person is in the presence of, or thinking about, some situation or circumstance which has assumed an unusual element of threat or difficulty".

It is obvious therefore that everyone will be at some point subject to the experience of anxiety. However if it persists for too long it can be classified as a psychiatric disorder.

This study shows that anxiety manifests itself at different times during patient's radiotherapy treatment and after treatment. Regardless of the degree of anxiety, it can substantially interfere with the quality of patient's lives and therefore needs to be evaluated and treated.

The most anxious time for patients overall was at simulation when patients arrive for the planning of their radiotherapy treatment. This occurred regardless of whether they were one of the 56 who completed all questionnaires, or whether they were the original cohort. At this time 40-50% of patients indicated high anxiety, depending on the questionnaire used. Some 27% were evaluated as probable 'cases' with the HADS by Moorey et al (1991) and in this study 20% indicated a probable 'case'. The mean score (Mean=6.9) is higher than in other studies that used the HADS questionnaire, (Hammerlid et al 1997, Nordin & Glimelius 1999).

Stark et al (2002), using touchscreens, measured 48% with anxiety at the 8 and over level with the HADS. These patients were in Out-Patients and not coming for radiotherapy planning. Their anxiety should have been less. Did the touchscreen cause an increase in

anxiety? Patients with cancer tend to be 60 plus, and are not very used to computer technology. Many are frightened by screens other than a TV screen. This could have given a higher than normal average percentage.

There was a linear decline over the course of treatment in anxiety. Over treatment anxiety ranged with the HADS from 40% to 24%. STAI State ranged from 50% to 33%. Other studies with cancer patients have shown equally high numbers, Carroll et al (1993) reported 48%, Derogatis (1983) reported 47% and Shrag et al (1989) 44%, though neither of these studies were specifically radiotherapy patients undergoing treatment.

This study however emphasises the importance of specifying specific meaningful times. Calendrical times of monthly intervals are not appropriate in this population undergoing various treatments to cure/palliate their cancer. Anxiety is highly mobile while undergoing radiotherapy treatment. This helps to explain the differences in the range of anxiety levels in the literature from 0.9% to 49% in one review (van't Spijker et al 1980). This lack of specificity can cause inaccuracies. Only in Holland's longitudinal study of 1979 does it specifically mention:

> "on the patient's initial visit to the Radiotherapy Clinic, she was examined by the radiotherapist who devised a treatment plan with her. She was then seen by one of two psychiatrists"

thus indicating that she was tested after the planning procedure.

From 6 months to five years post treatment, patients were tested on a different basis as treatment had finished. Patients were firstly tested at six monthly intervals, and from two years, on a yearly basis. The number of cases, at about 20% of the population, remained approximately the same for both anxiety questionnaires, except at the five year mark when it dropped. This might be due to the effect of finishing the questionnaires and a feeling of success at passing the five year barrier. Analysis of the data by the variable of gender showed different results.

Women:

The data from simulation to 4 weeks post treatment, which outlines the first ethical permission, showed a linear decline in anxiety for the women. This decline to the end of treatment was shown by both the STAI and the HADS. The women were the most anxious group on arrival for their planning (Mean=7.6 sd 3.9). Studies have confirmed that women are more susceptible to anxiety and report more problems (Ware & Snow 1993). Marasate et al (1991) found 15% of breast patients with high anxiety. Fallowfield (1994) found 17-23% of breast patients with high anxiety over a three year period. The current study had

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percentages of between 45% and 23% for the breast patients through treatment depending on the timing of the questionnaire. The levels of anxiety were also dependant on the anxiety questionnaire given, whether it was the STAI or HADS. Aass et al (1997) found twice as many cases (16%) with women as with men (8%), and this difference was significant. Aass et al did not test patients specifically at simulation. All their patients were tested on a specific day. A few would have been having their simulation, but the majority were having routine out-patients appointments. This could explain the large variation in the cases compared with the current study, which using the HADS found 45% of the women had scores of 8 and over, with 23% indicating a 'probable' case, that is 11 plus on the HADS. Higher scores are found with the STAI, 54% of the women indicating a 'case', with 42% 'probable'.

Analysis with the 56 'completers' also showed a similar pattern, with women showing highest anxiety at simulation. However the mean scores for this cohort are lower than the original cohort (Mean=6.59 sd 3.2). Similarly the number of 'cases' is lower, with 34% indicating anxiety over the cut-off point of 8, and 17% indicating a 'probable' case. However with the STAI State questionnaire, 56% indicated a 'case', with 49% a 'probable' case.

What is causing this difference in the number of 'cases' with these two well validated questionnaires? It could be the wording on the questionnaires. The HADS asks patients

'Read each item and place a tick in the box opposite the reply which comes closest to how you have been feeling in the past week.'
The STAI State says:

'Read each statement and then blacken in the appropriate circle to the right of the statement to indicate what you feel **right** now, that is, **at this moment**. There are no right of wrong answers. Do not spend too much time on any one statement, but give the answer which seems to describe your present feelings best'. Note the bold letters on 'right' and 'at this moment' emphasising the present.

The STAI Trait makes the same statement as the State but ask patients to indicate how you *generally feel*. Again this is in italics and bold.

From these statements it would appear that the STAI State would give a more accurate response to how the patients are feeling before their planning starts. How you 'generally feel' and how you feel 'in the last week' are backward concepts, as opposed to 'how you feel at this moment'. The analysis of the STAI trait and HADS shows a much higher correlation, $r=0.663$, $p<0.001$, than the STAI State and STAI Trait, $r=0.460$, $p<0.001$. For a population

undergoing treatment the STAI State appears to give more accurate information for specific time points during that treatment.

By the end of treatment anxiety cases for women had dropped to 29% as measured by the STAI and 30% as measured by the HADS. This highlights the sensitivity of the STAI over a condensed period of time to show the fluctuations in anxiety in the population. The women displayed a gradual decrease in the number of cases from simulation, 54%, 1st treatment, 49%, mid-treatment 37%, to end treatment 29%. At four weeks post treatment an increase in cases, 32% occurred. This was not the case with the HADS questionnaire.

Analysis on the two questionnaires shows that correlation is higher post treatment apart from mid treatment when a certain amount of adaptation could have occurred.

Table 72: Showing Correlations of HADS and STAI State for the 56 'Completers':

Treatment Times	Correlations
Simulation	0.596*
First Treatment	0.551*
Mid Treatment	0.815*
End Treatment	0.684*
Four Weeks Post Treatment	0.712*
Six Months Post Treatment	0.819*
One Year Post Treatment	0.804*
Eighteen Months Post Treatment	0.870*
Two Years Post Treatment	0.767*
Three Years Post Treatment	0.798*
Four Years Post Treatment	0.782*
Five Years Post Treatment	0.780*

Significance at the <0.05 level

This table (Table 72) emphasises the point that in a normal time frame 'how you are feeling in the last week' and 'how you are feeling at this moment' do not greatly differ in the absence of an anxiety provoking situation.

Looking at the data from 6 months, (Table 73) the number of 'cases' of anxiety fell. Apart from year 3, the number of anxiety 'cases' is very similar for the two questionnaires.

This could therefore indicate that the HADS is a more appropriate tool to use from 4 weeks post treatment, when there is no immediate threat present. When testing through treatment the STAI State/Trait are more appropriate questionnaires.

Table 73: Percentage of Cases for Women Using STAI State and HADS from 6 Months to 5 Years Post Treatment

Questionnaires	T6	T7	T8	T9	T10	T11	T12
HADS	17	19	19	17	22	19	15
STAI	17	20	14	14	14	17	17

T6=6 months post, T7=1year post, T8=18 months post, T9=2 years post, T10=3 years post, T11=4 years post, T12=5 years post.

The women cohort contained a high percentage of breast patients. In order to eliminate a gender bias the women were split into 2 categories, breast and non-gender related. The non-gender related was all sites minus breast and cervical cancers. The breast patients had continuously significantly lower scores than the non-gender related patients for the whole study. Breast patients now are given more psychological support and this seems apparent in their scores. The non-gender related females were significantly more anxious that the non-gender related males throughout treatment. This adds confirmation to the high anxiety of the female population at this time. The non-gender related females continued to have higher scores for the next five years. In contrast breast patients had the lowest scores. The breast patients therefore might be distorting the anxiety scores of the female cohort, especially in the latter half of the study. This is further confirmed by the analysis on the 'completers'. The non-gender related females have consistently higher scores throughout the study. However they only number 6.

As there were no significant differences between the 'completers' and the larger cohort who survived from 6 months to 5 years, the findings of the original cohort can be used. This showed persistent anxiety with non-gender related females throughout treatment and five years after. More research is needed with this cohort.

Men

Men's anxiety scores were not so volatile as the women's. With the larger initial cohort the ratio of men to women is 1:2. Men's scores in this cohort were much lower at simulation (Mean=38.73 sd 9.1) than women's (44.12 sd 14.26). Women were significantly more anxious at simulation and at 1st treatment with both questionnaires. With the STAI State 44%

of the men were still anxious, with 29% 'probable' cases. The HADS showed a smaller percentage with 33% indicating anxiety and 12% 'probable' cases.

During treatment the overall mean falls, but in contrast with the women cohort, from mid-treatment onward the scores of the men show a rise with the HADS Questionnaire. This rise occurs at the end of treatment with the STAI State. This could be a response to treatment ending and loosing the backup of professional medical advice. At this point an upward trend is apparent with both questionnaires. The number of cases anxiety 'cases' overall fell from 44% at simulation to 35% at four weeks post treatment with the STAI State. There are now however more 'cases' of men with anxiety than women (32%). This was also shown with the HADS, 26% men in contrast to 23% women.

Analysis on the 'completers', shows a slightly different picture. The numbers of men in this cohort are small (n=15) with a ratio of one man to three women. At simulation 13% indicated a 'case', this rises to 27% at the end of treatment. With the HADS there is a peak in the number of 'cases' at the end of treatment. With the STAI State 33% indicate a 'case' at simulation, at mid-treatment 42% are indicating anxiety. This falls to 20% at the end of treatment.

From 6 months to five years (Graph 25) men's anxiety continues to be higher than women's apart from year 3 with both questionnaires. The number of cases similarly continues to be higher than the women's.

Therefore the pattern of anxiety for men and women during treatment is different. Women are initially significantly more anxious than the men at simulation and at 1st treatment. By the end of treatment men's anxiety scores are rising.

After treatment, men became the most anxious group for nearly all the post-treatment testing times but significance was not reached. Men's mean score fell over treatment, but rose at 4 weeks post treatment. This increase at four weeks post treatment is confirmed by both anxiety questionnaires. This confirms Hammerlid et al's (1999) findings when they state that women are more anxious initially, at diagnosis, and when they first come for treatment, but this is not repeated over time. This finding is different from the literature when women are considered more anxious than the men and report more problems (Ware & Snow 1993). What is causing these different patterns of anxiety in men and women?

A number of different theories have been suggested to explain the difference in men and women, such as psychological theories on coping behaviour, social theories, biological theories and gender identity. However the most likely theories are a complex interaction

between psychosocial (including cultural) biological, social behaviour, and gender roles. In this study when patients arrived for simulation, they were surrounded by highly technical equipment, highly skilled staff and an alien clinical atmosphere. It is therefore not surprising that in response to what could be considered in evolutionary terms 'danger', anxiety results. Did the women, as Leigh et al (1987) suggest, cope with a realistic appraisal, whereas men cope with denial. One of the men in the current study wrote "I do not have cancer" on his form. A surprising comment as the word 'cancer' is used in the radiotherapy department both verbally and written. This is a coping mechanism and the men appear to need greater time to adjust to their cancer diagnosis. This denial could also prevent men for seeking appropriate help when symptoms the first symptoms are present. Thus when a diagnosis of cancer is given are men more angry and depressed because they have not sought medical help early enough as they have been denying that anything is wrong? It could be suggested that men take longer to confront issues that are painful for them. They have an intermediary step of denial, before realization. Although some men had come to terms with this realization quicker than others, women tend to be more accepting of their illness and to voice their anxieties concerning illness and death (Chiapetta et al 1970, Lester 1971).

Many studies have shown a difference in anxiety in women and men with respect to death. Women are more able to express their anxiety and men deny their anxiety with relationship to death. This difference in coping styles appears to be due to some extent to women's sociability skills, which appears to extend to illness and how the genders cope. Leigh et al (1980) as previously discussed suggests that anxiety in men is not admitted and that this causes a maladaptive approach to health and emotions. They suggest that when men are being treated for a potentially fatal illness, the clinician needs subtly to enquire into their health awareness and emotions. In a study in 1999 (Green & Pope) women were found to make much more use of medical services than men. One could hypothesize from this either that women are more neurotic than men, or that they confront illness quicker and or are more realistic.

Another theory, which could explain this anxiety difference, is related to identity. Our culture promotes gender stereotypes. This results in a masculine identity which can include behavioural traits such as aggressiveness, invulnerability, competitiveness (Moynihan 1998). These attitudes can also encourage inhibitions on men's display of emotions, particularly pain or discomfort. It encourages the belief that men should be 'stoic'. These ideas concerning their masculinity may affect men's decisions about health behaviour (Eisler 1995).

This could result in men and women having different coping mechanisms. The social acceptability of admitting an illness, especially cancer, and seeking help may differ between men and women. Disclosure of health concerns is evidence of a weakness or vulnerability. Illness is often seen as a weakness in men. Admitting to illness is admitting to vulnerability and could be considered as a 'chink' in the armour of masculinity, which has been worn since childhood. Indeed it has been shown that men are less likely to seek medical care, to report symptoms or regularly to visit the physician than women (Waldron 1976, Waldron 1991). Health surveys have shown higher morbidity for women and higher mortality for men (Waldron, 1983; Wingo et al, 1995). This could be because men may delay medical help, so that by the time assistance is sought the case is urgent (Clarke & FitzGerald, 1999).

In contrast a woman's stereotypical image is one of taking responsibility for her health and the health of her family. Women are socialised to assume health responsibilities. This sense of responsibility may enable her to monitor symptoms and hence to take curative action. Klemm et al (1999) studied gender differences on internet cancer support groups. Women gave comfort, encouragement and support and men information, suggesting that the stereotypical role continues.

Murphy (1998) hypothesized that men are socialised (and maybe biologically programmed) to value concrete rather than abstract concepts. That is men wait until the disease is obvious (concrete) before seeking help.

Moynihan (1998) discusses men's social roles. Men discuss sport, politics, business among themselves. Emotions and health concerns are private. This could affect their information-seeking and health promoting behaviours. Meissner et al (1992) suggests that men are more likely to get information from the internet. Leigh et al (1987) suggests that men cope with cancer with denial. If we look at the statistics for male cancers, namely testicular, prostate and bowel the morbidity and mortality is high, indicating that men may, at least at first, respond with denial until the disease has progressed to a state when treatment is less effective. In the current study 157 women participated, and 112 men. With regard to the palliative cohort (96), 58 were men, showing a much higher proportion of men were palliative patients in comparison with women (38). However in the total cohort the number of women exceeded the number of men by the ratio of 2:1. This could add credence to the hypothesis that men do not confront illness. Furthermore men's adaptation to cancer appears from this study to be less strong than women's. This was confirmed in previous studies (Fife et al 1994, Greimel et al 1989).

This knowledge of gender-specific differences could usefully be applied in general patient care and education. Screening, early detection and symptom recognition needs to be implemented in a manner which appeals to men. Education and socialisation of young men need to take place to show that good health, which entails screening and seeking advice creates a positive self image. This proactive behaviour will reduce morbidity and mortality.

Treatment Intent

Palliative patients throughout the study showed irregular patterns compared with the radical patients with differences in the levels of anxiety measured. Throughout treatment and one year post, the palliative patients are significantly more anxious than the radical patients. The HADS shows that both palliative and radical patients peak at simulation. The STAI State shows a peak at mid treatment for the palliative patients. Indeed the palliative patient cohort which had the highest mean scores on all three anxiety scales questionnaires was the palliative patients having more than five treatments (the long multi-fraction group LMF) and these patients caused this peak at the mid treatment point. This group tends to have advanced cancer, stages 3 or 4. Many are newly diagnosed patients whose tumour is advanced on diagnosis. Some have had surgery and others are having radiotherapy treatment only to shrink the tumour. This particular cohort of patients is extremely anxious and need support. Many have not had time to adapt to their terminal diagnosis and the women in particular are very vulnerable. They have significantly higher scores than the men.

Both palliative and radical patients showed a decline over treatment as measured by the HADS. The peak was at simulation with 53% of palliative patients scoring 8 and over. This percentage fell to 45% at 4 weeks post treatment. In contrast 48% of the radical patients indicated a 'case' at simulation and 29% at 4 weeks post. The radical patients indicated a more adaptive response to the treatment than the palliative patients. Further analysis was carried out to see, at the 4 weeks post treatment point, if this was due to the higher percentage of males in the palliative cohort. However 52% of the female palliative patients were indicating an anxiety 'case' in comparison with 40% of the male palliative patients.

Cassileth et al (1986) suggested that as death approaches State and Trait become fused. They write

> "these two sets of scores are so closely correlated that they appear to measure a single construct or emotional factor in the particular population"

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The palliative patients in the current study are the most anxious cohort. They are significantly more anxious with regard to Trait anxiety than the radical patients. Indeed their State and Trait scores are not dissimilar (41.60 and 39.20 respectively), in comparison with radical patients (42.06 and 36.97 respectively) indicating that what Cassileth et al suggested could be true that many palliative patients are continually in a highly anxious state (see Table 67). The Trait scores of the non survivors palliative patients was 38.93 and the State score was 38.57 at simulation. In contrast the surviving palliative patients mean Trait score at simulation was 43 and State score was 51. The Trait score though high, was much lower than the State score.

Some of the palliative patients who had a single fraction were treated and simulated on the same day. This group had higher Trait anxiety (Mean = 38.41) and their state anxiety (Mean=40.45) and HADS levels (7.1) were similarly high though not as high as the survivors.

After radiotherapy treatment has finished the hospital physician does not see the patient for another six weeks. At four weeks post treatment the patients received by post the next set of questionnaires. This was the first time that patients had responded to a postal questionnaire. All the other questionnaires had been filled in before treatment in the radiotherapy centre. Fifteen patients had died since the study started, 251 questionnaires were sent out and 218 were returned, giving a response rate of 87%. The single fraction patients are included in the current numbers if they were still alive and willing to participate. Even after treatment had finished, 24% of patients are anxious and 12% very anxious.

After an initial period of relief after coming for daily treatment, patients may become more anxious as they now realise they no longer have the daily support of the medical personnel.

Further analysis reveals that at this time point the palliative men patients had more 'probable' cases of anxiety since simulation. Further analysis was carried out to see if the effect of the male palliative patients was due to the single fraction group (SF) who were not included at the time of the last testing. The mean for the SF group was higher than the other groups but significance was not reached. Indeed there were no significant effects for any of the palliative groups, SF, SMF or LMF palliative with regard to anxiety throughout their treatment. It could be hypothesized that for these particular palliative men who are very anxious, treatment has not cured them, hope has dropped, anxiety has risen as they are no longer able to deny their condition.

At the end of the study four palliative patients were still responding to the questionnaires.

In conclusion a high proportion of patients experience anxiety when they come for the planning of their treatment. Health professionals need to be aware of how very anxious these patients are. Information in the form of literature, videos or prior visits to the department can help lessen this distress. As they go through treatment changes in their psychosocial equilibrium occur due to adaptation. However, a significant number of patients continue to show clinically meaningful anxiety that needs to be treated. The successful management of anxiety disorders depends on a judicial management of both psychological and pharmacological treatments. In a controlled randomized study looking at the efficacy of relaxation and imagery for controlling anxiety and depression in radiotherapy patients, Bridge et al (1988) found that the group whom had relaxation and visual imagery had significantly less mood disturbance than the control group, with women over 55 years receiving the most benefit. Emotional support, religious faith/beliefs, information, positive attitude, distraction are all coping strategies that patients have found helpful, Wainstock, J. (1991), Of these emotional support was the most helpful and positively correlated with adjustment, Zenmore & Shepel (1989).

The results of this study indicate the importance of specificity in the timing of questionnaires when patients are undergoing difficult treatments. It highlights how anxiety changes over time. Some anxious patients do adapt, but even years after treatment has finished a quarter of patients are still registering as 'possible' cases. Anxiety therefore can persist for some cancer patients, unless it is treated. Maher(1993) points out that the term 'remission' is anxiety provoking as it implies the patient is not cured and that the cancer will inevitably return. This induces more anxiety for the patient.

Patients who need special attention are the palliative patients especially if they were having more than five treatments, women at simulation and 1st treatment and men at the end and post treatment. Health professionals need to be aware of the anxious state these patients can be in when they arrive the department for treatment and the difference with respect to gender. GPs should similarly be informed if patients, especially the men are showing signs of raised anxiety at the end of treatment and these patients need to be followed up. Therefore the author would suggest testing patients at first treatment and at the end of treatment. The results of these tests should be placed in the patient's notes. Physicians should therefore be able to see the extent to which the score is lowering or rising and accordingly suggest appropriate further testing with a psychologist if needed. This is especially important as anxiety at first treatment can predict 42% of the anxiety after treatment has finished.

The patients who had died by four weeks post treatment, 15 in all, had significantly higher depression scores, had lower state scores and higher trait scores than the survivors at simulation. Their Trait and State scores had become 'fused'.

Although a high correlation was found between the STAI State and the HADS anxiety component these two questionnaires do not measure identical anxiety. This was particularly noticeable in the beginning of this study when the patients were tested over short intervals. The HADS asks patients how they have been feeling in the past week. The STAI State asks patients how they feel 'at this moment'. The trait component asks patients how they 'generally feel'. This indicates the importance of the wording on these questionnaires and also illustrates that patients do respond accurately to the wording. Hall et al (1999) criticised the HADS they found its results were not consistent with the PSE. However the PSE asks patients how they felt within the last four weeks. This time scale is much larger than the State/HADS.

This paper highlights the fact that though the majority adapt some patients (20% plus) continue to feel anxious years after their treatment has finished. This confirms Thomas et als (1997) finding that anxiety is persistent in some cancer survivors.

Depression

The pattern of depression in patients undergoing radiotherapy treatment was very different to that of anxiety. Anxiety gradually fell over the course of treatment as patients adapted to their radiotherapy. This was not the case with depression.

The incidence of depression in the normal population is approximately 6% (Locke & Regier 1985, Lépine et al 1997). With medically ill, hospitalized patients the incidence is higher at 22-24% (Schwab et al 1967). Depression in cancer patients varies even more from 4.5% to 58% (Maissie & Holland 1990). In a literature review Sellick & Crooks (1999) cited serious depression as occurring between 6-15% of the cancer population. Previous studies have shown that approximately one third of radiotherapy patients report clinically significant depression (Jenkins et al 1998). The levels generally were much lower in the current study, except for the palliative patients. The variation on these percentages depends on a number of factors. This study highlights gender, age, site and treatment intent as being variables involved in the depression equation. Other factors which appear to be related; a previous psychiatric history, the amount of social support the patient is receiving, lack of control of pain and other side effects of cancer. Another factor to emerge from this study is the specificity of timings of the questionnaires. The depression levels varied over the five years. Other studies have shown variations in the levels of depression depending on the assessment tool (Derogatis et al 1983, Hinton 1973). These vary from psychiatric interview to a self-report questionnaire. This study used a well-validated self-report questionnaire, the HADS although its strength on the depression component has been questioned (Hall et al 1999).

However moderate depression if left untreated can develop in 80% of cases to severe depression (McCullough et al 1992). Therefore it is very important that patients are screened and treated for the depression when it arises. This study shows that depression develops over treatment. The average score of all patients was 4.30 (sd 3.30) when patients first arrived for the planning of their treatment. This was lower than the anxiety levels. At simulation the number of patients who could be classified as either a probable or possible case was 16% in the current study. This increased for palliative patients to 25%. Particular note could be made of the male palliative patients with 28% of this cohort registering at eight and over. Moorey et al found 9% were probable cases of depression from their cohort of cancer patients. This number was confirmed by Aass et al (1997). In the current study therefore a

quarter of the palliative patients were indicating depression, but few were receiving treatment. Why not? Berney et al (2000) writes:

"There may be multiple reasons for this unsatisfactory situation. Among them are the uneasiness of physicians at the prospect of talking about sensitive issues, such as emotional states, or the belief, even among psychiatrists – that depression is somehow inevitable in the terminally ill".

When patients are given the opportunity to talk about their emotions, clinical and scientific reports show that the patient's feel a sense of relief (Razavi & Stiefel (1994).

With a cut off point of 11 to indicate a probable case the percentage was lowered to five overall, and with the palliative patients, 7%. The studies of Moorey et al and Aass et al were not specific to patients about to undergo radiotherapy treatment. In the Aass et al study patients were tested on two randomly selected days in an out patients clinic. Most are returning for check-ups and approximately 20% were receiving radiotherapy or chemotherapy. From this cohort the patients who were about to undergo treatment were significantly more depressed. This could be one of the reasons why the level of depression is lower in the current study. In Moorey et al's study only patients who were considered to have a survival time of more than one year were included. In the current study all patients attending radiotherapy department were considered eligible.

Why is depression so much lower than anxiety for these patients? It could be hypothesized that patients first attending for treatment could feel hopeful and optimistic about their outcome which could lower their depression levels, especially at the start of treatment.

This study also shows that the number of depression 'cases' over treatment increased from 16% at simulation to 20% at 6 weeks post treatment. Hammerlid et al (1999) found very similar figures in their analysis with 16% of patients at simulation and a rise at the end of treatment. Montazeri et al (1998) using the HADS found that depression had doubled over a three month period. Their findings are very similar to the currents study. Anxiety fell, but depression increased significantly from their baseline.

By the end of treatment depression has risen for all patients and is just under the simulation level. This could be associated with the increased burden of coming for treatment daily coupled with their symptom/side effect burden. In Holland et al's (1979) study they found similar results. Women were more not less depressed at the end of treatment and this was coupled with increased overt anger which Holland et al felt was caused by patients feeling worse, less hopeful and more despairing. It could also be caused by the termination of treatment which resulted in less emotional support by staff. Nearly half of the patients in this

study would have liked a telephone call from a member of staff during the period of end of treatment to follow-up clinic. A prior time for a telephone call could have been made so that patients could voice any fears or worries. The radiographer involved in giving daily treatment would be ideal for this and this would assure the patient of continuity of care and give them the emotional support they need.

When asked to consider a number of factors, the fear of cancer diagnosis and progression, restriction on activities and side effects of treatment were all considered to rank as number one, (Gotay C C 1984).

For the five years post treatment the levels of depression remained at about the 15% mark. Analysing data on the 56 'completers' showed that depression rose from one case at simulation to an average of 15% during the last five years. The end of treatment can cause more stress because of the lack of support of medics and the unpredictability that isolates cancer from other diseases. This increase in depression years after treatment finishes, was noted by Bard (1987).

"Fear of recurrence remains for the cancer survivor, either consciously or subconsciously, and uncertainty of outcome reinforces the sense of hopelessness and loss of control that began with the cancer diagnosis" (Bard 1987)

Seligman (1992) stated that:

"When traumatic events are unpredictable....safety is also unpredictable: no event reliably tells you that the trauma will not occur and that you can relax...In the absence of a safety signal, organisms remain in anxiety or chronic fear"

These concepts helped to form his hypothesis on how helplessness can lead to depression. Patients can remain fearful and anxious after a traumatic event, unless safety can be reliably predicted. Because cancer can develop silently, patients lack these safety signals than can indicate that the disease has been cured.

Health practitioners can help patients by gently insisting on the success of their treatment. This coupled with information and a reassurance that the patients can ask questions should help in providing the very necessary safety signal.

Do gender differences occur in Depression scores?

Women

The women's depression score was lower than the men's throughout the study. At simulation the percentage of cases for men was 14% and for women 12%. By 4 weeks post treatment the number of 'cases' for women had risen to 20. Lansky et al (1985) recorded a

depression rate of 5% in female cancer patients. Aass et al found no difference in gender with number of probable cases as 8 and 9% respectively for men and women. The current study found that 6% of women had scores of eleven and over. From six months onwards women had significantly lower scores than the males, apart from year four. The non-gender related females had lower depression scores than the male non-gender related patients until the end of the study. This verified the gender findings that men were more depressed than the women in this study. Women's depression rose at the end of treatment, but from 6 months onwards depression was always higher for the men. The scores of the breast patients were the lowest. This emphasis the importance of the psychosocial back-up that these breast patients are now offered and shows that it is effective in reducing both anxiety and depression in this population.

Men

Men throughout the five years had higher depression scores than the women. Analysing the 'completers' at simulation women had one case, men none. The men at simulation and 1st treatment recorded no depression 'cases'. The number of men in this cohort is small (15), in comparison with the women (41). However t-test with the larger cohort (Part 2) showed no significant differences between these two cohorts. The pattern is remarkably similar, with the men consistently having higher depression scores than the women. Analysis over the whole period with the larger cohort therefore showed that depression and gender had a significant effect over the whole time of the study.

In a study undertaken in 1992 (Lloyd-Williams) radical patients who had just completed a course of radiotherapy treatment were tested with the HADS, 33% scored nine and over on the depression subscale. Men were more depressed than the women, 35% and 31% respectively. This is higher than the patients in the current study with 15% of men and women indicating a 'case' at the end of treatment. Lloyd-Williams (1994) does not say how long after treatment that her patients were tested. Neither did Lloyd-Williams evaluate patients over time. Also it is impossible to assess if patients who are being continually tested in a longitudinal study feel more supported and thus less anxious and less depressed.

Historically women are considered to be at excess risk of depression, so why are men consistently more depressed whilst undergoing radiotherapy treatment and for five years after? Is it that men feel the burden of disease more than women? Today theories of etiology of both anxiety and depression suggest powerlessness as an important component in both anxiety and depression, although other factors do come into account. The American

psychologist Seligman (1975) thought that depression was a state of 'learned helplessness, hopelessness' brought on by previous failures. This theory has now been combined into a theory that states that depression is due to cognitive habits. The habit of misattributing success and failure which leaves the patient feeling powerless and incompetent and finally depressed. Depressed patients often lack social support and or have unhappy relationships. These perceived feelings of inadequacy may lead to a lack of social power. Hann et al (2002) showed that the more perceived support and the higher the satisfaction with family functioning the less the depression. A larger social support network was associated with less severe depression in women cancer patients.

Gray (1982) suggests that anxiety and depression are linked, that depression occurs after a period of sustained anxiety. He believes that neurochemicals that normally cause arousal in the brain become depleted due to the continuous anxious state. This could be the explanation why women, who at simulation were extremely anxious, became depressed at four weeks post treatment. The levels of anxiety had fallen but the numbers of women scoring as possible or probable depression cases increased after treatment. This could also explain why men have higher depression scores throughout the study, but significance is only reached after treatment has finished. If this theory of Gray's is coupled with Seligman's theory of 1992, it gives an interesting hypothesis. Namely, that patients remain fearful in the absence of a safety signal and this increased and constant anxiety/fear could further deplete the specific neurochemicals which could lead to helplessness and depression. This requires more research.

Penny Hopwood (2000) found a difference in gender with lung patients. Women with good performance status were twice as likely to be suffering from depression as the men.

Carrol et al (1993) screened for anxiety and depression with 809 cancer patients either attending clinics or as in-patients. The circumstances of their testing were very different. The cohort was mixed, some were having treatment, others were attending for follow-up and others were in-patients. However the results are similar to the current study. Male patients, 60 years old or more, were significantly more likely to have high depression scores. Similarly patients who were in-patients, which could suggest they were the palliative patients and the more seriously ill patients had higher depression scores that the out-patients.

Bebbington in an article 'Psychosocial causes of depression (1999) stated that:

"It is possible that the sex ratio of depression incidence varies according to time and place, and this variation is a reflection of women's variable social circumstances"

Thus questioning that women have higher rates of depression than men all the time. This study confirms this finding in that men throughout radiotherapy treatment had higher levels of depression than women, although significance was not reached until post treatment.

The only other variable to reach significance in this current study is age. Patients aged 65 plus being significantly more depressed than the other age groups. What is causing this increase in depression in the elderly population? Depression has been shown to increase with age in the general population (Moum et al 1991) and illness could further reduce people's confidence and self esteem.

"This dependence on other people enhances the sense of helplessness and vulnerability created by the disease process" (Simon & Pardes 1977).

McCrae R R (1982) studied coping mechanisms with respect to age. The only areas where he found a difference with the middle aged and older population was that they

"were less inclined than younger men and women to rely on the theoretically immature mechanisms of hostile reaction and escapist fantasy" (McCrae 1982).

However, he does point out that his sample were all in good general physical and mental health. The current sample are all elderly patients that have all been treated for cancer. They could be suffering from physical limitations that, in turn, could limit their environment, which could bring about feelings of helplessness and hopelessness. Rodin & Langer (1977) found that

" a sense of control may be particularly important to the well-being and even longevity of the elderly".

It is therefore important that these elderly patients are supported emotionally, socially and practically. Fifty percent of the current radiotherapy population was over 65 plus. Older men traditionally were in a position of social power. In the hospital, however, they feel sick, dependant, vulnerable, powerless and have no control over an alien situation. As a result men in particular could suffer from depression. In contrast women are more used to feeling vulnerable and dependant and thus may have developed better coping skills.

Those patients who felt tired continued to be significantly more depressed. Similarly those patients who felt worse were significantly more depressed. Aass et al found that fatigue was predictive of depression. Mock et al (1997) found that exercise in the form of a walking program throughout treatment improved not only patients' physical functioning but also their emotional functioning. Symptoms of fatigue were also reduced. This study points to patients who have some form of control in their lives which in turn enhances the quality of their lives.

Throughout the whole five years plus treatment and follow up, men are more depressed than the women. Other studies have shown that women report more depressive symptoms at follow up (De Leeuw 2000) and this study contradicts these previous findings. However the current study looked specifically at patients undergoing radiotherapy treatment and the side effects of treatment could be interfering with the depression rates. This does not explain the unexpected finding that men from the start of treatment are more depressed than women. It could, however, by hypothesized that male depression is far more prevalent than previously thought, especially in the Northern Hemisphere. Here it could be masked for social and cultural reasons. Oncologists, GPs and other health professionals need to understand that depression occurs more in men than women who are undergoing or who have had radiotherapy treatment. Screening needs to be targeted towards this group.

Treatment Intent

The palliative patients were the most depressed cohort, and were significantly more depressed than the radical patients through treatment and afterwards. Indeed, as a percentage, there were twice as many possible and probable cases of depression with the palliative patients than the radical. A quarter of the palliative patients had scores of 8 and over at simulation. This rose through treatment, to 42% at mid-treatment and 32% 4 weeks post.

Recent estimates of depression have put the rate of depression as between 15% to 20% (Razavi et al 1990, McDaniel et al 1995). However these estimates were not looking specifically at palliative patients undergoing radiotherapy treatment. Even in the current study there is a huge difference in the level of depression between the palliative patients and the 'completers'. The 'completers' contain 3 palliative patients but this cohort had much lower percentage of 'cases' ranging from 2% at simulation to 16% at the end of five years.

Large differences have been found in the depression rate of palliative cancer patients. These range enormously from 10 to 50%. Minagawa et al (1996) found 18% had depression. The current study shows a much higher rate than this. Kramer (1999) assessed palliative lung patients and found 50% had scores of 8 and over at some point in their illness. In particular the mean depression scores of the palliative men patients were higher than the women. However this difference was not significant. This is in complete contrast to the anxiety scores of the male and female palliative patients. Hopwood & Stephens (2000) with palliative lung patients found a third suffered from depression and a further third from borderline depression. These are higher figures than the current study and may be due to the fact that the lung

patients were not actively involved in treatment and secondly lung patients may be particularly prone to depression.

The palliative patients at mid-treatment are a small cohort. They consist of only the Long multifraction group (LMF) who received more than five radiotherapy treatments. A total of 42% of this group indicated 'caseness'. This group appears to suffer more than other patient groups from depression but the male palliative patients are the most vulnerable group with 45% having scores of eight and over. Four weeks after treatment thirty two percent of the palliative patients similarly had scores of eight and over, 16% could be considered as 'possible' cases and 16% as 'probable' cases. Jenkins et al (1998) found one third of radiotherapy patients were suffering from clinically significant depression. This study is very similar to the current findings. However the numbers of patients indicating depression does depend on the timing of the questionnaire, with mid-treatment being a very difficult time for palliative patients.

Depression over treatment shows a very different pattern from anxiety. Adaptation has not taken place: many patients are more depressed at the end of their treatment than at the beginning. The palliative patients are particularly at risk of depression. Further analysis showed that those palliative patients having more than five treatments were particularly at risk, regardless of gender. Throughout the course of treatment men were more depressed than women, and this is in sharp contrast to normal population data.

Depression develops after treatment has started. The depression component on the HADS has a lower predictive power than the anxiety component (Hopwood et al 1991). Depression could therefore be under estimated in this study.

Repeated measures analysis of variance for depression over the course of the study showed a significant effect for gender and depression.

For the survivors of the study there is a significant difference between the men and the women and also between those patients who are 65plus who are significantly more depressed. In sharp contrast Aass et al (1997) found that neither age nor gender had any effect on depression in patients receiving radiotherapy treatment.

At simulation those patients who were participating in complementary medicine were significantly less depressed than those who did not. Sollner et al (2001) writes

"cancer patients consider complementary and alternative therapies supplementary to standard medical methods and one way of avoiding passivity and of coping with feelings of hopelessness" (Solner et al 2001).

Cognitive behavioural therapy looks at the psychological problem and attempts to identify maladaptive thoughts, behaviour and irrational beliefs by confronting them with reason. Subjects are then taught coping skills to help with them with restructuring. These techniques can help control pain and depression by breaking the circle of hopelessness and depression. Nursing interventions in the form of meaning and purpose are advocated by Lewis (1989). Weekly support group meetings is recommended by Spiegel et al (1981) for patients with metastatic breast cancer. These groups discussed issues such as terminal illness and relationships with the family and friends. Emotional support, religious faith/beliefs, information, positive attitude, distraction are all coping strategies that patients have found helpful, Wainstock, (1991). Of these emotional support was most helpful and positively correlated with adjustment, (Zenmore & Shepel, 1989) and psychotropic medications.

Psychiatric interventions that induce effective coping and reduce distress do appear to have a beneficial effect on the survival time of patients (Fawzy et al 1993).

Vulnerability factors for depression are:

a previous history of psychiatric illness. Robinson et al (1985) showed that patients who had suffered from anxiety or depression previously had significantly higher scores.

lack of a confiding relationship

lack of emotional support

inability to sleep

family history of depression

suicidal thoughts or thoughts of death.

The incidence of psychiatric illness in terminally ill patients is high. Levels of 25% of patients die with untreated depression and anxiety (Foley, 2000). Both can be treated with a consequent improvement in patients' quality of life. It is patients who need treatment not the just the disease.

Distress

Many patients arriving for radiotherapy treatment are psychologically distressed. Distress is measured by combining the anxiety and depression scores to give a unitary score. Using 13 as a cut-off to indicate psychological distress and eighteen to indicate major depressive disorders, the picture at simulation showed high levels of emotional dysfunctioning with 53% of patients scoring levels of thirteen and over including 16% scoring 18 and over. Aass et al (1997) used 19 as their cut-off point for major depressive disorder and found a rate of 13%. The current study similarly found a 13% rate of distress using 19 as a cut-off point. Ibbotson et al (1994) used 15 as the cut-off point and had a rate of forty percent. With a similar cut-off point the current study had a rate of 29%, a lower rate.

Derogatis et al (1983) cited 32% as suffering from psychological distress. Derogatis used a psychiatric interview, which is a stronger assessment tool than a self-assessment questionnaire. Derogatis however tested patients in an Out Patient Clinic, not prior to planning for radiotherapy treatment.

The HADS has been well validated (Johnston 2000). However it is a screening tool not a diagnosis.

From 6 months onward the overall levels of distress remained fairly consistent from 27% at 6 months to 25% at year 4. At year 5 there was an inconsistent drop which may have been due to the termination of the study, plus a realisation that they had survived five years.

Using paired T test, Irwin et al (1986) found that levels of distress between start of treatment and the end of treatment was significantly lower. The present study showed that anxiety was lowered significantly from the time of the first treatment to four weeks post. However depression increased significantly.

Irwin's times for testing were not so specific as the present study. They tested within the first week of treatment, in contrast to the present study which tested patients both before simulation and before the first treatment. Irwin et al saw all patients before the pre-treatment simulation and at this point they signed the consent form. They were not tested at this particular point. Patients in the Irwin study were then retested six weeks after the first testing, which should be approximately within one week of the end of treatment. However this depends on the number of fractions that were given to the patient. In the current study the greater specificity in the testing times is likely to have resulted in more accuracy in the results. Questionnaires were given to patients to fill in by the radiographers as they waited for their last treatment and were then collected on site.

Irwin et al's last testing was at the patients' two month post treatment check up. The current study tested patients at four week post treatment. This was the first postal questionnaire for the present study.

Treatment Intent

One third of palliative patients at simulation had distress levels between thirteen and eighteen, and a further 20% scored eighteen and over. In contrast 18% of the radical patients could be considered a possible case and 13% a probable case. Those palliative patients having more than five treatments scored higher than any other patient group with a mean of 14.07 (sd 5.82). Minagawa et al (1996) using a structured Clinical Interview for DSM111-R(SCID) identified 53.7% palliative patients as suffering from psychiatric morbidity. This study using questionnaires identified a similar number, 53%. Simulation does seem to be a particularly distressing time for these patients.

Palliative patients were significantly more distressed than radical patients. By the time of the 1st treatment, the overall levels of distress had fallen to 49% as had the mean scores. However, the number of possible cases for palliative patients remains static at one third and probable cases at 19%. Palliative patients at the start of treatment have significantly higher mean scores than the radical patients.

By mid treatment the overall levels had fallen. However the palliative patients, all of whom have been designated into the long multifraction (LMF) group , have reached a peak of 13.78 (sd 6.31). This is a particularly difficult time for these patients with 26% registering as a possible case and 30% as probable cases. Palliative patients are significantly more distressed than the radical patients. All other patient groups show a decrease in 'cases'.

Palliative patients were still more distressed than radical patients and this was significant, although the mean for both patient groups had fallen. The LMF palliative group still had the highest mean score for distress. At this point in the study the numbers of palliative patients numbered 55, and the LMF palliative group numbered 22. It is not a big sample but it is indicative of the emotional distress that these patients are suffering.

Four weeks after treatment had finished and distress overall has risen since the end of treatment. Thirty two percent of patients have distress levels of thirteen and over. The palliative patients had high scores at simulation, 52%. This has now fallen to 45% after treatment, which is still very high. This sample now contains fifteen single fraction (SF) patients. It is the first time they have been included since the beginning of treatment. The mean of the palliative patients is 13.05 (sd 6.47), when the SF group is removed the mean is

lowered to 12.07 (sd 7.31). Therefore the inclusion of this group does have an effect on the overall mean.

The palliative patients having more than five treatments are significantly more distressed than the other groups. The distress mean scores for the palliative patients have risen and in contrast the radical patients' mean has fallen. This is emphasized by the number of probable cases for radical patients - which is 9%: for palliative patients it is 26%. Four weeks after treatment over a quarter of patients are registering at the 18 and over level indicating high emotional dysfunctioning. There are more very distressed palliative patients four weeks post treatment than at any other time point – apart from mid-treatment when the cohort of palliative patients was a small specific group of LMF palliative patients.

The number of palliative patients in the study dropped from 22 at 6 months to 8 at year one. Statistical analysis on this declining cohort was not practical. However the three palliative 'completers' did not suffer from anxiety, depression or distress apart from at simulation and first treatment when anxiety was present.

Gender

Throughout treatment, gender was not significant, however the patterns varied for men and women, with women having more distress at simulation. Levels of distress fell from 41% at simulation to 29% at the end of treatment for women. The men are the only patient group to show an increase in the mean at this point. The number of 'cases' dropped from 37% to 25% at mid treatment and an increase to 30% at the end of treatment. However the numbers of men and women are not even, 81 and 131 respectively and therefore this can be questioned. Palliative women had higher mean score than the men with 45% having scores thirteen and over. Levels of distress remained constant for women, but have risen fractionally for men.

From the end of treatment men had higher mean scores than the women. Graph 23 illustrated the difference in male and female distress levels through treatment. The graph shows a mirror image picture, with women exhibition high distress at simulation and first treatment and levels then falling. Men's distress showed a similar pattern but with levels rising from mid-treatment until 4 weeks post treatment.

At the 4 weeks post treatment 32% of women had scores of 13 and over. Gallagher et al (2002) looking at distress of breast cancer patients found 34% could be suffering from psychological morbidity. At the 6 month testing point this was significantly reduced with 26% suggesting a 'case'. In the present study 30% of the breast patients indicated

psychological distress at 4 weeks post treatment. At six months this had significantly fallen to 18%, a lower figure than Gallagher et al.

Irwin et al did find a similar pattern of psychological distress occurring within the male and female patients, the male depression mean scores rising at the end of treatment, and women being highly anxious at the time of first treatment. Irwin only used three testing points, and missed the time of simulation, which has shown to be the most distressing time. They also found 8 to 14% of men with higher depression scores than the women. Irwin et al found that both men and women with prior distress had the same levels later, therefore, they felt that radiotherapy treatment did not have a different effect on men and women. This needs to be questioned. They did not test patients prior to treatment or prior to simulation but within one week of the start of treatment.

The current study shows the importance of testing patients at simulation when they were the most distressed. This is a baseline from which Irwin et al should have assessed their patients. Neither did Irwin et al test patients in the middle of treatment. Their second point was six weeks after the first and was when patients had finished treatment. With no pre-treatment baseline how can Irwin et al refer to prior levels of distress? Their prior levels measurements were taken when their patients had already started treatment. However it is interesting to note that at the point of time that they did test patients, they did find similar differences in gender.

Looking at the larger cohort of 48 men at 6 months, men have more 'cases' of distress and this continues for the 5 years of the study, with declining number of men (at 5 years n=22). However the 56 'completers' verify this finding. With only 15 men in this cohort, the distress 'cases' are still higher than the women's for the whole 5 years post treatment. The levels range from 27% at 6 months to 47% at year 5. By analysing this cohort into non-gender related cancers, the female non-gender related patients have the highest mean scores at simulation. Breast patients have the lowest scores from mid-treatment onwards. They have high scores at simulation and first treatment. This confirms the findings of the original larger cohort that women were initially more distressed than men.

At the end of 5 years analysing the 'completers', not only are the men more distressed than the women, but distress had increased post treatment. By year 3, 33% indicated distress, year 4, 53% and year 5, a drop to 47%. These are high levels and these statistics warrant further research. This result confirms Pettingale's (1998) study in which he found men

patients more distressed than women and that men's lives were more upset by cancer than women's.

Palliative patients throughout treatment had significantly higher scores than the radical patients. At four weeks post treatment over a quarter can be classified as 'probable' case, this includes 39% of the Long Multi-Fraction (LMF) group of palliative patients. The cohort of LMF palliative patients should be routinely tested as this group are especially susceptible to high distress levels both during and post treatment.

Sites

Zabora et al (1986) found that lung cancer patients had the highest distress levels at simulation and this study confirms this finding. The 'completers' showed that the non gender related females had the highest scores at simulation. until 6 months post treatment. At this point the non gender related males, who had the lowest scores at simulation, had the highest scores until the end of the study. This study therefore showed that men who were had a non gender related cancer had the highest distress scores. Further research is needed here.

This study highlights that some patients continue to feel distressed years after treatment has finished. Men were continuously more distressed than the women from the post treatment point onwards. Lynch (1977) suggested that sociability creates coping skills that in turn develop strategies to cope with illness. As women are more sociable than men, these coping skills might be more developed. Men are less willing to admit weakness or distress, in contrast, women are prepared to speak about their distress and their illness. Therefore social activity could be playing a crucial role in illness and recovery.

Palliative patients during the course of treatment were particularly distressed. These needs should be addressed particularly as these levels appear to be continuously high.

How do patients feel and what are their needs?

Just as anxiety is a mobile factor in this study so are the information needs of these patients. During the various stages of their 'recovery' period following radiotherapy treatment, patient's needs change and this requires attention.

Six months post treatment 40% of patients who had previously been happy with the information they had received when leaving the radiotherapy department, now wanted more. At this point in the Out Patient Department leaflets on post radiotherapy should be available for patients. These should be site specific. As one patient put it

'I think if more people's reactions were asked for and collated and expressed by the medical profession cancer wouldn't appear so scary.' Knowledge about what to expect and look for eases anxiety and depression.

For the first year following radiotherapy patients seem vulnerable and need more support from health professionals. Assurance on the success of treatment and information can provide the necessary 'safety' signals that patients appear to need. This should help in lowering both anxiety and depression.

Side effects also seem to change overtime with 60% experiencing side effects at the end of treatment. This changed to 20% at year 2. At the end of the study, year 5, 28% are still experiencing troublesome side effects. Eighteen months seems a particularly vulnerable time with a rise from 28% at year one to 41% at 18 months.

Similarly fatigue continues to be an on-going problem with patients. Nearly half of the patients felt tired 5 years after treatment, with levels rising from year 3. This population largely consisted of patients aged 65 years and over whom will have less energy. However it is a major problem with all cancer patients. Fifty-two percent had never spoken about fatigue with their doctor even though they had experienced it so some degree (Stone et al 2000). This commonly occurring problem needs to be recognised by the medical profession so that patients' quality of life can be improved.

Predictions

Can anxiety, depression or psychological distress be predicted? This study confirms that firstly anxiety at simulation can predict 42% of the anxiety at the end of treatment. Nordin & Glimelius (1999) in their study showed that anxiety and depression at diagnosis could account for 35% of the variance of anxiety and depression at 6 months. The current study shows the importance of screening for anxiety at simulation. However can anxiety be predicted for five years post treatment? This study shows that 15% of the anxiety at simulation can be predicted at five years. As simulation is a particularly difficult time, especially for the women, a better predictor is anxiety at first treatment. The rate is increased from 15% to 23%. The analysis of the 'completers' further showed 42% of anxiety at first treatment could account for anxiety at the end of five years. These are high figures and show the importance of screening patients for anxiety at either simulation or preferably first treatment.

Secondly, anxiety reached its peak at simulation and was still very high at first treatment. However the pattern for depression was different in that it reached its peak at the end of treatment. Testing patients for depression at simulation accounted for 40% of the variance at the end of treatment and a further 2% could be explained by palliative treatment. As depression manifests itself later than anxiety the best predictor of depression at five years is depression at 4 weeks post treatment. Thirty-eight percent of the depression at five years post treatment can be explained by depression at 4 weeks post treatment. These results confirm the importance of re-screening patients for depression particularly when they come to the hospital for their Out Patient appointment.

Thirdly, psychological distress can similarly be predicted. Distress at first treatment seems a better predictor of distress at the end of treatment, with distress at first treatment explaining 47% of the distress at the end of treatment. Furthermore distress at the 4 weeks post treatment point can account for 42% of the distress five years later.

This study therefore emphasises the importance of screening patients at specific times so that patients' anxiety and depression can be addressed and the patients' quality of life improved. With the high predictive rates that this study has shown these issue can now be addressed at specific times during and after patients' treatment.

In this longitudinal study over five years some indicators for survival have emerged, but require more research.

Firstly, Cassileth et al (1986) hypothesized the State and Trait scores of the patients became 'fused' as death approached. This study repeats this finding. The two concepts of 'how you generally feel' and 'how you feel at this moment' become the same with the approach of death.

Secondly, Leigh et al (1987) hypothesized that increased levels of anxiety and depression may be predictive of survival. Low or high levels could indicate short or long survival. Further analysis showed the 45% of the high anxiety scorers survived five years. This study showed that high levels of State anxiety were indicative of long survival for women but not necessarily for men. High State anxiety was more indicative of a shorter survival for men. With eleven possible anxiety 'cases' for men at simulation, only one survived five years. With 26 probable 'cases' of anxiety, 17 died.

In contrast with 45 probable 'cases' of anxiety for women, 26 survived.

Thirdly, Leigh et al stated that the survivors had higher trait anxiety. This study contradicts these findings. This study found that the survivors had significantly lower trait scores than the non survivors.

Fourthly, the patients who died in the current study were significantly more depressed. Analysis of the 'completers' showed that at simulation only one woman patient was depressed.

Indicators of survival appear to have lower Trait anxiety, coupled with higher State anxiety and low depression. The palliative patients (n=4) who survived five years had high Trait anxiety (43. sd 8.83) but their State anxiety was very high, (51.66 sd 1.92) and their depression was low (3.25, sd 2.65). Their State and Trait were not 'fused', and their depression levels were low. The HADS score for anxiety was similarly high (8.50 sd 4.36).

Chapter 10

Medical implications

This study highlights the importance of screening for psychiatric distress in patients undergoing therapy. Psychological assessments need to be incorporated routinely into patients' management of their disease. Whether or not depression is a symptom of the cancer is irrelevant. Both anxiety and depression require treatment in order to improve the quality of these patients' lives. Psychological questionnaires are a cheap option, however routine questions also need to be incorporated into the patient's medical assessment to indicate if the patient is at psychological risk.

In this study the palliative cohort contained more men than women thus emphasising that men seek advice on their medical condition too late. Gender specific differences found in this study should be incorporated in education and general patient care.

How can health professionals alleviate the high anxiety found at simulation? In a recent article by Harrison et al (2001), it was found that videotapes were very effective in reducing anxiety in patients about to be treated by radiotherapy. Other suggestions include speaking to someone who has undergone therapy to alleviate the patients' fears, cognitive behavioural therapy and relaxation. In the current study patients were asked if they would have liked a prior visit to the department. Over a third replied in the affirmative. These were mostly women.

Fear can be caused from ignorance. Informed patients who know what their side effects could be and know what their treatment incorporates will be less distressed. Patients need good accurate information both prior to and after treatment. Both anxiety and depression has been quoted as being caused by a lack or loss of control (Abramson et al 1978). Patients seek to have control in what is considered an uncontrollable disease. The use of, and interest in complementary medicine is a sign of coping in cancer patients. It can be looked upon as a means of information seeking and a problem solving/active coping mechanism (Sollner et al 2000) and this should be encouraged. With the current use of the internet as a source of information, it will be interesting to see if this has an affect on the needs of the patients and if a reduction in depression follows. Further research is needed in this area.

GPs and other health professionals need to be warned that after radiotherapy treatment patients can be distressed, particularly men, palliative patients and the elderly. Previous studies have highlighted the higher levels of psychological morbidity among young cancer

patients (Jarrett et al 1991, Edlund 1989). In Harrison's and Maguires's (1993) article they confirmed that the younger patients were subject to greater distress when coping with emotional issues but older patients were subject to more limitations imposed by treatment and the disease. The older survivors of this study were subject to significantly more depression. Practical support such as shopping, transport and social support could help to alleviate the depression rate in this population. Depression can be treated successfully by psychological problem solving techniques. This involves patients using their own skills and resources in relation to present and future problems. Depression can also be treated successfully pharmacologically. However, staff need to be aware of the drug interactions that can occur. Similarly drugs should be checked if the patient is depressed as interferon and prednisone can induce depression. GPs need to be more aware of these problems with cancer patients.

In the current study, nearly half of the patients would have liked to have a telephone call during the four weeks between end of treatment and follow up. Both anxiety and depression was subject to a rise at this point. This could be an economical way of giving support to the patients.

Support needs to be tailored to the patient's requirements. The patient's in this study used a variety of support groups. What works for one person does not necessarily work for another so that patients do need to know what is available. Breast patients who had support from the Breast Care nurse and other professionals were significantly less distressed than any other group throughout treatment, apart from simulation. In 1998 the first psychiatric consultation-liaison outpatient clinic was opened in Taiwan in a radiotherapy clinic, and this has been proven to improve psychiatric evaluation and early detection so that interventions can be offered (Chie et al 2001). Patients can thus feel free to accept all treatment available to them both physically and psychologically to improve the quality of their lives and possibly survival.

The elderly are often reliant on hospital transport and thus may not be able to make use of those facilities in the hospital which offer care and support when they come for treatment. There needs to be more co-operation between the radiotherapy departments and hospital transport.

This study has shown that the fusion of State and Trait plus high depression scores could be indicative of low survival. This could be helpful in assessing appropriate hospice care, however this requires more research.

The literature review looked at assessment of psychological distress by health care workers and this was not satisfactory. Psychiatric interviews are too expensive. Self-assessment questionnaires are the most cost effective, even though they can result in false positives and negatives. This study has shown that anxiety and depression can be predicted. The author would suggest testing patients at first treatment and when they come for their first out patient appointment. The radiotherapy receptionist could give patients on arrival for their planning and or 1st treatment, anxiety and depression questionnaires to fill in whilst they wait. The patient completes it immediately. It is then placed in a specialized scanner, which scores each paper. The receptionist reads off the results and marks the scores for anxiety, depression and distress in the patients' notes. This will then give the oncologist a cue to ask more relevant questions such as family history of psychiatric illness or social support to see if the patient is at risk. The oncologist is then able to make an informed decision as to whether the patients needs further tests or assessments by a psychologist. In this way psychological testing can be routinely incorporated into patients' assessment. Those with high scores should be tested regularly and or assessed further. For patients with high scores at the end of treatment, the oncologist should be encouraged to include this data in the letter to the GP.

GPs need to enquire more into men's psychological state after they have had radiotherapy treatment. Contrary to data on the normal population, men are more depressed than women and a special note needs to be made of this so that the quality of life can be improved for these patients. Information needs to be given to both GPs and patients on what can happen after treatment and what can be done to help. If patients are told that feeling depressed is normal after radiotherapy treatment then they will not feel so stigmatised and may seek appropriate help.

Chapter 11

Problems

This is a longitudinal study in which patients were assessed at regular intervals pre, during and after treatment. This was a very daunting time-consuming task but effective. However it is inevitable that a study of this format would be subject to problems.

The main problem was the high attrition rate of the patients due to death. This is inevitable when dealing with a cancer patient population. Compliance was kept to a maximum by testing patients in the hospital during treatment, but after treatment the author was reliant on information from a postal questionnaire and inevitably not all patients answered all questionnaires. This meant that different cohorts are being analysed at each testing. The author has tried to deal with the attrition rate by analyzing the data in separate parts. Firstly through treatment, when attrition was not so much a problem, although 15 patients died in this period. Secondly, Part 2 analysed patients from six months to five years post treatment. This cohort inevitably contained patients who died and patients who did not fully participate. Thirdly, Part 3 contained only the people who completed all the questionnaires, all of the times. This reduced the number participating substantially. Statistical analysis on site became a problem with such small numbers. However t-tests revealed no significant difference between the patients participating in Part 2 of the analysis and patients participating in part 3.

The patients analysed in Part 3, were not a true representation of all radiotherapy patients. a bias was introduced with the healthy replying. Comparisons were made between the survivors and non-survivors. However, the patients were not matched and therefore this data could be questioned. This problem of attrition is a continuous one with a longitudinal study, particularly when dealing with cancer patients. However Part 1 and Part 2 contain a true representation of patients attending for radiotherapy.

The sample size should have been larger when dealing with a population with a large attrition rate. However financial constraints did not permit this. It could also be questioned in that too many variables are used, different sites, gender, age, and treatment intent and social class. However the author wanted an overall perspective. Patients are not treated in isolation of other patient groups. Health professionals treat them as individuals not as categories and guidelines for patients receiving treatment were one of the aims of this study. Would any specific group stand out as being more prone to psychological distress?

Patients received a battery of questionnaires some of which are not part of this thesis. They included the European Organisation of Research and Treatment of Cancer Quality of Life Questionnaire Core 30 (EORTC QLQ-C30), the Cancer Locus of control (CLOC), a Health Beliefs Questionnaire coupled with a questionnaire on complementary therapies. One of these questionnaires patients did not like responding to, and this affected the compliance rate. Questionnaires such as SF-36 were not included, as the patients would have been overloaded.

This was the first study to take place from the Lynda Jackson Centre that had only just opened. To a large extent staff was unaware of the aims and objects of the unit. Better liaison with the radiographers was needed prior to the study. Meetings should have been held with all staff and notices given to them informing them exactly as to what was happening.

All patients arriving for simulation were interviewed before their appointment by two researchers. This was a big undertaking in a busy department. Cooperation of the staff was further needed as the radiographers handed out forms to the patients before treatment on the first day, at mid treatment and at the end of treatment. Patients were all given identity numbers, known only to the researchers, so organization had to be high. Occasionally patients were missed when they first arrived as the researchers were trying to do too many things. More staff was needed for such a big project. However 316 were interviewed during that calendar month.

Ethical permission was split into two sections, through treatment and four weeks post marked the delineation. Patients had to be written to and their permission re-sought for the time schedule six months to five years. This inevitably caused the attrition rate to fall further.

Patients were tested at six monthly and yearly intervals after treatment finished. Most of the treatments finished at the end of November beginning of December. This meant that the postal questionnaires coincided with the Christmas post. This did not help the attrition rate.

As patients got increasingly ill some had difficulty filling in the forms. The research questionnaire especially has gaps. If it could be ascertained that the gaps were just inadvertently missed and that the patient was otherwise healthy the form was returned with accompanying letter, however if the patient was obviously not well the forms were not used. Many patients wrote personally to the researcher voicing queries or worries and a response was given, although this increased the workload.

With regard to the depression component of this study, information about prior personal and family history of depression should have been sought, as these are known risk factors.

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Only questions with relation to anti-depression drugs were obtained and this is not sufficient. The HADS is not so robust on the depression scale. Another questionnaire such as the Hamilton rating scale for depression (HRSD) would have made the depression analysis more convincing especially as the HSRD includes feelings of hopelessness, helplessness and worthlessness as well as cognitive/behavioural disturbance (Hedlund & Vieweg 1973). However, this questionnaire, too, has received criticism and patients already had six questionnaires to fill in, of which only three are being discussed in this thesis. It was felt that patients could not be burdened with more questionnaires. Indeed more questionnaires would have possibly increased the attrition rate.

The question on fatigue should have been included with the first set of research questionnaires. It was only included from 18 months post treatment

Chapter 12

Conclusion

This study provides a number of important findings. Firstly it shows that the prevalence of anxiety was greater than that of depression, especially at the start of treatment, thus confirming other studies (Carroll et al 1993, Marasate, 1991). Over time most patients adapted psychologically to their disease and its treatments. However a significant number of patients continued to feel distressed after their treatment had finished. These patients' psychological needs should be treated. GPs, district nurses and other health professionals need to be more aware of these patients' psychological requirements. This study would therefore contradict the findings of the meta-analysis of van't Spijker et al (1997) who stated that psychiatric problems in cancer patients did not differ from the normal population. Patients attending radiotherapy departments are extremely anxious. Some of the anxiety has been shown to be transient, but many patients especially palliative patients have high levels of anxiety throughout treatment and afterwards with a hard core remaining distressed for five years.

Secondly anxiety and depression manifest themselves at different times, anxiety at simulation, depression after treatment has finished. Health professionals, especially GPs need to be more aware of this so that patients can be tested and/or asked appropriate questions at these sensitive times and help accordingly given. Sellick & Crooks in 1999 wrote

"cancer care organisations must develop guidelines of specific emotional maladies and set standards of practise for the delivery of service. To do less would be to fail in our often stated intent to be truly comprehensive and to provide the necessary treatment and care for people living with cancer........The need has been established, the importance of addressing the need has been clearly stated, the steps required in practice guideline development are relatively simple, and the evidence is available to substantiate the various methodologies that may be used. What remains is to do it".

Patients are still waiting.

Thirdly, gender is an important factor. Previous studies have been mixed. Cella 1987, Nordin et al (1996), Brandberg et al (1995) found women more distressed than the men. Pettingale et al (1998), found men more distressed than women. Plumb & Holland (1977), and Holland et al (1986), cited men as suffering more from depression than women. This longitudinal study has shown that both anxiety and depression occur at different times for men and women. This could account for the differences found in these studies. Women were

initially more anxious but men were more anxious after treatment had finished. Men were more depressed than the women throughout the study even with the 'completers' cohort. This is in contrast to the general population where women are considered to be at more risk of depression. Leibenluft (1999), and the National Cormorbidity Survey (1994) found depression two to three times more common in women than men. Therefore the findings of the current study are unusual. Lansky et al (1985) found that depression in their female cancer patient population was within the range of the general population. The current study's findings are similar. Lansky et al were not testing patients having radiotherapy treatment and after, although some patients had received chemotherapy and radiotherapy.

Lamsky et al only tested women, some of which had recently had their diagnosis, whilst others had been diagnosed years before. They found a depression rate of 5.3%. According to their study predictors of depression for women were physical disability and previous depressive episodes. Depression in this study over five years varied for women between 5% and 20%. The 5% was unusual and was at five years, probably an artificial result due to the completion of the study. Mostly the range was between 12% and 20%.

More men die of cancer worldwide than women (Silverberg et al 1987, American Cancer Society 2000[3]). In this study there are more men non survivors. There are less men than women in the current study, but more palliative men than palliative women. This could appear to indicate that men arrive for treatment too late. Women are regularly required to attend for pap smears, breast mammograms. Men do not have these regular testing procedures, neither do they seek medical care as routinely as women. They are socialised to think that illness is a sign of weakness, thus ignoring cancer symptoms and delaying medical help. These important gender-specific findings should be applied in general patient care and education awareness campaigns.

Fourthly, palliative patients were more anxious and depressed than radical patients throughout the study. Those palliative patients having more than five treatments were especially at risk from psychological problems. Many of the palliative patients were being treated for a recurrence. Wainstock et al (1991) found that 78% of patients with a recurrence found it more upsetting than initial diagnosis. It was a greater death threat and also involved difficult treatment decisions and resulted in more side effects. Patients were also suffering more during the advanced stages of this disease and were thus more tired and more fearful of

[3] Cancer Facts and Figures. (2000) Atlant GA. American Cancer Society.

pain (Wainstock 1991). Breibart (1995) cites depression as being in 20-25% of this cancer patient population. This study provides similar findings. However Breibart also found the incidence of depression increases with advanced disease, illness, pain and disability. The current study confirms this finding. Palliative patients had significantly higher levels of depression throughout treatment and after. It is necessary for staff to identify early signs of depression and various fears as these not only have an effect on the life of the patient but also on the patient's family. Kramer (1999) wrote:

"I suggest that community nurses and GPs be encouraged to use HADS to screen for depression in patients receiving palliative care."

This is endorsed by Sellick & Crooks (1999) who stated that good practise guidelines should include screening of

"every new cancer patient for symptoms of depression using a valid instrument such as the HADS or Beck Depression Inventory".

This study would re-endorse this statement. Questionnaires could be given out when the patient is registered by the receptionist. Whilst waiting in the waiting room the patient scores the questionnaire and then returns it to the receptionist. She places it in a specialised scanner which read off the results. The receptionist then adds the results to the patient's notes. This acts as a cue for the oncologist/GP to ask appropriate questions to see if a psychiatric referral is necessary. The GP can accordingly inform the district nurse if necessary and also arrange for other appropriate help.

Fifthly this study stresses the importance of specificity in timings of the questionnaires in order to get accurate measurements over time. By testing patients immediately before simulation, before their treatments and four weeks after treatment, accurate recordings of their emotional functioning were made at specific time points. This was then continued for five years after treatment. Although these latter testing were all by postal questionnaires, they were all given to patients within a specific time frame. Studies with cancer patients had previously shown large variations in anxiety and depression levels with patients. This study shows the importance of testing all patients at specific time points and not at calendrical times

Sixthly, no psychiatric interviews were undertaken in this study. The evaluation of patients was done strictly by self-administered questionnaires. Both questionnaires have been well validated, although the depression component of the HADS is not so reliable and it has a tendency to under diagnose. This study does show that accuracy in the wording of the questionnaires is important. If patients are being tested continuously over treatment, a

questionnaire such as the STAI State would be more appropriate to assess patients immediate response to anxiety. Here the wording is 'at this moment'. This is in contrast to the HADS which asks patients 'in the past week'. Patients' answers appear to reflect these differences, with a higher percentage of patients being more anxious at simulation and during treatment with the STAI State. This difference overtime evened out, so that post treatment testings gave similar readings with both questionnaires. The HADS therefore is more suitable for post treatment testing or in an Out Patient Department when the patient is not subjected to an anxiety provoking situation which needs to me measured. The STAI State is better used for patients confronted with an anxiety provoking situation.

The author cannot assume that these patients, especially those scoring 11 and over on the HADS would meet the criteria for a mental disorder. The HADS is only a guide as it gives estimates rather than accurate measures. It does however indicate that further evaluation is needed.

Seventhly, patients post treatment required more information, especially if they had side effects from treatment. Gynaecological cancers, bladder, prostate head and neck and lung patients suffered especially from side effects. Staff and GPs need to be more aware of these patients' needs. Five years post treatment a quarter of patients still had side effects from treatment. Those patients who felt worse were significantly more distressed. Nearly half of the patients felt tired five years after treatment. More research needs to be focused on fatigue and side effects to see what help would be appropriate. Asking patients how they feel could also be incorporated into patient's interviews.

Finally this study highlights that men's psychosocial adjustment to cancer is poor. After treatment has finished men are consistently more psychologically distressed than the women. This could be due to a number of factors including men's personal social support mechanism and men's different coping skills. More research is required in this specific area.

This study was hampered by a high attrition rate. It was felt important that all the patients were analysed throughout treatment whether they completed or not as this gave a picture of the psychological distress that occurs in the radiotherapy department during treatment. If the 'completers' only were used in the analyses, it would have failed to show the patients at most risk of psychological distress, namely the palliative patients. The third analyses of the 'completers' showed how anxiety and depression are still present in approximately 20% of this population years after treatment. This study also showed the high

predictive value of anxiety and depression at simulation and end of treatment respectively, thus emphasizing the importance of screening all patients having radiotherapy treatment.

Patient cancer care in the 2000s still does not routinely incorporate psychological factors in the care of the patient. The Campaign for Effective and Rational Treatment (CERT) has calculated that more than 70,000 cancer patients are suffering unnecessarily from the debilitating results of cancer and its treatments. Cancer care professionals have the means to access the tools required to treat psychological distress, but they often fail to understand the importance of this care. Survival has increased but not necessarily patients' quality of life. Patients' needs should be assessed. Accordingly there is a need for routine screening of patients. Those patients identified can be offered additional services to prevent further distress following treatment. Today there is no reason why patients should be left feeling truly depressed. However health carers do not routinely test the cancer patient, neither do they ask simple questions. A good interview technique before treatment can disclose problems. Questions such as:

'what is your sleeping pattern like?' 'Do you have emotional support?' 'Have you had any psychological problems in the past?' 'Does your family have a history of depression?' 'Do you have thoughts of death/suicide?'

Jenkins et al in their article written in 1998 wrote:

"All patients with clinically significant depression endorsed at least one of the following items: thought of death or suicide, feeling restless, or diminished mood response to good events. Endorsement of any one of these symptoms should prompt a more through evaluation of depression" (Jenkins et al 1998)

Is the psychological state of patients ignored because it is too expensive and too complicated to assess patients? Or is it because of the lack of appreciation of the potential benefits? Work by Maguire & Pitceathly (2002) highlights this problem in their article 'Key communication Skills and How to Acquire Them'. They emphasize that communication skills were not previously taught. Emotional and social problems were blocked by the physician in their patient dialogue to ease the physicians's discomfort.. Maguire & Pitceathly list the necessary skills for good communications:

"Eliciting patients' problems and concerns

Giving information

Discussing treatment options

Being supportive"

They back this up with effective training methods. With these methods being implemented at under-graduate level it bodes well for the future.

This current study shows that a significant number of patients, both prior to radiotherapy treatment, during and after are anxious and depressed. If it is not economic to test all patients, this study has indicated pointers to show which patients are in need.

This study has shown that a significant number of patients after five years still have side effect from radiotherapy. Half of the patients were feeling tired. These patients need to be identified and offered help which can improve substantially the quality of their lives. Exercise has proven to be effective in treating fatigue. However, support needs to be customized for the individual and multidisciplinary – it can vary from: individual therapy, group therapy, information, support groups and cognitive behaviour therapy. Helbom et al (1998) suggest that those patients who do not truly need psychological treatment drop out after a couple of sessions. If drugs are used to control depression, careful consideration needs to be used for the appropriate drug as drug-interactions can make the patients psychological state worse. Depressive drugs can cause difficulties with the older population especially if they are suffering from cardio-vascular problems. Finally with regard to elderly patients, social support in the form of financial, equipment and transport is needed and will contribute to lowering patients' anxiety and depression.

The NHS has limited resources to fund psychological testing. More patients are now surviving their cancer and quality of life issues are becoming more important for radical as well as palliative patients. The results of this study further appear to suggest that depression and anxiety can be predicted through treatment from tests at simulation or first treatment. Risk factors include previous psychological treatment, a lack of good social and emotional support network, depression at simulation/first treatment, male gender and high Trait anxiety.

With respect to the survivors in this study, men and those 65 plus age groups were significantly more depressed. This study also confirms Magruder-Habid et al (1989) finding that depression is significantly under-diagnosed in a medical setting.

The discovery of cancer can cause a deep all-pervading sense of disorientation. This disorientation often persists throughout the illness whether the patient recovers or dies[4]. Overnight the patient's status is changed from a 'healthy' person to a cancer 'patient' with all the feeling and emotions that are evoked with that word. This study has shown that some patients do adapt more easily than others to their cancer and its treatment. It also highlights how anxiety and depression exist in some patients being treated and how these emotions can

[4] The Multidisiplinary Care of Cancer Patients (1992) Council of Europe, Strausbourg, p7.

persist for years. Funding and organisation should be made available so that quality of care can be increased for these distressed patients.

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APPENDIX 1

HOSPITAL ANXIETY AND DEPRESSION SCALE

HAD SCALE

| ID No. | Initials | D.O.B. | Date | Schedule | Machine |

Read each item and place a tick in the box opposite the reply which comes closest to how you have been feeling in the past week.

Don't take too long over your replies: your immediate reaction to each item will probably be more accurate than a long thought-out response

Tick only one box in each section

I feel tense or 'wound up':

Most of the time .... ☐

A lot of the time .... ☐

Time to time, occasionally .... ☐

Not at all .... ☐

I still enjoy the things I used to enjoy:

Definitely as much .... ☐

Not quite so much .... ☐

Only a little .... ☐

Hardly at all .... ☐

I get a sort of frightened feeling as if something awful is about to happen:

Very definitely and quite badly .... ☐

Yes, but not too badly .... ☐

A little, but it doesn't worry me. .... ☐

Not at all .... ☐

I can laugh and see the funny side of things:

As much as I always could .... ☐

Not quite so much now .... ☐

Definitely not so much now .... ☐

Not at all .... ☐

Worrying thoughts go through my mind:

A great deal of the time .... ☐

A lot of the time .... ☐

From time to time but not too often .... ☐

Only occasionally .... ☐

I feel cheerful:

Not at all .... ☐

Not often .... ☐

Sometimes .... ☐

Most of the time .... ☐

I can sit at ease and feel relaxed:

Definitely .... ☐

Usually .... ☐

Not often .... ☐

Not at all .... ☐

I feel as if I am slowed down:

Nearly all the time .... ☐

Very often .... ☐

Sometimes .... ☐

Not at all .... ☐

I get a sort of frightened feeling like 'butterflies' in the stomach:

Not at all .... ☐

Occasionally .... ☐

Quite often .... ☐

Very often .... ☐

I have lost interest in my appearance:

Definitely .... ☐

I don't take so much care as I should .... ☐

I may not take quite as much care .... ☐

I take just as much care as ever .... ☐

I feel restless as if I have to be on the move:

Very much indeed .... ☐

Quite a lot .... ☐

Not very much .... ☐

Not at all .... ☐

I look forward with enjoyment to things:

As much as ever I did .... ☐

Rather less than I used to .... ☐

Definitely less than I used to .... ☐

Hardly at all .... ☐

I get sudden feelings of panic:

Very often indeed .... ☐

Quite often .... ☐

Not very often .... ☐

Not at all .... ☐

I can enjoy a good book or radio or TV programme:

Often .... ☐

Sometimes .... ☐

Not often .... ☐

Very seldom .... ☐

APPENDIX 2

SPIELBERGER'S STATE ANXIETY INVENTORY (STAI)
Long and short version

STAI SHORT

A Self Evaluation Questionnaire

A number of statements which people have used to describe themselves are given below. Read each statement and then circle the most appropriate number to the right of the statement to indicate how you feel **right now at this moment.**
There are no right or wrong answers. Do not spend too much time on any one statement, but give the answer which seems to describe your present feelings best.

	Not at all	Somewhat	Moderately	Very much
1. I feel calm	1	2	3	4
2. I am tense	1	2	3	4
3. I feel upset	1	2	3	4
4. I am relaxed	1	2	3	4
5. I feel content	1	2	3	4
6. I am worried	1	2	3	4

Please make sure that you have answered **all** the questions

SELF EVALUATION QUESTIONNAIRE

DIRECTIONS: A number of statements which people have used to describe themselves are given below. Read each statement and circle the right statement to indicate how you feel right now, that is, at this moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feelings best.

Please make sure that you have answered ALL the questions.

		Not At All	Somewhat	Moderately	Very Much So
1.	I feel calm	1	2	3	4
2.	I feel secure	1	2	3	4
3.	I am tense	1	2	3	4
4.	I feel strained	1	2	3	4
5.	I feel at ease	1	2	3	4
6.	I feel upset	1	2	3	4
7.	I am presently worrying over possible misfortunes	1	2	3	4
8.	I feel satisfied	1	2	3	4
9.	I feel frightened	1	2	3	4
10.	I feel comfortable	1	2	3	4
11.	I feel self-confident...	1	2	3	4
12.	I feel nervous	1	2	3	4
13.	I am jittery	1	2	3	4
14.	I feel indecisive	1	2	3	4
15.	I am relaxed	1	2	3	4
16.	I feel content	1	2	3	4
17.	I am worried	1	2	3	4
18.	I feel confused	1	2	3	4
19.	I feel steady	1	2	3	4
20.	I feel pleasant	1	2	3	4

APPENDIX 3

SPIELBERGER'S TRAIT ANXIETY INVENTORY (STAI)

SELF-EVALUATION QUESTIONNAIRE
STAI Form Y-2

Name _____ Date _____

DIRECTIONS: A number of statements which people have used to describe themselves are given below. Read each statement and then blacken in the appropriate circle to the right of the statement to indicate how you *generally* feel. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe how you generally feel.

	ALMOST NEVER	SOMETIMES	OFTEN	ALMOST ALWAYS
21. I feel pleasant	①	②	③	④
22. I feel nervous and restless	①	②	③	④
23. I feel satisfied with myself	①	②	③	④
24. I wish I could be as happy as others seem to be	①	②	③	④
25. I feel like a failure	①	②	③	④
26. I feel rested	①	②	③	④
27. I am "calm, cool, and collected"	①	②	③	④
28. I feel that difficulties are piling up so that I cannot overcome them	①	②	③	④
29. I worry too much over something that really doesn't matter	①	②	③	④
30. I am happy	①	②	③	④
31. I have disturbing thoughts	①	②	③	④
32. I lack self-confidence	①	②	③	④
33. I feel secure	①	②	③	④
34. I make decisions easily	①	②	③	④
35. I feel inadequate	①	②	③	④
36. I am content	①	②	③	④
37. Some unimportant thought runs through my mind and bothers me	①	②	③	④
38. I take disappointments so keenly that I can't put them out of my mind	①	②	③	④
39. I am a steady person	①	②	③	④
40. I get in a state of tension or turmoil as I think over my recent concerns and interests	①	②	③	④

APPENDIX 4

CONSENT LETTER – ETHICAL PERMISSION 1

Dear Patient

Quality of Care Study

We are trying to improve the quality of care for patients coming to the Radiotherapy Department and would be very grateful if you could participate in this study.

In particular we are looking at problems which patients may experience during radiotherapy, including anxiety, and the different ways in which they cope with them.

To do this we have to ask a variety of questions which have been helpful in previous studies - many of these may seem irritating or irrelevant to you, and we apologise in advance! With the benefit of your experience, we hope to be able to help other cancer patients.

The study involves a number of questionnaires, which we will be asking you to complete at various stages during and after your treatment.

- before your treatment begins you will be given 5 short questionnaires.

- if you are returning for a course of treatment, you will be given 3-4 short questionnaires, at your first main treatment session, at the mid-point of your course of treatment and again at the last session

- one month after the end of your treatment we will either give or post to you further short questionnaires, to see how you are getting on at home.

We also need to ask your permission to check details of your current treatment by looking at your notes.

All responses are in strict confidence, individual information will not be disclosed and completed questionnaires will not be retained in your case notes.

If you do not wish to take part in this study, of course your treatment will not be affected in any way.

Thank you.

Yours faithfully

Chris MacKenzie (signature)

Chris MacKenzie

Ilse Feigel (signature)

Ilse Feigel

....

I agree to take part in the studies looking at different ways in which radiotherapy patients cope with their treatment.

Date.....................

Patient name.. Patient signature..

Researcher name....................................... Researcher signature.......................................

APPENDIX 5

LITERATURE ON
LYNDA JACKSON MACMILLAN CENTRE

APPENDIX 6

LIST 1 – DEMOGRAPHIC DETAILS

List 1

Sex   Male   Female

Marital Status   Single   Married

                             Divorced   Co-habiting

Age

Social Class   I   II   IIIm

                             IIIn   IV   V

Occupation   Employed   Retired

                             Unemployed   Housewife

                             Other_____

Type & Site of Tumour

_____

Treatment   Palliative   Radical

                             In Patient   Out Patient

Any Special Immobilisation Devices Used

_____

Is the Treatment   Simple   Complex

Number of Treatments _____

Machine Used

_____

Does the Patient use Hospital Transport   Yes   No

APPENDIX 7

RESEARCH QUESTIONNAIRE
Given to patients
At end of treatment and 4 weeks post treatment

Research Questionnaire 1 + 2 + ANALYSIS

*For each question, please circle either YES or NO
and, where appropriate, add comments*

All information received in response to this questionnaire will be treated in strict confidence

Do you feel you were given enough information before your radiotherapy treatment?

.... YES

.... NO

Do you feel you have been given too much information?

.... YES

.... NO

Would you have felt more confident, if you had made a visit to the Radiotherapy department, before treatment to meet the staff who would be looking after you and see where you would be treated?

.... YES

.... NO

Did you feel you needed more support, while undergoing radiotherapy?

.... YES

.... NO

Did you talk with the counsellor over the treatment period?

.... YES

.... NO

Did you ever feel frightened during your radiotherapy treatment

.... YES

.... NO

If YES, would you have liked to talk to someone about this?

.... YES

.... NO

Did you experience any anxiety or fears about your illness at the weekends?

.... YES

.... NO

Did you experience any anxiety or fears after your treatment ended?

.... YES

.... NO

Did the machine you were being treated on ever breakdown?

.... YES

.... NO

Were you accompanied when you attended the radiotherapy department for treatment?

.... YES

.... NO

Do you now feel ....Better?

.... No Change?

.... Worse?

Do you have any dependants?

.... YES

.... NO

Are you taking any medicines?

.... YES

.... NO

If YES what.......................................

....

....

Are you still suffering from any symptoms as a result of your radiotherapy?

.... YES

.... NO

Do you have at least one relative or friend in whom you can confide?

.... YES

.... NO

Do you have any financial worries............. Yes............. No

Did you go to the Lynda Jackson Centre?...... Yes............. No

If yes what facilities did you use?

I used counselling.................................... Yes............ No

I used relaxation..................................... Yes............ No

I used yoga.. Yes............ No

I looked at books................................... Yes............ No

I looked at the tapes............................... Yes............ No

I used group therapy............................... Yes............ No

Was there a delay in your diagnosis?............. Yes............ No

Have any of your family had cancer?............ Yes............ No

Is there anyway which your radiotherapy
treatment could have been made less stressful?.. Yes............ No

If yes, how?...

Other than your current illness have you suffered
a recent stressful event eg bereavment, divorce? Yes............. No

APPENDIX 8

LETTER
Sent to patients at
4 weeks post treatment

**Mount Vernon and
Watford Hospitals
NHS Trust**

Mount Vernon Hospital
Rickmansworth Road
Northwood
Middlesex HA6 2RN
Telephone 0923 826111

direct line 0923 844177
fax 0923 844172

Dear

You may remember when we first talked to you about our study that we mentioned that we would be sending you a final set of questionnaires one month after your radiotherapy treatment finished. Please find them enclosed.

Please would you kindly make sure that ALL QUESTIONS on all the forms are answered. A stamp addressed envelope us enclosed and we should be grateful if you would return the completed questionnaires as soon as possible.

Thank you for your help and patience

Yours sincerely

Chris Mackenzie

Ilse Feigel

APPENDIX 9

LETTER
**Sent to patients for new ethical permission
+
leaflet on Lynda Jackson Macmillan Centre**

MOUNT VERNON HOSPITAL
Radiotherapy Department

Dear

QUALITY OF PATIENT CARE

We would like to thank you very much for participating in our study. It has been extremely helpful to get direct feedback from you. Your replies are enabling us to improve our quality of care for patients attending our radiotherapy department. We are particularly looking at problems which patients may experience during their cancer treatment, including anxiety, and the different ways in which patients cope.

The response rate to the questionnaires has been so good that, with your permission, we would like to send you a further short set of questionnaires every six months for the next two years. Thereafter we would like to send them to you annually for another three years bringing it to a total of five years altogether. The first one would be in May 1994 and would comprise five short one page questionnaires. It would not be as long and detailed as the last set which you so very kindly answered.

We also need to ask your permission to check details of your current treatment by looking at your notes.

All responses are in strict confidence. Individual information will not be disclosed and completed questionnaires will not be retained in your case notes.

If you do not wish to take part in this study, of course your treatment will not be affected in any way.

Should you _not_ wish to participate further would you please return this letter to us in the stamp-addressed envelope provided.

Thank you very much for your help,

Christine Mackenzie   Ilse Feigel

....

I no longer wish to participate in the study

Patient Name ....

Date...

Lynda Jackson - Macmillan Centre
for Cancer Support and Information
Mount Vernon Hospital

PACK 6 months treatment (6)

Example of Questionnaire

Dear *6 (6 months)*

QUALITY OF PATIENT CARE

Thank you so much for agreeing to further participate in our study. Enclosed are the questionnaires and we would be grateful if you would complete them and return them in the stamp-addressed envelope provided.

Thank you very much for your help.

Yours sincerely

Christine Mackenzie   Ilse Feigel

APPENDIX 10

RESEARCH QUESTIONNAIRE 3
Sent to patients at
6 Months Post Treatment

RESEARCH QUESTIONNAIRE 3

For each question, please circle either YES or NO or other answer where appropriate, and add comments

All information received in response to this questionnaire will be treated strict confidence

Do you still have any side-effects as a result of your radiotherapy?................YES
....NO

After your treatment, do you now feel
....better?
....no change?
....worse?

What did you feel about the length of time between finishing your treatment and seeing the consultant in the Out Patients Clinic?
1..........................Was it too long to wait?
2.. OK
3.. Too short

Would it have been helpful if someone had telephoned you during this time to check how you were getting on?
....YES
....NO

Did you feel the need to contact your GP for advice concerning radiotherapy treatment? ....YES
....NO

If yes, was your GP able to answer your queries...YES
....NO
Comment..

Did you feel you were given adequate information when you left the radiotherapy department?
....YES
....NO

How long did it take you to travel **T O** the hospital from home ....

Have you had any further treatments?...YES
....NO
If Yes what?
Surgery...YES/NO
Radiotherapy................................YES/NO
Chemotherapy..............................YES/NO
Hormonal/Tamoxifen.....................YES/NO
Complementary.............................YES/NO
Additional Medicine/s....................YES/NO
What?..
....

Did you feel a need to get more information on your illness?
....YES
....NO

If yes where did you get your information from?
....Doctor/GP?
.................................Bacup/Cancerlink
...................................Family/Friends
....Other

Have you visited or telephoned the Lynda Jackson Cancer Support Centre since you received our last questionnaires?......................................YES
....NO

If yes, was the contact at the Lynda Jackson Centre helpful?
1.. Very
2.. Adequate
3.. Not at all helpful

Other than your cancer which has been treated do you have any other illness?...YES
....NO
If yes,what?..

APPENDIX 11

LETTER
Sent to patients at
1 Year Post Treatment

1 yr. post treatment.

Mount Vernon and
Watford Hospitals
NHS Trust

(7)

Mount Vernon Hospital
Rickmansworth Road
Northwood
Middlesex HA6 2RN
Telephone 0923 826111

direct line   0923 844177
fax   0923 844172

Dear

Re: Quality of Care Study

Thank you very much for returning our last set of questionnaires in May. We were very
grateful. The information we are collecting from patients is being used by the hospital to
assess their quality of care. As a result of some of the information we have received some
changes have already been made.

We enclose herewith the next set of questionnaires for you to fill in.

Thank you very much for your help,

With best wishes,

Chris Mackenzie and Ilse Feigel

Director: Dr E Jane Maher   Manager: Judy Young

APPENDIX 12

RESEARCH QUESTIONNAIRE 4
Sent to patients at
1 Year Post Treatment

ID No	Initials	D.O.B	Date	Schedule

RESEARCH QUESTIONNAIRE 4

For each question, please circle either YES or NO or other answer
Where appropriate, and add comments

All Information received in response to this questionnaire will be treated in
strict confidence

Do you have any side-effects from your radiotherapy treatment in Autumn 1993? ---- YES
--NO

If YES, have they occurred since the last questionnaire-------------------------------- YES
--NO

Compared with one year ago, do you now feel
--better?
--no change
--worse

Compared with 6 months ago, do you now feel
--better?
--no change
--worse

Would it have been helpful if someone had contacted you from the radiotherapy department in the last 6 months?
--- YES
--NO

Have you visited your GP about your cancer in the last 6 months?
--- YES
--NO

Since being diagnosed, have there been any changes in your place of work?
--- YES
--NO

Since being diagnosed, have there been any changes in your income?
--- YES
--NO

Since May, have you had any further treatments?
--- YES
--NO

If YES, what?

Since May, have you felt a need to get further information?
--- YES
--NO

If YES, where did you get your information from?

Do you have any suggestions which could have made life easier during and after your radiotherapy treatment
--- YES
--NO

If YES, what?

In the last year, do you feel you have had enough emotional support?
--- YES
--NO

If YES, from whom?

APPENDIX 13

LETTER
Sent to patients at
18 Months Post Treatment

Lynda Jackson Macmillan Centre for Cancer Support and Information

Mount Vernon and
Watford Hospitals
NHS Trust

Mount Vernon Hospital
Rickmansworth Road
Northwood
Middlesex HA6 2RN
Telephone 0923 826111

direct line 0923 844177
fax   0923 844172

May 1995

Dear

It is now 18 months since your radiotherapy treatment has finished. We have been busy analysing your responses. Some patients felt that they did not receive enough information when they left the radiotherapy department concerning normal side effects or how to contact staff. We have now produced a series of booklets. We are enclosing a copy of the one which now will be given to patients when they leave the department. We hope you will find it helpful. We would also be grateful if you could give us some advice on it. Does it answer any queries you might have?. We have enclosed a sheet which we should be very grateful if you could fill in for us.

This study is giving us so much information as to how patients feel during and after their radiotherapy treatment. Thank you so much for taking the time and trouble to fill in all these forms for us. To improve our service to patients we must find out patients' needs so that we can supply the best possible care.

With many thanks,

Chris

Chris Mackenzie

APPENDIX 14

RESEARCH QUESTIONNAIRE 5
Sent to patients at
18 Months Post Treatment

Research Questionnaire

For each question, please circle either YES or NO, or tick boxes, where appropriate, and add comments

All information received in response to this questionnaire will be treated in strict confidence

ı the last questionnaire, a number of ıatients said they would have liked to ıave spoken with a patient who had lready had radiotherapy treatment. Vould this have helped you?

....YES

.... NO

.....................................MAYBE

Vould you feel able to talk to someone, vho was about to have radiotherapy?

....YES

.... NO

...................................MAYBE

ʳ YES, how soon after your radiotherapy reatment, do you feel you would be villing to do so?

.... 3 MONTHS

.... 6 MONTHS

.... ONE YEAR

.... 18 MONTHS

.... OTHER

Vhilst waiting for transport or treatment, vould you have liked to have watched elevision?

....YES

.... NO

...........................DON'T KNOW

)o you have any other suggestions for he waiting room?

....

....

Have you <u>had</u> to change your diet since your diagnosis of cancer?

.....................................YES

......................................NO

Do you try to eat a more healthy diet?

.....................................YES

......................................NO

Looking back over your radiotherapy treatment, what words best describe your experience? Please tick ALL that apply

Anxious ....☐

Efficient....................................☐

Powerless.................................☐

Frightening...............................☐

Caring ....☐

Reassuring...............................☐

Angry..☐

Friendly....................................☐

Distressing ....☐

Depressing...............................☐

Time-consuming.......................☐

Isolating....................................☐

Sore/painful.............................☐

Other ....☐

....

....

....

....

APPENDIX 15

**BOOKLET ON
'COPING NOW THAT YOUR RADIOTHERAPY TREATMENT
HAS FINISHED'**

APPENDIX 16

SHEET ON BOOKLET
Sent at
18 Months Post Treatment

SHEET ABOUT BOOKLET:
'Coping now that your Radiotherapy Treatment is finishing'

This is the latest leaflet in the series produced by the Lynda Jackson Macmillan Centre.
We responded to the needs of the patients who felt they wanted some written information at the end of a course of treatment.
We asked the advice and help of many people in order to produce this leaflet, and now we would value **your** opinion, as **you** are one of the first in a group of people to receive it. We hope that you will be willing to answer these questions and return them to us in the stamped addressed envelope supplied. We would like to thank you very much for cooperating with us.

Would you please let us have your comments, ticking the most suitable answer for you. Please continue your comments on the back if you wish.

1   **How easy was the leaflet to read?**   very easy .... ☐
quite easy .... ☐
not easy at all ..... ☐

2   **How clear was the explanation?**   very clear .... ☐
quite clear .... ☐
not clear at all ..... ☐

3   **Did it tell you what you needed to know?**   everything .... ☐
most things ...... ☐
nothing useful ..... ☐

4   **How helpful is this kind of information ?**   very helpful ...... ☐
quite helpful ..... ☐
not helpful at all .... ☐

If you <u>didn't</u> find it helpful or useful, would you be able to tell us why ?

Can you tell us of any questions you had which were not answered by the leaflet?

and just out of interest, have you ever visited the Lynda Jackson Macmillan Centre?   yes .... ☐
no .... ☐
didn't want to ..... ☐
never heard of it ..... ☐

if you visited the centre, would you please tell us how you heard of it

and if so, did you find it helpful   - yes ..... ☐
- no ..... ☐

APPENDIX 17

LETTER TO PATIENTS
Sent at
2 Years Post Treatment

Mount Vernon and Watford Hospitals NHS Trust

Mount Vernon Hospital
Rickmansworth Road
Northwood
Middlesex HA6 2RN
Telephone 01923 826111
direct line   01923 844177
fax   01923 844172

Dear

My sincere apologies for inflicting these forms on you at Christmas. I know it is the last thing that you will want to do. I have, however, reduced the forms to a bare minimum. I should be extremely grateful if you would return them to me in the stamp-addressed envelope.

The data which we have collected so far has been very helpful in all sorts of ways. The staff at Mount Vernon have become much more aware of patient's needs both physically and psychologically. Anyone who has returned to the Radiotherapy Department will have noticed that it is less crowded and we hope more efficient. Your comments and questionnaires have helped us to realise, from a patients point of view, what it feels like to have radiotherapy treatment. We have to thank you for making this possible.

With best wishes for a very happy Christmas and New Year,

Christine Mackenzie

APPENDIX 18

RESEARCH QUESTIONNAIRE 6
Sent at Patients
2 Years Post Treatment

ID No	Initials	DOB	Date	Schedule

Research Questionnaire

For each question, please circle either YES or No, or tick boxes, where appropriate, and add comments

All information received in response to this questionnaire will be treated in strict confidence

Do you still have any problems related to your radiotherapy?

....YES

....NO

If YES, please write down what the problem is

....

....

....

Do you feel tired?

....YES

....NO

Have you had any further problems related to your cancer, if so what?

....

....

Do you think this is due to your radiotherapy?

....YES

....NO

Compared with May 1995
Do you feel

Better ....☐

Worse ....☐

No Change..☐

Looking back over your treatment, has your experience had a positive effect?

....YES

....NO

or a negative effect?

....YES

....NO

Has your life changed since your treatment?

....YES

....NO

if YES, can you say how?

....

....

Have you contacted the Lynda Jackson Centre at all?

....YES

....NO

if YES, could you please tell us why?

....

....

Please tick the words, that best describe how you feel now:

Happy ....☐

Uncertain ....☐

Thankful...☐

Fearful ....☐

Content...☐

Depressed ....☐

Careful...☐

Anxious..☐

Listless..☐

Other...☐

Have you, since the last questionaire, received any new complementary medicine, including counselling?

....YES

....NO

If so, what...

....

APPENDIX 19

LETTER TO PATIENTS
Sent at
3 Years Post Treatment

Nov. 1996

Dear

Once more the Christmas season is here and I am inflicting my now yearly questionnaires on you again. I am sure its the last thing you want to do , however I should be very grateful if you would return them to me in the stamp-addressed envelope.

The data we have collected is continuing to guide us in your needs. We are hoping that our results will have an impact on the care of cancer patients nationally. Thank you for making this possible.

With best wishes for Christmas and the New Year,

Christine Mackenzie

APPENDIX 20

RESEARCH QUESTIONNAIRE 7
Sent at Patients
3 Years Post Treatment

ID No	Initials	DOB	Date	Schedule

Research Questionnaire

For each question, please circle either YES or No, or tick boxes, where appropriate, and add comments

All information received in response to this questionnaire will be treated in strict confidence

Do you still have any of problems related to your radiotherapy that you mentioned before?

-- YES
--NO

If YES, please write down what the problem is.

Have you had any new problems that you think are due to radiotherapy?

-- YES
--NO

If YES, please write down what the problem is

Have you had any new problems that you think are related to your cancer?

-- YES
--NO

If so, what?

Do you feel tired?

-- YES
--NO

Compared with November 1995, do you feel

Better? --- ☐
Worse?--- ☐
No Change? ------------------------------------- ☐

How are you sleeping?

No problem ------------------------------------- ☐
Trouble going to sleep ------------------------- ☐
Awake early------------------------------------- ☐
Other --- ☐

How is your appetite?

Good-- ☐
Bad --- ☐
Normal --- ☐

Have you

Lost weight? ---------------------------------- ☐
Gained weight? ------------------------------- ☐
Remained the same?-------------------------- ☐

Have you tried any new complementary medicines in the last year?

--YES
-- NO

Do you need to seek any information about your cancer now?

--YES
-- NO

If so what

_____

Do you belong to a Cancer Patient Support Group?

--YES
-- NO

Have you had any further radiotherapy treatment since September 1993?

--YES
-- NO

If YES, did you find the experience any different?

--YES
-- NO

If YES, how?

Has anything sad/happy happened to you in the last year?

--YES
-- NO

If so what

APPENDIX 21

LETTER TO PATIENTS
Sent at
4 Years Post Treatment

Mount Vernon and Watford Hospitals NHS Trust

Mount Vernon Hospital
Rickmansworth Road
Northwood
Middlesex HA6 2RN
Telephone 01923 826111

direct line 01923 844177
fax 01923 844172

15/1/98

Dear

I must first apologise for the delay in getting you're annual form-filling package from me. I have moved both my office and my home and I became a little over-whelmed! I thought you would not mind getting all my forms after Christmas, when you have more time to fill them in.

I do hope that 1997 was a good year and that you had a wonderful Christmas and New Year.

We are continuing to use your comments in a variety of ways. By studying patients feelings overtime we are beginning to understand more fully what the long-term needs for patients are and how we can cater for these needs.

From your response to an earlier questionnaire, many patients would have liked more support when their radiotherapy treatment ended. However patients do not want to return to the department after weeks of treatment. A study is now taking place which links patients up via touch-tone telephone. This enables them to discuss problems should they arise and to call on the help of professionals if needed. This would give a support group but with professionals available should any problem occur. We are currently evaluating this idea. We have therefore included a question related to this on the current research questionnaire.

As it is now over 4 years since we started this project, we have this year enclosed a different questionnaire along with the old familiar ones.

Thank you so much for taking the time to fill in these endless forms. Next year will be the last. I really have appreciated all the efforts you have made, your comments have been invaluable.

With very best wishes for 1998

Yours sincerely

Christine Mackenzie

Director: Dr E Jane Maher

Manager: Judy Young

APPENDIX 22

RESEARCH QUESTIONNAIRE 8
Sent at Patients
4 Years Post Treatment

ID No	Initials	DOB	Date	Schedule

Research Questionnaire

For each question, please circle either YES or No, or tick boxes, where appropriate, and add comments

All information received in response to this questionnaire will be treated in strict confidence

Do you still have any of the problems related to your radiotherapy that you mentioned before?

-- YES

---NO

If YES, please write down what the problem is.

Have you had any new problems in 1997 that you think are due to radiotherapy?

-- YES

---NO

If YES, please write down what the problem is

Have you had any new problems in 1997 that you think are related to your cancer?

-- YES

---NO

If so, what?

Have you had any further treatment since September 1993?

-- YES

---NO

If so, what?

Radiotherapy ------------------------------------ ☐

Chemotherapy ------------------------------------ ☐

Hormone Therapy------------------------------- ☐

Other medicines e.g. anti-depressants -- ☐
If so, what?

Do you feel tired?

-- YES

---NO

Compared with November 1996, do you feel

Better?-- ☐

Worse? --- ☐

No Change? --------------------------------------- ☐

Have you tried any complementary medicines in the last year e.g. aromatherapy, acupuncture, counselling?

-- YES

---NO

If so, what?

Since your cancer, have your relationships with friends:

remained the same? ------------------------ ☐

got more superficial?------------------------ ☐

got closer? -- ☐

Other?--- ☐

Has your circle of friends

increased?-- ☐

decreased?--- ☐

changed? --- ☐

other? --- ☐
please specify

We are currently undertaking a study to evaluate a telephone support system. Six patients will talk together for approximately an hour each week for four weeks. This is done in the privacy of their own home via a telephone link. Two professionals will also be linked in to offer support, if necessary. All these telephone calls are being paid for. Some patients will have just completed radiotherapy treatment and will be waiting for their first follow-up appointment. Others will have finished some time ago. Each group is either male or female and patients can be of any age. Would you be interested in participating in such a group?

-- YES

---NO

If YES, we would like to contact you by letter when a suitable vacancy occurs in a new group and give you a more detailed explanation.

APPENDIX 23

LETTER TO PATIENTS
Sent at
5 Years Post Treatment

Lynda Jackson Macmillan Centre for Cancer Support and Information

Mount Vernon and
Watford Hospitals
NHS Trust

Mount Vernon Hospital
Rickmansworth Road
Northwood
Middlesex HA6 2RN
Telephone 01923 826111
direct line   01923 844177
fax   01923 844172

26/1/99

Dear

Firstly I must apologise for the lateness with this questionnaire. Last year I was moving house and office, this year I have been in hospital. I had an operation to remove a tumour from my foot and this limited my mobility. However I am now getting back to normal.

You will be pleased to note that this is the last set of questionnaires from me. This study has now been in operation for five and a half years. This time I have included all the questionnaires which you had at the very beginning when you first attended the radiotherapy department.

In the Research Questionnaire I have also asked if you would like to receive a condensed write-up of the study . Please feel free to add any comments, nice or not on this questionnaire. We would like to know if you particularly disliked/liked any of the questionnaires which you have filled in and if so which ones. Our aim has been to get feedback from you so that we can help future patients during this difficult time.

We cannot thank you enough for all the form-filling which you have done for us over the past five years. I will certainly miss my annual contact with you. All that remains is to thank you most warmly and wish you good health this year and in the years to come.

With best wishes

Chris Mackenzie

APPENDIX 24

RESEARCH QUESTIONNAIRE 9
Sent at Patients
5 Years Post Treatment

			Jan 99	12
ID No	Initials	DOB	Date	Schedule

Research Questionnaire

For each question, please circle either YES or No, or tick boxes, where appropriate, and add comments

All information received in response to this questionnaire will be treated in strict confidence

Do you still have any of the problems related to your radiotherapy that you mentioned before?

--- YES

---NO

-------------------------- .CAN'T REMEMBER

If YES, please write down what the problem is.

Have you had any new problems in 1998 that you think are due to radiotherapy?

--- YES

---NO

--- NOT SURE

If YES, please write down what the problem is

Have you had any new problems in 1998 that you think are related to your cancer?

--- YES

---NO

--- DON'T KNOW

If so, what?

Looking back over the last 5 years do you feel that you could have received more help for any of the problems you have experienced?

....YES

....NO

...............................NOT APPLICABLE

If Yes, can you suggest what could have been done.

Do you feel tired?

--- YES

---NO

Compared with November 1997, do you feel

Better?-- 1

Worse?--- 1

No Change? -- 1

Have you tried any complementary medicines in the last year e.g. aromatherapy, acupuncture, reflexology?

--- YES

---NO

If so, what?

In the last year have you changed your diet, started an exercise program, joined a support group or similar which could be labelled self-help?

--- YES

--- NO

If Yes, what?. --

Looking back over the last 5 years can you tell us what *you* found were the three most difficult experiences *for you* in order, starting with the worst, then the next worse etc?

E.g. Getting the diagnosis, surgery, radiotherapy, chemotherapy, hormone therapy, waiting for test results, some other experience

1st ---

2nd ....

3rd ---

Please turn to next page

Research Questionnaire continued

For each question, please circle either YES or No, or tick boxes, where appropriate, and add comments

All information received in response to this questionnaire will be treated in strict confidence

Looking back over the past five years can you tell us the worst three times for *your family/close friends,* in order, starting with the worse, then the next worse etc?
Getting the diagnosis, surgery, radiotherapy, chemotherapy, hormone therapy, waiting for test results, or some other experience like waiting between surgery and radiotherapy, or after radiotherapy etc.

1st ....

2nd ....

3rd ....

Would you like to be sent a summary of our report of this study?

....YES

....NO

Would you be interested to meet others who took part in this study?

.... YES

....NO

Would you agree to us contacting you?

....YES

....NO

Now that the study is finishing, will you tell us how you felt about taking part – please tick any that apply.

I found it helpful to be participating in something that would help other patients.............. ☐

I found it unhelpful because it reminded me of my cancer... ☐

It helped me come to terms with my illness..... ☐

It gave me confidence to talk to my doctor... ☐

It made me realise my reactions were normal ☐

It made me worry in case I experienced any of these problems or feelings............. .... ☐

Do you have any comments you would like to make?

....
....
....
....
....
....
....
....

Thank you for all your responses and help during the course of this study.

APPENDIX 25

Index Card

1. ID NO :
2. INITIALS :
3. HOSPITAL NO :
4. DATE OF BIRTH :
5. GENDER : MALE(M) OR FEMALE(F)
6. MARITAL STATUS :
7. SOCIAL CLASS :
8. OCCUPATION :
9. RADICAL(R) OR PALLIATIVE(P)
10. PRIMARY SITE :
11. STAGE :
12. TREATMENT AREA :
13. NO. OF FRACTIONS :
14. TREATED FROM :   TO :
15. SF(1)   or   SMF(2)   or   LMF(3)
16. SECONDARIES :
17. RELAPSE STATUS :   DATE :
18. ALIVE(A) OR DEAD(D):   DATE :
19. OTHER TREATMENTS :

APPENDIX 26

**Complementary Medicine Questionnaire
Devised by Ilse Feigel**

COMPLEMENTARY THERAPIES QUESTIONNAIRE

Have you tried any complementary therapies since you last filled in a set of questionnaires for this study? ....YES/NO
IF NO, you do not need to proceed further. IF YES, what did you try? Please list therapies tried, and rate their effectiveness.

		VERY HELPFUL	QUITE HELPFUL	A LITTLE HELPFUL	NOT AT ALL HELPFUL
1.	ACUPRESSURE	1	2	3	4
2.	ACUPUNCTURE	1	2	3	4
3.	ALEXANDER TECHNIQUE	1	2	3	4
4.	AROMATHERAPY	1	2	3	4
5.	ART THERAPY	1	2	3	4
6.	AUTOGENIC THERAPY	1	2	3	4
7.	BEHAVIOURAL THERAPY	1	2	3	4
8.	BIOFEEDBACK	1	2	3	4
9.	BREATHING TECHNIQUES	1	2	3	4
10.	CHIROPRACTIC	1	2	3	4
11.	COLONIC IRRIGATION	1	2	3	4
12.	COLOUR THERAPY	1	2	3	4
13.	COUNSELLING	1	2	3	4
14.	CRANIAL OSTEOPATHY	1	2	3	4
15.	DRAMATHERAPY	1	2	3	4
16.	FLOATATION THERAPY	1	2	3	4
17.	HEALING	1	2	3	4
18.	HERBALISM	1	2	3	4
19.	HOLISTIC TREATMENTS	1	2	3	4
20.	HOMOEOPATHY	1	2	3	4
21.	IRIDOLOGY	1	2	3	4
22.	MASSAGE	1	2	3	4
23.	MEDITATION	1	2	3	4
24.	MOVEMENT/EXERCISE THERAPY	1	2	3	4
25.	MUSIC THERAPY	1	2	3	4
26.	NATUROPATHY	1	2	3	4
27.	NUTRITIONAL MEDICINE	1	2	3	4
28.	OSTEOPATHY	1	2	3	4
29.	PSYCHOTHERAPY	1	2	3	4
30.	REFLEXOLOGY	1	2	3	4
31.	REFLEXZONE THERAPY	1	2	3	4
32.	RELAXATION	1	2	3	4
33.	SHIATZU	1	2	3	4
34.	TAI-CHI-CH'UAN	1	2	3	4
35.	VISUALISATION	1	2	3	4
36.	VITAMIN THERAPY	1	2	3	4
37.	YOGA	1	2	3	4
38.	CANCER SUPPORT GROUP	1	2	3	4
39.	TELEPHONE SUPPORT/INFO	1	2	3	4

APPENDIX 27

PUBLISHED PAPER ON STUDY

APPENDIX 28
Table2: Demographic and Medical Characteristics at 1st Treatment

Table 2: Showing Demographic And Medical Characteristics at 1st Treatment

DEMOGRAPHIC	Nos	%	MEDICAL	Nos	%
Gender			**Sites**		
Female	147	57.0	Breast*	101	39.0
Male	110	43.0	Lung	39	14.0
			Prostate	25	9.0
Social Class			Skin**	24	9.0
			Other***	15	7.0
Class A	13	5.0	Gastro-int	13	5.0
Class B	39	15.0	Bladder	12	5.0
Class C1	79	30.0	Head & Neck	10	4.0
Class C2	68	26.0	Gynae	10	4.0
Class D	48	19.0	NHL	5	1.0
Unclassified	10	5.0	Unknown	3	1.0
Marital Status			**Treatment Intent**		
Married	174	68.0	Radical	166	65.0
Widowed	45	17.0	Palliative	91	35.0
Divorced	18	7.0	**Ages**		
Single	16	6.4	18-25	3	1.0
Separated	6	2.1	26-50	44	17.0
Unknown	1	1.0	50-65	83	32.0
Partner	4	1.5	65+	127	50.0

*   Includes one male breast patient
**   Includes only superficial tumours, melanoma is included in 'others'.
***   Includes glioblastoma, sarcoma, mesothelioma, Hodgkin's Disease, melanoma

APPENDIX 29
Table3: Demographic and Medical Characteristics at Mid-Treatment

Table 3: Showing Demographic And Medical Characteristics at Mid-Treatment

DEMOGRAPHIC	Nos	%	MEDICAL	Nos	%
Gender			**Sites**		
Female	115	68.0	Breast*	87	51.0
Male	53	32.0	Lung	8	5.0
			Prostate	12	5.0
Social Class			Skin**	8	5.0
			Other***	10	6.0
Class A	8	5.0	Gastro-int	10	6.0
Class B	28	16.0	Bladder	7	5.0
Class C1	54	32.0	Head & Neck	9	5.0
Class C2	35	21.0	Gynae	9	4.0
Class D	36	22.0	NHL	5	3.0
Unclassified	7	4.0	Unknown	3	3.0
Marital Status			**Treatment Intent**		
Married	112	66.0	Radical	145	86.0
Widowed	23	14.0	Palliative	23	14.0
Divorced	11	6.0	**Ages**		
Single	14	8.0	18-25	3	2.0
Separated	4	3.0	26-50	36	21.0
Unknown	0	0.0	50-65	60	350
Partner	4	3.0	65+	69	42.0

*   Includes one male breast patient
**   Includes only superficial tumours, melanoma is included in 'others'.
***   Includes glioblastoma, sarcoma, mesothelioma, Hodgkin's Disease, melanoma

APPENDIX 30
Table4: Demographic and Medical Characteristics at End of-Treatment

Table 4: Showing Demographic And Medical Characteristics at End of Treatment

DEMOGRAPHIC	Nos	%	MEDICAL	Nos	%
Gender			**Sites**		
Female	131	61.0	Breast*	89	41.0
Male	84	39.0	Lung	25	12.0
			Prostate	18	8.0
Social Class			Skin**	8	5.0
			Other***	12	6.0
Class A	10	4.0	Gastro-int	12	6.0
Class B	34	15.0	Bladder	8	4.0
Class C1	67	31.0	Head & Neck	10	5.0
Class C2	55	26.0	Gynae	10	5.0
Class D	41	20.0	NHL	5	2.0
Unclassified	8	4.0	Unknown	4	2.0
Marital Status			**Treatment Intent**		
Married	143	66.0	Radical	160	74.0
Widowed	33	15.0	Palliative	55	26.0
Divorced	15	7.0	**Ages**		
Single	14	7.0	18-25	3	1.0
Separated	6	3.0	26-50	39	18.0
Unknown	0	0.0	50-65	72	34.0
Partner	4	2.0	65+	101	47.0

APPENDIX 31
Table5: Demographic and Medical Characteristics at 4 Weeks Post Treatment

Table 5: Showing Demographic And Medical Characteristics at 4 Weeks Post Treatment

DEMOGRAPHIC	Nos	%	MEDICAL	Nos	%
Gender			**Sites**		
Female	134	61.0	Breast*	92	42.0
Male	84	39.0	Lung	26	12.0
			Prostate	21	9.0
Social Class			Skin**	20	9.0
			Other***	10	5.0
Class A	11	5.0	Gastro-int	12	6.0
Class B	32	15.0	Bladder	8	4.0
Class C1	67	32.0	Head & Neck	10	5.0
Class C2	58	28.0	Gynae	10	5.0
Class D	41	20.0	NHL	5	2.0
Unclassified	0	0.0	Unknown	5	2.0
Marital Status			**Treatment Intent**		
Married	147	68.0	Radical	155	72.0
Widowed	33	15.0	Palliative	63	28.0
Divorced	14	6.0	**Ages**		
Single	13	6.0	18-25	2	1.0
Separated	6	3.0	26-50	35	18.0
Unknown	0	0.0	50-65	72	34.0
Partner	4	2.0	65+	108	47.0

* Includes one male breast patient
** Includes only superficial tumours, melanoma is included in 'others'.
*** Includes glioblastoma, sarcoma, mesothelioma, Hodgkin's Disease, melanoma

APPENDIX 32
Analysis of Research Questionnaire at End of Treatment

Analysis of Research Questionnaire at the end of treatment

The questionnaire was divided into four different sections; information and control, social support, psychological well being, and physical well-being. A total number of two hundred and fifteen patients (80%) completed the requisite number of questionnaires.

The research questionnaire at the end of treatment consisted of twenty eight questions, (See Appendix 7)

Information and Control

Question 1, *Do you feel you were given enough information before your radiotherapy treatment?*

All patients are sent a booklet before they attend the department. Is this information adequate? Nineteen patients (9%) only felt it was not sufficient. This cohort consisted of twelve women and seven men, ten radical patients and 9 palliative and 95% from social classes C and D. These patients were being treated primarily for bladder (33%); unknown; (25%); prostate (20%); gastro-intestinal patients (20%).

Information eases anxiety, Ridgeways & Mathews, 1992)[1], further analysis was carried out to see if the patients who had enough information were less anxious. Although there was a difference in the means, the 'enough' information group having a mean of 5.21 as opposed to 5.89. This difference was not significant. Eight patients (44%) of the cohort exhibiting high anxiety came into the group of 'not enough information' and one (5%) of those patients scoring 11 and over on the HAD Scale.

Question 2, *Do you feel you have been given too much information?*

Only four (2%) patients replied in the affirmative, two palliative men patients and two women radical women patients. Those who thought they had been given too much information were significantly more depressed, p=0.017.

Question 18 – *Did you go to the Lynda Jackson Macmillan Centre?*

At the end of treatment 18% (39) patients had visited the centre, thirty women and nine men. Patients, who came on transport, spoke of their disappointment at not

being able to go to the centre as they were worried about missing their transport home and having to wait hours, or having to keep others waiting.

The other set of six questions all relate to the above question and were only answered by those who had visited the centre.

Question 19 - *I used counselling ....Yes/No*

A total of seventeen patients used the counselling facility, fourteen women and three men.

Question 20 – *I used relaxation ...Yes/No*

Seven patients said they had used relaxation, six women and one man.

Question 21 – *I used Yoga...Yes/No*

Three patients used yoga, one woman and two men.

Question 22 – *I looked at the books...Yes/No*

There is a large display of pamphlets giving information on a wide range of topics in the reception area of the Lynda Jackson Centre. There is also a large collection of books which patients can browse through to gain information on specific cancers and treatments. The number of patients who looked at the books was twenty seven, twenty-one women and six men.

Question 23 – *I looked at the tapes...Yes/No*

The Lynda Jackson Centre is equipped with a number of specialist tapes. Videos from recent TV programmes are available for patients to view together with other relevant material. The number of patients that used this facility was eight.

Question 24 – *I used group therapy...Yes/No*

Group therapy only started at the end of this study therefore numbers are low, two in all.

Social Support

Question 4 – *Did you feel you needed more support while undergoing radiotherapy?*

Only fourteen patients (6%) felt they needed more support while being treated with radiotherapy. Fifty percent of patients suffering from Non-Hodgkin's lymphoma and Unknown primary, felt in need of more support during treatment.

Dividing the patients into groups, the palliative women patients (18%) were the most in need and those women in the age group 26-50 particularly if they were single or separated.

Those patients who responded in the affirmative to this question were significantly more depressed (p=0.003) and more distressed (p=0.01) if they had dependants.

Question 5 – *Did you talk with the counsellor over the treatment period?*

A total of 26% of patients said they had talked to a counsellor. A quarter of radical patients and 27% of palliative responded in the affirmative and 23% of women and 30% of men. There was only a very weak correlation between talking with the counsellor and needing more support (r=0.103). There were no significant differences in psychological distress in those patients who had talked with the counsellor and those who had not.

Question 11 – *Were you accompanied when you attended the radiotherapy department for treatment?*

Approximately half (51%) of the patients were accompanied. The palliative patients received more support (61%) than the radical cohort (50%). No significant differences in anxiety or depression were found whether patients were accompanied or not.

Question 16 – *Do you have at least one relative or friend in whom you can confide?*

A total of 97% said they had a 'confidante'. From the six people who felt they had no 'confidante', five were men and one, a palliative women patient. The mean for the group without a 'confidante' was higher in both anxiety and depression.

The group with a 'confidante' had a mean of 5.22 and the group without, 7 for anxiety. With depression, the group mean with a 'confidante' was 4.10 and without 5.50.

Psychological Well-Being

Question 3 – *Would you have felt more confident if you had made a visit to the Radiotherapy Department before treatment to meet the staff that would be looking after you and to see where you would be treated?*

Over a quarter of the patients would have liked to make a prior visit to the department Of the total of two hundred and nine patients who answered this question, six patients had already visited the department. This was evenly divided between radical and palliative patients, 26% radical and 28% palliative. More than twice as many women wanted a visit compared with the men, 34% and 14% respectively. The biggest cohort was the palliative women patients (43%).

Question 6 – *Did you ever feel frightened during your radiotherapy treatment?*

A total of 20% (43) of the patients said they felt frightened, 27% women and 8% men. Patients who were being treated for tumours of 'Unknown' primary and Non Hodgkin's Lymphoma were especially susceptible. The patients who felt frightened had significantly higher anxiety rates than those who did not ($p < 0.007$ HADS, $p < 0.011$ STAI State).

Question 7 – *If yes, would you have like to talk to someone about this?*

Only those who responded that they had felt frightened replied to this question and over half (58%) said they would have liked to speak with someone about the problem. One patient wrote that she

"had a giddy spell on the couch but that the staff had helped her overcome

her fear of being left alone"

Question 8 – *Did you experience any anxiety or fear about your illness at the weekends?*

Patients did experience fear at the weekend. Altogether 26% (56) replied in the affirmative. This was fairly evenly distributed between the women (28%) and men (24%). The palliative patients were the most anxious with 38% replying in the affirmative, especially the female palliative women (45%). All the patients who had 'Unknown' origin cancer experienced this fear. A significant difference was found in anxiety and depression, with those patients experiencing fears at the weekend being the highest group (Anxiety HADS $p < 0.001$, anxiety STAI State $p < 0.001$, depression $p < 0.001$)

Question 9 – *Did you experience any anxiety or fears after your treatment ended?*

This question was to be answered only by patients when they received the same questionnaire four weeks later.

Question 10 – *Did the machine, you were being treated on, ever break down?*

Having a machine breakdown during treatment is a frightening experience for patients. The number who responded in the affirmative to this question is high at 32%. It was distributed between men and women, 34% and 27% respectively. Further analysis revealed no significant results.

Question 13 – *Do you have any dependants?*

Having dependants could alter anxiety levels. An overall total of 68% had dependants. This consisted of 60% of the women and 84% of the men, 66% of the radicals and 78% of the palliative patients. Further analysis using GLM showed that palliative patients were significantly more distressed if they had dependants (depression $p<0.003$ and more distressed $p=0.01$).

Question 17 – *Do you have any money worries?*

Financial problems could be a cause of high anxiety. Only 17% (36) of patients felt they had financial worries. No significant effects were found with money, or without it in relationship to anxiety or depression.

Question 25 – *Was there a delay in your diagnosis?*

A total of 17% (38) had a delay in diagnosis. In particular, half of the cancer of the bladder patients experienced this delay. Further analysis on anxiety and depression revealed no significant results.

Physical Well-Being

Question 12 – *Do you now feel better, no change, worse?*

By the end of treatment 35% (75) felt better, 46% (99) 'no change', and 12% (25) felt worse. Dividing into patient groups, 42% of the palliative patients felt better, 50% 'no change' and 8% worse. All the palliative patients who were 'worse' were in the age group 50-65+. 50% of the male palliative group felt better. The radical cohort, 36% felt better, 50% 'no change' and 14% worse. With regard to site of the cancer, 75% of those patients with Non Hodgkin's Lymphoma felt worse. Further analysis revealed a significant difference in depression for patients who felt worse, ($p=0.031$)

Question 14 – *Are you taking any medicines?*

Over 70% was taking medicines, which range from tamoxifen to aspirin. Four of the patients were on anxiolytics and three on anti-depressants.

Question 15 – *Are you still suffering from any symptoms as a result of your radiotherapy treatment?*

At the time of the end questionnaire, 60% of the patients had symptoms from their radiotherapy treatment. The radical patients were suffering more than the palliatives – with 64% and 47% respectively having symptoms. The radical women were the largest cohort with 67%. Only patients suffering from skin cancer were except.

There appeared to be a difference in anxiety in patients who had side-effects from treatment (Mean 5.527) and those who did not (Mean 4.894) but this difference was not significant ($p=0.255$). Similarly, with depression those patients who had symptoms from their treatment had a higher mean (Mean 4.433) than those who did not (Mean 3.705), but this difference was not significant ($p=0.146$). A negative correlation was found between those patients who felt worse and those suffering from any symptoms as a result of their treatment ($r=-0.78$)

Question 26 – *Has any of your family had cancer?*

To be told one has cancer is frightening – it has even been referred to as the "standardized nightmare of our society" Rosser & Maguire, 1982[2]

If one has already had a friend or relative with cancer, anxiety could be further heightened.

A total of 58% replied in the affirmative. Further analysis with anxiety and depression was not significant.

Question 27 – *Is there anyway in which your radiotherapy treatment could have been made less stressful?*

At the end of treatment, 57% responded in the affirmative. A space was left so that patients could add comments and 22% took the opportunity. These responses were subdivided. Positive responses accounted for 35% and comments ranged from

"No, everyone caring and friendly" and "I think the radiotherapy staff are wonderful. They show so much care, concern and comfort" to

"Very satisfied"

Secondly, waiting time was mentioned by 25% of the patients. Their critical remarks ranged from

"Only by less waiting for appointment (know this is difficult)", to

"Better appointment system"

Thirdly, travel was cited by 17% as being very stressful. Comments ranged from

"If only it had been carried out at my local hospital", and

"Travelling was the most stressful part of the treatment"

Fourthly, information, 14% of patients wanted more information. Remarks such as

"A little more preparation and medical help with the excessive diarrhoea I suffered", and

"The number of treatments wasn't clearly specified".

Question 28 – *Other than your current illness, have you suffered a recent stressful event, e.g. bereavement, divorce?*

A total of 26% had suffered a recent stressful event. Analysis was carried out to see if anxiety or depression were related to the stressful event. No significant effects were found.

APPENDIX 33
Analysis of Research Questionnaire at 4 Weeks Post Treatment

Analysis of Research Questionnaire

The questionnaire (See Appendix 7) sent out to patients four weeks after their treatment finished was the same as the questionnaire given to patients at the end of treatment and was divided into the same sections. Questions pertained to information and control, to social support, to psychological well-being and to physical well-being. A total number of two hundred and eighteen patients responded to this questionnaire. The patient cohort was different to those responding to the end of treatment questionnaire as it contained the single fraction patients.

Information and control

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Patients had all received a booklet giving them information. In this question, one hundred and seventy three (80%) patients felt they were given enough information. A significant difference was found on the STAI State anxiety scale, $p=0.048$. Those patients who responded 'No' were significantly more anxious and depressed $p=0.025$.

Question 2, *Do you feel you have been given too much information?*

Only two patients from a sample size of two hundred and eighteen thought they had been given too much information. This cohort consisted of one radical female and one palliative man. No significant differences were found.

Question 18 – *Did you go to the Lynda Jackson Macmillan Centre?*

Four weeks post treatment forty one (19%) patients said they had visited the centre. This cohort consisted of only four (2%) palliative patients. A total of thirty two (24%) women and nine (10%) men had visited. It was only from patient feedback that it was realized that patients' friends and relatives were using the centre while the patients were being treated. This was therefore not included in the questionnaire.

A set of six questions all relating to the above question were only answered by those who had visited the centre.

Question 19, *I used counselling ….. Yes/No*

A total of seventeen used the counselling facility. This number consisted of fourteen female radical patients, and two male radical patients, one palliative female.

Question 20, *I used relaxation….. Yes/No*

A total of forty two responded to this question. Five replied in the affirmative, four radical and one palliative patient.

Question 21 – *I used Yoga…. Yes/No*

One radical male patient had used yoga.

Question 22 – *I looked at the books…. Yes/No*

A total of fifty eight responded, of which 47% (27) replied in the affirmative. This cohort consisted of only radical patients, eighteen women and nine men.

Question 23 – *I looked at the tapes…. Yes/No*

There is a large number of tapes on cancer and various treatments in the Lynda Jackson Centre. The number of patients who used this facility was six, four radical and two palliative women.

Question 24 – *I used group therapy…. Yes/No*

Only one radical woman patients responded 'Yes'.

Social Support

Question 4 – *Did you feel you needed more support while undergoing radiotherapy?*

Four weeks past treatment, twenty six (12%) patients felt they needed more support. This cohort consisted of twelve radical females, seven palliative females, three radical males and four palliative male patients. The sites involved were breast (12%), 'unknown' origin (33%) and NHL (40%) and lung (23%). Those patients who felt they needed more support had higher anxiety and depression and this difference was significant (anxiety $p<0.001$, depression < 0.001.

Question 5 – *Did you talk with the counsellor over the treatment period?*

A total of forty six (21%) patients had spoken with the counsellor. They consisted of twenty one radical and three palliative women and thirteen radical and nine palliative men. People might have construed that this question related

specifically to the counsellor at the Centre. Therefore it should have read 'Did you talk with a counsellor during the treatment period? There were no significant differences in psychological distress in those patients who had talked with the counsellor and those who had not.

Question 11 – *Were you accompanied when you attended the radiotherapy department for treatment?*

Over half of the patients were accompanied. The palliative patients (61%) received more support than the radical patients (50%). A total of 62% of the male palliative patients were accompanied and 59% of the female palliative patients. No significant differences were found in anxiety or depression whether patients were accompanied or not.

Question 16 – *Do you have at least one relative or friend in whom you can confide?*

Only three patients (1%) felt they did not have someone to confide in. This group consisted of one female palliative patient, one radical and one palliative male patient. The mean of the group who had a confidante was 4.9 for anxiety. For the group, which did not have a confidante, it was 6.75. However, this difference was not significant.

Psychological Well Being

Question 3 – *Would you have felt more confident if you had made a visit to the radiotherapy department before treatment to meet the staff that would be looking after you and to see where you would be treated?*

Of the total of two hundred and nine patients who answered this question, six patients had already visited to the department. A third of the patients would have liked to visit the department prior to treatment. More than twice as many women wanted to make the visit than men. The women palliative patients were the largest cohort with 43% wanting to visit. Three quarters of the NHL patients would have liked a prior visit, 42% of the breast patients and two thirds of those with cancer of 'unknown' origin.

Question 6 – *Did you ever feel frightened during your radiotherapy treatment?*

A total of 20% (43) of the patients said they felt frightened. The highest cohort was the radical women, of which 30% felt frightened. One third of the breast patients, 30% of the head and neck patients and gynaecological and a quarter of the bladder patients all experienced fear during treatment.

Those patients who felt frightened were significantly more anxious ($p<0.001$) and distressed ($p=0.039$) than those patients whom did not feel frightened.

Question 7 – *If yes, would you have liked to talk to someone about this?*

At the time of the first postal questionnaire, twenty five (58%) patients said they would have liked to talk to someone about the problem. At the time of this questionnaire thirty (70%) of the forty three who felt frightened would have liked to have spoken to someone.

This cohort consisted of twenty four women, nineteen radicals and five palliatives and six men, three radicals and three palliative. The largest cohort with reference to site was 50% of the NHL, 'Unknown' origin, and 'other' and 36% of the breast patients.

Question 8 – *Did you experience any anxiety or fears about your illness at the weekends?*

Patients did experience fear at the weekends. A total of 35% (74) replied in the affirmative, with palliative patients (40%), in particular, experiencing anxiety at the weekends. The largest group was the female palliative patients of which 42% experienced anxiety at the weekends. Patients who were being treated for cancer of 'unknown' origin, NHL (66%), lung (54%) and head and neck and gynaecological (40%

Those patients experiencing anxiety or fear were significantly more anxious ($p<0.001$) and depressed, ($p<0.001$).

Question 9 – *Did you experience any anxiety or fears after your treatment ended?*

A total of two hundred and sixteen patients responded to this question. From this cohort, 40% (87) did experience anxiety after their treatment had ended. This number consisted of 39% of the radical women patients, 42% of the palliative women patients, 42% of the male radicals and palliatives. Particular sites to note were 'unknown' origin (100%), NHL (80%), bladder (62%), 50% gynaecological and lung patients and 48% prostate.

Those who experienced anxiety or fear after their treatment were significantly more anxious, distressed and depressed than those who were not (p<0.001).

Question 10 – *Did the machine, you were being treated on, ever break down?*

Having a machine breakdown while undergoing treatment is frightening for the patient. Over a third of the patients experienced this. Further analysis revealed no significant results.

Question 13 – *Do you have any dependants?*

Having dependants could have a psychological effect on the patients. Of the patients who answered this question, 71% did have dependants. The mean anxiety for those patients who had dependants was 5.42, and those who did not have dependants was 4.03. This difference was significant (p=0.031). Similarly, the mean for psychological distress was 6.9 for those whom had dependants and 5.8 for those who did not and this difference was significant (p=0.05). No significant differences were found in depression.

Question 17 – *Do you have any money worries?*

Financial problems could lead to patients feeling more anxious. Only 23% of patients felt they had financial worries. No significant effects were found between those patients who felt they had money worries and those who did not except in the STAI State, p=0.024.

Question 25 – *Was there a delay in you diagnosis?*

A delay in diagnosis could have caused an increase in anxiety. A total of 22% (47) did experience a delay. No significant differences were found in depression or distress for those patients experiencing a delay. However, those patients who experienced a delay in diagnosis were significantly more anxious in both HADS and STAI State, than those who did not, p=0.009 and p=0.20 respectively

Physical well-being

Question 12 – *Do you now feel better, no change, worse?*

Overall 52% felt better, 32% 'no change' and 12% worse. With the radical patients, 36% felt better, 50% 'no change' and 14% worse. The palliative patient group did better with 66% feeling better, 24% 'no change' and 10% worse. With regard to the site of the cancer, 40% of those patients with NHL felt worse as did 20%

of those patients with head and neck tumours. Further analysis revealed significant difference in distress, $p<0.001$, depression, $p<0.001$ and anxiety, $p<0.05$. A post hoc Tukey-HSD test showed that in terms of distress, patients, who felt better, had significantly lower distress levels than those patients who had 'no change' in their condition and those patients who felt worse. Similarly, those, who did not think their condition had improved, had significantly lower distress than those who felt worse. Similar results occurred with the variable of depression. With anxiety, the patients who felt better had significantly lower anxiety levels than both the 'no change' patients and the patients who were feeling worse. There was no significant difference between those feeling worse and the no different patients.

Question 14 – *Are you taking any medicines?*

Two thirds of the patients were taking medicines. These ranged from tamoxifen to aspirin. Four of the patients were on anxiolytics and four on anti-depressants.

Question 15 – *Are you still suffering from any symptom as a result of your radiotherapy treatment?*

Four weeks from the end of their treatment, 49% of the patients still had side-effects from their treatment. The radical patients were suffering more than the palliative, 50% and 46% respectively. With respect to the site of the cancer, 78% of the head and neck patients, 70% lung and bladder patients, 47% of the prostate all those of 'unknown' origin, and 40% of the breast patients were all having symptoms still.

The means of patients having symptoms was higher than those without symptoms. Further analysis to see if those patients having symptoms were more anxious, depressed and or distressed revealed significant results with distress, $p=0.007$, and depression $p=0.002$. Anxiety was not significant.

Question 26 – *Have any of your family had cancer?*

A total of 58% (124) patients said they had cancer in their family. Analysis was carried out to see if anxiety, depression or distress were heightened because of this, but no significant results were revealed.

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Over half (56%) responded that their treatment could not have been made more stressful, with 29% (64) patients making comments on the forms. A number of patients (33%) made positive comments. These ranged from

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those of 'unknown' origin, and 40% of the breast patients were all having symptoms still.

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Question 27 – *Is there anyway in which your radiotherapy treatment could have been made less stressful?*

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'The staff at Mount Vernon could not have been more kind and helpful',

to

'The staff created a confident inspiring atmosphere'.

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'The number of treatments wasn't clearly specified'.

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'If treatment could have been nearer home', and

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'Avoid using the word 'cancer' on hospital buildings and notices' to

'One physician should always attend the same patient – shunting kills a

patient as new physicians are ignorant'.

Four (6%) of patients specifically mentioned the lack of post treatment contact. These are some of the comments:

'I would have liked more information on the after-effects', and

'5 weeks of treatment – 4 days per week. Saw a doctor each Monday for

about 10 minutes. The last Friday I just left. Nobody said anything

except I would hear from a doctor in 4-6 weeks'.

One final comment:

'When completed you could be told what to expect until you see the

Consultant some weeks later'.

Question 28 – *Other than your current illness, have you suffered a recent stressful event e.g. bereavement, divorce?*

A quarter of the patients had suffered a recent stressful event. The means for depression, anxiety and distress scores for the patients who had suffered were higher than for those who had not. However these differences was not significant.

APPENDIX 34
Analysis of Research Questionnaire at 6 Months Post Treatment

Analysis of Research Questionnaire Given at 6 Months Post Treatment

The research questionnaire consisted of fourteen questions (See Appendix 10). These questions were divided into four different sections; information and control, social support, psychological well-being and physical well-being.

Information and control

Question 5 – *Did you feel the need to contact your GP for advice concerning radiotherapy treatment?*

Only twenty seven patients (18%) had needed to contact their GP for advice about their radiotherapy treatment. The large majority did not feel the need. The palliative male patients are a small group in this study but 25% (3) did contact their GP and 19% (16) of the radical female patients and 18% of the radical male patients. Only one palliative women patient contacted the GP about treatment. One respondent failed to tick the appropriate box and another replied

"Under no circumstances – for 6 weeks when first ill he repeatedly sent
me home with antibiotics".

Those patients who responded 'yes' were significantly more anxious (p=0.003) and distressed (p=0.016) than those patients who answered 'no'.

Question 6 – *If yes, was your GP able to answer your queries?*

Although twenty seven patients had responded 'yes' to the above question, thirty two patients responded to this question. A total of twenty two replied in the affirmative and three with comments

"Yes, within limits"

"Yes, had to look things up" and

"Yes, a little".

Ten patients said

'no'.

One patient wrote

'I will be seeing him'

Question 7 – *Did you feel you were given adequate information when you left the radiotherapy department?*

A quarter of the patients did not think the information was adequate. This could be specifically related to certain sites. Three quarters of the patients suffering from bladder cancer, over half of the lung patients, 37% of the gynaecological patients and a third of the prostate patients felt the information was not sufficient.

Some patients added comments

"I was not warned of any ill effects to silicon implants",

and another wrote

"None at all", and

"I was told I would in future want to pass water more frequently – not that there would be mild incontinence".

Question 10 – *Did you feel a need to get more information on your illness?*

From the one hundred and forty five responses, fifty eight (40%) felt they needed to get more information. The biggest cohort was those suffering from lung cancer, (82%), bladder (50%), breast (43%) and Non Hodgkin's Lymphoma (40%). Over half (54%) of the palliative patients wanted more information.

Those patients who felt a need to get more information were significantly more anxious on both the STAI State and the HAD Scale (p=0.012, and p=0.039 respectively)

Question 11 – *If yes, where did you get your information from?*

Several of the respondents cited several sources for their information. A total of twenty five got their information from the GP/doctor, fourteen from Cancerlink/Bacup, eight from family and friends and fourteen cited 'other'. Several patients specified 'other' by writing comments such as, books, Macmillan nurse, breast nurse. Three patients wrote 'nowhere', 'I didn't and 'no one yet'. Only the women patients cited family and friends for their information. Over 50% of the men got their information from the doctor, two from Bacup and seven from other sources.

Psychological well being

Question 3 – *What do you feel about the length of time between finishing your treatment and seeing the consultant in the Out Patients Clinic?*

The great majority (87%) felt the length of time was OK. Only 13% (17) patients felt it was too long to wait and one person ticked it was too short. One respondent wrote

' do not know'.

Physical well being

Question 1 – *Do you still have any side-effects as a result of your radiotherapy treatment?*

A total of forty eight (33%) were still suffering from side-effects of the treatment, which finished six months previously. The lung and NHL patients with over 60% still suffering together with 50% of the head and neck and prostate patients appear to be particularly susceptible to side-effects. At the time of the first postal questionnaire, 48% still had side-effects. This number has been reduced by nearly a third in the past five months. Approximately a third of the radical patients (34%)and 30% of the palliative patients still had side-effects. Several of the respondents added their side-effects such as

'persistent pain in shoulder'

'Thickening of scar tissue which has displaced the silicon implant'.

Another example was

'Occasional violent hiccups when eating'

'Heartburn and occasional pain in the area treated'.

Further analysis to see if those patients having symptoms were more anxious, depressed or distressed revealed no significant results.

Question 2 – *Do you now feel better, no change, worse?*

A total of 48% (70) felt better, 42% (60) 'no change' and 10% (14) worse. . At the time of the last questionnaire 52% felt better, 32% no change and 12% worse.

Two palliative women patients and two palliative men felt worse than at the last testing, making up 18% of the palliative cohort. Only 8% of the radical patients felt worse. The largest cohort to feel better was the male radical patients (58%). Both female and male palliative patients felt equally bad with 18% responding that they felt worse. With consideration to the site of the tumour, 75% of the bladder patients felt better and 100% of those patients with 'unknown' origin cancer. However, 27% of the prostate patients felt worse as did 23% of the lung and 20% of the NHL patients

Significance was not reached with any of the variables.

Question 8 – *How long did it take you to travel to the hospital from home?*

As radiotherapy is so specialised and Mount Vernon is situated on the perimeters of London, its catchment area is large. The time spent travelling to the hospital varied from five minutes to two hours. The mean was 40 minutes. Therefore the return journey averaged one hour and twenty minutes. Travelling within London to a specialized unit would probably take the same time with disruption on London Transport and continual heavy traffic on the roads.

Question 9 – *Have you had any further treatment?*

A total of 44% had received further treatment, 52% of the radical cohort and 47% of the palliatives. The male radical were the highest group with 54% having further treatment. One patient wrote 'waiting'. Significance was not reached with any of the variables.

Question 10 – *If yes, what? Surgery, radiotherapy, chemotherapy, hormonal/tamoxifen, complementary.*

The largest cohort, thirty five, was taking hormones/tamoxifen. Fifteen marked additional medicines, which ranged from distalgesics, steroids and suppositories. Eleven ticked chemotherapy treatment, eight complementary medicine and five further radiotherapy.

Analysis was carried out to see if further treatments changed the psychological state, but none of the variables were significant.

Question 14 – *Other than your cancer, which has been treated, do you have any other illness?*

From the one hundred and forty three patients who responded to this question, 42% had other illnesses. The most common illness (27%) was circulatory disorders. The next was arthritis (15%), four suffered from thyroid problems and a similar number from diabetes, three from depression, two from bad backs and another two from vertigo. A category of 'other' housed such complains as emphysema, migraine. A few patients suffered from two or three disorders. The majority of the patients who responded in the affirmative were of the older age group with 52% aged 65 and over and 41% aged 50-65.

Social Support

Question 4 – *Would it have been helpful if someone had telephoned you during this time to check how you were getting on?*

A number (43%) of patients did think a telephone call would have helped. More women (47%) than men and more radicals (44%) than palliatives (36%) would have liked a call. Some patients mentioned that they had contact with the District Nurse and or the Breast Care Nurse during this time.

None of the variables were significant.

Question 12 – *Have you visited or telephoned the Lynda Jackson Cancer Support Centre since you received our last questionnaires?*

A total of ten patients had visited the Centre, eight radical women patients, one radical male patient and one palliative male patient.

Question 13 – *If yes, was the contact useful?*

From the nine responses, eight thought it useful and one female radical patient did not. One patient wrote

'I would have liked to visit them for therapy if I lived nearer'.

APPENDIX 35
Analysis of Research Questionnaire at 1 Year Post Treatment

Analysis of Research Questionnaire Given at One Year Post Treatment

The research questionnaire consisted of thirteen main questions with sub divisions (see Appendix 12). The questions were divided into four different sections; information and control, social support, psychological well-being and physical well-being.

Information and control

Question 10 – *Since May, have you felt a need to get more information?*

Twenty one patients (19%) of the one hundred and eleven who responded to this question answered positively. This cohort consisted of eleven (15%) radical female patients, three (43%) female palliative patients, three (11%) male radical patients and four (50%) male palliative patients.

The sub division of the question was:-

If yes, where did you get your information from? Dr/GP, Bacup/Cancerlink, Family/Friends, Lynda Jackson Centre, Other?

A total of thirteen patients visited their GP. Only one of the palliative patients did not go to the GP – a man. One female radical breast patient got her information from Bacup/Cancerlink. Another radical woman patient with a tumour categorized under 'Other' got her information from family and or friends. No patients had returned to the Lynda Jackson Centre. Seven patients circled 'other' and these included Watford General and Dr Maher. Those who needed to get more information were significantly more anxious (p=0.003) than those who did not need to get any information.

Question 6 – *Have you visited your GP about your cancer?*

From the one hundred and sixteen patients who ticked this response, forty three (37%) had visited their GP, one third of the female patients who responded and nearly one half of the males (46%), and all the lung and head and neck patients.

The subdivision of this question was

If yes, was your GP able to answer your queries.

From the positive responses, thirty one (66%) thought the GP had been able to answer their query and seventeen (35%) did not. Eleven of the breast patients were not satisfied with their GPs response and fourteen radical and three palliative patients.

Life threatening disease like cancer can make patients change their life style in order to attain a feeling of control. The next question looks at these changes.

Question 7 – *Since being diagnosed have there been any changes in*

1. your place or type of work?

Twenty of the twenty one patients who replied in the affirmative were radical patients, seventeen female and four male. One person commented that they

'had moved to a less stressful job earning more money!'.

For most people, the change in job was related to a loss of income -

'I'm presently working on part-time medical grounds, but have to soon decide whether I'm able to work full-time hours'.

One patient made the comment

'Lost my job because I could no longer do the repetitive movement required for working on scanning tills'.

No significant differences with relationships to the variables of anxiety of depression were to be found.

2. Income?

This population tends to be near retiring age and some patients will have taken early retirement with its subsequent fall in income, others will have reached retirement age during the study. From the one hundred and twelve responses, 27% had experienced a change in income. Only two of the palliative patients had experienced a change in income. There were no significant differences with the variables of anxiety or depression.

3. Use of cigarettes?

Only eleven (22%) had changed their habit of smoking. 60% of the head and neck and lung patient made up this cohort with 6% of the breast patients. There were no significant difference in anxiety or depression and use of cigarettes

4. Use of alcohol?

Nine patients had experienced a change in alcohol habits. However, as with the cigarette question it was not ascertained whether it was less or more. The number of men was six and women was three. There were no significant differences with change of use of alcohol and anxiety and or depression.

5. Diet?

A quarter (26%) of the one hundred and eleven patients who responded had changed their diet and was evenly distributed between men and women. Half of the male palliative patients had changed their diet and 29% of the female radical and palliative patients. Patients added a range of comments.

'I eat more now. A complete disorder.

Another comment was

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'I am much less keen to follow a slimming diet. I don't discipline myself as much as I used to, as I figure shortage of some nutrient might have triggered the cancer'

Another comment was

'I am trying to increase healthy eating' and

'I have stopped eating meat'.

A final comment was

'Have been to Weightwatchers and lost 1 stone gained from steroids whilst having chemo'.

No statistical differences were found in anxiety and depression.

6. Marital Status and important other relationships?

Nine patients experienced a change in marital status. This number consisted of five radical females, one palliative female and three radical male patients. One patient wrote

'currently in Ward 10 receiving radiotherapy and had just got married'.

Four patients had further experienced changes in other important relationships. No significance was attained with the variables of anxiety and depression.

7. Moved home?

Five patients had moved their home. All were radical patients, three women and two men. No significance was reached with the variables of anxiety and depression.

Psychological Well Being

Question 5 – Would it have been helpful if someone had contacted you from the radiotherapy department in the last six months?

In the last set of questionnaires, patients were asked if they would have liked a telephone call from the department, in between the last treatment and seeing the consultant six weeks later. A total of 43% of patient would have liked this. After one year 23% (27) would have liked contact. This was split evenly between the men and women. The patients who would have liked contact from the department are not necessarily the patients who have side-effects from their treatment. No significant difference in anxiety or depression was found between those patients who would have liked a call and those who did not.

Physical Well Being

Question 1 – Do you have any side-effects from your radiotherapy treatment in Autumn

1993?

Over a quarter (28%) of the patients one year after their treatment still had side-effects. Six months previously 31% had side effect. Principal sites are prostate, gynaecological and lung with 43%. 20% of the breast patients are still having side-effects. 23% of the palliative and 29% of the radicals still have side-effects from their radiotherapy treatment. No significant results were recorded.

The next question is a subset.

If yes, have they occurred since the last questionnaire?

A total of sixty one replied, when only thirty three patients said they had side-effects. From this cohort, sixteen patients said they had the side-effects only in the last six months. Only three of the patients were palliative. 60% of those being treated for lung cancer thought the side-effects had occurred since the last questionnaire. Is this the cancer returning rather than side-effects?

Question 2 – *Compared with one year ago do you know feel better, no change, worse?*

Over half of the patients (56%) felt better, a third felt 'no change' and 11% felt worse. Patients who felt better were significantly less depressed (p=0.005) and less distressed (p=0.048) than patients who felt worse (Post Hoc Tukey). A quarter of the palliative patients felt worse in comparison with 9% of the radical patients.

Question 3 – *Compared with 6 months ago do you now feel better, no change or worse?*

A total of 51% felt better since the last questionnaire, 39% no change and 10% felt worse. A third of the palliative patients felt worse but 44% felt better. Only 7% of the radical cohort felt worse than six months ago. Those patients who felt better had significantly lower depression (p=0.012) and distress (p=0.049). A post Hoc Tukey-HSD showed that those patients who felt better had significantly lower depression than those patients who felt no change. Similarly, the patients who had no change had significantly lower depression than those patients who felt worse.

Question 8 – *Since May have you had any further treatment? If yes what? Surgery, Radiotherapy, Chemotherapy, hormonal/tamoxifen, complementary medicine, additional medicines or other?*

Over a quarter of the patients who responded to this question had experienced further treatment. Seven had experienced further surgery, one radical and one palliative woman and five radical men patients. Three patients had further radiotherapy, one radical and two palliative men. Nine had undergone chemotherapy and seventeen hormonal treatments. This number included thirteen radical women, three palliative women and one radical man. Four had taken complementary medicine and eight had taken additional medicine. Three patients

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had written

'other'; 'vagifem vaginal tablets'; 'sodium diclofenac and complementary massage to water retention area'.

Question 11 – *In the last 6 months have you had any illness? If yes, what?*

One third of the patients had been ill, the majority with 'flu or a similar virus, others had shingles, arthritis. Angina, anaemia, chest infections and diabetes were also cited. One patient wrote

' recurrence of cancer and inflamed bowel through radiotherapy'.

Half of the palliative patients had experienced illness. No significant differences were found.

Social Support

Question 12 – *In the last year do you feel you have had enough emotional support? If yes, from whom?*

Over 80% of the patients felt they had enough emotional support. Those patients who felt they had not enough support were 18% of the female radical patients, and one female palliative patients. Six male radical patients also felt a lack of emotional support.

The support received was mostly from their family friends (68) and the Macmillan nurse (5) and the doctor and hospital (9). Others cited Hospice, colleagues or no one.

Patients who felt they had emotional support were significantly less anxious (p=0.001), less depressed (p=0.001) and less distressed (p=0.001).

The final question does not fit into any of the above categories

Question 13 - *Do you have any suggestions, which would have made life easier during and after your radiotherapy treatment? If yes, What?*

A total of 26% wrote their suggestions. The majority of these refer to the psychological aspects of cancer, although one patient wrote

'to have radiotherapy unit at Luton and Dunstable Hospital'.

The area which comments were mostly focused on was social support, after care and information. The most common comments were similar to the following:

'more emotional and psychological support' and

'some form of automatic counseling i.e. as an integral part of my treatment'

'We have no self help group and I wanted to meet other women with young children – we have no started a group which started last week'.

A breast patient wrote:

'Some form of compulsory counseling. Although a counselor was available

because she was on holiday when I was diagnosed I never saw anyone. Looking back I wish I'd seen someone as the mental side of having cancer is far worse that the physical side'.

One patients suggested

'Speaking before hand with someone who has been through the same thing'. Another patient wrote:

' to be given the option to talk to other people in the same situation'

Other comments were focused on aftercare:

'An invitation to return to Mount Vernon after discharge if there were any queries re side-effects'.

Other comments were practical

'Stronger elastoplast should be used to secure the shields. It is frightening when they fall off because you imagine radiation penetrating your lungs – especially if it happens when the nurses are out of the room'.

Several suggestions about more information came from patients

'Back up information and extra follow-up from hospital etc'.

'More information about tamoxifen, its side-effects and history of success'.

'I feel I could have been given more information on side or lasting effects from treatment'.

'Being told all the truth about treatment, drugs etc'.

One final comment from a patient

'very selfishly would have liked not to have spent so much time waiting for treatment – realize that was inevitable because of blood count analysis etc – but not really anything to do'.

APPENDIX 36
Analysis of Research Questionnaire at 18 Months Post Treatment

Analysis of Research Questionnaire Given at 18 Months Post Treatment

The research questionnaire consists of seventeen main questions with some subsets, (see Appendix 14). The questions were divided into four different sections: physical well-being, information and control, social support and psychological well-being.

Physical well-being:

Question 1 – *Do you think you may have had any problems related to your radiotherapy treatment? If yes, please list.*

One year after treatment, 28% of the patients had side effects. At eighteen months post treatment, a total of 41% of patients felt they had problems related to their radiotherapy treatment. 43% of the radical patients and 22% of the palliative patients still had problems associated with their treatment. There are only nine palliative patients left in the study. With respect to site, 38% of the breast patients, 60% of gynaecological and gastrointestinal, 50% of the prostate and NHL and a third of the bladder patients all felt they had a problem as a result of their treatment.

The problems varied considerably depending on the area treated. The following are a range of comments from the various sites.

Head and neck patients focused on dryness in the area of the mouth and eating problems:

'Eyes sore and very dry lips', and

'Unable to eat anything at all'

One patient raised another point,

'Slightly deaf in left ear and pain in should bone and muscles'

Lung patients suffer from

'Digestive problems and treatment area still "hot spots" at times', and

'Tiredness'.

Breast patients complained of difficulties with their arm.

'Minor arm and shoulder damage',

'my left arm is continuously swollen',

'Scar tissue was still painful when using arm', and

'As I have an implant it seems to have moved upwards'.

A prostate patient said

'their bladder was so damaged by radiotherapy caused by incontinence leading to urostomy'.

A cervix patient wrote down in detail the problems occurring after her treatment:

'1.   Slight spasmodic bleeding from rectum

2.   Small leak of urine to vagina – consultant suspected fistula but could not be located by tests

3.   Bleeding after intercourse'.

Significance was not reached with the variables of anxiety and depression.

Question 2 – *Since your radiotherapy treatment have you felt more tired?*

With a sub question,

If yes, do you feel this is due to your radiotherapy treatment?

Eighteen months after their treatment over 50% (52) of patients felt more tired. This was evenly divided among men and women, however, 43% of the radical patients were more tired in contrast to 22% of the palliative patients. The entire lung, bladder and those patients of unknown origins in the current study were more tired.

With respect to age, 55% of the patients aged between 26 and 50 felt more tired as did 55% of patients aged 50-65, in contrast to those aged 65 and over where 45% felt more tired.

Patients who felt more tired were significantly more anxious (p=0.020) and distressed (p=0.025). However, depression did not reach significance.

From the patients who answered in the affirmative, 59% felt their tiredness was due to their radiotherapy treatment. Three patients wrote 'maybe', and this category should have been included. A total of 40% of the palliative patients and 61% of the radicals attributed their tiredness to the treatment. All the NHL patients and 60% of the breast patients also thought that the radiotherapy was responsible for their tiredness.

Question 3 – *Has you energy level now returned to normal?*

For the majority of patients (67%), their energy levels have returned. The third of patients, who were lacking energy, consisted of 29% of the women cohort and

42% of the men. All the palliative men were lacking energy in contrast to all palliative women who said their energy was back to normal

Those patients, who lacked energy, were significantly more anxious (p=0.05), depressed (p<0.001), and distressed (p=0.003) than those patients whose energy levels had returned to normal.

Question 4 – *How long did it take? 3 months, 6 months, 1 year, 18 months, not back yet?*

A third of the patients thought it took three months for their energy to return to normal after treatment. This consisted of a quarter of the radical female patients, 60% of the palliative female patients and 48% of the male radical patients.

20% thought it took six months for their energy to return to normal. This consisted of 25% of the radical females and 15% of the male radical patients.

9% felt it had taken a year for the energy levels to be normalized. This cohort consisted of 11% of the female radical patients, 20% of the female palliative patients and 4% of the male radical patients.

By eighteen months, another 4% felt their energy levels had returned. This number consisted of one female palliative patient and four female radical patients.

One third of the patients felt their energy had still not returned. This cohort consisted of all the male palliative patients. These patients had cancer of various sites, bladder, NHL, 'unknown origin' and myeloma. However, two thirds of the radical prostate patients and all the radical lung patients felt their energy levels had not returned. A third of the female radical patients were suffering from a lack of energy. A total of 30% of those being treated for cancer of the breast made up the largest group.

There was no correlation between those who felt their energy levels had returned to normal and those who had attributed their tiredness to radiotherapy. However, those patients whose energy levels had returned within three months were significantly less depressed (p=0.003) and less distressed (p=0.031) than those patients whose energy levels had not yet returned to normal

Question 5 – *Compared with November last year do you now feel better, no change, and worse?*

From the ninety nine responses, 46% felt better, 48% no change and 5% felt worse. The group of patients who felt better consisted of 48% of the radical females, 46% of the radical male, 20% of the palliative females and 50% of the palliative males. Those patients who felt worse were 7% of the radical and 20% of the palliative women.

Those patients who felt worse were significantly more depressed (p=0.012) than the other groups.

Question 6 – *During the last 6 months have you had a cancer check up with Mount Vernon, another hospital? If yes, please write which hospital.*

A quarter of the patients had returned to Mount Vernon for a follow up appointment. One patient wrote boldly on his form

'I do not have cancer'.

Three quarters of the patients had checkups with other hospitals, eleven had been to Luton and Dunstable, nine to Watford General, six to Edgware, five each to Barnet General, Northwick Park, Hillingdon and QE11 Welwyn Garden City, four to the Lister, Stevenage and three to Wexham Park. Others had travelled around the region including Charing Cross and the Royal Marsden.

Some patients (6) had not gone to the hospital for a checkup but ticked the GP. A total of eighteen, 25% of the seventy three responses said they had been to the GP. In the previous questionnaire, 37% had been to their GP about their cancer.

Information and control

Question 16 – *Do you try and eat a more healthy diet?*

A total of 82% tried to eat more healthily. This included all the palliative patients participating. There was no significant difference in the variables of anxiety and depression between those patients who tried to eat more healthily and those who did not.

Question 15 – *Have you had to change your diet since your diagnosis of cancer?*

Fourteen (14%) of the ninety six respondents said they had to change their diet. This cohort consisted of eight breast patients, two lung and prostate patients, one head and neck and one gynaecological patient.

Question 9 – *If you have or had symptoms, which you thought might be your cancer coming back, would you contact: your GP, your consultant's secretary, your specialist nurse, the casualty department, a support group, or other.*

Over half of the patients (52%) of the hundred replies would contact their GP. Another quarter (27%) would contact the consultant's secretary. Eight patients would do both and another would also contact the specialist nurse and/or support group. One patient said they would contact their GP and wait for a routine appointment. Three patients would see the specialist nurse and one would go to casualty. Two patients would wait for their routine appointment. A further two said they would contact the consultant's secretary and wait for a routine appointment. One patient ticked other and wrote 'not sure'.

Psychological well being

Question 8 – *Have you had to bring forward a routine appointment because you were worried?*

A total of sixteen (16%) patients has had to bring forward their appointment, as they were worried. This number consisted of eight breast patients, one prostate, three 'other', two gastro-intestinal, one gynaecological, and 1 NHL. Three of the patients were palliative women, 10 were radical women and 3 radical men.

Question 17 – *Looking back over your radiotherapy treatment, what words best describe your experience? Anxious, Efficient, Powerless, Frightening, Caring, Reassuring, Angry, Friendly, Distressing, Depressing, Time-consuming, Isolating, Sore/Painful, Other.*

Some patients ticked more than one response. Over half of the patients thought the treatment made them anxious. Another 58% thought the treatment was efficient. Only 15% found it powerless, and 20% found it frightening. In contrast, 62% found the treatment 'caring' and 53% re-assuring. Only two patients felt angry

about their experience. Another eight patients found it an isolating experience, 12% distressing and 18% depressing. Approximately a third (33%) described it as being 'time-consuming' and 22% found it sore/painful. A further ten ticked 'Other'. The following are comments from patients:

'uncertainty'

'I felt sick most of the time'

'Burning sensation afterwards and needle sharp pains'

'It was the travelling that was time-consuming not the actual treatment'

'Very pleased with treatment. Thank you'.

Social Support

Question 9 – *In the last questionnaire a number of patients said they would have liked to have spoken with a patient who had already had radiotherapy treatment. Would this have helped you?*

A total of 46% of the one hundred replies felt it would have helped them, and 27% thought it might have helped. 24% of the women and 32% of the men said it would not have helped them.

Question 10 – *Would you feel able to talk to someone who was about to have radiotherapy?*

71% of the patients thought they would be able to talk to a new patient who was about to undergo radiotherapy treatment. This cohort consisted of 68% of the women and 80% of the men patients. A further 17% thought 'maybe' they could talk to a patient about to undergo treatment.

Question 11 – *If yes, how soon after your radiotherapy treatment do you feel you would be willing to do so? 3 months, 6 months, 1 year, 18 months, other?*

From the eighty one responses, forty two (52%) felt they would be ready in three months. Some patients wrote on the form 'immediately'. Others wrote that they had spoken to patients when they had first arrived and were looking apprehensive. Nine patients (11%) felt six months was an appropriate time and another nine patients thought one year. Twelve patients suggested eighteen months and nine ticked 'other'.

Two of the questions did not come into the main categories

Question 13 – *Whilst waiting for transport or treatment would you have like to have watched television?*

Over a quarter (29%) of the patients would have like to have watched TV. Some patients specifically stated programs such as informational needs of the cancer patient, or comic programmes to make them laugh. Ten of the patients ticked 'don't know'.

Question 14 – *Do you have any suggestions for the waiting room?*

A total of twenty nine did come up with suggestions.

Firstly videos;-

'Peoples programmes who have suffered and any advice for others'.

'Maybe the chance to see video interviews and diary extracts from patients before, during and after treatment and the chance to visit people who are willing whilst having chemo and radiotherapy'

'An informative video on the radiotherapy treatment, i.e. an interview with recent patients would probably ease the worry of new patients'.

Secondly the following are comments concerning the facilities in the department:

'Drinking water; the drinking water in the big waiting area was often empty'.

'Few more chairs – each patients seems to bring someone else with them for transporting or support. Other than this waiting room quite pleasant'.

'More chairs'

'More space'

'It always seemed rather crowded to me'

'More space – but as that is not possible, a good job is being done'

'A bit crowded sometimes but this is understandable'

'The main waiting room was satisfactory but one end of the corridor was drab and uncomfortable'

'More up-to-date magazines with a more rapid turnover'.

'Would have liked to have been able to use the facilities such as aromatherapy'.

'Some of the food smells from the coffee shop were off putting due to feelings of nausea'.

APPENDIX 37
Analysis of Research Questionnaire at 2 Years Post Treatment

Analysis of Research Questionnaire Given at 2 Years Post Treatment

The research questionnaire consists of eight main questions, which relate to physical well-being, social support and psychological well-being (Appendix 21).

Physical well being

Question 1 – *Do you still have any problems related to your radiotherapy? If yes, please write down what the problem is.*

Six months ago, 41% of patients had problems. Two years after treatment, this has fallen to 20%. This cohort consisted of seventeen (20%) radical patients and one (20%) palliative. The most affected sites were gastrointestinal (75%), gynaecological (43%), NHL (50%). Those patients who were aged 65 and over had far fewer problems than the other age groups.

Those patients who did not have any problems were significantly less anxious than those patients who did (p=0.034).

The most frequent comment was:

'Soreness and dryness'

Other common problems associated with radiation to the pelvic region gave rise to comments such as

'Diarrhoea and flatulence'

'Intolerance of certain foods'

Question 2 – *Do you feel tired?*

Only 93% of the patients answered this question of which 38% were still tired. This cohort consisted of 41% of radical and 67% of palliative women, 22% of radical men and all the palliative men (2). The most commonly affected sites were breast, head and neck, gynaecological, NHL and bladder. In the last questionnaire, a third of patients said they were tired.

Those patients who felt tired were significantly more anxious (p=0.009), more depressed (p<0.001) and distressed (p<0.001) than those patients who were not tired.

Question 3 – *Have you had further problems related to your cancer, if so what?*

A total of 14% had further problems and these included spread of disease and more radiotherapy or surgery. A range of comments was written:

'Poor general health (effects of menopause brought upon by tamoxifen)'

'Not sure, gaining weight due to huge appetite I have now'

'Modules removed but luckily no cancer'

'Ultrasound found cyst, yearly mammograms now'

Do you think this is due to your radiotherapy treatment?

Six patients did feel that their problems were related to their treatment, two breast patients, one skin, one gastrointestinal, two gynaecological,

Question 4 – *Compared with May 1995 Do you feel better, worse or no change?*

A total of 34% of patients was feeling better, 63% 'no change' and 3% worse. The patients who felt worse were one radical female breast patient, one radical male lung patient and one radical woman skin patient.

Those patients who felt worse were significantly more depressed (p=0.010, Post Hoc Tukey) than those patients who felt better.

Psychological well being

Question 5 – *Looking back over your treatment, has your experience had a positive effect? Or a negative effect?*

A total of 91% of the patients felt that the experience was a positive one, only four radical male and female patients did not.

Three patients thought it had a negative effect; two were female radical patients and one male radical patient.

Question 8 – *Please tick the words that best describe how you feel now – Happy, Uncertain, Thankful, Fearful, Content, Depressed, Careful, Anxious, Listless, Other.*

Patients could respond to as many words as they felt were appropriate to them. Thankful was ticked by 61% (58), happy by 47% (45), content by 42% (40), uncertain by 22% (21), careful by 14% (13), listless by 10% (10), 6% still felt fearful, 5% felt depressed and 2% (2) ticked 'other'.

Social Support

Question 7 - *Have you contacted the Lynda Jackson Centre? If yes could you please tell us why?*

A booklet was sent out with the questionnaires at eighteen months on 'Coping now that your Radiotherapy Treatment is finished', which was produced by the Lynda Jackson Macmillan Centre. Patients had also received a pamphlet about the Centre with the other postal questionnaires. A total of eleven (12%) of patients had contacted the centre, eight radical and one palliative woman and two radical men.

The reasons were various:

'I needed information and they were helpful'

'Personal problems related to cancer'

'Immediately after treatment in connection with diet and diarrhoea. They were very helpful'

'To have a massage, but was refused treatment'

'To talk'

'Had a talk about my mastectomy'

'The staff are so friendly and supportive. A chat with them at a relaxation session is very reassuring'.

'To get some literature regarding how to explain my illness to my daughter and to buy a relaxation tape and a Christmas card'

'If the end comes earlier than expected'

Question 8 – *Have you since the last questionnaire received any new complementary medicine including counselling?*

Only four radically treated women had participated in a new complementary medicine.

A final question, which comes into 'Other' category:

Question 6 – *Has you life changed since your treatment? If yes, can you say how?*

A total of 37% of patients felt their life had changed, 39% of the female radicals, 32% of the male radicals. 33% of the female palliative and 50%of the male palliative patients.

The comments varied between negative and positive.

'I can't do as much as I used to'

'I worry more about my health'

'Cancer is now widespread and terminal'.

'Seemed to have slowed down – very tired'.

'Cannot do some of the things I used to do'

'More aware that life is short'

'Makes me appreciate each day that my quality of life improves'

'Fitter'

'Taking things more slowly'

'Made me aware that trivial things are not so important and family and friends come first'

'General outlook – take more time for myself. Have more family holidays'

'Grateful for life'

'I do as much as I can – life is too precious to waste time'

'Made me appreciate everything and be very grateful'

'A very different outlook on life in general'

'I try to relax more – I try not to get "wound up" about small things'

'Got better'.

APPENDIX 38
Analysis of Research Questionnaire at 3 Years Post Treatment

Analysis of Research Questionnaire Given at 3 Years Post Treatment

The research questionnaire consisted on 13 main questions with some subsets. (See Appendix 22). The questions were divided into four different sections: physical well-being, information and control, social support and psychological well-being.

Physical well being

Question 1 – *Do you still have any of the problems related to your radiotherapy that you mentioned before? If yes, please write down what the problem is.*

29% of the patients still had problems. This cohort consisted of 29% radical patients and 25% palliative (one patient), and further subdivided into 28% of the radical women patients, 32% of the radical male patients and one palliative male patient. A year ago, 20% of patients had side-effects.

The problems varied according to the site.

Comments from breast patients were:

'Slight sensitivity on mastectomy scar'

'Have slight twinges in scar area'

'Lymphoedaema'

'Sometimes it's a bit of a pain'

Comments from head and neck patients included the following:

'Pain in my neck and shoulder bone'

'Surprised to find that neck can still be a bit painful- very slight'

'Difficulty in swallowing'

'Sore outside of nose'

'Very dry mouth, unable to eat'.

Those patients who had radiation to the pelvic area made the following comments:

'Bladder control is just that bit more difficult – though manageable. Dr warned me of this at the time'

'Dry skin'

'Radiation colitis – Pains in lower bowel and sometimes bleeding

'No control with bowels'.

Patients who had radiation to the upper torso

'Sore chest, can't eat hot food'

'Energy level not returned for golf say'

'Tiredness, lack of concentration'.

Question 2 – *Have you any new problems that you think are due to radiotherapy? If yes, please write down what the problem is?*

Seven radical patients, two men and five women felt they did have a new problem as a result of their radiotherapy treatment three years earlier. The problems were varied:

'Loss of teeth'

'My GP thinks stress is a lot to do with radiotherapy'

'Extreme discomfort on sexual penetration, coupled with slight blood loss'

'Skin area is a bit tight'

'Osteoporosis in the shoulder'

'Radiation affected the heart muscle, could not be helped as tumour attached there'

Question 3 – *Have you had any new problems that you think are related to your cancer? If so, what?*

A total of twelve (14%) felt they did have a new problem related to their cancer. This cohort consisted of 13% of the radical women patients, 14% of the radical men patients and one palliative female patient. A variety of comments were written:

'Cancer of the lining of the womb'

'Neck ache'

'Continued urinary infection'

'I could feel some pain in my chest but not in the same place every time'

'I have a stricture, I do not know if it is related'

'Mood swings'

'Operation, part breast off, no cancer found'.

'Blood in my water'

'My scar and behind it is very tender'

'I think my changed attitude to sexual contact is directly related to my cancer'

'Short of memory and always very tired'.

Those patients who though they had a new problem related to their cancer were significantly more anxious than those who did not (p=0.005).

Question 4 – *Do you feel tired?*

A year ago, 50% of patients were tired. Three years after treatment, 49% are tired. 70% of the patients aged between 26-50 are tired as compared with 40% of the 50-65 and 48% of the 65 plus group. This difference was not significant. All the palliative patients were tired, compared with 43% of the radical patients. Last year, only one of the palliative patients felt tired.

Those patients who felt tired were significantly more anxious, (p=0.001), more depressed, (p=0.001) and distressed (p=0.001) than those who did not feel tired.

Question 5 – *Compared with November 1995, do you now feel better, worse, no change?*

Three years after treatment, 40% are feeling better than they did the previous year, 53% feel the same and 7% feel worse than last year. The six patients who are feeling worse consisted of a palliative breast patient, a radical 'other' category patient, two skin patients and radical gynaecological patient and a NHL patient. Last year, 46% felt better, 48% felt the same and 5% felt worse.

Those patients who felt better or the same were significantly less depressed than those patients who felt worse (p=0.001 Post Hoc Tukey).

Question 6 – *How are you sleeping? No problem, Trouble going to sleep, Awake early, other?*

Over half (52%) of the patients were experiencing sleeping problems, 18% had trouble going to sleep, 24% awoke early and 10% had 'other' problems. Some patients who ticked 'Other' wrote comments which include:

'Wanted to sleep all day'

'Broken sleep'

'Disturbed erratic sleep'

'I wake in the night'

'Sleep intermittently'

Those patients who did not have a problem sleeping, or just had trouble going to sleep where significantly less anxious (p=0.001 Post Hoc Tukey) and depressed (p=0.001 Post Hoc Tukey) than those patients who woke early or cited 'other'.

Question 7 – *How is your appetite? Good, Bad, Normal?*

For the majority of patients (61%) it was good, 33% felt it was normal and 7% felt it was bad. Those patients who said their appetite was bad consisted of four radical breast patients, one radical head and neck patient and one palliative NHL patient.

Those patients whose appetite was normal or good were significantly less anxious (p=0.001, Post Hoc Tukey) and depressed (p=0.006) than those whose appetite was bad. (Group sizes are unequal Type 1 error is not guaranteed).

Question 8 – *Have you lost weight, gained weight, remained the same?*

Six patients had lost weight, five radical breast patients and one radical head and neck patient. A total of 42% of the radical patients and one palliative patient had gained weight. 51% of the patients weight had remained stable. One patient wrote:

'Bad appetite she did not think was related to cancer or its therapy but HRT. Now stopped HRT but can't lose weight. Eat far less than average'

Those patients who had lost weight were significantly more anxious than those who had not (p=0.001, Post Hoc Tukey) (Group sizes unequal Type 1 error not guaranteed).

Question 11 – *Have you had any further radiotherapy treatment since September 1993? If yes did you find the experience any different? If yes, How.*

Three patients had more radiotherapy treatment, one radical gynaecological patient, one radical NHL patient and one radical 'other' site patient. One patient wrote that he found the experience different as this time he had treatment to his penis!

Information and Control

Question 9 – *Do you need to seek any information about your cancer now? If so, what?*

Seven radical patients, four female breast patients, one prostate and one NHL felt they needed more information. Patients' comments included the following:

'A six monthly check with Consultant'

'To make sure I am alright'

'What problems may I have in the future from radiotherapy'?

'More information on the pros and cons of tamoxifen'

'Where I would find anymore lumps'

'To have a blood sample'

No significant differences were found with those patients who wanted more information.

Question 8 – *Have you tried any new complementary medicine in the last year?*

Five patients had tried new complementary medicine, all were women radical patients. No significant differences were found in anxiety or depression for those who had participated in complementary medicine and those who had not.

Social Support

Question 10 – *Do you belong to a Cancer Patient Support Group?*

Four patients belonged to a Cancer Patient Support Group, two radical breast women, one head and neck patient and one from site categorised as 'Other'. There was no significant difference between those patients who belong to a Cancer Support Group and those who did not.

Psychological well-being

Question 12 – *Has anything sad/happy happened to you in the last year? If so what?*

From the eighty seven patients who responded, 45% replied in the affirmative. The following are comments from patients who had experienced sadness.

'My daughter-in-law passed away with cancer and my son tried to commit suicide'

'My husband behaviour has changed. He's depressed all the time, drinks a lot and fights with me (physical) which leaves me very stressed all the time and very unhappy'

'My sick 13 year old granddaughter has been put into a residential home too far away for them to visit'

'My daughter is moving to the USA'

'My daughter has left her husband and living with us and my grandchildren'

'Polyp removed from bowel'

'Prostate op'

'6 weeks of shingles in the eye and head'

'I have had to retire early on health ground'

'Financial problems'

'Moved house'

The following are 'happy' comments

'My daughter got 4 'A's at 'A' level'

'Daughter's wedding'

'Son's wedding'

'My daughter had a baby'

'My first grandchild was born and my son gained entry to university and passed his driving test'

'I became a great grandfather'.

APPENDIX 39
Analysis of Research Questionnaire at 4 Years Post Treatment

Analysis of Research Questionnaire Given at 4 Years Post Treatment

The research questionnaire (See Appendix 25) consisted of nine main questions with some subsets. The questions were divided into three different sections; physical well-being, social support, psychological well-being.

Physical Well-Being

Question 1 – *Do you still have any of the problems related to your radiotherapy that you mentioned before? If yes, please write down what the problem is.*

Last year 29% felt they still had a problem related to their radiotherapy treatment. This year, it had fallen to 23% (17), with 23% (16) radicals and 25% (1) palliative. This cohort consisted of five radical breast patients, one radical skin patient, one radical gastro intestinal, two radical head and neck patients, two gynaecological patients, three radical NHL patients and one palliative NHL patient, one radical bladder patient and one of 'unknown' origin. None of the prostate patients felt they had a problem now. Only one of the remaining palliative patients had a problem related to his treatment. All the NHL felt they had side-effects from their treatment. Significance was not reached with the variables of gender and treatment. The NHL patients wrote:

'Very dry mouth and very tired still'

'Persistent dry mouth'

'Tiredness, lack of concentration and nervousness'

'Skin is still tight'

The patient whose tumour was of 'Unknown origin wrote

'My neck gets spasms of pain on the right and my shoulder'

Head and neck patients also refer to dry mouth symptoms:

'Dry mouth, soreness each side of nose, jaw bone, inside of ears and itchy head'.

Breast patients referred to soreness and pain:

'Cramp down side of ribs and not enough strength to pull myself up (i.e. getting out of the bath)'

'Pain in the arm and across the chest'

'Painful shoulder'

'Lymphodaema'

'Implant pushed out of position caused by combination of surgery and radiotherapy'

The skin patient referred to:

'My eyebrows and chin get very itchy at times'

A cancer of the cervix patient cited

'I.B.S.'

and another gynaecological patient

'Intermittent bouts of diarrhoea but less often than in the last period, but none the less just as embarrassing at the time!'

A colon patient wrote:

'Irregular bowel function'

Question 2 – *Have you had any new problems in 1997 that you think are due to radiotherapy? If yes, please write down what the problem is.*

Only five patients felt they had a new problem, which was due to their radiotherapy treatment, four radical breast patients and one radical head and neck patient.

The problems for the breast ladies varied from:

'Numbness of inner left hand'

'Cramps'

'Hardening of breast'

'Indigestion'

The only male patient had radiotherapy to his head and neck wrote:

'Blocked tear duct and watery eye'

Question 3 – *Have you had any new problems in 1997 that you think are related to your cancer? If so, what?*

Nine (12%) patients felt they had a new problem related to their cancer. Two of the palliative patients had developed new cancers. A NHL patient had a tumour surgically removed from her eye. Other patients complained of fibroids and lumps recurring. A prostate patient cited

'An increase in PSA levels'

Significance was not reached in anxiety and depression with those patients who had new problems.

Question 4 – *Have you had any further treatment since September 1993? If so what? Radiotherapy, Chemotherapy, Hormone therapy, Other, medicines including anti-depressants.*

A total of seventeen (22%) patients had received further treatment since September 1993.

Three patients (4%) had received further radiotherapy treatment. Two had treatment for new primaries and one for metastasis following cancer of the breast.

Four patients (6%) had received chemotherapy including two women breast patients and two gastro-intestinal patients.

Seven patients (9%)had received hormonal therapy. Six were breast patients on tamoxifen and one was a prostate patient.

Three (4%) patients were on antidepressants. Five patients (5%) had written that they had undergone more surgery. Unfortunately, this had been left from the list and this number could be larger. Four out of the five patients appeared to have new primaries and the fifth was a cystoscopy for a prostate patient.

Question 5 – *Do you feel tired?*

Last year, 49% of the patients were tired, this year, 42% of the participating patients are tired. 40% of the radical patients and 75% of the palliative patients felt tired.

Those patients who felt tired were significantly more anxious (p=0.001) and depressed (p=0.001) and distressed (p=0.001) than those patients who were not tired.

There was a significant difference in anxiety and depression according to age and whether patients were tired or not (p=0.01). A post Hoc Tukey showed that those patients who were aged between 26-50 were significantly more anxious than those patients aged between 50 and 65 and those aged over 65 if they had responded that they were tired. . Similarly, those patients aged between 50-65 were significantly less depressed than those patients aged over 65 or aged between 26-50.

Question 6 – *Compared with November 1996, do you feel better, worse or no change?*

Fifteen (20%) patients now felt better compared with last year, five (7%) felt worse and 72% (55) had remained stable. Last year, 40% of patients felt better, 53% felt the same and 7% felt worse. Those patients who felt worse consisted of two radical breast patients, two radical skin patients and one palliative breast patient.

Social Support

Question 7 – *Have you tried any complementary medicines in the last year e.g. aromatherapy, acupuncture, counselling? If so what?*

Five patients (7%) had tried complementary medicine. Four of these were women, three breast patients and one gynaecological. The man was a head and neck patient whom had the occasional massage. One of the breast patients wrote

> 'Been to spiritual healing, but this was not for her cancer but for her painful legs!'

The other breast patients used reflexology and relaxation.

Question 9 – *We are currently undertaking a study to evaluate a telephone support system. Six patients will talk together for approximately an hour each week for four weeks. This is done in the privacy of their own homes via a telephone link. Two professionals will also be linked in to offer support if necessary. All these telephone calls are being paid for. Some patients will have just completed radiotherapy treatment and will be waiting for their first follow up appointment. Others will have finished some time ago. Each group is either male or female and patients can be of any age. Would you be interested in participating in such a group?*

A total of thirteen patients said they would be interested. Six of these patients were being treated for cancer of the breast, the rest came from assorted sites. Men and women were equally represented.

Psychological Well-Being

Question 8 – *Since your cancer have your relationships with friend remained the same, got more superficial, got closer, other. Has your circle of friends increased, decreased, changed, other, please specify.*

The majority (87%) of patients' relationships has remained the same. The other 13% felt their relationships had got closer.

A total of 45% of women felt their circle of friends had increased in comparison with 29% of men. As this population tends to be older, patients wrote that they had a decrease in relationships as many of the contemporaries had died. 41% of the women thought that their relationships had remained unchanged in comparison with 62% of the men.

APPENDIX 40
Analysis of Research Questionnaire at 5 Years Post Treatment

Analysis of Research Questionnaire Given at 5 Years

This final questionnaire (see Apendix27) consisted of thirteen questions with some subsets. The questions were divided into four different sections: physical well-being, information and control, social support and psychological well-being.

Physical well being

Question 1 – *Do you still have any of the problems related to your radiotherapy that you mentioned before? If yes, please write down what the problem is.*

This question has been included in all the previous questionnaires. At the time of the first research questionnaire, which was given to patients on the last day of their treatment, 60% of the patients felt they had symptoms due to their radiotherapy treatment. Four years after treatment, 22% felt they still had a problem and, five years after, this percentage has risen to 28%, 22 patients. 7%, six patients, all men, said they could not remember.

Three of the palliative patients did not have a problem and one said

'he could not remember'

There was an increase in breast and prostate patients with problems. At the time of the first questionnaire, 60% of patients being treated for breast cancer had side-effects. This had dropped to 13% last year. This year, it has increased to 22%. Prostate patients, too, had an increase in problems this year with 60% experiencing problems, last year, none of the prostate patients had a problem. Previously, all the patients suffering from NHL experienced side-effects, however, by five years post treatment, this has fallen to 75%.

Those patients who said they could not remember if they had mentioned a problem before were significantly more anxious (p=0.006) and significantly more distressed (p=0.008) than those patients that answered yes or no.

Not all patients wrote the problem down. Those patients suffering from cancer of the breast mainly complained about

'Excess heat and numbness in upper arm. Also some swelling of the wrist'

'Lymphodaema'

'Weakness in left arm'

'I find movement in my left arm on the side I had radiotherapy quite painful at time'

'Very occasional pain the hollow of neck. Ditto breast pain'

'Scarring of the tissues'

'Displaced implant following surgery and radiotherapy'

'When tired feel sick in area of radiotherapy – more like nausea'.

Three of the five remaining cancer of the prostate patients had problems:

'Sex'

'Still have little energy'

'Nocturnal bathroom visits, continued flatulence'

Patients suffering from cancer of the cervix made the following comments:

'Regular diarrhoea and appearances of blood in my urine from time to time'

'Greater frequency on passing water'

A colon patient wrote

'Wind and bowel irregularities – side-effects from HRT'

A skin patient wrote

'Itchy at times'

NHL patients complained of

'Tightness of the skin'

'Bad arm/shoulder, swollen ankle'

Patients who had tumours of the head and neck immediately after treatment suffered quite badly. On the present survey, only one patient made a comment:

'Very dry mouth'

and the only surviving lung patient wrote

'Sore chest'

A patient being treated for Hodgkin's Disease wrote:

'Knackered circulation – especially in cold weather and increased tiredness as a result',

and the one patient suffering from a tumour of unknown origin wrote:

'Neck and right shoulder pain'

Question 2 – *Have you had any new problems in 1998 that you think are due to radiotherapy? If yes, please write down what the problem is.*

Only one woman patient suffering from NHL felt she had a new problem. Seven (9%) patients were not sure. The NHL patient wrote:

'Bad arm, shoulder swollen'.

A man who had been treated for cancer of the larynx wrote

'Dryness on my face, blotches over the cheeks'

A breast patient wrote:

'Left hand carpel tunnel problem. Beginning now in right hand so may

not be due to radiotherapy. Have seen Dr.'

Question 3 – *Have you had any new problems in 1998 that you think are related to your cancer?*

Eight (10%) patients now felt they had a problem, which could be attributed to their cancer. Only one of the patients was being treated palliatively. These eight patients were being treated for a variety of different site cancers; two had cancer of the breast, two cancer of the skin, one head and neck, one NHL, one prostate and one cervix. The cervix patient wrote

'Stomach tumour removed. Chemotherapy suggested but I declined'

The patient being treated for bladder cancer said:

'I have begun bleeding into my urostomy bag and am undergoing more

tests'

The breast patient wrote:

'Hysterectomy'

Skin patient wrote:

'Two more rodent ulcers removed from my face'

Prostate patient said:

'Cancer returned to prostate – or did it ever go?'

Finally, a patient who had previously been treated for cancer of the larynx now stated that he had

'Cancer of the prostate'

Question 5 – *Do you feel tired?*

This question has been asked in the previous questionnaires. Last year, 42% of this population felt tired. This year it has risen to 46%.

Patients that were tired were significantly more anxious, (p=0.032), significantly more depressed, (P=0.015) and significantly more distressed (p=0.010) than patients who were not tired. Further analysis using GLM showed that age and tiredness reached significance. Patients that felt tired were significantly more depressed p=0.009. Similarly, Post Hoc Tukey showed that patients aged 65 plus were significantly more depressed (p=0.008) than those patients aged 50-65.

Question 6 – *Compared with November 1997, do you feel better, worse, no change.*

Since the questionnaires last year, fifty (67%) patients felt their condition had not changed, twenty two (28%) felt better and seven (9%) felt their condition had got worse.

One patient wrote that he was feeling worse:

'Due to recent heart problems'

One year ago, 21% felt better and 72% felt no change in their condition.

Analysis showed that those patients who felt better had significantly lower anxiety (p=0.002) and depression (p=0.007) and distress (p=0.007). A Post Hoc Tukey showed that patients who felt better had significantly lower anxiety than those patients who felt worse (p=0.003) and those patients who had 'no change' (p=0.048). Similarly, those patients who felt better were significantly less depressed than those patients who felt worse (p=0.005) and less distressed (p=0.007).

Social Support

Question 4 – *Looking back over the last 5 years do you feel that you could have received more help for any of the problems you have experienced?*

Seven (9%) patients felt they could have had more support, three were breast patients, one prostate, one head and neck and one NHL. A woman NHL patient wrote:

'More explanations out everything'

A man wrote:

'Regular massage/acupuncture form a fully experienced expert'.

Four breast patients wrote comments:

'Lymph drainage. Massage regularly on the NHS'

'I worry more about any unusual pain that I get'

'A talk, before half my breast was taken away it has taken my over a year
to get over this. Counselling to patients seems to have been overlooked'

A man who had returned to the radiotherapy department for further treatment wrote:

'In the first instance I don't think I was made fully aware of all the help or
assistance'.

Finally a cervix patient wrote:

'A better knowledge of the affect the radiotherapy would have on my
bowel and bladder in the first instance would have allayed lots of worries
later associated to these problems'.

**Question 7 – *Have you tried any complementary medicines in the last year e.g.
aromatherapy, acupuncture, reflexology? If so, what?***

Nine patients (11%) had tried complementary therapies in the last year. All
were women. None of the palliative patients had participated. Last year, five patients
responded in the affirmative. The five breast patients had participated in a variety of
therapies.

'Reflexology, relaxation, aromatherapy'

was cited by one patient

'Aromatherapy, acupuncture and reflexology'

was cited by another. Another two of the women had participated in aromatherapy
and one in homeopathy. Two cervix patients had received aromatherapy and a colon
patient had used chiropractise. A patient suffering from Hodgkin's Disease wrote:

'Reflexology – once a week. Tell all your clients to have it – as it is
tremendously helpful – particularly post treatment'.

Significance was not reached with any of the variables.

**Question 8 – *In the last year have you changed your diet, started an exercise
program, joined a support group or similar, which could be labelled self-help?***

Seventeen patients (22%) had participated in some positive self-help. None of
the palliative patients was in this group. Nine of the patients had changed their diet,

three of them for other illnesses – two were suffering from diabetes and one from arthritis.

Several patients specifically mentioned low fat diet coupled with exercise. (This survey was taken at Christmas). Eight patients wrote

'Exercise'.

This ranged form dog walking, joining a gym to ballroom dancing. One patient was doing specific exercise for his heart.

Two patients had joined a support group – one a laryngectomy club and the other a telephone support line.

No significant differences were found in patients whom had used this positive self-help and those whom had not.

Psychological well being

Question 9 – *Looking back over the last five years can you tell us what you found were the three most difficult experiences for you, in order, starting with the worse, then the nest worse? E.g. getting the diagnosis, surgery, radiotherapy, chemotherapy, hormone therapy, waiting for test results, some other experience.*

Getting the diagnosis was the most difficult time for 66% of patients. One patient wrote

'Being given the diagnosis after being assured for 18 months that the lump was benign'

A further 8% felt waiting for test results was the most difficult time, 7% wrote surgery, 5% chemotherapy, 5% radiotherapy and 10% 'Other'.

Other was made up of wide ranging comments, which reflected patients own personal difficulties, such as:

'Not tasting food'

'Delay in starting treatment'

'Drinking a lot of water before the scan'

'Finding my way around Mount Vernon Hospital'

'Trying to find help – never have cancer in the summer holidays'.

The second worst experience for patients was surgery (29%), closely followed by radiotherapy (24%), then 'getting test results (16%) and then 'getting the diagnosis (16%). 3% voted respectively for 'side-effects' of radiotherapy, chemotherapy and information on and making of prosthesis. 'Other' accounted for 11% of the patients, which included:

'Gamma-med'

'A loss of personal privacy'

'Giving up golf'

'Discussing it with the family'

'Unable to go on holiday'

'Finding a parking place'

'Told cancer returned'.

The third worst experience for patients undergoing treatment was radiotherapy, with 28% of patients, especially men, making this their choice,. Second came 'test results' with 23%, followed by surgery (11%), with chemotherapy and initial diagnosis (6%) jointly in fourth place. Fifth was 'side effects' of radiotherapy (3%). The 'other' category accounted for 20% with comments such as:

'Recurrent new lump'

'Unable to eat'

'Worry about the treatment'

'Worry about long-term synopsis

'The length of time to recover'

'The almost immediate and extremely disturbing effect the radiotherapy had on my bowel'

'Not being able to walk without someone'

'Wrong diagnosis'

'Working while having radiotherapy'

'Not being able to reach for dressings in my locker'

'The realization of what one mentally had'

'The matter of fact way in which things were handled'

'Waiting between surgery and treatment'.

Question 10 – *Looking back over the past five years can you tell us the worst three times for your family/close friends, in order, starting with the worse, then next etc. Getting the diagnosis, surgery, hormone therapy, waiting for test results or some other experience like waiting between surgery and radiotherapy, or after radiotherapy.*

91% of patients answered this, presumably some patients were not able to ask their friends or family. A total of 70% thought getting the diagnosis was the worst time, 10% thought 'waiting for the results' and 4% thought chemotherapy. Radiotherapy was not mentioned and one patient only mentioned surgery. A further 8% included such comments as:

'Side-effects of radiotherapy

'Travelling for 6 and a half weeks to Mount Vernon for radiotherapy'

'When the cancer returned'

'Seeing how upset I was with hair loss etc during chemotherapy'

The second worse experience was surgery, 43%, then 'test results' (22%), radiotherapy (14%), 'getting the diagnosis (5%), 'worry about treatment' (4%). A further 12% included such comments as:

'Worry about long-term'

'The worry that it might come back again'

'The waiting and waiting'

'Being told the cancer has returned'

'Waiting for surgery'

'Worry about the length of time to recover'.

The third worse experience for friends and family was radiotherapy (30%), then 'test results' (7%), surgery (15%), worry about long-term outlook (7%) chemotherapy and 'endless waiting (6%) respectively. Comments included:

'Wrong diagnosis'

'Matter of fact attitude'

'Side-effects of radiotherapy'

One patient did not tick anything but wrote

'I live on my own and didn't tell the family until I went for surgery. They don't live close by and have their own problems'.

Question 14 – *Now that the study is finishing will you tell us how you felt about taking part? Please tick any that apply*

I found it helpful to be participating in something that would help other patients

I found it helpful because it reminded me of my cancer

It helped me come to terms with my illness

It gave me confidence to talk with my doctor

It made me realize my reactions were normal

It made me worry in case I experienced any of these problems or feelings.

Patients did tick several boxes if it was felt appropriate.

A total of 91% of patients found it helpful to participate in something that would help other patients.

Only seven (9%) found it helpful as it reminded them of their cancer. The seven included four patients being treated for breast cancer, two had skin cancer and one head and neck patient.

A total of 41% thought that the study helped them to come to terms with their illness, twenty women and thirteen men.

One third of the patients thought the study had made them more confident to talk with their doctor. Over half (52%) thought that the study made them realize that their reactions were normal and only five (6%) felt worried by the study.

Information and Control

Question 12 – *Would you like to be sent a summary of this study?*

Sixty (76%) wanted to receive a summary. Nearly half of the men and 25% of the women did not want to receive one.

Question 13 – *Would you be interested to meet others who took part in this study? Would you agree to us contacting you?*

A quarter of patients said they would be interested in meeting others who took part in the study. One woman wrote:

'don't know'.

The cohort who was interested consisted of 26% women and 22% men. One patient wrote

'Sorry No I really want to put the whole thing behind me. I have moved on in leaps and bounds over the past five years.

Nearly three quarters (72%) said they would agree to us contacting them, 77% of the men and 70% of the women.

Finally patients were asked

Do you have any comments to make?

The following are quotes from patients and are divided into the following sections,

1. their feelings.
2. the questionnaires.
3. support issues.
4. positive attitudes in coping with cancer.
5. the altruistic aspect of this study
6. their physical condition
7. positive responses to the staff.

1. Their Feelings

'Taking part in this series of questionnaires actually helped me to think about and admit what I was feeling about my treatment. I am not very good at admitting how I feel about things, but just being able to circle or tick something which affected me helped me to face the way I was feeling at the time'

'I could not discuss my feelings with anyone and even now only a few people know so that the questionnaires dealt with my deep mind'

'It made me feel lucky that I had not many problems and came to term with my illness'

'This study seemed to sum up how I was feeling and this made me realize my feelings were "normal".

'This is not something I like doing too frequently'

'I am glad I took part in the research, I knew that there were a lot of other people taking part in it and it made me feel I was not alone in my illness'.

2. The Questionnaires

'I found the to-ing and fro-ing of the questions a bit dizzying. The "strongly disagree", "agree" gets me cross-eyed. I never knew if I put what I intended'.

'Sometimes how I answered the questions depended upon how I felt at the time which may not have any bearing on the cancer, e.g. answering questionnaire following a heavy cold or a difficult time at work. Some questions felt repetitive some I had mixed feelings about which made them difficult to answer'

'A bit laborious but OK as it is only once a year'

'When you believe yourself to be cured it is rather irritating to keep answering the same questions. The same questions put another way is also very annoying. I understand however why the information is useful. The questions are rather black and white and one cannot qualify. The questions make one realize what it would be like if incurable cancer was ever one's diagnosis'

'Questions about my physical and mental state were quite easy and straight forward'

'Occasionally I felt confused when answering the questions because I wasn't sure whether problems I experienced were attributable to my cancer or not. Also self-evaluation – are we supposed to evaluate our moods/state of mind in general terms or only as relating to our cancer'.

'I sometimes found it difficult with the negative questions I find it easier with the positive questions. I have also found it difficult with degrees of answer e.g. as in disagree- strongly, moderately, slightly'.

3.   Support Issues

''I found the chemotherapy very frightening and would have given up after three months if I had not had the support of my husband'

'Yes, Macmillan nurses seem to take an interest when diagnosed with cancer and then they never seem to be there anymore. Anyhow I'm really well and getting on with my life'

'Normally at the 5 year mark appointments are gradually trailed off – She wants to keep me, still once a year. It is extremely reassuring to have this support'.

4. Positive Attitudes in Coping with Cancer

'I would like to say that one has to be positive and each day/year is a bonus'

'Although I wanted to help I didn't like being reminded. Being a positive person I don't like looking backwards'

'I found being positive about having cancer helped me to cope with it'

'Having a positive mental attitude throughout I believe has helped me through it along with a little help from my friend'

5. The Altruistic Aspect of this Study

'I think if more people's reactions were asked for and collated and expressed by the medical profession cancer wouldn't appear so scaring. This is why it is important for patients to help other it may apply to'.

'I hope the responses you have received will help fellow sufferers'

'The study has been helpful to me in respect I felt in some small way helping future sufferers and that I wasn't just forgotten about after treatment. The trouble was radiotherapy didn't kill off all the cancer cells so I am told'

'Taking part in the survey made me realize that there are many more people who are going through the same traumas as me and knowing that the survey may help others has helped me

6. Their Physical Condition

'Drugs I need to take would appear to have adverse result i.e. blood pressure, heart, gout, water retention, diabetes, thyroid'

'I do not think my trouble was too serious (skin patient), I would not have been too concerned if I had to have further treatment'

'The Zoladex injections I have once a month in the surgery have reduced the cancer level and I am extremely grateful for this'.

7. Positive Response to the Staff

'To thank staff for their kindness and help in taking worry away'.

'I was treated very well indeed and everyone so very kind and helpful'

'Thank you for all you do'

'It's good to know that you and others care'

'It's nice to know that somewhere somebody cares. At 76 years of age, it's more unusual. Thank you'

'I found everybody so kind right from start to finish'

'The treatment from surgeon to doctors and nurses at the hospitals both MV and Watford G were so wonderful, they helped me through the whole time. There is always an exception to this and that was a nurse who was supposed to be a cancer patient support – But she was soon sorted – so for all forgotten'

'To express my gratitude for immediate and effective treatment received which has extended my life by 5 years so far'

'Thanks to all the people at MV who helped me to reach where I am now. A very successful businesswoman in the cleaning business called Supermaids'

Finally, two miscellaneous comments

'I now would like to be left alone to get on with my life and try to forget the past as much as possible'

'My sense of humour helps when I feel a bit down in the mouth'.

APPENDIX 41
Table30: Demographic and Medical Characteristics at 1 Year Post Treatment

Table 30: Showing Demographic And Medical Characteristics at 1 Year Post Treatment

DEMOGRAPHIC	Nos	%	MEDICAL	Nos	%
Gender			**Sites**		
Female	82	69.0	Breast*	61	51.0
Male	36	31.0	Lung	7	5.0
			Prostate	7	7.0
Social Class			Skin**	12	10.0
			Other***	5	4.0
Class A	5	5.0	Gastro-int	4	4.0
Class B	18	17.0	Bladder	3	3.0
Class C1	42	35.0	Head & Neck	5	4.0
Class C2	29	20.0	Gynae	7	6.0
Class D	20	17.0	NHL	5	4.0
Unclassified	4	4.0	Unknown	2	2.0
Marital Status			**Treatment Intent**		
Married	77	67.0	Radical	101	86.0
Widowed	18	14.0	Palliative	17	14.0
Divorced	6	4.0	**Ages**		
Single	10	8.0	18-25	0	0.0
Separated	5	4.0	26-50	22	18.0
Unknown	0	0.0	50-65	43	37.0
Partner	2	2.0	65+	53	45.0

*   Includes one male breast patient
**   Includes only superficial tumours, melanoma is included in 'others'.
***   Includes glioblastoma, sarcoma, mesothelioma, Hodgkin's Disease, melanoma

APPENDIX 42
Table31: Demographic and Medical Characteristics at 18 Months Post Treatment

Table 31: Showing Demographic And Medical Characteristics at 18 Months Post Treatment

DEMOGRAPHIC	Nos	%	MEDICAL	Nos	%
Gender			**Sites**		
Female	70	69.0	Breast*	53	52.0
Male	32	31.0	Lung	3	3.0
			Prostate	6	6.0
Social Class			Skin**	10	10.0
			Other***	6	6.0
Class A	6	6.0	Gastro-int	5	5.0
Class B	18	18.0	Bladder	3	3.0
Class C1	34	33.0	Head & Neck	5	5.0
Class C2	25	24.0	Gynae	5	5.0
Class D	17	17.0	NHL	4	4.0
Unclassified	0	0.0	Unknown	2	2.0
Marital Status			**Treatment Intent**		
Married	67	66.0	Radical	93	91.0
Widowed	14	14.0	Palliative	9	9.0
Divorced	6	6.0	**Ages**		
Single	9	9.0	18-25	0	0.0
Separated	5	5.0	26-50	20	20.0
Unknown	0	0.0	50-65	42	42.0
Partner	1	1.0	65+	40	39.0

*   Includes one male breast patient
**   Includes only superficial tumours, melanoma is included in 'others'.
***   Includes glioblastoma, sarcoma, mesothelioma, Hodgkin's Disease, melanoma

APPENDIX 43
Table32: Demographic and Medical Characteristics at 2 Years Post Treatment

Table 32: Showing Demographic And Medical Characteristics at 2 Years Post Treatment

DEMOGRAPHIC	Nos	%	MEDICAL	Nos	%
Gender			**Sites**		
Female	68	72.0	Breast	51	54.0
Male	27	28.0	Lung	1	1.0
			Prostate	5	5.0
Social Class			Skin**	9	9.0
			Other***	5	5.0
Class A	4	4.0	Gastro-int	4	4.0
Class B	20	21.0	Bladder	3	3.0
Class C1	29	31.0	Head & Neck	5	5.0
Class C2	24	26.0	Gynae	7	7.0
Class D	16	18.0	NHL	4	4.0
Unclassified	0	0.0	Unknown	1	1.0
Marital Status			**Treatment Intent**		
Married	66	0.0	Radical	90	95.0
Widowed	13	0.0	Palliative	5	5.0
Divorced	3	0.0	**Ages**		
Single	7	0.0	18-25	0	0.0
Separated	4	0.0	26-50	21	22.0
Unknown	0	0.0	50-65	40	42.0
Partner	2	0.0	65+	34	36.0

**   Includes only superficial tumours, melanoma is included in 'others'.
***   Includes Hodgkin's Disease, melanoma

APPENDIX 44
Table33: Demographic and Medical Characteristics at 3 Years Post Treatment

Table 33: Showing Demographic And Medical Characteristics at 3 Years Post Treatment

DEMOGRAPHIC	Nos	%	MEDICAL	Nos	%
Gender			**Sites**		
Female	68	74.0	Breast	48	52.0
Male	24	26.0	Lung	2	2.0
			Prostate	5	5.0
Social Class			Skin**	8	9.0
			Other***	5	5.0
Class A	5	5.0	Gastro-int	2	2.0
Class B	17	19.0	Bladder	3	3.0
Class C1	28	30.0	Head & Neck	7	8.0
Class C2	21	22.0	Gynae	7	8.0
Class D	17	18.0	NHL	4	4.0
Unclassified	0	0.0	Unknown	1	1.0
Marital Status			**Treatment Intent**		
Married	64	69.0	Radical	90	95.0
Widowed	13	14.0	Palliative	5	5.0
Divorced	3	3.0	**Ages**		
Single	7	8.0	18-25	1	1.0
Separated	3	3.0	26-50	19	21.0
Unknown	0	0.0	50-65	38	41.0
Partner	2	2.0	65+	34	37.0

**   Includes only superficial tumours, melanoma is included in 'others'.
***   Includes, Hodgkin's Disease, melanoma

APPENDIX 45
Table34: Demographic and Medical Characteristics at 4 Years Post Treatment

Table 34: Showing Demographic And Medical Characteristics at 4 Years Post Treatment

DEMOGRAPHIC	Nos	%	MEDICAL	Nos	%
Gender			**Sites**		
Female	54	71.0	Breast	39	51.0
Male	22	29.0	Lung	0	0.0
			Prostate	5	7.0
Social Class			Skin**	8	10.0
			Other***	4	5.0
Class A	4	5.0	Gastro-int	3	4.0
Class B	18	24.0	Bladder	3	4.0
Class C1	23	31.0	Head & Neck	4	5.0
Class C2	16	21.0	Gynae	5	7.0
Class D	14	19.0	NHL	4	5.0
Unclassified	0	0.0	Unknown	1	1.0
Marital Status			**Treatment Intent**		
Married	55	72.0	Radical	72	95.0
Widowed	9	12.0	Palliative	4	5.0
Divorced	2	3.0	**Ages**		
Single	5	6.0	18-25	0	0.0
Separated	3	4.0	26-50	17	22.0
Unknown	0	0.0	50-65	29	38.0
Partner	2	3.0	65+	30	40.0

**   Includes only superficial tumours, melanoma is included in 'others'.

***   Includes Hodgkin's Disease, melanoma

APPENDIX 46
Table35: Demographic and Medical Characteristics at 5 Years Post Treatment

Table 35: Showing Demographic And Medical Characteristics at five years post

DEMOGRAPHIC	Nos	%	MEDICAL	Nos	%
Gender			**Sites**		
Female	57	72.0	Breast	39	49.0
Male	22	28.0	Lung	1	1.0
			Prostate	5	6.0
Social Class			Skin**	7	9.0
			Other***	5	6.0
Class A	5	8.0	Gastro-int	3	4.0
Class B	17	22.0	Bladder	3	4.0
Class C1	23	30.0	Head & Neck	4	5.0
Class C2	17	22.0	Gynae	7	9.0
Class D	14	18.0	NHL	4	5.0
Unclassified	0	0.0	Unknown	1	1.0
Marital Status			**Treatment Intent**		
Married	53	67.0	Radical	75	95.0
Widowed	11	14.0	Palliative	4	5.0
Divorced	2	2.0	**Ages**		
Single	6	7.0	18-25	1	1.0
Separated	4	5.0	26-50	16	20.0
Unknown	0	0.0	50-65	32	40.0
Partner	3	4.0	65+	30	39.0

**   Includes only superficial tumours, melanoma is included in 'others'.
***   Includes Hodgkin's Disease, melanoma