AN EXAMINATION OF THE PERIOD BETWEEN SURGERY AND RADIOTHERAPY FOR PATIENTS WITH MALIGNANT GLIOMA AND THEIR FAMILIES

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PhD Thesis

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THIS THESIS IS THE SOLE WORK OF THE AUTHOR. ALL REFERENCES AND SOURCES OF DATA WITHIN THE THESIS ARE FROM ORIGINAL SOURCES.
Acknowledgements

I would like to thank Dr R Grant, Dr S Rodgers and Dr G Smith, for their encouragement and supervision throughout the development and completion of this thesis and to Prof. I Whittle for providing the funding to enable me to undertake my PhD studies.

Acknowledgements have to be given to my Dad and Derick for all their support, encouragement and patience throughout my academic life. Without them I would have never attempted to undertake and complete a PhD thesis.

All my work colleagues over the past five years have been very supportive of me and without the patients and carers who participated in this study it would never have happened.

This thesis has to be dedicated to my Mum as without her love, support and encouragement throughout my life I would never have attempted to achieve what I have. Thank you Mum.
ABSTRACT

INTRODUCTION & BACKGROUND TO STUDY
The most prevalent type of primary brain tumour is the malignant glioma (Davies & Hopkins 1997). The prognosis for this type of tumour is poor (6-12 months) and the treatment offered to patients with this diagnosis is palliative. It is, therefore, imperative that throughout their illness they, and their carers, receive optimum care (Davies & Hopkins 1997, Gupta & Sarin 2002, Efficace & Bottomley 2003).

STUDY AIM
To examine the practical and emotional issues that patients with a malignant glioma and their carers experience between their surgery and radiotherapy.

STUDY DESIGN
Using a comparative descriptive design, this study prospectively examined 51 patients and their carers between their surgery and radiotherapy. The study explored changes in neurological functional status, frequency and severity of anxiety and depression levels, prevalence of side effects of dexamethasone therapy and level of disruption to lives and life quality of patients and their carers.

STUDY FINDINGS
Lack of information and appropriate support, initiate a maladaptive emotional and physical response to the diagnosis of malignant glioma. The age, past medical history and familial commitments of patients are factors which influence the physical and emotional response exhibited.

RECOMMENDATIONS
If nurses and/or other health care professionals consider the age, past medical history and family commitments of patients, undertake regular assessment of the patients' neurological functional state and closely monitor the dosage and effectiveness of dexamethasone therapy, they could anticipate and predict the physical and emotional response of patients and their carers to the diagnosis of malignant glioma between surgery and radiotherapy. Overall implementation of these recommendations would ensure that the support needs of patients and carers could be met between surgery. Consequently, during this time the quality of the lives of these individuals could be optimised.
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Appendix 6  Level of Life Disruption Questionnaires
Appendix 7  Patient Proforma
Appendix 8  Patient Information Leaflet
Appendix 9  Consent Form
Appendix 10  EORTC Questionnaire
INTRODUCTION

The following three chapters will provide a review of the literature that underlies the development of the research aim and questions of the study. The following chapters have evolved with the study and aim to:

- Chapter 1 - Provide the reader with an accurate insight to the incidence, classification and aetiology of malignant brain tumours and indicate the types of treatment patients may receive.
- Chapter 2 - Provide a review of the current literature to indicate the potential psychosocial response of patients between surgery and radiotherapy and develop a theoretical basis for the response exhibited.
- Chapter 3 - Emphasise the importance of effective nursing care in the management of malignant glioma and the need for further research into the physical, psychological and social needs of these patients’ in the period between surgery and radiotherapy.

Search Strategy

To ensure a systematic and comprehensive review of the literature was included within this thesis, comprehensive literature searches were undertaken by the researcher at regular time points throughout the study. The majority of literature searches were undertaken using electronic databases. At times hand searching was employed to locate some useful and relevant articles that were identified through alternative sources e.g. attendance at conferences, communication with peers and amongst published papers reference lists.
The complex nature of the topic of investigation ensured that a wide range of key words and thesaurus terms had to be applied to a number of databases at various stages of the study. The databases searched were: AMED, ASSIA, British Nursing Index, Cancerlit, Cochrane Central Database of Controlled Trials, CINAHL, EMBASE, Management Information Consortium, ISI Web of Knowledge, MEDLINE, PsycINFO and ZETOC. The searches were generally undertaken upon literature published from 1990 – onwards. The search strategies applied to these databases throughout the study can be described using the two main topics of investigation and the research design employed;

- malignant brain tumours
- coping with diagnosis and treatment and
- research design; descriptive studies.

To ensure all the literature was retrieved the researcher had to combine some of the key word search strategies detailed in Tables 1.1, 1.2 & 1.3 and extend the years of publication beyond, 2000 – present. Internet sites e.g. Department of Health, Scottish Executive, National Institute for Clinical Excellence (NICE) were also searched for information or literature relevant to the study.

All types of study designs were included in the searches. Only literature written in English language was included. The number of hits that each search generated varied considerably depending on the primary search term e.g. malignant brain tumour generated significantly less hits than cerebral metastasis. The majority of literature retrieved that pertained to the care of patients with malignant brain tumours was related to outcome measures such as tumour size, time to progression and overall survival. However, through searching the databases for literature that related to other cancer diagnoses a large amount of material was retrieved that related to coping with diagnosis and treatment. The researcher used all the literature retrieved from the searches to develop the literature review, establish the research aims and questions and determine the study design.
Table 1.1  Search Terms used for Malignant Brain Tumour

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<td>• Life Disruption</td>
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<td>• Dexamethasone</td>
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<td>• Anaplastic Astrocytoma</td>
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- Carer Experience
- Clinical Nurse Specialist
- Communication
- Depression
- Discharge/Post Surgery
- Nursing Care
- Patient Experience
- Patient Information
- Psychological Distress
- Radiotherapy
- Service Costs
- Stress
- Support Network
- Uncertainty
- Waiting for Treatment /Delay
### Table 1.3  Search Terms Used for Research Design

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CHAPTER 1:
The Care of Patients with Malignant Brain Tumours

1 INTRODUCTION

This chapter will consider the incidence, classification and aetiology of malignant brain tumours. The morbidity and mortality of malignant brain tumours will be discussed in conjunction with the treatment options available to patients and the planning of services required to deliver this treatment. There is generally a great deal of consensus within the literature about the incidence, presenting symptoms, pathophysiology, treatment modalities, prognostic factors and survival rates for malignant brain tumour patients. The most recent large multi-centre study that investigated patterns of care for malignant glioma patients was entitled the Glioma Outcomes Project. This prospective audit was undertaken between 1997 – 2000 in the United States of America. It enrolled 788 patients with malignant glioma Grade III and IV (Laws et al 2003, Chang et al 2005). The clinical presentation, preoperative care, surgical management, adjunctive therapies after definitive diagnosis and survival outcomes of each patient was reported. It was concluded, in general, that the care offered to these patients was in keeping with recently published guidelines. This chapter focuses upon the literature with a sound evidence base.

1.1 THE INCIDENCE OF MALIGNANT BRAIN TUMOURS

From registration databases it is concluded that the incidence of primary brain tumours within the United Kingdom is 4-6 per 100,000 (Muir et al 1994). Using multiple overlapping sources the incidence has been calculated in the South East of Scotland to
be 9 per 100,000 a year (Grant et al 1996). The incidence of cerebral metastases is 12.5%
per 100,000 within South East of Scotland (Grant et al 1996).

Primary brain tumours can be classified and graded using the World Health Organisation
(WHO) Classification of Tumours affecting the Central Nervous System (see Table 1.4). Primary brain tumours (WHO grade III and IV) and metastatic brain tumours are
classified as malignant. These classifications imply an aggressive tumour with poor
prognosis that requires urgent medical intervention to control its growth or minimise the
adverse effect it is having upon the patient’s neurological function. The type of medical
intervention a patient receives depends upon the grade of the tumour, the location of the
tumour, the age and functional status of the patient.

Table 1.4: WHO Classification of Tumours Affecting Central Nervous System
{adapted from Tatter (1995)}

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<tr>
<td></td>
<td>Anaplastic Ependymoma</td>
<td>WHO Grade III</td>
</tr>
<tr>
<td>Low Grade Glioma</td>
<td>Astrocytoma</td>
<td>WHO Grade II</td>
</tr>
<tr>
<td></td>
<td>Mixed glioma</td>
<td>WHO Grade II</td>
</tr>
<tr>
<td></td>
<td>Oligodendroglioma</td>
<td>WHO Grade II</td>
</tr>
<tr>
<td></td>
<td>Ependymoma</td>
<td>WHO Grade II</td>
</tr>
</tbody>
</table>

1.2 CLASSIFICATION OF BRAIN TUMOURS

Primary Brain Tumours can be graded as high grade and low grade. They are classified
according to the cell of their origin and the stage of their development (Brada & Thomas
1995). The WHO grades astrocytomas into four grades; Grade 1 are the least malignant
and Grade IV are the most malignant (Zulch 1982, Tatter 1995). The causes of primary
brain tumours are generally unknown (McKinney 2005). A number of epidemiological
studies have been undertaken to try and determine risk factors related to the
development of primary malignant brain tumours (McKinney 2005, Wrench et al
2002). However, to date there have been no predisposing environmental or genetic risk
factors linked solely to their development (McKinney 2005). It is believed that brain tumours arise from one or more genetic mutations in cellular deoxyribonucleic acid (DNA) (Brada & Thomas 1995, Singh et al 2004). These mutations may be inherited or caused by any chemical, physical or biological agents that are known to be neurocarcinogenic.

A small percentage (1-2%) of brain tumours are associated with familial conditions such as neurofibromatosis, tuberous sclerosis and familial adenomatous polyposis (Brada & Thomas 1995, Wrensch et al 2002). Although some studies have proven that high dose exposure to ionising radiation is attributable to the development of brain tumours further large epidemiological studies are required to further investigate their cause (McKinney 2005). The low incidence of malignant brain tumours within the population makes it very difficult to perform epidemiological studies.

Metastatic brain tumours originate from a primary tumour outside of the brain and common sites for this primary tumour are the lung, breast, gastrointestinal tract and genitourinary tract (Hickey 1997).

1.3 **The Anatomical Location of Brain Tumours**

The presenting signs and symptoms of patients with brain tumours are caused by raised intracranial pressure and local or general brain dysfunction (Brada & Thomas 1995). The anatomical location of a brain tumour will influence the patient’s presenting symptoms and signs, as the normal functioning of that area that becomes impaired (see Figure 1.5). As a tumour grows and cerebral oedema increases, the following symptoms and signs of raised intracranial pressure become apparent: deterioration in level of consciousness, abnormal pupil reaction, eye movement disorders, weakness, sensory deficits and changes in respiratory function (Hickey 1997).
Headache and seizures are the most common presenting symptoms of a brain tumour patient but other focal (hemiparesis, dysphasia, hemisensory or diplopia) and non focal symptoms (confusion, memory problems, personality changes, unsteadiness) are present in smaller percentage of patients (Salander et al 1999, Grant 2004, Chang et al 2005). The presenting symptoms and signs of a brain tumour depend upon the site of tumour and mass effect of tumour. These attributes of the brain tumour can be determined by neurological clinical examination and Computerised Tomography (CT) and/or Magnetic Resonance Imaging (MRI) scan. The treatment options considered for patients with malignant brain tumours are based upon these baseline investigations (Britton & Ng 1998). The potential options are steroid treatment, surgery, radiotherapy and/or chemotherapy.

1.4 PROGNOSTIC FACTORS
Age, functional status, histopathology are known to be significant prognostic factors for patients with malignant brain tumours (Bussiere et al 2005, Florek et al 2005). Prior to
making any recommendation about treatment to patients it is recommended that clinicians consider these factors. The Medical Research Council (MRC) prognostic index (Table 1.6) was developed to assist clinician’s assessment of patients (MRC Brain Tumour Working Party 1990). There are currently National Institute for Clinical Excellence (NICE) guidelines being developed for the treatment of brain tumours, publication of these guidelines will provide additional guidance for clinicians.

Table 1.6 The MRC Prognostic Index (MRC Brain Tumour Working Party 1990)

<table>
<thead>
<tr>
<th>Prognostic factor</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age:</td>
<td></td>
</tr>
<tr>
<td>&lt;45</td>
<td>0</td>
</tr>
<tr>
<td>45-59</td>
<td>6</td>
</tr>
<tr>
<td>&gt;60</td>
<td>12</td>
</tr>
<tr>
<td>Clinical performance status:</td>
<td></td>
</tr>
<tr>
<td>0-1</td>
<td>1</td>
</tr>
<tr>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>3-4</td>
<td>8</td>
</tr>
<tr>
<td>Extent of neurosurgery:</td>
<td></td>
</tr>
<tr>
<td>Complete resection</td>
<td>0</td>
</tr>
<tr>
<td>Partial resection</td>
<td>4</td>
</tr>
<tr>
<td>Biopsy</td>
<td>8</td>
</tr>
<tr>
<td>History of fits:</td>
<td></td>
</tr>
<tr>
<td>&gt;3 months</td>
<td>0</td>
</tr>
<tr>
<td>&lt;3 months</td>
<td>5</td>
</tr>
<tr>
<td>None</td>
<td>10</td>
</tr>
</tbody>
</table>

Index = sum of scores for each factor.

1.5 STEROID THERAPY

Steroids are used to control cerebral oedema and they improve the neurological signs and symptoms in two thirds of patients (Vecht 1994). Although there are no comparative studies of steroids, Dexamethasone, is the steroid that is prescribed for up to 99% of patients', because its mineralocorticoid activity is lower than that of other steroids.
(Vecht 1994, Gupta & Sarin 2002, Chang et al 2005). In the initial stages of brain tumour management dexamethasone dosages of 16 mg daily are commonly prescribed. This dosage is usually maintained until the next stage of the patient’s treatment has been determined (Brada & Thomas 1995, Grant et al 1999, Gupta & Sarin 2002). The starting dose, tapering and stopping of dexamethasone therapy is empirical and to date no studies have been undertaken to indicate the most effective dosage for malignant glioma patients (Gupta & Sarin 2002). The reversal of symptoms witnessed after the commencement of dexamethasone can be remarkable. However, the mechanism by which dexamethasone resolves these symptoms is generally uncertain (Miller & Ironside 1997, Gupta & Sarin 2002).

There are many side effects of dexamethasone therapy and it is important that these are minimised (Regnard & Tempest 1992, Twycross 1994, McNamarra & Kilbride 1999). It is important that nurses and patients are involved in monitoring the side effects of dexamethasone therapy (Auken & Crawford 1998, McNamarra & Kilbride 1999). The onset of side effects after starting dexamethasone is variable. Insomnia, irritability, psychotic reactions, hyperglycaemia, hypertension and gastric upset can be apparent soon after administration (Twycross 1994). Other side effects such as fluid retention, depressed immune response, and biochemical imbalances may be of slower onset. Steroid therapy has to be withdrawn in five percent of patients due to the onset of side effects. The withdrawal of dexamethasone therapy at an inappropriate stage within brain tumour management can be fatal, as the cerebral oedema may no longer be controlled (Twycross 1994).

In an attempt to overcome the potential detrimental effects of dexamethasone therapy it is important to monitor the patient closely whilst they are receiving this drug (Regnard & Tempest 1992, Twycross 1994). Many drugs and other conditions interact with dexamethasone. Therefore, the patient’s concurrent medications and medical history should be studied (Murphy 1997). There is some ambiguity about the link between peptic ulceration and the administration of dexamethasone. Some authors recommend the concomitant use of a Histamine 2 (H2) receptor antagonist with dexamethasone and
others recommend that a patient should have the presence of one or more risk factors before this prescription (Brada & Thomas 1995, Twycross 1994). Hyperglycaemia is a serious side effect encountered by some patients receiving dexamethasone. It necessitates monitoring of the patient’s blood and urine glucose levels (Twycross 1994). The presence of hyperglycaemia requires dietary or drug treatment and this has implications for the patient. Dexamethasone can also cause bacterial and fungal infections due to immunosuppression (British Medical Association & Royal Pharmaceutical Society of Great Britain 1997). Oral candidosis can occur in one third of patients with advanced cancer who receive corticosteroids (Hanks et al 1993). Insomnia has also frequently been identified to be a problem amongst patients who are receiving dexamethasone. It is clinically apparent that prescribing dexamethasone before 18.00hrs can reduce this problem (Brada & Thomas 1995). Electrolyte imbalance can follow the administration of dexamethasone and is often associated with fluid retention and hypertension (British Medical Association & Royal Pharmaceutical Society of Great Britain 1997, Gonzalez & Hulshof 1993). Urea and electrolyte levels should be checked to detect any biochemical imbalance (British Medical Association & Pharmaceutical Society of Great Britain 1997). Irritability is a side effect of dexamethasone witnessed in approximately 10% of patients (Twycross 1994). The behaviour or personality of patients with malignant brain tumours may change after commencement of dexamethasone therapy; however, no study has been able to attribute this solely to dexamethasone.

Despite the monitoring of dexamethasone therapy being recommended within the literature some patients still suffer unnecessarily from the side effects of dexamethasone therapy.
1.6 **Surgery for Malignant Brain Tumours**

The objectives of offering surgery to a patient with malignant brain tumour are:

- To establish pathological diagnosis
- To relieve distressing symptoms and improve quality of life

The histological diagnosis of a brain tumour determines prognosis and allows for planning of further treatment (Brada et al 1997). An audit of patients with malignant brain tumours estimated that 10% of individuals would be misdiagnosed and receive inappropriate treatment without a biopsy (Grant 2004). The adverse consequences of this are related to the misinformation that patients and their families receive about their survival period and the effect that this has upon the planning of their daily activities and future lives (Brada et al 1997). A surgeon can usually obtain an adequate sample of tissue for histological grading by undertaking a freehand or image guided biopsy under local or general anaesthetic (Brada & Thomas 1995). Despite being more time consuming, image guided biopsy techniques are acknowledged to be more accurate and safer than the freehand technique (Brada & Thomas 1995, Rampling et al 2004). Tumour location can influence the surgeon’s biopsy technique. A superficial tumour situated in a non eloquent area of the brain could be located by a freehand biopsy technique with minimum risk to the patient. A diffuse tumour that is deep and inaccessible should only be considered for an image directed biopsy as it is this technique that is recognised as the ‘gold standard’ (Brada & Thomas 1995, Rampling et al 2004). Tumour resection would be completely inappropriate for these tumours as the patient would potentially suffer from post operative functional deterioration. The benefits of a surgical procedure (relief of distressing symptoms and improvement of quality of life) must be considered in conjunction with the patient’s risk of morbidity and mortality, as any risk of iatrogenic insult should be minimised for patients with a poor prognosis from an incurable disease (Brada & Thomas 1995, Rampling et al 2004).
Patients with a malignant brain tumour can be offered a biopsy and/or a complete resection of their tumour. There is no conclusive randomised control trial evidence to indicate that resection is superior to biopsy (Metcalf & Grant 2001). However, within the literature it is commonly stated that compared to patients who undergo biopsy alone, patients undergoing a craniotomy and resection of their tumour survive longer (Gupta & Sarin 2002, Laws et al 2003, Grant 2004, Rampling et al 2004). It is suggested that the lengthened survival of patients who undergo a complete resection is related to the proportion of enhancing tissue that remains after surgery (Laws et al 2003). Further studies need to be undertaken to confirm this. The decision to undertake a tumour resection and/or a biopsy of a tumour is dependent upon the surgeon, the tumour location and size and the age and functional state of the patient (Grant 2004).

The patient's age, pre operative and post operative functional status are known to have a strong influence on patient survival. Individuals aged less than 65 who have a good performance score survive longer than individuals who are older and/or have a perceived poorer performance status (MRC Brain Tumour Working Party 1990, Gregor 1997, Prestwick et al 2005). This knowledge can and should influence the treatment offered to patients (Brada & Thomas 1995, Gregor 1997, Prestwick et al 2005). The importance of surgery to prolong survival and improve quality of life is limited without further treatment because of the rapid regrowth rate of the malignant tumour. Therefore, when considering surgery, the surgeon has to consider whether the patient would subsequently be suitable for radiotherapy treatment. If a decision is made that surgery would not enable the patient to be offered radiotherapy, surgery may still be considered to confirm diagnosis and/or to temporarily relieve the focal symptoms of the tumour and raised intracranial pressure.

1.7 RADIOTHERAPY FOR MALIGNANT BRAIN TUMOURS

Radiotherapy has been shown to significantly increase the survival of patients with malignant brain tumours (Walker et al 1980, Davies et al 1996a, Gregor & Cull 1996). The infiltrative nature of malignant brain tumours predicts they will readily recur and
makes them theoretical unsuitability for radiotherapy, as they are not easy to distinguish from normal brain tissue (Gregor 1997). The dose fractionation scheme of radiotherapy offered to patients with malignant tumours has to be a compromise between; the high dose needed to slow tumour growth and the concern of high morbidity due to radiation induced side effects in the patients where long-term survival may be achieved. Over the past few years a number of studies have helped inform radiation oncologists’ about what type of radiation treatment they should offer patients (Rampling 1998, Rampling et al 2004). There are guidelines for radiation oncologists to consider when planning treatment for patients with malignant primary brain tumours. The acceptable and effective tumour dose for patients who are under 65 and are in good functional status is 60 Gray (Gy)\(^1\) in 30 fractions delivered to the defined tumour plus a two to three centimetre margin (Gregor 1997, Rampling et al 2004). This is called radical radiotherapy. The recommendations for patients over 65 and/or those with poor functional status are less clear. It is unlikely that six weeks of therapy is justifiable for patients whose prognosis is four to six months and therefore these patients can be offered 30 Gy of radiotherapy over two weeks (Rampling et al 2004). This regime is commonly referred to as a “palliative” radiotherapy course. Controversially a recent randomised control trial in patients aged over 65 suggests that there is added survival of two months with radical radiotherapy (McAlsee et al 2003). As there is no agreement about what dose of radiotherapy is the most effective for patients aged 65 or over the choice of treatment is determined by the patient’s radiation oncologist. An even shorter “palliative” course of radiotherapy can be offered to patients with metastatic tumours as their survival rate is considered even poorer (Gregor 1997).

Patients who are under 65 and have a good functional status merit the delivery of high dose radiotherapy as this treatment will lengthen their survival from three to twelve months (Roa et al 2004). Older patients or patients with a poor functional state will only

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\(^1\) Gray (Gy) is a unit measurement of radiotherapy.
have a prognosis of around four to six months irrespective of their treatment; therefore it would be inappropriate to overburden them with long treatment regimes and side effects (Rampling et al 2004, Roa et al 2004). Radiotherapy is damaging to the tumour and normal brain tissue and this has negative consequences for the patient (Rampling et al 2004). Hair loss, fatigue and somnolence are side effects that are evident in the acute phase of radiotherapy treatment but over time these can subside (Roa et al 2004). Longer term effects are vascular and white matter changes that can result in loss of memory, changes in personality and speech problems. At all times the radiation oncologist has to consider the prognosis of the patient in conjunction with the potential side effects of the treatment in order to determine the optimal treatment regime for each particular patient (Gregor & Cull 1996). To do this they need to ensure that they consider the patients prognostic factors: age, diagnosis and functional status.

The performance status of patients prior to the commencement of radiotherapy is crucial. Changes in the performance status of patients prior to and/or during radiotherapy can influence their treatment plan and this can have a dramatic outcome upon the patient and family. The tool used to measure performance status prior to radiotherapy should be carefully considered.

In some centres the radiotherapy is planned using a combination of CT and MRI scans performed upon the patient prior to surgery. In others repeat MRI scans are undertaken a week prior to radiotherapy (personal communication). There is some debate amongst radiologists and neurosurgeons over this variation in planning of radiotherapy treatment and, to date, no study has conclusively shown that either planning option has a significant impact upon survival rates.

It is acknowledged throughout the United Kingdom that individuals are not starting their radiotherapy within the recommended time scale (Davies & Hopkins 1997, Kilbride 1999). The period of time between surgery and radiotherapy is dependent upon many factors: the speed of post operative wound healing and neurological recovery, availability of appointment with a radiation oncologist, discussion of treatment options,
appointments for treatment planning and availability of treatment times on linear accelerators. Studies suggest that malignant primary brain tumours may double in size over a period of 15 – 21.1 days and this could result in tumours growing out with the radiotherapy field measured from the pre operative scan (Yamishita & Kuwabara 1983). However, without conclusive evidence in the current health care climate, it is unlikely that repeat imaging will be authorised prior to commencement of radiotherapy, due to the additional cost that this would imply for every brain tumour patient undergoing radiotherapy.

Patients and their families should be fully informed about their diagnosis, prognosis and treatment options prior to the commencement of radiotherapy. The discussions between health care professionals, the patient and their families should include details of the advantages and potential adverse effects of radiotherapy of which fatigue and hair loss are the most prevalent (Gregor 1997). After these discussions patients and their families should choose whether they wish to commence radiotherapy treatment. The sequence of these events will differ depending on the treatment centre. In most centres within the United Kingdom patients receive their surgery and diagnosis, prognosis and treatment options in one hospital and then are referred to another for radiotherapy consultation and treatment. Hypothetically, if these patients are fully informed after surgery about radiotherapy treatment, they have time, prior to their radiotherapy treatment, to deliberate whether they wish to proceed with radiotherapy prior. In the other few hospitals both the surgery and radiotherapy are offered on one site. Generally these patients are informed of their diagnosis, prognosis, and treatment options in the one consultation and can be asked to consent to treatment at this time. All patients should be offered the opportunity to take time to think about their treatment options. If unsure patients will be recommended to take time and consider the information given to them about the treatment options and the implications of this for them and their families.

After the completion of radiotherapy patients are followed-up indefinitely to detect for a recurrence of the tumour (Brada et al 1997). On recurrence of the tumour further treatment options should be considered in fit younger patients whose time since
diagnosis has been ‘normal’ (Rampling et al 2004). The most common treatment options upon recurrence are re – resection and/or chemotherapy.

1.8 CHEMOTHERAPY FOR MALIGNANT BRAIN TUMOURS

Chemotherapy can be offered in conjunction with surgery and radiotherapy for the management of certain malignant brain tumours (primary CNS lymphoma, malignant oligodendrioglioma) to improve survival (Gregor & Cull 1996, Rampling 1997). The contribution of chemotherapy to the management of anaplastic astrocytomas (AA) and glioblastoma multiforme (GBM) remains modest. Most chemotherapy is unable to cross the blood brain barrier in sufficient concentrations to be therapeutic (Brada & Thomas 1995). Chemotherapy treatment offered to patients in the UK upon recurrence of their tumours is procarbazine, CCNU (lomustine) and vincristine (PCV) (Guerrero et al 1998, Rampling et al 2004, Stupp et al 2005). Studies have indicated that the delivery of PCV to patients who have suffered from AA and GBM tumour recurrence can increase their median survival from three to six months (Rampling et al 2004). The administration of PCV has to be closely monitored to ensure that the treatment benefits are balanced with the patients’ tolerance of the treatment. The common side effects of PCV are accumulative nausea and accumulative myelosuppression (Rampling 2004). In the United States the use of PCV in conjunction with radiotherapy is offered to patients newly diagnosed with malignant glioma. The benefit of this treatment in newly diagnosed patients is dubious (Stewart & GMT group 2002). Systematic reviews have concluded that although there may be a lengthened survival (two months) the clinical benefit of this for patients has not been investigated adequately (Stewart & GMT group 2002).

BCNU impregnated wafers (Gliadel©) put into the resection cavity of malignant brain tumours have been shown to increase median survival by 2 months when given at first tumour resection, compared with placebo wafers (Westphal et al 2003).
Temozolomide is an alternative chemotherapeutic agent that has been proven to be more efficacious than high dose oral Procarbazine and has been recently shown to extend median survival by 2 months. (Stupp et al 2005). The side effects of this agent are said to be better tolerated than those of PCV and within some studies patients have reported a better life quality (Stupp et al 2005). In the future it is anticipated that temozolomide will be used routinely on recurrence of AA and GBM but currently the most common agent used within the United Kingdom is PCV. A randomised control trial of Temozolomide versus PCV is ongoing in the United Kingdom.

NICE are currently evaluating the use of BCNU impregnated wafers (Gliadel©) and Temozolomide for treatment of Primary Brain Tumours. Currently these treatments are not routinely offered to patients within the UK.

Despite some advances the treatment options offered to patients with malignant glioma still result in a poor outcome. There is a need for further studies to investigate the use of anti cancer treatments, gene therapy, immunotherapy and oncolytic viral therapy for the treatment of these tumours. However, until new treatments are developed the current treatment options available have to be carefully considered for each patient. The tumour type, tumour location, patient's age, functional status and personal circumstances all have to be considered along with the feasible treatment options to ensure that the optimum outcome is going to be achieved for the individual patient. How all these factors are considered is dependent upon the treatment centre, the health care professionals involved and the personal wishes of the patient.

To provide some background detail, the process of care that is followed within the National Health Service Trust, where the study was undertaken will be described in Section 1.9.

1.9 TREATMENT PROCESS WITHIN STUDY CENTRE

The Royal College of Physicians (RCP) guidelines for the management of malignant glioma do not provide treatment protocols and, therefore, the treatment offered to
individuals is at the discretion of their clinician. The catchment area for the study site is the South East of Scotland, which encompasses Lothian, South Fife, East Central and Borders Region which has a population of 1.6 million. The study site is a tertiary referral centre and, therefore, patients are referred from a number of sources. On referral to the neurosurgeons and/or oncologists a number of factors have to be considered. After a CT scan has been undertaken the location of the tumour has to be considered in conjunction with the patient’s age and functional status. It is likely that a patient referred from a secondary care setting who is over 70 with a poor performance status would only be offered steroid treatment. However, it is argued that if the steroid treatment significantly improves the individual’s functional status, then further treatment may be beneficial. Nearly all patients referred with a malignant tumour will be offered steroid treatment; the dose that they are commenced upon is at the discretion of the consultant in charge of their care. As diagnosis cannot be confirmed without pathological diagnosis, many patients will have at least a biopsy, or if appropriate, surgical excision. After surgery the patient will be referred to the Edinburgh Centre for Neuro-oncology. The neuro-oncology nurse specialist will attempt to meet the patient on the neurosurgical ward for an initial introduction. She will also arrange an out patient neuro-oncology clinic appointment when the patient’s provisional histological diagnosis is known. At the neuro-oncology out patient appointment the patient and their carer will be informed of their pathological diagnosis, prognosis and their future treatment options. Normally at this appointment the patient and neuro-oncologist agree the treatment plan and the patient provides their consent for this. They are informed at the time of their consent that treatment will commence in roughly six weeks and that an appointment card will be sent to them in the post.

Depending upon the date of their appointment and their health state, the patient may be discharged from hospital before their neuro-oncology appointment, or they may remain in hospital and be discharged from the neuro-oncology clinic to home. If they are not fit for discharge, they may be transferred to their referral hospital. As the clinic is on a set day each week the wait between surgery and the clinic appointment depends upon the
date of surgery, the length of time taken for pathology results to be processed, the spaces available at the clinic and the speed of referral to the neuro-oncology service.

A clinical nurse specialist (CNS) was appointed to the neuro-oncology service in 1998 and is responsible for the supportive care of all malignant and non malignant brain and spinal tumour patients referred to the study centre (average number of referrals is around 150 per year). The CNS is employed to provide care for the patients and their families from diagnosis to death and after. The demands placed on the CNS are great due to the short prognosis and multiple health problems of these patients during the course of their illness. Patients and carers become very dependent on a knowledgeable practitioner who is readily available to them. The demand from patients and carers on the CNS generally heightens once a relationship is developed and this tends to be on commencement of their radiotherapy (Kilbride et al 2001). Although the patients and carers may meet the CNS on the neurosurgical ward and at the neuro-oncology clinic it is when they return to the hospital daily for their six weeks of radiotherapy that their dependency, on a friendly knowledgeable individual who they see regularly, is established.

Whilst working as a research nurse it became apparent to the researcher that the period between surgery and radiotherapy posed many difficulties for the patient and their family. Within this period the patients were recovering from surgery, being informed of their diagnosis and poor prognosis and facing the implications that this had upon their life and their family. In addition they had to deal with the prospect of receiving more treatment in the near future that had potentially severe side effects. Despite being provided with information leaflets and a contact number for the neuro-oncology CNS, patients and their families were in the period between surgery and radiotherapy attempting to deal independently with problems that were continually arising. At times some of these problems went unresolved and this was causing additional stress for the patients and having a significant impact upon their lives. The length of time between surgery and radiotherapy varied significantly between individuals and the problems faced by many patients continued throughout this time. It became apparent over time, to
the researcher, that the longer the wait for treatment the longer patient's and their carer's were exposed, coping with significant problems and the associated stress.

1.10 WAITING FOR TREATMENT

Some studies have been undertaken to measure the impact that waiting for treatment has upon patients and their families (Rigge 1994). Most of these studies have been observational in design as it would be unlikely that an ethics committee would approve a randomised trial that would examine the impact of deliberately extending waiting times of patients. The conclusion from many of these studies has been that effective management is as important as effective interventions as ill people deteriorate without treatment (Rutledge et al 2000a & b). It was the researcher's belief that in the case of individuals waiting for radiotherapy for a malignant brain tumour the deterioration was physical, social and psychological. The cause of this deterioration, however, was uncertain but had to be investigated since waiting for radiotherapy for malignant brain tumours is an unrelentless problem in many countries world wide (Munro & Potter 1994, Scottish Executive 2001). This uncertainty about the period of time that people will continue to experience provided the rationale for the proposed study.
CHAPTER 2
COPING WITH MALIGNANT GLIOMA

2 INTRODUCTION

Although many studies have been undertaken that aim to investigate the most effective means of treating patients with malignant glioma (see Chapter 1) fewer studies have been undertaken that investigate the impact of the diagnosis on their lives. Historically (pre 1990) many of the studies undertaken within the area of neuro-oncology tended only to measure the impact of the disease on the physical aspects of individuals’ lives (Lovely 1998, Huang et al 2001, Salo et al 2002). Many of these studies used the Karnofsky Performance Scale (KPS) to indicate how a new treatment or the diagnosis had influenced the patient’s life quality. The KPS (Appendix 1) measures solely the patient’s physical state and it is heartening to note that, although it is still used, over the past 15 years there have been significantly more studies undertaken that aim to investigate; the effect a diagnosis of malignant glioma has upon the physical, psychological and social (psychosocial) aspects of individuals lives’.

Every study that has investigated the impact of a cancer diagnosis and cancer treatment has contributed to the development of a number of theories and models that help explain the coping and response mechanism exhibited by patients when they are given this diagnosis. In the researcher’s opinion, a framework for the study of coping, illness behaviour and outcome, developed by Shaw (1999), effectively combines some of the theories from health psychology that have been individually used by authors to explain a patient’s response to a diagnosis of cancer. This chapter will critique some of the literature that has described patients’ and their carers’ response to the diagnosis of malignant brain tumours and other cancers to justify the researcher’s opinion.
2.1 IMPETUS FOR STUDY

It is widely acknowledged within the literature that there needs to be more studies to investigate the psychosocial issues being experienced by patients who have been given a diagnosis of malignant glioma (Gregor & Cull 1996, Salander et al 1996, Lovely 1998, Huang et al 2001, Gupta & Sarin 2002). Although a large number of studies have been undertaken with patients (and their families) who suffer from various other types of cancer at various points in their illness, very few of these studies have investigated the psychosocial issues experienced by malignant glioma patients. To date the studies undertaken amongst patients with malignant glioma have not explored the psychosocial issues experienced by patients in the period between their surgery and radiotherapy. However, their findings can provide some insight to what patients may be experiencing in this time (Salander et al 1996, Adelbratt & Strang 2000, Salander et al 2000, Heimans & Taphoorn 2002, Salander & Spetz 2002, Giovagnoli et al 2005). All patients differ in their physical, emotional and psychological responses at each stage of their illness, diagnosis and treatment and therefore, each stage of the illness has to be investigated (Weisman 1981, Rumnsey & Harcourt 1998, Adams 1991, Lindop & Cannon 2001). This thesis aims to provide nurses and other health care professionals with some insight into what patients with malignant glioma and their carers are experiencing between surgery and radiotherapy.

There has been some scepticism within the literature towards the development of studies that investigate the psychosocial issues of patients with malignant glioma. Some authors believe that due to physical and mental deterioration preventing some patients participating in interviews, valid and reliable findings cannot be established through qualitative research designs. For this reason they claim that studies amongst malignant glioma patients should be ‘anchored in randomised trials’ (Gregor & Cull 1996 p1500). The researcher of this study would claim that randomised trials cannot solely determine the psychosocial needs of patients and despite the difficulties some attempt has to be made to ensure that the current treatment and care offered to these patients is meeting their psychosocial needs.
It is anticipated that between surgery and radiotherapy a patient may encounter a number of psychosocial issues that may cause them to exhibit an emotional and physical response to their illness (Northouse 1989, Halm et al 1993, Northouse et al 1995). All these factors could individually or collectively invoke an emotional and/or physical response within patients e.g. insomnia and/or anxiety. What is debated within the literature is whether this response is caused solely by the patient or by an interaction of the patient and their physical, functional and social context (Mishel et al 1984, Halm et al 1993, Mills & Sullivan 1999). Coping (or lack of coping) is used to describe the way in which people react to different situations. The response to coping can be measured and is commonly termed as the coping response (Lazarus & Folkman 1984). The coping response exhibited by behaviour can be explained by a theory of coping. The theory of coping developed by Lazarus & Folkman (1984) is highly acclaimed. It has been applied successfully within a number of studies. They claim that the cognitive and behavioural state of an individual is a combination of personal and environmental factors. When coping with a new situation (stress), the individual’s psychological, physical and social well being is affected as a number of personal and environmental factors change (Lazarus & Folkman 1984). Over the years, a number of research based studies have identified factors that influence the way an individual copes with a situation e.g. information and knowledge (Mishel et al 1984, Courtens et al 1996, Salander 1996, Fox & Lantz 1998, Giovaganli 1999, Salander & Spetz 2002).

2.2 STUDIES INVESTIGATING BEHAVIOUR AND ILLNESS RESPONSE OF MALIGNANT GLIOMA PATIENTS

It was previously acknowledged that there has been little work undertaken that investigates the psychosocial response of patients with malignant glioma to their diagnosis. However, prior to justifying the theoretical framework for this study it is important that these studies are critiqued and their findings considered. The main studies that have been undertaken in this area encompass a diverse range of methods, theories and patient characteristics. All of these factors have to be considered when their findings
are being related to an investigation of the time period between surgery and radiotherapy for patients with a diagnosis of malignant glioma.

A number of the studies undertaken have used specific quality of life instruments to try and gain some insight to the psychosocial needs of patients with malignant glioma (Weitzner et al 1996, Giovagnoli 1999, Salo et al 2002). Others have used more in depth data collection methods e.g. semi structured interviews (Davies et al 1996b, Salander 1996, Salander et al 1996, 2000, Salander & Spetz 2002, Fox & Lantz 1998). The use of quality of life (QoL) and health related quality of life tools (HRQoL) is well discussed within the literature and still there is no general consensus about what quality of life is and how it should be measured. Despite lack of consensus regarding the definition of quality of life there are a significant number of quality of life instruments available that have been used in many studies. There are only a few quality of life measurement instruments that have been devised specifically for brain tumour patients:

The European Organisation for Research and Treatment and Cancer Quality of Life Questionnaire (EORTC QLQ – C30); The Functional Assessment of Cancer Therapy with brain sub scale (FACT BR) and The PRESTON profile (Lyons 1996) are three quality of life measurement tools that have been developed to gain some indication of the impact that a diagnosis of malignant glioma has upon the physical, emotional and social functioning of patients (Heimans and Taphoorn 2002).

The EORTC QLC–C30 measures future, uncertainty, visual disorders, motor dysfunction and communication and it allows for measurement of seven single symptoms e.g. headache and hair loss. It has been used in numerous studies and has been assessed for reliability and validity (This instrument is described in more detail in Chapter 4). The FACT BR scale was developed from a general cancer specific tool (FACT G) that measured physical, social, family, emotional and functional well being as well as the quality of relationship with the physician (Cella et al 1993). The themes included in this questionnaire were developed from unstructured interviews with patients and families. The FACT G is a valid instrument for use amongst general cancer patients
and the Brain (BR) supplement to this data collection tool has been shown to collect substantially different types of data than that collected in core questionnaire (Cella et al 1993) within one study the FACT BR had poor correlation with the KPS (Weitzner et al 1996). Until recently the KPS was seen as one of the main outcome measures within brain tumour studies and as the FACT BR has poor correlation with it the researcher believes that this may be the reason why it has not been widely used within studies. The PRESTON profile measurement tool does not measure level of cognitive impairment and has not undergone validity and reliability assessment (Heinmans and Taphoorn 2002). It was developed from a small study (n=30) and has not been widely acknowledged within the neuro-oncology literature.

It is argued that the usefulness of using quality of life scales to measure the psychosocial response to a diagnosis is limited; however, the findings of the studies that have used these scales have to be considered as they have contributed significantly to the current body of knowledge in this area.

2.3 REVIEW OF THE STUDIES THAT HAVE MEASURED PSYCHOSOCIAL ISSUES USING QUALITY OF LIFE INSTRUMENTS

Weitzner et al in 1996 undertook a study of 48 patients with primary brain tumours (30% had GBM). All of the patients involved in the study had a KPS score of 80 or above (indicating that the patients were relatively well). At one point between 1 and 154 days from diagnosis two quality of life measures (Ferrans and Powers Quality of Life Index for Cancer and Psychosocial Adjustment to Illness Scale Self Report) were taken upon each of the patients. From an analysis of these scores the researchers concluded that the extent of the tumour, poor performance status, being a women, being divorced, undergoing aggressive treatment and being unable to work all contributed to a poorer level of life score. Interestingly, the authors also concluded that age and tumour grade did not influence the results. As discussed in Chapter 1 tumour grade and age are known to influence treatment and performance status, this study indicates that aggressive treatment and performance status affect quality of life but age and tumour grade do not.
Without specific details about the diagnosis of the patients involved in the study and the exact time points of data collection for each of these patients the researcher was hesitant when interpreting these findings. It would have been beneficial for the researcher to know the age and gender of the patients with high grade glioma within the study. The findings of this study cannot be generalisable to the brain tumour population as the inclusion criteria indicates that patients with a poor functional state were excluded. Additionally the study does not identify at what point within 1 – 154 days from diagnosis each of the patients reported a poor life quality. However, it is important when considering the time period between surgery and radiotherapy to remember that some of the factors identified within this study e.g. diagnosis and performance status may affect the response exhibited by the patients.

Giovagnali (1999) studied 57 brain tumour patients’ quality of life and compared it to the quality of life scores of 24 patients with other chronic neurological disease. He collected the quality of life measurements from patients who were undergoing chemotherapy treatment and what was interesting is that he found as had other studies, (Salander et al 1996, Davies et al 1996b) that many of the patients appeared to be unaware of their prognosis. There was a low percentage of patients with a GBM (14%) within this study and the time of data collection varied significantly between the patients. The range of months for data collection from radiotherapy was between 1 – 154 (mean 27.02). Overall Giovagnali (1999) concludes within this study that patients with brain tumours do not report any significant difference in quality of life compared to patients suffering from other chronic neurological disorders. From the results of other studies the researcher would claim that this finding is related to the type of brain tumour patients that were included in the study. If some patients were alive at 154 months and the mean months from radiotherapy was 27 many of the patients included within this study must have had a diagnosis of a glioma WHO Grade I or II. The researcher argues that the diagnosis of a Grade I or II glioma is completely different from that of a Grade III or IV diagnosis due to the significant difference in prognosis, treatment and onset of symptoms. Interestingly in a follow up report to this study (Giovagnoli et al 2005) it is
stated that the results from the study undertaken in 1999 cannot be generalisable as the patients included were highly selective. They conclude that the few patients with WHO grade IV glioma did report a poorer quality of life than the other glioma patients and that prevalence of anxiety was not noted in the later stages of disease (after radiotherapy and on commencement of chemotherapy). Although it is recognised that this study has limitations it does highlight that high grade glioma patients are at heightened risk of psychosocial problems at certain times of treatment. This finding was reinforced by Salo et al (2002).

In 2002, Salo et al aimed to investigate the quality of life reported by patients with primary brain tumours pre operatively. Ninety Seven consecutive patients admitted within 18 months to their hospital in Finland were asked to complete two generic quality of life measurements. The Sintonenec 15 Dimension scale measured 15 dimensions of quality of life (e.g. breathing, mental function, speech, working capacity, eating and continence) and the Nottingham Health profile aimed to measure a profile of life quality rather than a score of life quality by asking patients to state yes or no statements pertaining to health problems. The data from this study once analysed indicated that pre operatively people with right sided tumours, anterior tumours and tumours graded III and IV have a poorer quality of life. Salo et al, 2002 bravely claims these results can be viewed rationally when it is acknowledged that ego and consciousness may be located on left side of brain and right side of brain is more associated with negative feelings. The results of this study are very unique as although the patients included had a range of brain tumours they were all at the same stage of their illness. Unfortunately, as the results are justified on a theory of ego and consciousness that has not been proven the study has to be interpreted with caution.

The usefulness of quality of life measurement tools is widely discussed within the literature and it is generally acknowledged that although beneficial there are a number of difficulties of using these measurement tools amongst brain tumour patients (Lovely 1998, Heimans & Taphoorn 2002). There is wide acceptance that individuals who have a deteriorating level of functional and psychological ability will not complete
questionnaires (Lovely 1998, Huang et al 2001) and that these data collection tools can only quantify the range of quality of life issues being measured (Huang et al 2001). For this reason a number of authors have adopted alternative methods of collecting data about the physical, psychological and social issues experienced by patients with malignant glioma. A number of researchers have adopted interviews as a means of data collection from this group of patients and this has provided a new body of knowledge within neuro-oncology.

2.4 REVIEW OF STUDIES THAT HAVE USED INTERVIEWS TO MEASURE PSYCHOSOCIAL ISSUES

After an initial review of the literature it appeared that there have been a number of studies undertaken that use interviews or case studies to investigate the psychosocial issues of patients with malignant brain tumours. However upon close examination of these papers it is highlighted that a few of them are reporting on the same study.

The work published by Salander (1996) and others (1996, 2000, 2002) all report findings from one prospective study that recruited patients in the years 1991 – 1993 in Sweden. Salander et al (1996) acknowledged at the outset of this study that although it was difficult to measure quality of life in a life threatening situation where nothing could be done to change reality it was important to attempt to understand the experience of being diagnosed with a brain tumour. Thirty patients with malignant brain tumours, aged between 18-70 and WHO performance scale 0-2 were approached to participate in the study. The patients and carers involved in the study were interviewed at three time points: post surgery, two months after completion of their radiotherapy and five months after radiotherapy. An additional interview was undertaken with the carers one month after the patient had died. The content of the interviews included; the patient’s experience of medical care, knowledge and ideas of the disease, relation to partners and friends and interests and future plans. The papers that have been published from this study have focussed on four main elements and unusually have included different sample sizes from the original cohort. The four papers are entitled:
• The Creation of Protection and Hope (1996) (n= 19 - 11 of the patient’s results were withdrawn due to mental impairment and personality changes).

• Brain Tumour as a Threat to Life and Personality: The Spouses Perspective (1996) (n=24 – no explanation given).

• How was life after treatment (2000) (n= 28 – two of the patients were withdrawn as their experience could not be interpreted as fourth interview not undertaken).

• How do patients and carers deal with the serious facts of malignant glioma (2002) (n= 25 – no explanation given).

Salander et al (1996) reported that all of the patients included within the study appeared to have some knowledge about their diagnosis and prognosis and gained hope and protection about this in different ways. 7/19 gained hope from their body, as these patients were feeling well they used this knowledge to contrast with the knowledge they had about the disease. 13/19 patients managed better as they gained hope and help from others e.g. hope and encouragement from a spouse or relation, hope from the skill and expertise of the surgeon and/or hope from others who had a poor diagnosis but were doing well. 16/19 patients gained protection by not asking questions related to prognosis and 8/19 interpreted their information positively to cope better. In summary, Salander et al (1996) segregated his participants into three categories hopeful: less hopeful and hopelessness and, interestingly, when he looked at the functional state of the individuals within each of these groups it was the individuals with poor functional state that were the least hopeful.

Within the interviews with carers from this study Salander (1996) investigated the experience of the carers living with a patient with the diagnosis of a malignant tumour. After analysis of the interview transcripts Salander (1996) stated that a spouse’s reaction to the patients diagnosis and reaction to the situation that arose from this diagnosis could be classified in three ways:

• Crisis delayed until disease progresses – This was a situation when the patient behaved normally and used cognitive manoeuvres as the major mode of coping.
The spouse feels very close to the patient and cognitive manoeuvres is also their form of coping.

- Immediate crisis – This situation arose when the patient is disabled and dependent and uses cognitive manoeuvres to cope. The spouse recognises this, acknowledges the change in their marital relationship and transfers from spouse to carer.

- Crisis delayed until patient returns home – The patient’s personality has changed and he/she has become demanding. Cognitive manoeuvres are used to cope. The spouse recognises the loss of mutuality and distances him/herself from the relationship. The results from this study were not surprising to the researcher. From experience the relationship between the patient and their spouse is affected at some point after diagnosis. Although this study indicates that you can identify when a relationship changes it does not provide the reader with any factors that may influence this e.g. age, number of years married.

In 2000 Salander et al reported on a third aspect of the study, life after treatment. He categorised life after treatment for 28 patients into two categories:

- Time of disease – The percentage of time since diagnosis that people had perceived the disease had prevented them participating in every day life.

- Every day life – Was the length of time patients felt they lived how they lived prior to their diagnosis.

For each patient they measured; time of everyday life and time of disease from the end of their radiotherapy (2months from diagnosis in Sweden). For 36% of patients the time after treatment was time of disease (3.5 months). These patients suffered from disease progression from radiotherapy until their deaths. For 64% of patients they had time for every day life (median 6 months) before the entered time of disease (median 6 months). These results were very interesting and although it is difficult to distinguish from the paper the age, gender and diagnosis of the patients in each group it highlights that 1/3rd of patients diagnosed with malignant glioma cannot resume ‘normal life’ after diagnosis of the disease. Some 2/3rds patients can resume a relatively ‘normal’ period of life after
radiotherapy. This ‘normal’ life may not be as intense as the life they had before radiotherapy but a sense of living was expressed by the patients and carers.

The focus of the article published in 2002 by Salander & Spetz was related to dealing with the diagnosis of malignant glioma. The interesting finding within this part of the study relates to the absence of reciprocal communication between patients and their spouses regarding the terminal aspect of the disease. Upon analysis of the interviews Salander & Spetz (2002) identified four social processes that patients and their spouses enacted in relation to the diagnosis and prognosis:

- The patient does not seem aware, the spouse aware but pretends not to be (4/25 couples).
- Both are aware but the patient does not want to share: they drift apart (5/25 couples).
- Both are aware but they do not talk about the gravity of the situation (14/25 couples).
- Neither patient or spouse are aware they carry on living as before (2/25 couples).

Salander & Spetz (2002) thought that these findings were very interesting as they believed that in Sweden ‘openness’ in cancer care is promoted. However, within the discussion it is acknowledged that the lack of awareness about diagnosis and discussion surrounding this area is related to the patients’ preference. To cope better with the diagnosis patient’s would; dismiss certain information, prefer not to receive information or ask for specific information regarding their prognosis.

Together the studies undertaken by Salander (1996) and Salander et al (1996, 2000, 2002), have contributed greatly to the body of knowledge regarding the psychosocial issues experienced by patients with malignant glioma. Additionally unlike other studies he has attempted to try and provide some theoretical basis for the psychosocial response witnessed. Although the findings of the work undertaken by Salander and others are very useful when considering the time period between surgery and radiotherapy for
patients with malignant glioma, that there are some things that affect the reliability and validity of the study findings:

- The study sample was quite small (n=30).
- Patients with a poor performance score were excluded.
- The age, diagnosis and gender of the patients in the findings could not be distinguished.
- The sample size varied between each report of the study.
- The time between diagnosis and completion of radiotherapy in Sweden is less (2 months) than in UK (3 – 5 months).
- The number of topics covered within each interview to have generated all the theories from the study was very diverse. The depth that could be covered in this time about each subject has to be held in question.

It was acknowledged in one of the studies by Salander & Spetz (2002) that many of the patients within the study would have not been aware of their prognosis as this is an aspect of care not openly discussed in Sweden. However, it states in another study (Salander 1996b) that all patients had some awareness. Salander provides no explanation for this differing perspective within his two papers but within another paper he was keen to highlight, when critiquing another study, that when undertaking studies with malignant brain tumour patients you should be careful about making statements about people’s awareness of diagnosis (Salander 1997). Within this critique he indicated that people may deny awareness of their prognosis for many reasons and this may be what is exhibited by researchers when they witness patients not appearing to acknowledge their prognosis.

A study by Davies et al (1996a & b) was undertaken to investigate the experience of patients and their relatives after diagnosis and treatment of malignant glioma. They studied 75 patients with the diagnosis of a supratentorial glioma grade III – IV and aged between 18- 75 and 66 of their close carers. Patients were interviewed at diagnosis (n=75), after radiotherapy (n=58) and after recurrence (n=27). The themes covered in the
unstructured interviews were: awareness of likely prognosis, problems caused by illness in every day life and satisfaction with treatment and social relationships.

Although a high percentage of the patients involved in the study (95%; 71/75) were aware of their diagnosis, their awareness of prognosis varied at their first interview;

- 19 of them were fully aware of their prognosis
- 24 patients were rated as aware of their prognosis but believed they had reasonable chance of cure
- 32 patients indicated they had no awareness of prognosis at all.

Interestingly 75% of the relatives interviewed were aware of the prognosis at time of radiotherapy and felt their role was to support the patients with their illness. As the illness progressed patients became more aware of their prognosis.

The level of distress at three months after diagnosis was quite low amongst 91% of the patients. This was moderately related to their awareness of diagnosis. Two thirds of relatives were rated as experiencing a moderate to high level of distress. Generally, it was noted that relatives were experiencing greater distress that the patients at the times of interview. This finding was related to their awareness of prognosis.

Patients' views on the impact of diagnosis on every day life were positively related to the rating of disability. The more disabled they were the more likely they were to report a negative impact on life quality. The patient's perception of radiotherapy treatment was also related to their level of disability. Dissatisfaction after radiotherapy was related to a perception of them not improving after the treatment. Interestingly it was noted that only 40% of patients within the study achieved a period of stability or remission. Throughout the study 21% of patients were dissatisfied with their radiotherapy treatment and this finding was not related to awareness of diagnosis, hair loss or level of distress.

When we consider the findings of Davies et al (1996b) it is important to consider the timings of the interviews. Patients and their carers were asked about prognosis upon commencement of their radiotherapy treatment (3 – 8 weeks after diagnosis Davies et al
As will be discussed later, their lack of acknowledgement about their prognosis may be their way of protecting themselves from the psychological threat of the illness. It could be their coping response to a poor prognosis that has heightened their lack of awareness. The treatment stages of malignant glioma are quite different and asking patients to reflect on periods of time that have past could be very difficult as remembering what it was like before is challenging for patients. Although the findings of Davies et al. (1996b) can be scrutinised it is important for the researcher to remember that patients and their carers have a different experience and their level of disability can influence this experience.

Fox & Lantz (1998) undertook an explorative study with patients and carers using semi structured interviews and asked them “Tell me how having a brain tumour affected your every day life?” Initially the researchers interviewed seven patients (and their carers) individually; they then undertook group interviews with a further sixteen individuals and their carers. The authors state that the age, diagnosis and stage of illness of the participants differed but they do not clarify the exact characteristics of the 23 individuals involved. The study claimed that there were five main conceptual themes that explained how a brain tumour affected individuals’ lives – The Stigma of Mind -Body Illness, Invasive Disease of Self, My Family has a Brain Tumour, Dealing with Medical Diplomats and Quality of Life – no substitute for living. Unfortunately, the validity of these results cannot be established as the proportion of the sample that expressed the feelings described in the article are not detailed. However, within the article it is reiterated that the functional and cognitive deterioration that patients note within themselves is the origin of their altered life quality. It is this deterioration and/or change that affects them being able to accomplish what they aimed to in life and this causes them fear and anxiety.

Adelbratt & Strang (2000) undertook a study of 20 patients with grade III and IV malignant brain tumour and 15 of their carers. The aim of this study was for them to explore whether and to what extent patients and their families experienced death anxiety and explore how they expressed these experiences. Unfortunately, it is not stated in the
article where in the patients' illness trajectory the interviews took place and death anxiety is not defined. The number of interviews that were undertaken on each patient and carer is not clear but it is stated that interviews were undertaken until data saturation was reached. The main findings of their study were presented in six themes: emotional reactions that could be related to death anxiety, existential fear anxiety and pain, contradictions, trigger situations, coping strategies and new values for life. The percentage of participants who expressed the reactions to death anxiety described in each of these themes is unknown. However, they conclude that death anxiety is witnessed by patients with malignant brain tumours. They state that people express fear, shock, anxiety, anger, despair and sadness towards their diagnosis and illustrate this by quotes that indicate patients are anxious about their treatment and future. What is confusing for the researcher is that they then conclude this is all related to death. It is proposed that if the uncertainty about treatment was removed from these patients then perhaps their fear and anxiety about the treatment may be reduced.

The patients within this study were afraid of losing their cognitive function and were frightened of the future and not being with their family. Adelbratt & Strang (2000) related to this fear to dying and indicated that at times some trigger phenomena exacerbated these thoughts and feelings e.g. headache. The researchers indicated that from the interviews they could determine the coping strategies people used to deal with their death anxiety e.g. positive thinking, repression, denial and emotional isolation. How and why Adelbratt & Strang (2000) made these associations was not fully explained however what is interesting is that they did believe that coping strategies could be witnessed. The researcher believes that if these authors had related their findings to one theory or framework of coping, the findings of their study could have been further validated.

Adelbratt & Strang (2000) stated that many of the carers experienced a social death of the patient prior to their death: the change in person that was witnessed caused them to have lost them anyway. They felt that they were mindful of the person and were always looking for signs of deterioration. Within their discussion Adelbratt and Strang (2000)
relate their findings to others who have researched death anxiety and conclude that within their study they were witnessing primary anxiety of death being transferred into something less toxic for the patients and family.

From the literature it can be surmised that although we have slightly more insight into what factors may diminish the quality of life of patients with malignant brain tumours e.g. functional state, marital status, awareness of prognosis (Weitzner & Meyers 1996, Lovely 1998, Huang 2001) and some information about why the psychosocial problems exist e.g. creation of hope through significant others (Salander 1996a 1996b) we still do not have sufficient information to state exactly what psychosocial issues exist amongst patients with malignant glioma at certain stages of their illness. Studies have been undertaken at specific stages of diagnosis (Giovagnoli 1999, Salo et al 2002). However, as the time points of data collection within these studies varied so dramatically and the cohort of patients varied significantly no conclusive findings have yet been established. Other prospective studies have reported finding over a period of time 0-7 months (Salander et al 2000) and 0-12 months (Davies et al 1996b) and these studies have not allowed us to look at specific time periods in close detail. The researcher believes that it is important in the future that studies focus upon certain periods with the illness trajectory of patients with malignant brain tumours, without this detail optimal care cannot be achieved.

2.5 STUDIES INVESTIGATING BEHAVIOUR AND ILLNESS RESPONSE OF PATIENTS WITH OTHER MALIGNANT DIAGNOSES

The period of time that people wait between surgery and radiotherapy is dependent upon many factors. The time period between diagnosis and radiotherapy could vary from seven days – three months for some patients (Grant et al 1999). A few studies have been undertaken with patients after their diagnosis of cancer and the results of these studies indicate that over time changes can be noted in the patient’s psychosocial status.
Courtens et al (1996) followed 51 patients for one year after a diagnosis of cancer. These patients were asked to complete questionnaires and participate in interviews at three months after diagnosis and one year after this date. Seventy-nine patients were initially approached to participate in this study and it is acknowledged from the outset that the majority of the 51 individuals included in the study (n=43) had a relatively good prognosis. The study aimed to examine patients quality of life, measure changes in social support networks and investigate whether changes in social support were related to quality of life.

The patients included in the study were mostly married, had a low socioeconomic status and their mean age was 61. Quality of life was measured using previously validated and reliable instruments – Sickness Impact Profile and the Roterdam Symptom Checklist. At three months after diagnosis around half of the patients in the study reported problems of sleep, home management, mobility, social interaction and recreation. Although it is not clear if every patient reported an improvement one year later it is stated, on average there was a significant improvement in function measured at data collection point two. Seriousness of disease, age and socioeconomic status were all found to be important predictors of quality of life. The study measured social support through semi structured interviews. They asked people to write down names and relationships of significant persons and then asked them to measure perceived emotional support – discussing confidential problems and instrumental support – what practical tasks did they undertake. The findings indicated that generally people had quite a small number of people in their social support group at three months (8.5) that all provided them with more emotional (score 4/5) than instrumental support (3/5). The researchers highlight that one year later the number of people in a support circle had decreased and that the level of support had reduced. However, from a closer look at the findings it is obvious there is no significant change. Overall the study concluded that people with fewer symptoms and a better quality of life perceived more emotional support and that people with a poor functional state perceived more instrumental support.
Oberst & James (1985) undertook a study of 40 newly diagnosed cancer patients and their spouses in the pre discharge (one-two days) and post discharge period (10, 30 & 60 days). The background of this study was centred around investigating a potential 'crisis period'. From other studies and their experience these authors suspected that there may be a number of factors that affected the behaviour and coping of patients and their families upon discharge; post discharge syndrome – feelings of anxiety, tiredness and ennui that are reported from the majority of patients after surgery; crisis theory – the fact that many people do not acknowledge the severity of their condition until 7-28 days after diagnosis; dependence on carers.

To examine the post discharge ‘crisis’ period the authors used the State Trait Anxiety Inventory and unstructured interviews. The interviews focussed upon readiness for discharge, prediction of needs, progress at home and social support. The post surgery prognosis for many of these patients (75%) was very positive, the majority were male (77%) and, therefore, many of the patients involved in the study had been the breadwinners.

The themes that were created from the interview data were concerns, coping strategies, strategy effectiveness, resolution of concern and openness to intervention. The biggest concern of patients and their carers up until 60 days after discharge was health. Interestingly, work and finances were not a common concern amongst any patients or their carers. Interruptions in normal employment, housework schedules, child care, domestic and social activities were salient amongst patients and carers up to three months post discharge. After three months many of the patients returned to work. Uncertainty and anxiety about treatment and its efficacy was prevalent up to 60 days in both patients and carers and in some cases heightened after this time. All patients and carers were relatively well informed about diagnosis and procedures but had very little information about follow up care. After some time at home they became angry as they had not been told more about their symptoms. At times it was expressed that patients had problems negotiating the healthcare system.
Although this study was undertaken 20 years ago on a group of patients who had a relatively good prognosis it is evident that discharge from hospital after treatment for illness can be problematic for both the patients and the carer. Unfortunately, at this time the authors did not interpret their findings from a theoretical basis. However, studies that have been undertaken since have provided some rationale for the behaviour exhibited by patients and their carers when discharged from hospital with a diagnosis of cancer.

In 1989 Northouse interviewed 50 mastectomy patients and their husbands in hospital and one month after surgery to investigate any adjustment concerns, reactions to the mastectomy incision, what phase of illness was most stressful and identify factors which helped them cope. Interestingly, Northouse (1989) used family systems theory as a framework for her study. According to family systems theory the illness of one family member can affect the physical, psychological and social state of other family members (Barry 1996). Using family systems theory the reciprocal nature of relationships within families can allow the emotional, physical and social behaviour of individuals within the family to be explained (Barry 1996).

Content analysis of the interview data allowed Northouse (1989) to develop themes of analysis similar to the ones identified by Oberst & James (1985). Concerns of survival and disruption to lifestyle were predominant for the patients and the carers for the period of the study. Interestingly, when asked what phase: pre surgery, treatment (hospital) or adaptation (home) was most stressful most patients and their husbands said pre surgery when they were waiting to know their diagnosis. This was a time of uncertainty and anxiety and it was these factors that made the time very stressful. When asked what helped them cope, the patients and their husbands stated emotional support that came from their carers, friends and professionals, religious beliefs, information and attitude.

From the results of these studies and others we can see that the concerns of patients in one phase of their illness are different from others. Uncertainty, lack of information and lack of guidance from health professionals were all identified within this study to be sources of problems for patients. This study supports the finding from Oberst & James.
(1985) and indicates that health care professionals should be investigating the phases of illness and identifying the need for support in these periods. Unfortunately, Northouse (1989) did not refer her findings back to family systems theory. However, her study did contribute to the knowledge of this time after surgery.

Influential factors of the psychological responses exhibited by patients after a diagnosis of cancer were investigated by Maunsell et al (1992). Prior to this study there were many claims within the literature that potential risk factors for breast cancer patients suffering emotional distress were: age, education, marital status, stage of diagnosis, stressful life events and history of depression prior to diagnosis. However, Maunsell et al (1992) undertook this study to further investigate these claims as she felt that they were inconclusive. 235 patients were studied at two time points after their surgical treatment for breast cancer (three and 18 months). At each of these time points the patients were interviewed by one nurse and were asked questions about a number of aspects of their lives: perception of social and personal support, daily activities, impact of recent stressful life events, and history of depression. They also at these same time points completed the Psychiatric Symptom Index (PSI). Analysis of the results was undertaken on 205 patients and the PSI was the primary outcome measure. The findings of the study indicated that past stressful events and a history of depression all were strong indicators of poor psychological adjustment. Age, education and marital status had little influence within this study.

The cause of a psychosocial response to cancer was also investigated by Mishel et al (1984). Prior to undertaking the study Mishel et al (1984) noted that although there was a psychosocial response to a diagnosis of cancer witnessed there had been little explanation of why this response was being witnessed amongst patients. She believed from her previous studies that there may be key variables that influenced a patient's psychological response: uncertainty, optimism, seriousness of illness and loss of control over physical function (Mishel 1981, Mishel et al 1984). Mishel et al (1984) studied 54 women with a mean age of 52, eight -90 days (mean 21 days) after their diagnosis. Each patient was asked to complete the Mishel Uncertainty in Illness Scale, Psychological
Adjustment to Illness Scale and Beck Hopelessness Scale. Upon analysis the researcher concluded that there was a weak association between uncertainty, optimism and seriousness of illness. However, they found that lack of physical function was associated with uncertainty and heightened social problems. This heightened uncertainty led to people being sad about the future, being less motivated, having low levels of expectation and suffering family disruption.

After a diagnosis of malignant glioma the majority of patients are discharged home to await commencement of their radiotherapy treatment. Although there have been no studies undertaken to investigate the reactions of these patients at this time some studies have been undertaken that investigate the response of patients with other cancer diagnoses when they are discharged home.

From this overview of the literature it can be concluded that a number of factors have been identified that can influence the way an individual copes with a diagnosis of cancer: seriousness of disease, extent of tumour, gender, marital status, physical state, treatment, grade of tumour, uncertainty, information and knowledge, history of depression and serious past life events (Mishel et al 1984, Oberst & James 1985 Northouse 1989, Courtens et al 1996, Salander et al 1996, Fox & Lantz 1998, Giovagnali 1999, Salander & Spetz 2002). The psychosocial outcome caused by a diagnosis of cancer has also been observed and many patients may encounter changes in their social support circle, lifestyle, marital status, family role, personality and working life (Mishel et al 1984, Oberst & James 1985, Northouse 1989, Courtens et al 1996, Salander et al 1996, Fox & Lantz 1998, Giovagnali1999, Salander & Spetz 2002). The interaction of the influential factors and the measured outcome is complex but can be explained using the conceptual framework developed by Shaw (1999). This framework incorporates many of the previously described factors and was devised to help people study and understand the coping strategies and coping responses exhibited by individuals during illness – Figure 2.1. It has been developed from a number of the main theories of coping that have been devised and tested within a large number of behavioural studies. Although there are some elements of coping that have been omitted
within the framework e.g. uncertainty, the value of the framework is that it encompasses the majority of the main theories described within the literature. A discussion of this framework in conjunction with some of the studies undertaken in this area provides a good conceptual basis for understanding the behaviour that may be witnessed amongst patients with malignant glioma and their families between surgery and radiotherapy.
Figure 2.1 Framework for Research on Coping, Illness, Behaviour and Outcomes. Shaw (1999), pp 1247.
2.6 FRAMEWORK FOR STUDY OF COPING

The framework illustrated in Figure 2.1 was developed to help explain, how individuals appraise and cope with situations and the effect that this process has upon them (Shaw 1999).

2.6.1 The Situation

It is important when you are describing the coping of an individual to determine whether you are looking at it being determined by the individual or the situation. From the studies we have reviewed so far it is known that when given a diagnosis of cancer it is a combination of the characteristics of the individual e.g. gender, age, marital status and past events and the situation e.g. severity of illness that can influence the response exhibited. Shaw (1999) claims that all situations have person and situation variables that have to be considered when explaining the behaviour of individuals and it is the presence and combination of these variables that exhibits the response. The situation for patients with malignant glioma between surgery and radiotherapy is that they have suffered from symptoms of a brain tumour, undergone surgery and have been given a diagnosis of malignant glioma. According to Shaw (1999) it is their appraisal of these factors that explains their response exhibited.

2.6.2 Appraisal of a Situation

A number of elements can affect the way a patient views things – their appraisal of the situation (Shaw 1999). From the literature review we can acknowledge that amongst brain tumour patients there may be certain elements that dominate a patient’s appraisal of the situation e.g. poor performance status and aggressive treatment (Courtens et al 1996, Weitzner et al 1996, Salander et al 2000, Curren 2001). According to coping theory, the rationale behind this is that an individual’s appraisal of the situation is associated with how they perceive the situation will affect their lives (Lazarus 1966). From the small number of studies that have been undertaken amongst patients who
receive a diagnosis of malignant glioma we know that individuals will consider their diagnosis in conjunction with the symptoms experienced (Davies 1996b), their family situation (Lovely 1998), their knowledge of the disease and the prognosis (Salander 2002) and then they will react to the diagnosis accordingly. Although the framework developed by Shaw (1999) does not state the specific factors that influence the behaviour exhibited by patients to a situation the categories that she states influence the behaviour relate well to the studies that have been undertaken with cancer patients. Shaw (1999) states that it is;

- Illness Representation
- Social Group
- Personal Values
- Personality Traits
- Availability of Coping Mechanisms and
- Previous Experience.

That influence a person’s appraisal of the situation. Shaw (1999) believes that upon consideration of each of these factors people can interpret the behaviour exhibited by patients. From the studies that have investigated a patient’s experience of cancer and cancer treatment the researcher believes that this framework is very useful in bringing various theories together. It consequently provides a useful heuristic devise to explain the potential experience that will be exhibited by patients with malignant glioma between surgery and radiotherapy.

2.6.3 Illness Representation

‘Illness representation is dependent upon a person’s construction of what an illness it, how it has happened and what the likely outcome is’ (Shaw 1999 p 1247). To create an illness representation patients are said to use both their understanding of the illness and their emotional reaction to that knowledge (Lazarus 1978). In the past the features of an illness that can influence an illness representation have been found to be an outcome of both cognitive and emotional processing. Cognitive processing occurs from;
• identity – the presence or absence of illness (symptoms)
• consequences – the physical, social and economic consequences of disease and felt emotional consequences
• causes – the perceived cause of disease and time line – the time frame for development of illness (Leventhal & Nerenz 1985)
• cure (Lau & Hartman 1983).

Emotional Processing occurs from the perception of threat that an illness has upon one’s life.

**Cognitive Processing**

From the studies that have been undertaken with patients who suffer from malignant glioma it is know that the presence or absence of symptoms has a significant impact on patients lives (Davies et al 1996, Weitzner et al 1996, Fox & Lantz 1998, Huang et al 2001). Many studies have concluded that a poor quality of life is related to a deteriorating mental and/or functional status. As two studies have indicated that between 36-40% of patients with a malignant glioma suffer physical and/or mental deterioration before and /or after diagnosis (Salander et al 1996, Davies et al 1996b, Salo et al 2002) it can be assumed that at some stage this percentage of patients will create a negative illness representation to the diagnosis of malignant glioma. They will associate the disease with a deteriorating mental function and then represent the diagnosis with a negative life quality.

Salander et al (1996) indicates that patients with a malignant glioma may use cognitive measures to cope with the impact of their diagnosis. They demonstrated how people created hope by creating relationships with others that made them feel more hopeful. Cognitively these people created situations in their head that protected them from dealing with the impact of their prognosis. The cognitive processing that happens as a consequence of a malignant glioma diagnosis cannot happen in isolation from the emotional processing. The perception of an illness upon one’s life is translated from cognitive elements into emotional elements (Shaw 1999).
Not every patient who receives a diagnosis of malignant glioma will suffer from immediate physical or mental deterioration and currently there have been no studies undertaken that indicate the response of these patients immediately after their diagnosis. Other studies have indicated that the knowledge of a diagnosis of cancer can have a negative response and this according to Shaw (1999) could be due to prior knowledge about the disease, the prognosis and the treatment options. It is reported that the diagnosis of cancer initiates a number of feelings, despair, isolation, vulnerability, retreat and helplessness (Thomas 1978, Northouse 1984, Brockopp et al 1989, Salander et al 2000). In the first three months after the diagnosis of a brain tumour the emotional responses of denial, anger, fear, anxiety and guilt have all been identified (Adelbratt & Strang 2000, Curren 2001). These personal accounts support the impact that the diagnosis of a malignant brain tumour is perceived to have:

"the shock has been enormous ... the fear was paralysing" (Noble 2002 pp2).

"removal of a linchpin from the life of a man whose happy engagement in working profession depended on his fullest use of brain" (Corbin & Strauss 1988 pp24).

Studies have shown that there can be both an emotional and behavioural response to a diagnosis (Mishel et al 1984) and that a diagnosis of cancer can produce a more alarming response than the diagnosis of other diseases (Mishel et al 1984, Halm et al 1993, Mills & Sullivan 1999). It is suggested that it is not the actual word, cancer that elicits the feelings of fear and anxiety amongst patients; it is the implication of these words on a number of facets of the individual’s life (Courtens et al 1996). In his biographical account of living with a cancer diagnosis John Diamond illustrates this point eloquently:

"Not knowing about the 57 varieties (of cancer cells) all I heard was that I had cancer. Mr Mady (the consultant) didn’t mention the natural corollary – that I was going to die soon – but I supplied that for myself. For the one thing that everyone knows
about cancer is that it kills. There is no curing the cancer patient: the most that can be hoped for is a temporary remission while the appeal court argues about the precise date of execution” (Diamond 1998 p37).

Arguably the biggest implication from the words cancer and/or incurable disease is shortened survival and impending death (Northouse 1989). Death anxiety is a term that is used to describe the ‘negative’ feelings, emotions and behaviour that people exhibit towards their own death (Adelbratt & Strang 2000). In their study of death anxiety amongst brain tumour patients these researchers did indicate that they witnessed emotions and feelings that could be attributed to death anxiety but admitted these relationships were blurred by the metaphors that patients used to describe their emotions. Within this study patients referred to their fear of treatment and an uncertain future but ironically felt hopeful for the future. It is difficult to comprehend why patients with a malignant glioma are not obviously focussing upon their impending death. It may be that on closer inspection of their behaviour it can be concluded that impending death is influencing their behaviour and response. However, it appears from the literature that they are dealing with the immediate as opposed to the long term future (Davies et al 1996b, Salander 1996, Salander et al 1996, Adelbratt & Strang 2000). Their knowledge of prognosis may also be influential. The studies that have been undertaken with brain tumour patients indicate that the awareness of patients and carers about their prognosis is very variable (Davies et al 1996b, Salander 2002). Whether patients have not been informed about their prognosis, did not understand the prognosis given to them or denied or dismissed the facts about their prognosis is not established from the studies undertaken to date. However, when investigating the period of time between surgery and radiotherapy we have to remember that to date it is indicated that in the early stages of diagnosis many patients and their families are dealing with other factors apart from death e.g. impact on lifestyle and roles, physical deterioration and treatment (Oberst & James 1985, Salander et al 1996, Adelbratt & Strang 2000, Salander et al 2000) and numerous studies have indicated that physical deterioration is one of the main factors that affects the psychosocial behaviour of malignant glioma patients (Weitzner 1996, Giovagnali et al 2005).
It is suggested that if a person looks, or feels unwell, they may react differently to the diagnosis (Leventhaul & Nerenz 1985). This theory is well supported by research undertaken amongst malignant brain tumour patients. Patients’ with a malignant brain tumour who suffer a change in their functional state are more likely to report a poorer life quality than the patients whose functional state remains intact (Davies et al 1996b). Most types of surgery have been shown to invoke some physical and emotional reactions amongst patients (Hughson et al 1988). Surgery amongst breast and gastrointestinal cancer patients that alters physical appearance can cause patients not to be able to look in the mirror or resume a ‘normal’ relationship with their partner (Grandstaff 1976, Hughson et al 1988). Although the diagnosis of brain tumour patients has been noted to change the relationship between patients and carers there is no conclusive findings to indicate the cause of change (Salander 1996).

The anxiety and depression states of patients pre and post surgery have been noted to alter, depending on the type of surgery, and, within one study it was the physical symptoms of the disease, as opposed to the diagnosis that caused heightened anxiety (Hughson et al 1988). The impact that loss of neurological function has upon an individual’s quality of life has been studied. These studies have found very conflicting views from patients (Morris et al 1981, Hughson et al 1998). Some patients have said their loss of neurological function had created a very positive impact on their quality of life, whereas others have stated that they have experienced a negative impact (Weitzner & Meyers 1996, Goldstein et al 1998, Adelbratt & Strang 2000). According to the framework for coping, the reason for this is that individuals have appraised their diagnosis differently and therefore their illness is conceptually represented differently. From the researcher’s experience and the review of the literature she believes that few individuals with a diagnosis of malignant glioma, who are experiencing a loss of neurological functioning, will report a positive impact on quality of life. Individuals may indicate that the diagnosis has allowed them to appraise their lives differently and gain new value from life (Adelbratt & Strang 2000). However this process will not dismiss the feelings that their lives have been affected.
In addition to their experience of the symptoms of the disease to create an illness representation it is suggested that patients have to use the information they collate from the generalised pool of information available, the information obtained from direct contact and their experience of the illness (Shaw 1999). The impact that information has upon the individual’s appraisal of the situation is widely debated (Shaw 1999). Patients can be categorised into two groups: ‘monitors’, those who seek information and ‘blunters’ who avoid or distract themselves from information (Butow et al 1997). Butow et al (1997) indicated that patients can change regularly from being ‘blunters’ to ‘monitors’ and vice versa. The information disclosed to individuals and the amount of autonomy they desire in their treatment depends on their stage of illness, the type of individual they are, the health professionals looking after them and their relatives (Bilodeau & Degner 1996, Butow et al 1997). After undertaking a lengthy literature review, it was concluded that there is some disagreement about what factors influence the need for information amongst patients and carers. It is suggested that some individuals need information to gain some sense of control over the disease (Brockopp et al 1989) and others need the information to create some hope (Salander et al 1996, Brockopp et al 1989). One study has suggested that the association between personal control and hope is poor but concluded that, stage and extent of illness do affect some patients’ preference for information (Butow et al 1997, Mills & Sullivan 1999, Bilodeau & Degner 1996). There is some consensus within the literature that indicates that carers tend to want more information than patients (Salander 1996).

It is difficult from the studies undertaken to date to anticipate how information will influence a malignant glioma patient’s appraisal of the situation. As it is known that the information patients desire varies from stage to stage of their illness and treatment (Adams 1991). It is likely that between surgery and radiotherapy patients may desire information about their proposed therapy, the sequence of future events, the side effects of treatment, symptom management and prognosis (Adams 1991). How they retrieve this information and how they interpret it cannot be established without further studies.
The way that a patient interprets their illness through illness representation is dependent on numerous factors. To gain some insight into the effect that these factors have upon the way that patients with malignant glioma cope between surgery and radiotherapy a study will need to measure functional status, side effects from the treatment, their knowledge and the impact that the diagnosis has upon their lives.

2.6.4 Social Support

Social support includes a number of components and is suggested by Shaw (1999) to have an impact on the way people cope with a situation. The exact composition of these components vary but generally it includes emotional support, appraisal support (affirmation, feedback) informational support and instrumental support such as money and/or labour (Mills & Sullivan 1999). The two main types of social support that have been examined amongst cancer patients are informational support, and emotional support. As discussed in Section 2.63 patients may or may not seek information and may or not receive information about their condition. The support that patients perceive to receive from information varies. However, it is concluded within the literature that information should be given to individuals with cancer to help them cope with their diagnosis (Brockopp et al 1989, Amato 1991).

One study found that emotional support from both family and health care professionals was the factor that most significantly contributed to helping women with breast cancer cope (Northouse 1989). By providing support, family members improve the psychological and physical coping mechanisms, and this can ensure that there is minimum physical and emotional disruption for the patient (Koch 2000, Radina & Armer 2001). Radina & Armer (2001) indicated that one reason for this is that, if it is within the family’s capability to fulfil the support demanded, then they are in the best position to understand the patient’s appraisal of the situation. If handled appropriately, this will, in turn, prevent a negative response. It is perhaps for this reason that in situations where psychosocial problems are ‘mild’ the efficacy of lay carers in resolving these problems is better than professionals (Barker et al 1990). Many people tend to take
their psychosocial problems to their spouse, friend and/or neighbours. The intimacy that has existed within these relationships allows the problem to be resolved using interventions based on their carers detailed understanding of the patients characteristics and preferences (Barker et al 1990, Yates 1999). This ensures that family members are active participants in the cancer journey and play a vital role in patient’s recovery (Northouse 1984, Fridfinnsdottir 1997). Illness in one member can cause a reaction throughout the family unit (Northouse 1984, Maunsell et al 1992).

Upon discharge from hospital there is a great need for social support. Studies have reported that a patient’s anxiety is significantly lessened and coping ability heightened, when they are discharged home from hospital (Oberst & James 1985, Northouse 1989). However, within another study, fear of recurrence was more commonly reported when patients were discharged home and self care needs were significantly heightened (Northouse 1989). Carers of cancer patients have identified that the period immediately after surgery was more stressful than the pre operative period. This could be attributed to the automatic transfer of care from professionals to lay carers that generally happens at this time (Dyk & Sutherland 1956, Stoler 1982, Oberst & James 1985). A study has demonstrated that patients require on a likert scale from 0-12, a high to moderate level of care five weeks after their discharge from hospital (see Figure 2.2)(Oberst & James 1985). This care is often delivered by family and friends and the responsibility associated with this can be a major source of stress for carers.
Restoring meaning, order and purpose in one’s life is central to the process of adjusting to a diagnosis (Grossman et al 2000). It is proposed by the researcher that carers attempt to do this for patients by being both the formal and informal carer the majority of the time. This may also explain why carers commonly state they are less content than the patients about the information they receive (Salander 2002) and why carers after a three month period become unwell themselves (Oberst & James 1985).

The social and emotional support offered to patients between surgery and radiotherapy has not been studied in detail. However it is known from the researcher’s personal experience that upon discharge from hospital these patients have little or no input from health care professionals. Their main source of support is their family in this time period. If, as other studies have indicated that changes in marital and social relationships (Salander 1996, Adelbratt & Strang 2000) are frequent after a diagnosis of malignant disease the level of support being offered and the impact of this on the family has to be investigated further.
2.6.5 Group Differences

The effect of group difference such as, age, gender and marital status, on appraisal are debated widely in the literature. A study undertaken in 1989 investigated a number of 'person related factors' and 'situation related factors' that influenced information seeking and support amongst patients (Northouse 1989). The study highlighted that age and stage of disease had a significant influence on the level of information and support that individuals required (Northouse 1989). The impact of age on the coping response to a diagnosis of cancer varies from study to study. Hughson et al (1988) detected that when segregated by age cancer patients $\geq 45$ showed more anxiety than younger patients. In contrast, another study, investigating the same condition noted that younger patients displayed less anxiety (Morris et al 1981). A third study showed that emotional adjustment was more evident amongst older mastectomy patients, who were married longer and received more support (Jamieson et al 1978). Family Systems Theory claims that individuals and their families function cohesively to adapt to a changing situation and maintain equilibrium within the family unit (Barry 1996) and as discussed previously families are often the main source of support for patients.

The study undertaken by Weitzner & Meyers (1996) indicated that gender and marital status affected the quality of life being experienced by patients. However no other studies have confirmed this relationship. This finding can be explained using the Shaw (1999) framework as group differences e.g. age, gender, marital status will only be an influence on the illness behaviour if in combination with illness representation, social support, commitments, it makes a difference. From the discussion so far we could assume: That a woman who has recently divorced with a diagnosis of grade IV malignant glioma and suffering extensive physical weakness would perceive less emotional support, and poorer quality of life, than a woman in the same situation who is, happily married and has her family living around her to offer her both emotional and instrumental support. This perception of less emotional support within the divorced women could lead to feelings of hopelessness and this in turn could lead to other negative feelings. Although this scenario is anecdotal it emphasises how important the
framework developed by Shaw (1999) is when interpreting people behaviour. When looking at an individual’s situation you need to look at all the factors that have been shown in other studies that could influence the coping response. Group differences will only be significant in explaining behaviour if illness representation, social support, commitments, self efficacy and personality allow it to be.

2.6.6 Commitments

The impact that the illness has upon the current commitments of the individuals in relation to work and familial roles, may also have an influence on the way that patients ‘appraise’ the situation. In contrast to the number of studies that discuss the socially accepted phenomenon of the ‘sick role’,² that is commonly adopted by many patients and their families during and after injury and/or illness, few cancer patients are said to change their lifestyle unless disability forces them to (Weisman & Worden 1976). In fact some women with cancer have been reported to be encouraged to maintain their role within the household, as the family interpret this as the patient coping with their illness (Hilton 1996). This relates to the theory underpinning the framework illustrated in Figure 2.1. If family commitments remain the same, patients will not need to adapt or consider the impact of this factor when appraising the situation. Within many studies, the adaptation stage of cancer (1-2 months after diagnosis), is where there is a major change in the lifestyle behaviours of patients and their carers, such as time off work, or a change in family roles (Northouse 1989, Oberst & James 1985). It is after this stage that routine can return to normal (Northouse 1989). As it is in this time period patients with malignant glioma are waiting for their radiotherapy it is necessary to investigate what change in lifestyle, behaviour and familial roles may occur. Unlike other types of cancer, patients with a malignant glioma will be unable to return to their normal routine after two months as they will still be attending the hospital daily for their radiotherapy

² Sick role is a sociological phenomenon that supports the belief that when people encounter an illness they will readily accept and expect people to help them (Corbin & Strauss 1988)
treatment. The changes experienced within the period between surgery and radiotherapy will not be resolved in a short time scale. As was described by Davies et al (1996b) and Salander et al (2000) the majority of patients with brain tumours never manage to return to their ‘normal’ physical and psychosocial state. This finding indicates that between surgery and radiotherapy there may be many commitments that the malignant glioma patients cannot fulfil and the affect that this has upon them has to be measured.

2.6.7 Personality and Past Events

What a person has dealt with in the past, and the way that they have dealt with it, is suggested to have an impact on their ‘appraisal’ of a situation. A study undertaken by Maunsell et al (1992) attempted to determine risk factors of psychological morbidity after initial treatment of breast cancer. This study incorporated many risk factors such as age, marital status, past medical history. These factors had all been noted to potentially influence anxiety and depression levels within cancer patients in the past. It concluded that only 30% of the change in psychological morbidity after an initial diagnosis can be related to personality and past events, no other factors were noted to be influential within the findings (Maunsell et al 1992). Another study reported that a previous history of psychological upset can heighten psychological morbidity after a cancer diagnosis (Hughson et al 1988). Weisman & Worden (1976) described the illness trajectory of cancer patients from diagnosis to death. They acknowledged that in their adaptation stage (after learning about the diagnosis) people called upon coping strategies that best served them in the past. People were likely to approach a situation in a different way if their previous strategy proved unsuccessful in dealing with an event. Although these studies were not undertaken amongst patients with brain tumours it is important than when we are interpreting the behaviour of these people between surgery and radiotherapy that we consider their personality and past events.

2.6.8 Locus of Control

This is the one influence of appraisal within the framework that the researcher believes could be dismissed when discussing coping mechanisms of patients with a diagnosis of
cancer. This influence is based upon the belief that health can be viewed in three categories:

- **internal** – the extent to which individuals believe their health is the result of their own actions
- **external (powerful others)** – the extent to which individual believe their health is attributed to health professionals
- **external (chance or fate)** – the extent to which individuals believe their health is owing to chance or fate.(Shaw 1999).

The theory behind this categorisation is that individuals who believe that their own action affects their health are more likely to participate in health promoting behaviour. Studies that have investigated this theory have focussed on health promotion activities and the researcher proposes that as healthy behaviour will have very little impact on the survival of cancer patients, locus of control will not have an influence on their appraisal and coping response. What is more likely to affect their behaviour is their self efficacy.

### 2.6.9 Self Efficacy

According to this framework, when appraising a situation, patients think about what they can do about the situation (self efficacy). ‘Self efficacy’ gives one a sense of control; it is their subjective assessment of what they can do about the ‘situation’ (Schwarzer & Fuchs 1996). It is emphasised that the outcome of a strategy will only be as successful as the individual’s ability to implement it and, therefore, when devising a strategy most individuals will be realistic about their abilities. The notion of self efficacy is central to most health modification programmes such as smoking cessation and alcohol programmes. However, it is believed by the researcher that it may be useful when discussing the coping needs of cancer patients as throughout their illness, there are times when the ability of a cancer patient to self efficiate is diminished. From personal experience the researcher acknowledges that an individual with a malignant brain tumour is very limited in what they can do to improve their situation after surgery. They can choose to undergo radiotherapy and potentially lengthen their survival or choose not to undergo radiotherapy and live with the consequences of a shortened survival. This limited choice ensures that patients have little control over the situation and this can
cause what is described in the conceptual framework as low self efficacy. A low self efficacy is associated with depression, anxiety and helplessness, low esteem and pessimistic thoughts (Schwarzer & Fuchs 1996). If, as suggested, patients with a malignant brain tumour experience low self efficacy between surgery and radiotherapy the response of patients to this has to be investigated.

The provision, effectiveness and benefits of imparting information and knowledge to cancer patients are things that have been investigated by many authors (Brockopp et al 1989, Bilodeau & Degner 1996, Butow et al 1997, Adams 1991, Mills & Sullivan 1999). Brockopp et al (1989) looked at the use of information in resuming an individual’s sense of control. It is well acknowledged within the literature that people who have received a diagnosis of cancer feel that they have lost some control over the lives. Brockopp et al (1989) investigated the effect of information upon an individual’s perception of control using two validated measurement tools. Interestingly, Brockopp et al (1989) concluded that lack of information may not be causing individuals to feel out of control and they found a weak correlation between these factors. This finding contrasts significantly with the finding of Butow et al (1997) who collected data that measured information and involvement preferences, locus of control and familiarity with clinical setting amongst 80 patients with a diagnosis of cancer before a consultation, after a consultation and at their follow up appointment (3-6 months later). Their findings demonstrated that patients did gain some control through information and encouraged health care professional to impart as much knowledge as possible.

2.6.10 Health Threat

Shaw (1999) indicates that after ‘appraising the situation’ the individual judges and determines whether the situation represents a health threat. The severity of this threat is determined and action taken in response to this. The more severe a threat a situation is perceived to be by the individual, the poorer the psychological outcome and the more likely they are to seek help from a wide range of support available. From the discussion of all of the elements that influence an ‘appraisal’ of a situation, the researcher proposes
that after a diagnosis of malignant glioma an individual will feel very threatened. They will perceive the illness as devastating. They may have encountered some neurological functional deterioration and they will have little control over the treatment for the condition. In addition, they may face some changes in family roles. According to the framework for coping devised by Shaw (1999) these factors will all contribute to an emotional and physical response to the diagnosis that will be observable. By measuring this response the researcher wished to investigate why and how patients cope with a diagnosis of malignant glioma.

2.7 UNCERTAINTY – THE MISSING LINK

The researcher has one major criticism of the Shaw (1999) framework. Within the framework illustrated in Figure 2.1 the element of ‘uncertainty’ has not been given enough emphasis. Studies have shown that individuals who have more uncertainty about an illness perceive less control over it and this then initiates a feeling of heightened threat (Northouse et al 1995, Fox & Lantz 1998). In attempting to deal with this threat a patient can demonstrate more physical and emotional distress which can have an adverse reaction upon them and their carer’s lives. Mishel (1981) has discussed in detail the influence of uncertainty in illness response. He stated that individuals become uncertain when a situation cannot be adequately structured or categorised because there are insufficient clues (Budner 1962 as cited in Mishel 1981). Events, which provide uncertainty, have features such as vagueness, lack of clarity, ambiguity, unpredictability, inconsistency, probability, multiple meanings and lack of information. All these things can be introduced when you consider incomplete diagnoses, unclear feedback, unpredictable symptoms and unknown treatments (Mishel 1981). Individuals respond to uncertainty differently depending on their perception of the event. When one is uncertain the event can sometimes;

- not be properly recognised
- be properly recognised but not categorised
- categorised but categorised inappropriately.
It is this theory of uncertainty that indicates that adequate knowledge could have a positive influence on the threat response of individuals to uncertainty. If patients have enough knowledge about a situation then they are likely to be able to perceive the event, and categorise it rationally. If patients do not have enough knowledge they cannot resolve any uncertainty that exists about their illness, their physical symptoms, their future treatment and this may affect their coping response.

Rigge (1994) investigated the impact that waiting for treatment had upon a patient’s quality of life and interviewed patients who had waited up to two years for orthopaedic surgery. From the interviews it transpired that the patients, due to their inability to cope with the uncertainty about the wait, were suffering major disruption to their work and family life (Rigge 1994). The wait for cancer treatment is not comparable in length to that of patients awaiting orthopaedic surgery; however, it is acknowledged by the Scottish Executive and many health professionals that the wait between surgery and radiotherapy for patients with some cancers is too lengthy and could be a source of anxiety for patients (Munro & Potter 1994, Scottish Executive 2001). One study investigating the impact that waiting for cancer treatment had upon cancer patients reported that it was extremely difficult for certain individuals to cope with the knowledge that cancerous tissue was still in their bodies and could still be growing (Northouse 1989). As malignant brain tumours grow rapidly, it is realistic to suspect that many newly diagnosed brain tumour patients, who have been told about their requirement for radiotherapy, may display some anxiety about the tumour that may still be growing in their head. In addition, it can be assumed that the patients and their families may be experiencing some uncertainty about the future, and this may also affect them physically and emotionally throughout the wait for radiotherapy. Although uncertainty is not included within the framework from the literature the researcher believes that this has to be considered when observing the patient between surgery and radiotherapy.
2.8 THE OUTCOME – COPING OR NOT COPING

An ‘inadequate’ response to coping with a situation has been termed ‘maladaptive coping’ (Lazarus 1966). Maladaptive coping can adversely affect the emotional and physical health of an individual. According to the framework, after undertaking an ‘appraisal of the situation’ and then using this appraisal to establish the ‘health threat’ being faced by them, an individual will ‘create’ a way to deal with this and that will result in them adapting or maladapting to the situation.

Lazarus & Folkman (1984) defined coping as “cognitive and behavioural efforts to manage specific and internal and external demands that are ‘appraised’ as taxing or exceeding the demands of the patient” (pp 82). This definition reiterates what the framework describes and it is widely acknowledged within the literature. The coping response of individuals is created through an amalgamation of different factors and the way they interpret these creates a response, this response is termed as coping. The outcome to this can be positive or negative and the behavioural response exhibits a positive response ‘a good laugh’ or a negative response ‘a good cry’. Without a framework the illness behaviour of individuals cannot be explained adequately. In the researcher’s opinion the literature that exists that describes the behaviour of patients with a malignant brain tumour is weakened due to the lack of explanation of the behaviour that accompanies the findings. Many authors attempt to provide explanations but as the link between the findings and a theory are not clear it is difficult to interpret why the behaviour exhibited occurred.

Whether the behaviour exhibited between surgery and radiotherapy is described as coping or not coping is considered superfluous by the researcher. What is important is how and why they are coping in a particular way and what can be done to help them. These answers can only be achieved through using a framework of coping that encompasses all the suggestions made within the literature to date.
2.9 CONCLUSION

The emphasis of care delivered to patients with malignant brain tumours should focus upon minimising disruption to an already compromised life expectancy and to maintain and improve quality of life to patients and carers wherever possible (Curren 2001, Gupta & Sarin 2002, Efficace & Bottomley 2003). It is increasingly acknowledged that nurses, with appropriate skills and knowledge, are the key individuals to provide this level of care (Curren 2001). The type of information, treatment and support that a patient and their carer need will change over the course of their illness. It is only by exploring the functional and emotional state of patients at each stage of their illness that these differing needs can be met. In a condition where prognosis is extremely poor and a significant proportion of survival time involves treatment, life should not just be maintained, it should be nurtured. It has to remembered at all times that a sick person is not just a well person with disease: they are qualitatively different, physically, socially, mentally and cognitively (Degner & Sloan 1992). Therefore, the researcher proposes to prospectively examine the emotional and physical changes encountered in patients in the period between surgery and radiotherapy and will use the theoretical basis of this chapter to explain the behaviour observed. It is anticipated that by explaining the source of the behaviour nurses and/or other health professionals will be better informed about how to assess and meet the needs of patients and their carers between surgery and radiotherapy.
CHAPTER 3
THE NURSE’S ROLE IN SUPPORTING PATIENTS WITH MALIGNANT GLIOMA AND THEIR CARERS

3 INTRODUCTION
It is obvious from the literature that coping with a diagnosis of malignant glioma and the multiple physical and emotional problems associated with this diagnosis is extremely problematic for patients and their families (Amato 1991, Davies et al 1996a, Curren 2001, Grossman & Batara 2004). Trying to adjust and cope with the diagnosis of malignancy causes extreme stress for both the patient and the family. A nurse’s role in the management of patients with malignant glioma is essential for the emotional and practical welfare of the patient and their family (Davies 1997). Unfortunately, for a number of reasons such as, geographical location and limited resources, specialised nurses cannot provide adequate care for all patients with a malignant brain tumour at all stages of their illness.

3.1 THE ROLE OF THE NURSE IN ENABLING PATIENTS TO COPE
The literature the researcher suggests that nurses enable patients to cope with their physical and emotional problems, through providing support, encouraging self care and minimising the perceived health threat of an illness through the provision of information (Amato 1991, Davies 1997, Kilbride et al 2001). To enable coping, nurses have to establish an effective relationship with patients in order to understand and assess their psychological needs (Claxton 1993). If patient and nurse do not communicate effectively the nurse will be unable to accurately assess and interpret the impact of the illness from the perspective of the patient (Takemura & Kanda 2003).
3.2 **Availability of Clinical Nurse Specialists (CNS)**

When available, the care offered to patients by a neuro-oncology CNS is highly valued (Guerrero 1998). They can provide continuity of care, liaise with other team members and set up links to provide good terminal care in the community (Davies 1997). Not all patients diagnosed with a malignant brain tumour have access to a CNS. Patients who are not referred to a tertiary care setting but remain in or are discharged to their local hospitals will not experience the perceived benefits of the CNS.

The CNS can provide a significant amount of support to patients after their diagnosis (Robichaud & Hamric 1986). A major barrier to this support can be the distance between the clinical base of the CNS and the patient’s home (Brada & Guerrero 1997). The low incidence of malignant brain tumours in the population, dictates that the care for these patients has to be delivered in a small number of tertiary referral centres throughout the United Kingdom (Davies & Hopkins 1997). As it is not financially feasible for care to be delivered to patients with malignant brain tumour in their local hospitals, many patients have to travel long distances to the treatment centre where, if available, the clinical nurse specialist is based. As the distance prevents the clinical nurse specialist undertaking ‘home visits’ many have developed telephone clinics to ensure they are more accessible to all patients (Brada & Guerrero 1989, Curren 2001). There are disadvantages to the telephone clinic, e.g. being unable to speak to patients with a cognitive impairment and/or over reliance on CNS but until other sources of support closer to home are available to patients with malignant brain tumours it is the best alternative (Brada & Guerrero 1997, Curren 2001).

3.3 **Unidentified Needs**

Despite the availability of a CNS, patients with malignant brain tumours and their carers stated in two studies that when discharged from hospital after their diagnosis, their support needs were not met (Davies & Hopkins 1997, Grant et al 1999). From the
researcher's personal experience it can be surmised that there are a number of reasons for unmet needs amongst brain tumour patients:

- The patient may not know who to contact about their problems.
- The patient and their carers may not disclose the problems they face.
- When patients contact their General Practitioners they may not have sufficient expertise to provide suitable solutions for the patients.
- The CNS may be unaware that the patient and their carer were encountering problems.

As patients receive information about their condition from a number of specialists in the initial stages, e.g. the surgeon, the oncologists, the ward staff, the CNS, it is difficult for patients to identify who they should contact when, and how they should contact them (Curren 2001). In the past, studies have illustrated that it is the ‘availability’ of the clinical nurse specialist that benefits patients immensely (Kilbride et al 2001). However, until patients are familiar with the CNS and their role it is unlikely that they will access them readily.

As highlighted in Chapter 2, while coping with an illness patients may deny the symptoms and their prognosis, therefore, they will be unlikely to report these to others (Salander 1996a, Shaw 1999). If a CNS is not informed about the symptoms that patients are experiencing it is impossible for them to support and offer advice that would help both the patient and the family. However, it is suggested that with effective communication and close monitoring, experienced nurses can predict and interpret the problems being experienced by patients and their carers at each stage of their illness (Amato 1991, Takemura & Kanda 2003). The researcher proposes that the distance between the hospital base of the CNS and the patient’s home, impairs the level of communication necessary for the patient and carer to receive adequate support in the period between surgery and radiotherapy.
3.4 THE NURSE – PATIENT RELATIONSHIP

The establishment of an effective relationship can enhance patient care. To create this relationship there needs to be regular contact, trust and empathy (Amato 1991, Olsen 1997, Thorsteinsson 2002). Without effective communication, the encouragement of self care, readily available sources of information and adequate support, patients and their carers are known to cope inadequately (Kibler 1998, Amato 1991, Curren 2001). From the literature the researcher will attempt to explain why it may be lack of contact with members of the health care that exacerbates the problems experienced by patients and their carers between surgery and radiotherapy.

3.4.1 Communication

Communication with a knowledgeable practitioner is extremely important to patients and their families when dealing with a diagnosis of cancer (Northouse 1989, Amato 1991, Attree 2001). Patients state that by engaging in conversation, talking and listening to patients, nurses discover the needs and problems of patients (Attree 2001). However, the studies that have established a positive relationship between effective care and good communication, have all been undertaken with patients who have had regular, face to face contact with nurses (Northouse 1989, Attree 2001, Thorsteinsson 2002).

The style and pattern of communication between individuals and their families varies (Kibler 1998). Nurses need to become aware of the verbal and non verbal patterns of communication amongst patients and their families to facilitate an optimal level of communication (Kibler 1998, Attree 2001). Poor communication is commonly cited as a main source of ineffective care (Kibler 1998, Attree 2001). Patients with malignant brain tumours commonly encounter neurological deficits that alter their 'normal' communication pattern, e.g. dysphasia, hearing problems and changes in their personality, and these must be taken into consideration when assessing their communication patterns (Kibler 1998). Non verbal communication strategies such as touch and facial expressions are encouraged when communication is difficult. However these can only be used when there is face to face contact (Kibler 1998).
3.4.2 Self care

Through communication skills training it is possible for experienced nurses to anticipate and provide the necessary support needed for patients and their carers to care for themselves independently at home (Kilbride et al 2001). As discussed in Chapter 2, patients who feel they can control their situation are more likely to cope effectively with it (Schwarzer & Fuchs 1996). If adequate information and support are available patients may be able to cope effectively with their diagnosis and their symptoms. However, to provide this level of care, regular face to face communication and individualised assessments are required (Silverman 2003).

The unique nature of malignant brain tumours makes it difficult for the individualised care needs of patients to be anticipated without face to face contact (Kibler 1998, Amato 1991). Therefore, nurses have to be in close and regular contact with the patients and/or carers to assess changes as they occur. Once an effective relationship is established between a CNS and the patient this is achievable. However, the researcher believes that in the initial stages of brain tumour management achieving this level of relationship may be difficult due to lack of contact between the patient and CNS. Patients may lack the confidence or knowledge to know when and who they contact about changes in their condition.

3.4.3 Sources of Information

Information in all formats e.g. written and verbal, helps some patients regain some control over their condition and symptoms of their condition (Amato 1991, Butow et al 1997). Some researchers state that patients with malignant brain tumours and their carers should be encouraged by nurses to seek the information they require (Amato 1991, Kibler 1998). However, it is suggested by the researchers that it is difficult for patients and their carers in the initial stages of their diagnosis to know what information they require. If the informational needs of patients are to be adequately addressed it is necessary that these needs are ascertained and fulfilled on a regular basis (Butow et al
Without readily accessible sources of information and regular contact the informational support needs of patients cannot be met.

3.4.5 Support

Nurses can offer emotional and practical support to patients and their carers (Northouse 1989). However, if they are unaware of what support is required they cannot fulfil this role. According to the literature, families are in the best position to support patients as they can effectively interpret the patients ‘appraisal’ of the situation at all stages of their illness (Radina & Armer 2001). However, if the CNS could establish an effective relationship with the patient, the researcher believes, they would be able to effectively assess the changing psychological needs of the patient, and lessen the responsibility of caring placed on the carer between surgery and radiotherapy (Claxton 1993, Radina & Armer 2001).

3.5 Conclusion

As a nurse, the researcher wholeheartedly supports the belief that with the adequate information, knowledge, skills and time, nurses can ensure that patients achieve the optimum quality of life that is achievable for individuals (Amato 1991, Curren 2001). The availability of CNS to patients with brain tumours has significantly enhanced the care offered to patients. However the CNS alone cannot provide the level of care described within this chapter. They are not on call 24 hours per day and they have other responsibilities e.g. research and teaching. By investigating the time between surgery and radiotherapy, the researcher aims to provide suggestions of alternative forms of support that may be made available to patients and their carers between surgery and radiotherapy. It is anticipated that these suggestions may ensure that patients receive the necessary level of care during this time.
4.1 RESEARCH AIM & QUESTIONS

The overall aim of the research project is:

To explore the changes in neurological function and the emotional issues experienced by patients with malignant glioma and their families between surgery and radiotherapy.

In order to meet the proposed aim the researcher elected to investigate the following research questions.

1. Are there significant changes in the frequency and severity of patients neurological functional state between surgery and radiotherapy?

2. Are significant changes notable in the frequency and severity of patients anxiety and depression level between surgery and radiotherapy?

3. Is there an association between dexamethasone dosage and prevalence of side effects in patients between surgery and radiotherapy?

4. Do patients and their carers encounter changes in their quality of life between surgery and radiotherapy?

5. How are patients and carers’ lives disrupted between surgery and radiotherapy?

6. Can the reaction of patients and carers during the transitional period be explained using a framework for coping?
4.2 RESEARCH DESIGN

In order to be able to adequately explore and answer the research questions of the study an appropriate research design had to be selected. The study aimed to examine the relationships between the research variables in one specific patient group. A correlational research design was considered, but rejected as this type of design requires a large sample size to show statistical significance (Polit & Hungler 1997, Burns & Grove 2003). The sample size for this study was predicted to be small and, therefore, a correlational research design was deemed inappropriate.

A randomised control trial would have been an ideal research design for this study, as from the outset, the researcher believed that the length of time that patients waited from surgery to radiotherapy would have an impact on the variables being measured within the study. By undertaking a controlled trial that randomised patients to one of the two groups: ‘fast track radiotherapy’ (two-three weeks) and ‘slow track radiotherapy’ (five-six weeks), the factors that could influence the results could have been controlled e.g. age and gender. However, ethical considerations, resources, financial constraints and sample size made a randomised control trial design unrealistic for the study. By offering one group of patients radiotherapy more quickly than another group, the researcher could have potentially enhanced the care delivered to some patients and harmed others. It would only have been possible to undertake a randomised control trial if both groups could have been offered their radiotherapy in a shorter or equal than normal time for the study centre (six weeks). As the limited amount of equipment and staff within the treatment centre currently contributed to the six week wait for radiotherapy, the time between surgery and radiotherapy could only have been decreased for the purposes of a study, with a significant amount of resources. These resources were not available and are unlikely to be provided until some data are generated to demonstrate that the length of time between surgery and radiotherapy is potentially detrimental to the patients.

After much consideration of the alternatives the researcher decided to use a comparative descriptive design to investigate the research questions. This design is used to describe and examine differences in variables within two or more groups in a setting (Cormack
1991, Burns & Grove 2003). As no other studies have examined the period of time between surgery and radiotherapy for patients with malignant glioma and their families, this study was explorative. The main purpose of the study was to gain some empirical data about the period between surgery and radiotherapy for patients with malignant glioma and their families, and in turn develop some rationale for the findings. The variables that the researcher anticipated would have some influence on the study findings were: length of time between surgery and radiotherapy, diagnosis and treatment and by investigating only a group of patients with malignant glioma, the impact of these variables may not have been measurable. It was decided by the researcher and the supervisors of the study that in order to provide an enhanced description of the study period in respect of these variables, a comparison group should be introduced to the study design. The group that was identified to provide this comparative sample was patients with cerebral metastasis. Many of these patients follow a similar pattern of care to patients with a malignant brain tumour and more importantly, at the outset of the study it was presumed that these patients receive their radiotherapy in a shorter time period than most of the patients with a malignant glioma.

To enable a full exploration of the research questions, data were generated from two groups of patients (one group with malignant brain tumours and the other group with metastatic brain tumours) and compared using inferential and descriptive statistics and analysis of qualitative factors. This can be described as comparative descriptive design as the same variables were to be measured and explored in two different samples (Polit & Hungler 1997, Burns & Grove 2003). Figure 4.1 diagrammatically illustrates the framework for the study using a comparative descriptive design.

4 The nature of the diagnosis of cerebral metastasis lends itself to receiving a palliative dose of radiotherapy. The patient receives a dose of 20gy of radiotherapy over two weeks to the full brain. No planning within a simulator is required for this treatment and this significantly decreases the time patients' wait for their radiotherapy.
The study used a combination of approaches to explore the functional and emotional issues being experienced by patients and their carers between surgery and radiotherapy. Figure 4.1 diagrammatically illustrates the data collection tools, and method of analysis.
that were used to address each research question. From Figure 4.1 it is illustrated that Stage 1, 2 and 3 were undertaken on both the study groups; malignant glioma (Group one) and cerebral metastasis (Group two). As the aim of the unstructured interviews was, to give clarity and depth to the findings generated from the other data collection techniques, and the overall aim of the study was to explore the issues being encountered by patients with malignant glioma, unstructured interviews were only undertaken on group 1 (patients with malignant glioma). As the research questions indicate, the changes in functional and emotional issues were to be measured over the period between surgery and radiotherapy. For this reason the data collected in stage one of Figure 4.1 was repeated at various time points in the study.

The lack of studies that have been undertaken within this area and the outcome of other studies suggested that no single data collection tool could produce reliable and valid results for this study. To enhance the reliability and validity of the findings the researcher combined a number of data collection tools to address each of the research questions. The variables being studied within each research question could have been investigated solely using quantitative data collection methods. However, the researcher’s experience and knowledge of the issues that were being investigated indicated that the sole use of previously validated and reliable tools to investigate some of the sensitive issues would be inappropriate for this study. To gain insight into why patients were anxious at certain times, to explore specific issues regarding quality of life and to demonstrate why lives were being disrupted, methods of qualitative data collection had to be employed.

The integration of qualitative and quantitative data collection techniques within a single study is becoming more popular (Burns & Grove 2003). By integrating different data collection methods within a study the weaknesses of a single approach can be diminished (Polit & Hungler 1997). The strengths and weaknesses of both quantitative and qualitative data collection methods can be complementary (Sells et al 1995). Within this study the researcher believed that each method could fulfil each other’s deficiencies to ensure that each study variable could be investigated fully from the perspective of the
patient and carer. As this study was explorative in nature it was important that the findings of the study could provide an accurate insight to the study period. It was acknowledged at the outset of the study that employing a combination of data collection tools may highlight some discrepancies within the study findings. However, viewed positively this ensured that if discrepancies did occur within the study findings further investigation to provide a reason for this would enhance the validity of the study findings. The rationale for the choice of each specific data collection tools will be discussed in Section 4.4. The methods adopted for data analysis will be further discussed in Section 4.8.

4.3 PLAN OF DATA COLLECTION

If patients met the selection criteria for the study they were asked if they would like to participate in the study. If patients agreed to participate they were asked to complete a consent form and the first stage of the data collection process commenced. Figure 4.2 illustrates how and when the data for the study were collected. The data for Stage 1 were collected two - three days post surgery and Stage 6 data were collected two days prior to radiotherapy or six weeks after surgery – for ease of understanding this time point has been named final follow up. These time points signified the start and end points of the data collection period for each patient. Data were collected from patients weekly throughout the study period (stages 2-5). In order to enhance compliance, the researcher informed the subjects that they would be contacted every Wednesday afternoon. If patients did not receive or were not offered radiotherapy the final follow up data was collated six weeks after stage 1 (hypothetically this would have been the time when they would have received their radiotherapy). The unstructured interviews were undertaken with patients after commencement of their radiotherapy treatment, as the researcher wished them to reflect upon the total period between surgery and radiotherapy during the unstructured interview.
Figure 4.2  Plan of Data Collection

**Steps for Patients**

**Step 1: Face to Face**
- EFIT
- HAD
- Steroid Dosage
- Steroid Side Effects
- Quality of Life

**Step 2: Telephone Interview**
- Steroid Dosage
- Steroid Side Effects
- Quality of Life Issues

**Step 3: Telephone Interview**
- Steroid Dosage
- Steroid Side Effects
- Quality of Life Issues
- Questionnaire
- HAD
- Quality of Life
- Level of Life Disruption

**Step 4: Telephone Interview**
- Steroid Dosage
- Steroid Side Effects
- Quality of Life Issues

**Step 5: Telephone Interview**
- Steroid Dosage
- Steroid Side Effects
- Quality of Life Issues

**Step 6: Telephone Interview**
- Steroid Dosage
- Steroid Side Effects
- Quality of Life Issues
- Questionnaire
- HAD
- Quality of Life
- Level of Life Disruption

**Stage 7: Unstructured Interview**

**Steps for Carers**

**Stage A: Questionnaire**
- Level of Life Disruption

**Stage B: Questionnaire**
- Level of Life Disruption

- **Post Surgery**
  - 3 weeks after Surgery
  - Final follow up (pre radiotherapy or 6 weeks after surgery)
4.4 **Study Variables**

The dependent variables that the researcher wanted to measure within this study were determined by the literature review and the researcher’s own personal experience of dealing with these patients:

- **Functional Impairment** - The majority of studies that have been undertaken amongst malignant glioma patients have identified that the functional state influences the psychosocial response exhibited by patients (Weitzner et al 1996, Salander et al 1996, Fox & Lantz 1998, Giovagnoli 1999, Salander & Spetz 2002).

- **Anxiety and Depression** - Within a few studies the levels of anxiety and depression exhibited amongst brain tumour patients has varied considerably (Thomson et al 1999, Stark et al 2002). Studies amongst other cancer patients have indicated that anxiety and depression are main factors in determining the patient’s response to diagnosis (Mishel et al 1984, Hughson et al 1988, Stark et al 2002). Without measuring these variables the researcher believes that the practical and emotional issues being exhibited by patients between surgery and radiotherapy could not be undertaken adequately.

- **Dexamethasone Dosage & Side Effects of Dexamethasone** – The functional state of patients after surgery can potentially be greatly affected by the side effects of dexamethasone (Twycross 1994). There are no specific guidelines for the administration but it is recommended that the maintenance dose of dexamethasone after surgery should be kept as low as possible. To determine whether dexamethasone has any influence on the emotional and practical issues being experienced by patients the dose and side effects of this drug had to be measured.

- **Quality of Life** – To date no study has explored quality of life between surgery and radiotherapy for patients with malignant glioma. As quality of life is extremely important throughout the limited life of malignant glioma patients it is important that data is collected about quality of life at each stage of the treatment process.

- **Level of Life Disruption** – After a diagnosis of a malignant glioma the researcher anticipates that due to a number of factors e.g. deteriorating functional state, loss of driving licence, an individual’s everyday life will be disrupted. It was important for the researcher that this element of individual’s lives between surgery and radiotherapy was
measured separately within this study. From the literature and experience the researcher did not believe that any quality of life measurement tool would measure this aspect of the individual’s lives.

Whilst developing the study the researcher felt strongly that there would be a need not only to describe the behaviour exhibited by patients between surgery and radiotherapy but to explain it. Without an explanation of the cause of behaviour it is difficult for health care professionals to identify what they can do to support the patient. The model developed by Shaw (1999) was identified as a useful theoretical framework for this study as it combined many theories of behaviour that have been described in the past and would allow the researcher to describe the behaviour exhibited as a result of a number of factors, if necessary. The usefulness of the framework of illness behaviour developed by Shaw (1999) was addressed as a research question within this study as until data analysis the researcher could not indicate if the framework was going to be useful in helping to explain the behaviour of patients between surgery and radiotherapy.

A combination of data collection methods were used within the study to allow a thorough investigation of each variable. To ensure that the study findings adequately detected and measured the experience of the patients and their carers in the period between surgery and radiotherapy a different data collection tool had to be selected for each variable (see Table 4.3). Each data collection tool was selected to ensure the rigour and validity of the study findings. To adequately explore anxiety, depression, level of life disruption and quality of life a combination of qualitative and quantitative data collection tools was employed. The rationale for data collection tools selected is detailed in section 4.5.
Table 4.3  Outline of the Data Collection Methods Used

<table>
<thead>
<tr>
<th>Variable</th>
<th>Data Collection Method</th>
<th>Data Collection Tool</th>
</tr>
</thead>
<tbody>
<tr>
<td>Functional State</td>
<td>Quantitative</td>
<td>EFIT</td>
</tr>
<tr>
<td>Anxiety &amp; Depression</td>
<td>Quantitative &amp; Qualitative</td>
<td>HAD Scale (HAD) Interviews</td>
</tr>
<tr>
<td>Dex* Dosage</td>
<td>Quantitative</td>
<td>Chart, completed during Telephone interview</td>
</tr>
<tr>
<td>Side Effects of Dex*</td>
<td>Quantitative &amp; Qualitative</td>
<td>Checklist completed through telephone interview Interviews (Telephone &amp; Unstructured)</td>
</tr>
<tr>
<td>Quality of Life</td>
<td>Quantitative &amp; Qualitative</td>
<td>Structured Questionnaire (EORTC QLC 30) Interviews (Telephone Unstructured)</td>
</tr>
<tr>
<td>Level of Life Disruption</td>
<td>Quantitative &amp; Qualitative</td>
<td>Structured Questionnaire Devised for Study Interviews (Telephone &amp; Unstructured)</td>
</tr>
</tbody>
</table>

Dex* = Dexamethasone

The data collection tools selected had to be considered in conjunction with the illness behaviour model described in Chapter 2. If, as dictated by the model the behaviour of an individual is determined by a combination of factors; illness representation, social support, commitments, self efficacy and locus of control, data collection tools that allowed these elements to be measured in tandem with the outcome measures had to be integrated into the study. To gain insight into how the individuals perceived their illness, their response to it and they way they were coping the researcher knew a relationship of open communication would need to be established between her, the patients and the carers. Weekly contact with the patients throughout the study period allowed the development of this relationship and through the weekly telephone conversations insight could be gained into these aspects of individuals’ lives. The unstructured in depth
interviews with a few of the patients allowed clarification of some of these issues and added some depth to the data being generated regarding the cause of behaviour being exhibited.

There were a number of independent variables identified from the literature prior to commencement of the study. Independent variables are familiar to the researcher prior to the commencement of the study but cannot be entirely controlled by the study design (Burns & Grove 2003). Age, gender, diagnosis and length of time between surgery and radiotherapy lifestyle, education, emotional support and family functioning, were all factors that other studies have indicated could potentially affect the patient’s physical and emotional state (Northouse 1989, Northouse et al 1995). The researcher attempted to manage these variables within the study by collecting demographic details on the patient: age, marital status, dependents, diagnosis and applying selection criteria stated below. Using these selection criteria and taking cognisance of the demographic data allowed the researcher to measure the potential influence that the confounding variables had upon the outcome measures.

The inclusion criteria for the subjects studied were:

- All post surgical (biopsy or resection) primary brain tumour or cerebral metastasis patients within study site.
- Diagnosis of pathologically proven malignant glioma or cerebral metastasis.
- Males & Females between 16 and 60 years of age.

The exclusion criteria for subjects studied were:

- Patients who have undergone surgery or radiotherapy for excision of brain tumour or cerebral metastasis.
- Patients who will undergo surgery or radiotherapy at another treatment centre.
- Non English speaking patients.

Patients involved in any other study that will influence the transitional period between surgery and radiotherapy.
4.5 Data Collection for Dependent Variables

4.5.1 Functional Status

The study examined changes in the patients' neurological function between surgery and radiotherapy. It was anticipated that while waiting for radiotherapy there may be a change in the neurological function of the patients. Previous research has indicated that a malignant primary brain tumour may double in size over a period of 21 days (Yamishita & Kuwabara 1983). As most patients included within this study would wait in excess of 21 days for radiotherapy, it was hypothesized that there may be some growth of the tumour in this time and this may have an impact on the neurological function of the patient.\(^5\) By studying the neurological functional impairment of the patients post surgery and pre radiotherapy, the impact that the length of time and the other independent variables within the study had upon neurological function could be examined. The other independent variables that could have influenced the neurological functional state of patients between surgery and radiotherapy were age, gender, diagnosis, treatment, steroid dosage, location of tumour and impact of surgical intervention (Whittle 1996, Clyde et al 1998).

The Barthel Index and the Edinburgh Functional Impairment Test (EFIT) are two tests that have been designed to measure the neurological functional state of patients (Appendix 2 & 3). The Barthel Index is the rating tool most commonly used in studies examining neurological patients with moderate to severe disability, as it is easy to use, reliable and of prognostic value (Brazil et al 1997, Thomas et al 1995). A study has been undertaken to compare the sensitivity of the Barthel Index with the Edinburgh Functional Impairment Test (EFIT) for patients with malignant glioma. (Clyde et al 1998). It indicated that the EFIT was a more sensitive indicator of changes in functional

\(^5\) As an adjunct to this study 12 of the patients included in the study had two additional MRI scans post surgery and pre radiotherapy. Analysis of this data has indicated that there is significant growth of the tumour during the transitional period (Kilbride & Pennington 2003).
status over a short period of time (Clyde et al 1998, Grant et al 1999). This finding influenced the researcher to choose the EFIT measurement tool for this study, as a change in neurological functional state was being measured over a short period of time (three – six weeks).

The EFIT incorporates four tests that establish common types of neurological impairment: upper and lower limb impairment, memory and dysphasia. The tests that measure these are;

- Timed Ten Metre Walk – lower limb impairment
- Nine Hole Peg Test – upper limb impairment
- Memory – Williams Delayed Recall Test
- Dysphasia – Boston Aphasia Rating Scale.

Each test component of the EFIT has been proven to have to have good inter and intra observer reliability and validity amongst patients with brain tumours (Clyde et al 1998).

*Nine Hole Peg Test*

This is a test of manual dexterity and will indicate upper limb impairment. The patient is required to pick up wooden pegs one at a time and insert them into holes in a board. There are nine pegs in total. The length of time required to complete this task, from touching the first peg to successfully inserting the last peg, is recorded in seconds. Times for right and left hand are recorded separately as the location of the tumour and the handedness of the patients could have a potential impact on score. A score of <20 seconds is normal. Patients unable to complete the task because of weakness are assigned the maximum score of 180.

*Timed Ten Metre Walk*

This tests speed of walking and will indicate a lower limb deficit. Patients are asked to walk 10 metres as quickly and safely as possible without running. The time taken to cover a distance of ten metres is recorded in seconds. A time of <8 seconds is considered normal. Patients unable to walk or unable to complete the test are assigned a maximum score of 60 seconds.
**Williams Delayed Recall Test**

This is a test of memory and will indicate impairment in this function if present. The patient is shown a card with nine easily recognisable objects on it. The patient is asked to say what they call each object (this will identify if the patient is suffering a level of dysphasia and, if so, will alert the researcher to the influence this could potentially have upon the result) and then is asked to memorise them. Six minutes later the patient is asked to recall the nine objects. If unable to recall all nine the patient is given a verbal prompt to aid recall. If still unable to recall the forgotten item(s) the patient is given a visual prompt. They are shown a card with 16 items amongst which are the original nine and asked to recall the forgotten items. Responses are scored for each item as follows:

- 2 points for each item not recalled spontaneously
- 3 points for each item not recalled after verbal prompt
- 4 points for each item not recalled after visual prompt.

Points for each object are summated and an overall score for all items calculated. A score of $<16$ is considered normal. Patients unable to recall any objects after verbal or visual prompts or because of other impairments (anxiety, language difficulty) are assigned the maximum score of 81. There are three versions of the WDRT that can be utilised when the test is being repeated at different intervals on the same patient. This controls the positive impact long term memory may have upon the results in instances when the test is being repeated.

**Boston Aphasia Severity Rating Scale**

This is a test of language. Aphasia is defined as a defect or loss of the power of expression by speech, writing or signs or of comprehending spoken or written language, due to injury or disease of the brain. The patient is shown a picture depicting a scene and is then asked to describe what is happening in the pictures. Scores range on a likert scale from 6 (normal speech) to 0 (no useful communication possible).

The EFIT was undertaken at two time points in the study. The post surgical test was undertaken two to three days after the patient’s surgery, and the final follow up test was
undertaken two days prior to commencement of their radiotherapy or six weeks after diagnosis. It was decided that for patients who did not receive radiotherapy, the hypothetical 'pre radiotherapy' date was taken to be six weeks after the date of surgery. This ensured their results were comparable with the other patients in the study.

The functional impairment measurements of the patients were analysed using the formula that has been devised and proven to indicate a significant change within each score that has a high concordance with clinical opinion of functional change (Clyde et al 1998). The formula for detecting a significant clinical change within each patient for each of the tests incorporated within the EFIT is included in Appendix 4. A paired sample t test could have been used to analyse the results of the EFIT as this method of analysis would have allowed the researcher to detect the change in mean scores for different groups of patients. However, as the study aimed to investigate the variables influencing changes in functional status, it was important that each patient's change in clinically neurological function was detected. A significant change in one or more tests of the EFIT for each patient in the study could not have been detected using a paired sample t test.

4.5.2 Anxiety & Depression

The prevalence of anxiety and, to a lesser extent, depression in patients with different types of common cancer is well documented (Bilodeau & Degner 1996, Poole 1997, Zabora et al. 2001). Surprisingly, a study measuring the anxiety and depression levels of brain tumour patients before and after surgery indicated that anxiety and depression were not prevalent within this group of patients (Pringle et al 1999). When comparing the contrasting findings the researcher noted two important factors. The studies that implied anxiety was prevalent in the majority of patients after diagnosis used a qualitative means of measurement and studied groups of patients who were told of their diagnosis prior to surgery. Pringle et al (1999) used the Hospital Anxiety and Depression scale (HAD) to measure anxiety and depression. However many of the patients within her study would not yet have been informed of their diagnosis. Within this study the researcher aimed to investigate whether anxiety and depression were prevalent in
malignant brain tumour patients after being informed of their diagnosis by using the HAD scale and interviews.

It is stated that the Hospital Anxiety and Depression Scale (HAD) is a reliable self assessment tool, that can be utilised outwith and within the hospital setting (Zigmond & Snaith 1983, Grant et al 1999, Pringle et al. 1999). In comparison to other tools utilised to screen psychological disorders e.g. General Health Questionnaire, the HAD separates the concept of anxiety and depression, assesses the degree of change and is user friendly for the researcher and the participant (Zigmond & Snaith 1983). After careful consideration of the studies where the HAD scale had previously been used, the researcher decided to use the HAD scale, in conjunction with weekly telephone interviews and unstructured interviews to collate signs of anxiety and depression within the study. By using a combination of data collection measures the researcher hoped to ensure that accurate data about anxiety and depression were gathered, as there were some doubts that the HAD would be sensitive to anxiety and depression levels within this group of patients.

It could be argued that the researcher's anxieties about the HAD scale should have deterred its use within this study. However, as it is the most commonly used tool to measure anxiety and depression in the area of neuro-oncology, the findings of the study may have been criticised if an alternative had been used. In addition, its simplicity was very attractive for the study. The researcher was very aware of the impact that the physical and cognitive deterioration of patients could have on the response rate of the study.

The HAD scale was developed in 1983 by Zigmond & Snaith. It represents an attempt to detect the presence of anxiety and depression whilst excluding those effects that can mimic these disorders. The HAD scale has been found to have criterion validity and construct validity (Snaith & Taylor 1985). There is further work required to demonstrate inter rater and test-retest reliability. However, sensitivity to change has been demonstrated (Snaith & Taylor 1985). By using the HAD scale in conjunction with other
data collection measures its sensitivity amongst brain tumour patients can be explored through this study.

The HAD scale is a test of psychological well being (Appendix 5). It consists of 14 questions divided into two sub scales – one for anxiety one for depression - of seven questions each. Each question is rated by the patient on a four point scale. The score for each item represents the degree of distress suffered by the patient (0 = none, 3 = unbearable). Items for each sub scale are summated. A score of 11 + on either scale is taken to indicate a definite case of anxiety and/or depression.

Within this study the HAD score was collated at three time points: post surgery, three weeks post surgery and at final follow up stage. In addition, weekly telephone calls allowed the researcher to detect any anxious and/or depressive thoughts or feelings being expressed by the patients. The unstructured interviews also allowed for this and additionally offered the researcher an opportunity to explore these thoughts and feelings more with the patient and carer.

The HAD scores collated within the study were analysed using a Repeated Analysis of Variance Test (RANOVA), which will be discussed further in Section 4.7.

4.5.3 Quality of Life

As the intent of treatment for patients with malignant glioma is primarily palliative it is important that throughout their survival (median six – twelve months for most patients) they have a reasonable quality of life (Gupta & Sarin 2002, Efficient & Bottomley 2003). Some studies have examined quality of life in brain tumour patients at different points in their illness but no study has ever formally assessed quality of life whilst these patients are waiting for treatment (Weitzner et al 1996, Gupta & Sarin 2002). It was anticipated that many of the patients within the study would wait six weeks for their radiotherapy treatment. For a condition that has a median survival time of 12 months the time between surgery and radiotherapy would account for 12% of this. The time between surgery and radiotherapy for malignant brain tumours should be optimised for many reasons. During this time patients are not receiving any treatment, they have not yet
encountered the side effects of radiotherapy (hair loss, nausea and fatigue) and the surgery and dexamethasone therapy they have received should have improved some of the physical signs and symptoms of the cerebral oedema and the brain tumour. It was anticipated prior to the commencement of the study that patients might, if they did not encounter a number of physical and emotional issues, be at an optimum physical state to enjoy their lives during this stage of their illness. For this reason it was imperative that quality of life was measured in this study.

Some studies have been undertaken to examine the optimum measurement of quality of life amongst patients with malignant glioma. At the outset of this study - The European Organisation for Research and Treatment of Cancer (EORTC) Core Quality of Life Questionnaire with brain tumour supplement questionnaire (EORTC QLC - C30) - was still recognised as the most valid and reliable measurement tool amongst this group of patients (Gregor & Cull 1996, Weitzner et al 1996). A study group at the EORTC developed the questionnaire and it included 30 patient reported items that related to the health dimensions and symptoms of disease. The sub scales of the questionnaire correlated moderately to strongly with comparable items on Sickness Impact profile (SIP) and Cancer Rehabilitation Evaluation System (CARES). The depression scale correlated strongly with the hospital anxiety and depression scale (Bowling et al 1994). Internal consistency was demonstrated to reach acceptable levels apart from within the role functioning domain and inter rater reliability has been reported (Aaronson et al 1993). This core questionnaire was supplemented by a brain cancer module (BCM) questionnaire.

The BCM was specifically developed for use with brain cancer patients. It consists of 20 items, four multi item questions (uncertainty over the future, visual disorders, movement disorders and communication difficulties) and a seven item questions concerning headaches, drowsiness, seizures, hair loss, itching, weakness of both legs and difficulties with bladder control. Of the total 50 questions included in the combined EORTC QLC - C30 and BCM questionnaires 40 are measured on a 1-4 point scale where a low score represents good health (high level of function or low level of symptoms). Five of the
remaining seven items are scored on a two point scale (no=1, yes=2) where the response no indicates the presence of function or absence of symptoms. The remaining two items consist of a 1-7 likert point scale on which a low score represents good health. The range of possible total scores is therefore 50 – 196.

Whilst the EORTC QLC – C 30 has been reported to meet acceptable levels of validity and reliability it is a lengthy questionnaire and this may have encouraged a poor response rate within the study. As other quality of life tools are lengthy and it is commonly acknowledged that comparisons of different patients quality of life measures is difficult (Speigelhalter et al 1992), the researcher decided to use the EORTC and supplement this measurement of quality of life with qualitative data that would be generated from the level of life questionnaires and the interviews. This hopefully would ensure that the poor response rate from the EORTC scores would not allow some issues of quality of life from the patient’s perspective, to go undetected within the study. A quality of life score was collated at three time points within the study period: post surgery, three weeks post surgery and at final follow up stage.

4.5.4 Dexamethasone Dose & Side Effects

In the period between surgery and radiotherapy many patients are at home. Whilst at home patients are self-administering dexamethasone they were prescribed by the hospital on their discharge. It was anticipated that the patients would continue upon the dexamethasone regime they were discharged with until a member of staff at the treatment site reviewed them. As it is important that dexamethasone administration is monitored closely. The impact of dexamethasone therapy was measured within this study.

To determine if there were any side effects induced by the administration of dexamethasone therapy between surgery and radiotherapy, information was collated weekly from the patients by telephone. The side effects of dexamethasone monitored via the telephone were the ones most commonly cited in the literature: gastric upset, insomnia, weight gain, glycouria, and ankle swelling (McNamara & Kilbride 1998). As
the patients within the study were located over a wide geographical area the use of telephone interviews for collating this data were the most appropriate. Each week the researcher recorded the dose of dexamethasone being administered and the reported side effects being reported using a checklist devised for the purpose of the study.

4.5.5 Level of Life Disruption

The level of life disruption experienced by brain tumour patients has not previously been investigated. From experience the researcher presumed that certain aspects of life can potentially be disrupted after surgery for a patient with a malignant brain tumour e.g. work, financial status, family engagements, holidays and familial roles. To measure the level and type of life disruption experienced by patients in the study, a semi structured questionnaire was devised (Appendix 6). It was anticipated that the responses collated from this questionnaire would provide a basis to further explore this subject within the weekly telephone interviews and unstructured interviews. As the unstructured interviews were not to be undertaken on every participant and the telephone interviews were intended to collate information about a number of things, the semi structured questionnaire was beneficial for the generalisability of the findings. Common themes about the level of life disruption being experienced by the patients and carers were generated, from the questionnaire and some of these themes were explored in more depth, by the researcher, during the unstructured interviews.

The semi structured questionnaire focused upon three main aspects of an individual’s everyday life - family, work and social activities. By asking questions relating to each of these the researcher could measure the impact that a diagnosis of a malignant brain tumour and the wait for radiotherapy, was having upon the patients’ and carers’ lives. Patients and carers were asked three weeks after the date of surgery to rank their response to closed questions about disruption in their lives using a scale from ‘not at all’ to ‘very much’. The other closed questions asked about the activity of the individuals during the period between surgery and radiotherapy and required simple yes/no answers. Further clarification was sought about some specific activities by following up the
response to the closed questions with a more open-ended question e.g. if yes who did you contact.

The telephone conversations also collected valuable data about the patients’ and carers’ lives in the period between surgery and radiotherapy. This additional source of data generation was valuable in several ways. It ensured the reliability of the questionnaire, some data could be collected on subjects who failed to complete their questionnaires and clarification of any specific issues raised within the subject’s questionnaire response could be sought. The unstructured interviews allowed the issues that were having an impact on patients’ and carers’ lives to be thoroughly examined.

The data collected using the data collection tools described above were all collated on a patient proforma developed specifically for the study (Appendix 7). Once collated this information was then inputted to an access data base created for the study.

4.5.6 Unstructured Interviews

The ‘in depth’ interviews were used to provide more detailed information about the patients’ and carers’ experience during the transitional period. The interviews were undertaken to provide illustrative examples and quotations that illuminated the findings generated within the main study, and, to ensure that invalid conclusions would not be made from the researcher’s assumptions, motivations and interpretation of the quantitative data generated (Hakim 1987, Silverman 2004). Four subjects and their carers were purposively sampled (see Section 4.5) and asked if they would be willing to participate in an unstructured interview that would be undertaken in their home. A major difficulty that had to be resolved by the researcher at the outset of the study was the timing of these interviews. If the sampling of suitable patients for interview was not undertaken until completion of the study, many of the suitable patients would have died or would have cognitively deteriorated making them unsuitable for interview. Additionally, if interviews were not undertaken close to the transitional period, the problems that patients and carers had faced may have been forgotten or superseded by other priorities. For these two reasons the interviews were undertaken sporadically
throughout the study, on patients who the researcher, using her knowledge of the subject area and her relationship with them, felt would give an authentic insight into the patient and carers experience.

As the researcher had established a relationship with these patients throughout the study the questions asked within the interview were focussed upon exploring the main issues raised during the study period. This proved invaluable to the study findings, as during the interviews it was apparent that some of the issues that were raised by the patient and carer during the study had paled into insignificance since commencement of their radiotherapy. Slight prompts throughout the interview refreshed the patient’s and carer’s memories of these issues and ensured that the interviews focussed on the topics necessary. It was decided by the researcher to undertake the interviews in the patient’s home as this would encourage them to feel comfortable and safe while discussing very emotional issues. This would be beneficial for the patients, carers and the study.

4.6 Sampling

The target population for the study was all patients with malignant primary brain tumours and cerebral metastasis in South East of Scotland. The accessible population was all patients admitted to the study site for treatment of these tumours. A convenience form of sampling was used for the main stages of the study. Over a one year period the researcher applied the selection criteria, to all referred patients. Convenience sampling is criticised as being a poor approach to selecting subjects due to its inability to control bias (Cormack 1991). However, the aim, the disease process, the size of target population, the resource restrictions and the ethical reasons of this study dictated that a convenience form of sampling was the most appropriate for this study.

Through power analysis the researcher could have estimated the sample size necessary to adequately statistically investigate the research questions (Polit & Hungler 1997). However, through experience and findings from other studies the researcher knew that to achieve the size of sample that would statistically test the research questions would be
impossible due to time and resource limitations. The implications of this for the study are further discussed in Chapter 5.

The researcher used purposive sampling to select patients for the unstructured interviews. It was acknowledged by the researcher that this form of sampling would not allow the collation of generalisable data. However, as this was not the purpose of the interviews, this type of sampling was deemed appropriate (Burns & Grove 2003). The intention of the interviews was to add depth and meaning to the main study data, and, by selecting patient's appropriately, the researcher aimed to generate data that would provide the patients account of what had happened to them between surgery and radiotherapy and their rationale for this (Silverman 2004). Using the findings from the study the researcher aimed to select four patients to interview who differed in age, gender and family circumstances. The intimate relationship between the researcher and patient also allowed the researcher to select people who had appeared to cope differently in the period between surgery and radiotherapy. The demographics of the patients, selected for interview will be further discussed in Chapter 6.

There were many challenges to be faced during the data collection period. Collecting data regularly from a group of patients who lived throughout the South East of Scotland proved difficult. Prior to commencing the study it was realized that a large percentage of patients would be at home during the study period. This provided the impetus for choosing telephone interviews and postal questionnaires as the means of data collection.

4.7 THE INCOMPLETE DATA

Missing data may result from ‘unit non response’ meaning an entire assessment is missing, or an ‘item non response’ meaning that an assessment has only been partially completed. ‘Dropout’ occurs when a patient misses an assessment and is never observed again; ‘intermittent’ missing data occur when a subject misses an assessment but is subsequently observed at a later point in time (Burns & Grove 2003).
Methods have been proposed for the imputation of missing data e.g. last value carried forward, mean and regression imputation (Burns & Grove 2003). Mean imputation refers to the substitution of the mean score from the observed patients to the patients who are unobserved; this method can be enhanced by calculating the mean for the group of patients with similar characteristics (Wood 2003). Regression imputation replaces missing values by predicted values from a regression of the missing item with both previously observed scores for that patient and associated variables (Wood 2003). For the purposes of this study it was decided that only complete data sets were analysed and reasons for incomplete sets were recorded and assessed.

4.8 DATA ANALYSIS

The researcher collated quantitative and qualitative data throughout this study. The data collated were analysed using techniques suitable to the type and quantity of data generated. The statistical and qualitative tests of analysis the researcher applied to each of the data sets was determined by the study design and the analysis technique for each data collection tools is listed within Table 4.4.

Table 4.4 The Type of Data Generated and the Method of Data Analysis Applied

<table>
<thead>
<tr>
<th>Data Collection Tool</th>
<th>Type of Data</th>
<th>Method of Analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>EFIT</td>
<td>Statistical</td>
<td>Test of Clinical Significant Change in Functional State</td>
</tr>
<tr>
<td>HAD</td>
<td>Statistical</td>
<td>RANOVA test</td>
</tr>
<tr>
<td>EORTC QLC 30</td>
<td>Statistical</td>
<td>RANOVA test</td>
</tr>
<tr>
<td>Level of Life Disruption Questionnaire</td>
<td>Statistical &amp; Qualitative</td>
<td>Paired t Test</td>
</tr>
<tr>
<td>Telephone Interviews</td>
<td>Qualitative</td>
<td>Content Analysis</td>
</tr>
<tr>
<td>Unstructured Questionnaires</td>
<td>Qualitative</td>
<td>Content Analysis</td>
</tr>
</tbody>
</table>

All statistical data for the study were entered into Statistical Package Social Scientists (SPSS) from the Microsoft Access® database created for the study. All the data apart
from the responses to open ended questions within the level of life disruption questionnaire, notes from telephone interviews and the transcripts of unstructured interviews were entered into SPSS. This rendered the analysis of the numerous independent and dependent variables within the study manageable. The qualitative data, once transcribed into Microsoft Word®, were coded using a paper and pencil technique and content analysis was applied.

4.8.1 Statistical Analysis

To analyse the data the researcher used: a Paired Sample t Test; a Repeated Analysis of Variances (RANOVA) Test and Tests of Clinical Significance.

Paired Sample t Test

This test was applied to the nominal data that were collected from the level of life disruption questionnaire. As a t test can only be used to analyse normally distributed data frequency testing of the data was also necessary (Hinton 1995). To answer the research questions, the researcher had to investigate if there were any changes in life disruption measurable amongst the independent variables of the study e.g. gender. Was work life more disrupted for males than females within the study? The researcher used the statistical package SPSS to apply each of the paired sample t tests applied within the study (see Table 4.2). The results of this analysis are presented in Chapter 6.

RANOVA

Some of the tests within the study were undertaken three to seven times e.g. quality of life measures, HAD scores and side effects of dexamethasone. The data were to be analysed using a RANOVA test. As a RANOVA test can only be used to analyse normally distributed data, frequency testing of the data were also necessary (Hinton 1995). The benefit of the RANOVA for this study was that it could be applied on relatively few subjects and allowed a comparison of the mean amongst the independent variables e.g. age, gender, across each of the time points. This test allowed the researcher to demonstrate the influence that the dependent variables had upon the
differences measured amongst the EORTC results, the HAD results and the side effects of dexamethasone measured (Hinton 1995). Although RANOVA tests can be applied manually for the purposes of this study the test was applied through SPSS. The results of this analysis are detailed in Chapter 6.

*Tests of Clinical Significance*

A decision was taken by the researcher to apply tests of clinical as opposed to statistical significance to the functional data collated. When developed the EFIT was rigorously tested for statistical and clinical significance (Clyde et al 1998). This study indicated that by applying the calculations illustrated in Appendix 4 a significant change in the patient’s clinical state could be measured. As treatments options and patients perceptions of their illness would be more likely to be influenced by a clinical change in functional state, it was important for the researcher to measure a clinically significant neurological change as opposed to a statistically significant change. Tests of clinical significance were applied to the EFIT data generated. The researcher measured the impact of the independent variables within the study on the changes measured within the patient’s clinical state.

4.8.2 Content Analysis

As this study used both quantitative and qualitative data collection methods to investigate the study outcome measures, the approach selected to analyse the qualitative data had to be reciprocal to the quantitative analysis approach and vice versa. From a review of the literature it was identified that content analysis would allow the content of the focussed telephone interviews, the open ended responses within the questionnaires and the unstructured questionnaires to be analysed and contextualised according to the phenomena and/or categories under study (Weber 1985, Downe–Wambolt 1992).

Content analysis is a methodology that has been referred to within the literature for around 50 years (Krippendorff 1980) and the method of analysis now used by a number of researchers still refers to this seminal literature and the technique it describes. Content analysis provides;
"a systematic and comprehensive summary or overview of the data set as a whole" (Silverman 2001 p 182).

Content analysis provides the researcher with a systematic and objective process that allows valid inferences to be made from verbal data to describe and quantify specific phenomena or categories (Weber 1985, Downe-Wambolt 1992). By inspecting all the data available for recurrent themes or instances of similar thoughts, feelings and beliefs the researcher can through content analysis inform the reader about the areas under study (Krippendorff 1980, Silvermann 2004). The process of content analysis requires more than counting the occurrences of words; it requires interpretation of the meaning, intentions, consequences and context of the words through the inferences of the researcher (Downe-Wambolt 1992). The technique of content analysis encompasses a number of steps. It is recommended that a researcher address each of these steps when undertaking a content analysis as this will help to assure the credibility of the findings generated through this process (Krippendorff 1980). The steps of content analysis detailed by Krippendorff (1980) are;

- Selecting the unit of analysis
- Creating and defining the categories
- Pretesting the category definitions and rules
- Assessing reliability and validity
- Revising the coding the rules if necessary
- Pretesting the revisited category scheme
- Coding all the data and
- Reassessing reliability and validity.

To gain external credibility the sample from which the data is generated must be representative of the phenomenon of interest (Krippendorff 1980). To undertake content analysis the researcher must identify the units of analysis and these units must be guided by the research questions (Downe-Wambolt 1992). The unit of analysis selected from this study were: the telephone interview transcripts, the open ended responses reported from the level of life questionnaire and the transcripts from the unstructured interviews. Intentionally these sections of data were generated to add depth and meaning to four of the study outcome measures that were detailed within the research questions: anxiety
and depression, dexamethasone side effects, quality of life and level of life disruption. The telephone interview data was collected at seven day intervals from all the participants in the study. The unstructured interview data were collected from four participants after commencement of their radiotherapy. The level of life disruption questionnaires were collated three weeks after diagnosis. Each of these participants had a diagnosis of glioblastome multiforme and had commenced their radiotherapy treatment.

To describe the phenomena of interest through content analysis it is necessary for the researcher to create a set range of categories and then identify from the data a word, phrase or sentence that provides an example of each of these categories (Downe-Wambolt 1992, Mackenzie 1994). The emergence of categories for the purpose of content analysis is described ambiguously within some studies. However it is clear from ‘core’ content analysis textbooks that certain procedures are necessary to assure the validity of the categories and the subsequent findings. (Krippendorf 1980, Mackenzie 1994, Silverman 2001). To assure validity the categories and the target of inferences selected by the researcher should be generated from the research questions, the units of analysis, the relevant theories and previous literature (Downe-Wambolt 1992). One of the major criticisms of content analysis is related to this development of what is termed the ‘target’ or ‘a priori’ categories. It is suggested that the development of these categories constructs a conceptual grid for analysis that deflects from the uncategorised activities that may occur within the data (Silverman 2001). This criticism could be applied to the findings of this study; however, it is argued that the development and further description of uncategorised themes from the telephone interviews and unstructured interviews would not have addressed the research questions of the study. For the purposes of this study the researcher wanted to fully explore the outcome measures identified within the research questions: functional state, anxiety, depression, quality of life, and level of life disruption. Therefore, it was these topics and their influencing factors that had been identified through the literature review e.g. uncertainty and support, that generated the ‘priori’ categories for analysis (Silverman 2001). The priori categories and their criteria for selection are detailed within Table 4.5. This table
illustrates the coding system applied by the researcher to all of the qualitative data collected within the analysis stage. Once the priori categories and emerging categories were applied to all of the qualitative data there were some unexpected themes that frequently arose from the data that could not be coded using the pre determined categories and codes. The unexpected categories are detailed in Table 4.6.

Table 4.5  The Priori & Emerging Categories (Codes)

<table>
<thead>
<tr>
<th>Priori Categories</th>
<th>Emerging Categories</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anxiety</td>
<td>Source of Anxiety</td>
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<tr>
<td></td>
<td>Diagnosis</td>
</tr>
<tr>
<td></td>
<td>Waiting for Treatment</td>
</tr>
<tr>
<td></td>
<td>Lack of Information re treatment</td>
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<tr>
<td></td>
<td>Dexamethasone side effects</td>
</tr>
<tr>
<td></td>
<td>Spread of Tumour</td>
</tr>
<tr>
<td>Depression</td>
<td>Source of Depression</td>
</tr>
<tr>
<td></td>
<td>Diagnosis</td>
</tr>
<tr>
<td></td>
<td>Loss of Hair</td>
</tr>
<tr>
<td>Quality of Life</td>
<td>Issues Affecting Q of L</td>
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<tr>
<td></td>
<td>Physical Changes</td>
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<tr>
<td></td>
<td>Seizures</td>
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<tr>
<td></td>
<td>Lack of Normality</td>
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<tr>
<td></td>
<td>Dexamethasone Side Effects</td>
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<tr>
<td></td>
<td>Insomnia</td>
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<tr>
<td>Life Disruption</td>
<td>Sources of Disruption</td>
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<tr>
<td></td>
<td>Dependency/Lack of Control</td>
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<tr>
<td></td>
<td>Morbid Activity</td>
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<td></td>
<td>Behavioural Change</td>
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<td></td>
<td>Personality Change</td>
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<tr>
<td></td>
<td>Selfishness</td>
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<tr>
<td></td>
<td>Lack of Confidence</td>
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<tr>
<td></td>
<td>Change in Routine – home and work</td>
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<td></td>
<td>Childcare</td>
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</tbody>
</table>
Table 4.6  Unexpected but Recurrent Themes

<table>
<thead>
<tr>
<th>Unexpected Themes</th>
<th>Fear</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>Loneliness</td>
</tr>
<tr>
<td></td>
<td>Uncertainty</td>
</tr>
<tr>
<td></td>
<td>Disregard of Physical &amp; Psychological Problems</td>
</tr>
<tr>
<td></td>
<td>Lack of Support</td>
</tr>
</tbody>
</table>

To assure the credibility of the categories developed it is suggested within the literature that, once categorised, the data can be presented to the study participants for corrective feedback as this process can authenticate the experiences of the individual that have been portrayed by the researcher (Krippendorff 1980, Downe-Wambolt 1992). Although this process was considered by the researcher it was impractical for this particular study as at the time of analysis a number of the participants had clinically deteriorated or died making them unable to internally validate the findings. The results of this study are offered solely from the interpretation of the researcher and her recollection of the data collection period and some individuals could criticise the credibility of the study for this reason. However, in defence of the study findings it was the researcher’s in depth knowledge of; the subject, the participants and the source of the data, that made her the most appropriate individual to assess the value of the data due to the existence of its relationships with the other variables within the study (Krippendorff 1980). The researcher of this particular study was the only individual who had a broad understanding of what was going on and had a shared understanding with the participant in the study. As the following quote illustrates it was this insight of the researcher that ensures that the findings of this study are valid:

"Multiple meanings are always present in data – there is no right meaning, only the most accurate meaning from a particular perspective" (Downe-Wambolt 1992p 319).

By providing the extract of the script e.g. verbatim scripts with some background information that illustrate the findings discussed the researcher will allow the reader to assert their own interpretation of the findings to the study and in turn enhance the validity of the findings.
In content analysis it is suggested that there is a dichotomy between reliability and depth of meaning (Downe – Wambolt 1992). From the literature the researcher proposes that this dichotomy exists because the methods of assuring the reliability within content analysis do not complement the philosophical underpinnings of category development. There are three tests of reliability pertinent to content analysis: stability, reproducibility and accuracy (Krippendorff 1980, Weber 1985). The stability of categories can be ascertained when they are applied to the text more than once by the same coder without any inconsistencies (Weber 1985). However, as this process of assuring reliability only consists of one coder it is a weak test of reliability. Reproducibility of codes (categories) is ascertained when more than one coder applies the same categories to a text without inconsistencies (Weber 1985). However, as inconsistencies will always arise between coders and the process of negotiation or invoking authority will automatically introduce bias reproducibility is also seen as a weak test of reliability (Krippendorff 1980). Accuracy is the strongest test of reliability within content analysis; however, to apply this an existing standard categorisation system that has previously been developed has to be used (Weber 1985).

As discussed previously it is the researchers in depth knowledge of the subject and familiarity with the source of the data that makes the development of the categories for coding valid. If to assure reliability these codes (categories) have to be manipulated to ensure that different coders can apply them similarly to the text then the reliability of the finding is assured at the expense of their validity (meaning). To overcome this it is suggested within the literature that categories should be developed and clearly defined prior to categorisation and that once it commences there should be no manipulation (Krippendorff 1980). If, as the literature suggests there will never be complete consistency across individuals coding practices and that to assure reliability there should be no negotiation and manipulation of the codes (categories) (Krippendorff 1980, Weber 1985) it is proposed but not proven by the researcher that stability can be as effective as reproducibility in assuring the reliability of content analysis.
The coding system applied within this study was developed from a theoretical and experiential basis and was applied by the researcher to the data on a number of occasions throughout the analysis stage. The coding system developed allowed theoretical categories to be created from the original data that allowed the researcher to address the research questions and provide an insightful description of the subject's experience.

The application of the priori categories that were determined by the dependent variables of the study proved very beneficial for the validity of the study findings as it highlighted that the quantitative and qualitative data collected yielded some inconsistent findings. According to the statistical analysis of the questionnaires some of the dependent variables within the study were not prevalent amongst the majority of patients between surgery and radiotherapy e.g. anxiety and quality of life issues. However, whilst analysing and coding the qualitative data generated the researcher noted that there was frequent references to sources of anxiety and examples of quality of life issues. The outcome and resolution of this finding will be further discussed in Chapters 6 & 7.

4.9 CONCLUSION

By using a number of data collection tools the researcher endeavoured to gain as much information as possible about the experience of patients and carers during the period between surgery and radiotherapy. It was important for this study to ensure that the quantitative and qualitative data generated about each of the variables could be contrasted to give depth and breadth to the topics being explored. It was felt by the researcher that an adequate representation of the patient’s and carer’s experience of the period between surgery and radiotherapy could be created through both the quantitative and qualitative methods.
CHAPTER 5
ETHICAL IMPLICATIONS AND LIMITATIONS OF STUDY

5 INTRODUCTION
What follows is a discussion of the ethical issues considered and the limitations of the research approach adopted within the study.

5.1 ETHICAL IMPLICATIONS
Ethical approval for this study was sought and gained from Lothian Regional Ethical Committee. Application 1702/98/4/104 was granted approval prior to commencement of data collection period. There were few ethical considerations for the proposed study. However, the researcher addressed these to assure non maleficence to the patients involved.

A patient information sheet and consent form (Appendix 8 & 9) were distributed to the patients prior to consent being obtained. Prior to providing written consent the patient was given the opportunity to read the information sheet and ask any questions. Patients were fully informed of their right to withdraw from the study at any time and made fully aware that if they withdrew from the study their care would not be disadvantaged. As patients needed to fully understand the study and the study tests strict inclusion criteria for 'English speaking patients aged 18 and over' were applied to the study.

The patient’s anonymity was assured. All patients within the study were appointed a patient identification (id) number that was attached to all their data. The patient id number could only be related to their name by the researcher, and the database which allowed this was encrypted and accessible by a password only known by the researcher.
All data was safely and securely stored until completion of the study. Upon completion of the study all data will have to be destroyed. The Data Protection Act regulations were followed at each stage of the research process.

As a nurse, with professional accountability, the researcher was aware that she should not induce harm and she should prevent the patients within the study from harm (Nursing & Midwifery Council 2002). The dual role of researcher and nurse was potentially very difficult to manage, as the patients realised that the researcher had specialised knowledge of their illness and wanted to use her as a source of knowledge and support. The dependent relationship that developed between the researcher and the patients had some influence upon the study findings. When problems that could be resolved arose amongst the study participants the researcher had to intervene to minimise harm. For example, if a patient participating in the study was found not able to eat due to indigestion and oral thrush, the researcher would inform the staff looking after the patient about these problems and ask them to treat the patient appropriately. To minimise the impact that this intervention had upon the study findings the researcher documented each time a situation like this arose in an attempt to control the impact that this intervention had upon the study results.

The sensitive nature of this study indicated that inclusion into this study could have caused the patient and their carer distress. The researcher had to ask patients and carers about sensitive issues such as their feelings, their diagnosis and disruption to their lives. At times this initiated them to acknowledge the impact that their diagnosis was having upon their lives. Throughout the study the researcher was aware of this and endeavoured to ensure that if patients and carers required additional support it was provided by the CNS, a GP and/or the palliative care team. Due to lack of previous studies it was difficult to anticipate whether the support required by some patients within this study was heightened. However, the researcher noted that many patients and the carers required additional support with their medication, knowledge and advice during this study. This support had to be provided to prevent harm.
There were no financial implications for the patients and their carers in this study. The researcher provided stamped address envelopes, made all the telephone calls and travelled to the patients’ homes if necessary. The time implications were minimal and patients and their carers were informed from the commencement of the study what percentage of their own time would be required for them to participate in the study.

The ethical implications of this study were satisfied by informed consent, the researcher’s expertise of the area and obligations to professional accountability. The researcher was confident that through participation in this study no additional harm was induced to patients and their carers.

5.2 LIMITATIONS OF STUDY

A major limitation of the proposed study was sample size. The incidence of the diagnosis restricted the number of subjects that could be recruited to the study from one study centre. A number of options were considered to increase recruitment to the study over the study period. If time and resources were not a consideration for the study a multi centred study may have been possible. By recruiting subjects from more than one study centre the number of patients recruited could have been increased. The researcher considered undertaking the study across two study sites but as there was only one researcher and time was limited the resources were not available to realistically consider this option.

The size of the study’s sample did introduce some limitations to the study findings. The variables that the researcher anticipated would have some influence on the study findings were: length of time between surgery and radiotherapy, diagnosis and treatment, and, by investigating only a group of patients with malignant glioma, the impact of these variables may not have been measurable. It was decided by the researcher and the supervisors of the study that in order to provide an enhanced description of the study period in respect to these variables, a comparison group should be introduced to the study design. The group that was identified to provide this
comparative sample was patients with cerebral metastasis. Many of these patients follow
a similar pattern of care to patients with malignant brain tumours and more importantly,
at the outset of the study it was presumed that these patients receive their radiotherapy in
a shorter time period\(^6\) than most of the patients with a malignant glioma. Unfortunately
the benefit derived from using this group in determining what impact length of
transitional period had upon the results was limited. The study indicated that these
patients do not wait a significantly different amount of time for their radiotherapy in
comparison to the patients with malignant glioma. This finding ensured that the small
number of individuals recruited to this sample group did not significantly influence the
study findings.

To compensate for the small sample size this study was intended to be descriptive in
nature from the outset. The study was undertaken to provide some insight for health
professionals working within the area of neuro-oncology, into the physical and
emotional problems encountered patients with malignant glioma were encountering
during the transitional period. By clearly establishing the process of care within the
study centre and providing demographics of the study sample, readers of the research
can anticipate whether the findings of the study are relevant to the area they work
within. If they consider that any of the interventions and or influencing factors within the
study would alter the experience of the patients and carers within their hospital setting,
the replicable nature of the study design would allow them to investigate this further.

The validity and reliability of the study tools are discussed in length in Chapter 4. By
selecting a variety of tools to collate data on the dependent variables of the study the

\(^6\) The nature of the diagnosis of cerebral metastasis lends itself to receiving a palliative dose of
radiotherapy. The patient receives a dose of 20gy of radiotherapy over two weeks to the full brain. No
planning within a simulator is required for this treatment and this significantly decreases the time patients'
wait for their radiotherapy.
validity of the findings could be assured. The data collection tools utilised within this study was very carefully selected to ensure the validity of the findings and to enhance the credibility of the findings. Within the neuro-oncology forum there are some data collection tools that are perceived to be the 'gold standard' for collecting certain data, but, many of these are not suitable for patients with a deteriorating functional state. In an attempt to ensure that the expectations of experienced neuro-oncology personnel were fulfilled through this study and ensure that all the patients within the study participated fully a number of quantitative and qualitative data collection tools were used.

The use of a number of data collection tools made the data analysis stage of the study quite complex. To overcome the difficulties this posed for the researcher the findings of the study had to be presented in different sections. Upon reflection the researcher would advise anyone wishing to investigate a specific time period for patients with a malignant glioma to use a combination of methods as it does allow greater insight to the experience of the patient. The breadth and depth of the data generated enhances the researcher’s insight to the patients’ experience.

The level of life disruption semi structured questionnaire developed specifically for this study was the only self measurement tool used within the study that was not previously reported to be reliable and valid. From the outset of the study the researcher wanted to investigate certain specific aspects of the patients lives that would not be addressed within the EORTC e.g. impact of loss of driving license. Using her experience the researcher devised a questionnaire that would address issues that patients had stated to her caused some disruption in their lives prior to their radiotherapy. To overcome criticism of its use within the study, the researcher used the data from the telephone interviews and unstructured questionnaires to support the findings collated from the responses to the questionnaire.

The researcher attempted through using a number of data collection tools to generate as much data as possible from each patient. However, the measures adopted did not overcome the difficulties experienced. Patients were on occasionally on holiday,
readmitted to the district general hospital and/or were too sick to answer the phone. Completing and returning questionnaires was problematic for some patients with a deteriorating mental and functional state and when dealing with these conditions carers tended to ‘forget’ about the questionnaires sent to them. Despite these difficulties a large amount of data was collated and the incomplete data was dealt with accordingly.

The selection criteria used within the study to select patients for unstructured interview could be described as subjective. At the outset of the study the researcher wanted to undertake a small number of interviews to clarify and expand upon some of the issues that would be raised throughout the study period. The decision to undertake these interviews posed a difficult dilemma for the researcher. If she waited until the end of the study to undertake the interviews many of the patients recruited would be dead or suffering from a deteriorating performance status. Additionally, the experience of the time period between surgery and radiotherapy could have been superseded by other events making the patient’s recollection of the time period difficult. To overcome these problems the researcher decided to select the sample for interview throughout the data collection period. As the study aimed to describe the experience of patients between surgery and radiotherapy the researcher used her insight to the patients’ experience to select the patients. Two patients who appeared to ‘manage well’ and two who required a ‘lot of support’ were chosen for interview. By selecting patients who appeared to differ in their experience of the time between surgery and radiotherapy it was hoped that the researcher could identify why their experiences differed.

There is some doubt raised over the reliability and validity of data collated from malignant brain tumour patients. It is suggested that at times the condition can have an impact on their cognitive state, which can alter their perception (Salo et al 2002). This study aimed to examine the overall impact that the diagnosis of a malignant tumour had upon all the patients within the study. Therefore, each individual’s perception of their change in physical and emotional state had to be measured. When questioning the patients and the carers about their quality of life and level of life disruption it was important, for the purpose of this study, that the patient’s perception, the researcher’s
perception and carer’s perception were all collated. This allowed the results to accurately reflect the emotional and physical impact of the diagnosis of malignant glioma between surgery and radiotherapy.

The analysis of the data within this study had limitations due to the small sample size, the length of the study period and lack of resources. It was anticipated from the outset of the study that the findings from the statistical analysis of the findings would produce unremarkable findings. To detect a statistically significant change in quality of life or anxiety or depression it is acknowledged that data has to be generated from a large sample or over a long period of time. Due to non completion of questionnaires and the mean length of the study period 51.2 days statistical analysis was fruitless for this study. To prevent the study findings being dismissed due to this limitation the researcher decided to undertake test of clinical significance for the functional data and undertake some descriptive analysis of the other statistical data collected. Although the study may suffer some criticism due to this decision by the researcher this study was always intended to be a descriptive study and the analysis used has allowed some insight to be generated about the dependent variable within the study period.

It is recommended that content analysis is undertaken by more than one individual or that the coding of the data is represented to the subjects for external validation. Within this study due to financial and time restrictions the researcher undertook the analysis of the qualitative data alone. Data could not be represented to patients as by the time of data collection over 2/3rd of the patients had died. By providing transparency and openness about the process used to undertake the content analysis the researcher aimed to overcome some of the criticism that this flaw in data analysis may attract.

The limitations of this study have been acknowledged and if possible overcome at each stage of this study. A major benefit for the study is that its simplistic and thoughtful design will allow any researcher with limited resources to replicate the study and control many of the extraneous variables. The researcher would encourage any individual planning on undertaking another study within this stage of a patient’s diagnosis to
address some of the limitations indicated within this chapter to improve the study design, if possible e.g. collect data from patients from more than one site, use data collection tools that would ensure a more complete data set and employ some assistance for the data collection and analysis stage of the study.
CHAPTER 6
RESULTS

6 INTRODUCTION

There were 65 patients with a provisional diagnosis of malignant glioma or cerebral metastasis referred to the researcher and approached to participate in the study in a one year period (1999 – 2000). The researcher recruited n= 51 subjects into the study (14 patients were omitted from the study as they were lost to follow up (n=10) or their confirmed diagnosis was not as anticipated (n= 4) e.g. cerebral abscess. The subjects were recruited from a regional neuroscience centre with a catchment population of 1.6 million. It is generally anticipated that in a one year period this centre will treat on average 80 patients with a primary malignant brain tumour.

6.1 THE DATA COLLECTED

Despite difficulties (see chapter 5) a large amount of data were successfully collected from the n= 51 patients (see Table 6.1). To collate this data the researcher had to assess the neurological functional state of every patient twice (102 neurological functional assessments), speak to and assess each patient by telephone, weekly between their

7 The researcher collected the data for this study alone. At holiday times a replacement nurse was asked to telephone patients and collect essential data but as this person was doing this voluntarily due to circumstances out with her control some patients were not followed up regularly.

8 There were three reasons why the study only approached 65 patients of a potential 100 – 150 patients: Despite best efforts not all patients admitted to the study centre were referred to the researcher, the researcher was on holiday at three time points during data collection period and patients in concurrent trials (of which there were three at the time of this study) were not eligible for inclusion.
surgery and radiotherapy (247 telephone interviews), collate questionnaires three times throughout study period from both patients and carers (243 questionnaires) and undertake four unstructured interviews (six hours interviewing) with four of the patients within the study.
Table 6.1  Number (%) of Patients and Carers that Data was collated Upon at Each Stage of Data Collection and Reason for Incomplete Data

<table>
<thead>
<tr>
<th>Data Collection Points</th>
<th>No(%) Patient</th>
<th>No (%) Carers</th>
<th>Reason for Incomplete Data Set</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Post Surgery</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Demographic Details</td>
<td>51 (100)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>EFIT</td>
<td>49 (96)</td>
<td></td>
<td>Two patients had diagnosis in another study centre</td>
</tr>
<tr>
<td>HAD</td>
<td>38 (74)</td>
<td></td>
<td>Forms Incomplete</td>
</tr>
<tr>
<td>Steroid Dosage &amp; Side Effects</td>
<td>51 (100)</td>
<td></td>
<td>Forms Incomplete</td>
</tr>
<tr>
<td>Quality of Life</td>
<td>40 (78)</td>
<td></td>
<td>Forms Incomplete</td>
</tr>
<tr>
<td><strong>Three weeks post surgery</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HAD</td>
<td>21 (41)</td>
<td></td>
<td>Forms Incomplete</td>
</tr>
<tr>
<td>Steroid Dosage &amp; Side Effects</td>
<td>43 (84)</td>
<td></td>
<td>The researcher did not manage to contact patients every week as some patients were other hospitals and some were on holidays.</td>
</tr>
<tr>
<td>Quality of Life</td>
<td>18 (35)</td>
<td></td>
<td>Forms Incomplete</td>
</tr>
<tr>
<td>Level of Life Disruption</td>
<td>31 (61)</td>
<td>30 (59)</td>
<td>Forms Incomplete</td>
</tr>
<tr>
<td><strong>Final Data Collection Point</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>EFIT</td>
<td>49 (96)</td>
<td></td>
<td>Two patients change in functional state could not be recorded as they had original diagnosis in another hospital</td>
</tr>
<tr>
<td>HAD</td>
<td>35 (68)</td>
<td></td>
<td>Forms Incomplete</td>
</tr>
<tr>
<td>Quality of Life</td>
<td>36 (70)</td>
<td></td>
<td>Forms Incomplete</td>
</tr>
<tr>
<td>Unstructured Interviews</td>
<td>4 (8)</td>
<td>4 (8)</td>
<td>From the outset of the study it was only anticipated that four patients and their carers would be interviewed.</td>
</tr>
</tbody>
</table>
The researcher generated both quantitative and qualitative data to investigate the research questions. For clarity the results of the analysis of the quantitative data: EFIT, HAD Scale, EORTC scores and level of life disruption, will be presented in one section of this chapter (Section 6.3), the analysis of the qualitative data: telephone interview and unstructured interview transcripts, in another (Section 6.4). In Section 6.5 the data generated will be presented together to provide a combined response to each of the research questions. It has to be emphasised that the purpose of combining the qualitative and quantitative data collection techniques within this study was purely complementary, the qualitative data was collected simply to clarify, explain and elaborate on the quantitative data collected (Sandelowsdki 2000). Therefore it was not necessary for the researcher to transform the qualitative data set into a quantitative data set or vice versa (Sandelowsdki 2000). To avoid the criticism of bias that missing data can introduce to study findings, the researcher ensured that the results detailed pertain only to the proportion of the study sample that data were collated upon (see Table 6.1). An introduction to each section makes this explicit to the reader.

6.2 THE COMPLETE STUDY SAMPLE (N=51)

The study sample was representative of the malignant tumour population as there were more males within the study (28 Males, 23 females) and the median age of the sample was 55\(^9\) (range 22-80). All the patients within the study had a surgical procedure, biopsy or resection of tumour. \(n=46\) (90\%) of these patients were offered radiotherapy (\(n=2\) patients had a diagnosis of a low grade tumour and \(n=3\) were not offered radiotherapy). Unfortunately, only \(n=38\) (82\%) of patients who were offered radiotherapy received it;

- \(n=1\) (2\%) patient died prior to radiotherapy
- \(n=3\) (7\%) patients deteriorated prior to radiotherapy and were unfit for their treatment
- \(n=4\) (9\%) patients refused radiotherapy.

\(^9\) Malignant tumour incidence peaks in adults aged 50-59 years of age and tends to be more prevalent in males (Davies & Hopkins 1997).
Table 6.2 indicates the demographic details and tumour type of patients receiving surgery, radiotherapy and dexamethasone therapy throughout the study period. 40 (78%) of the patients were married, three (6%) were single, three (6%) were divorced, four (8%) were widowed and one (2%) was living with their partner.

Table 6.2 Characteristics of patients and tumours of those receiving surgery, radiotherapy and/or steroids. Figures are numbers (percentages) of patients

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Surgery n=51</th>
<th>Radiotherapy n=38</th>
<th>Steroids n=49</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>28 (55)</td>
<td>22 (58)</td>
<td>28 (57)</td>
</tr>
<tr>
<td>Female</td>
<td>23 (45)</td>
<td>16 (42)</td>
<td>21 (43)</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤60</td>
<td>35 (69)</td>
<td>30 (79)</td>
<td>33 (67)</td>
</tr>
<tr>
<td>&gt;61</td>
<td>16 (31)</td>
<td>8 (21)</td>
<td>16 (33)</td>
</tr>
<tr>
<td><strong>Hemisphere Affected</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Right</td>
<td>19 (37)</td>
<td>15 (39)</td>
<td>19 (39)</td>
</tr>
<tr>
<td>Left</td>
<td>20 (39)</td>
<td>15 (39)</td>
<td>19 (39)</td>
</tr>
<tr>
<td>Bio Lateral</td>
<td>12 (24)</td>
<td>8 (22)</td>
<td>16 (33)</td>
</tr>
<tr>
<td><strong>Tumour Site</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Occipital</td>
<td>3 (6)</td>
<td>2 (5)</td>
<td>3 (6)</td>
</tr>
<tr>
<td>Parietal</td>
<td>6 (12)</td>
<td>5 (13)</td>
<td>6 (12)</td>
</tr>
<tr>
<td>Frontal</td>
<td>9 (18)</td>
<td>5 (13)</td>
<td>6 (12)</td>
</tr>
<tr>
<td>Brain Stem</td>
<td>2 (4)</td>
<td>2 (5)</td>
<td>2 (4)</td>
</tr>
<tr>
<td>Temporal</td>
<td>12 (24)</td>
<td>10 (26)</td>
<td>10 (20)</td>
</tr>
<tr>
<td>Parietal Occipital</td>
<td>3 (6)</td>
<td>3 (8)</td>
<td>3 (6)</td>
</tr>
<tr>
<td>Temporal Parietal</td>
<td>2 (4)</td>
<td>2 (5)</td>
<td>2 (4)</td>
</tr>
<tr>
<td>Unknown</td>
<td>15 (29)</td>
<td>9 (24)</td>
<td>14 (28)</td>
</tr>
<tr>
<td><strong>WHO Grade</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I&amp;II</td>
<td>3 (6)</td>
<td>2 (5)</td>
<td>3 (6)</td>
</tr>
<tr>
<td>III&amp;IV</td>
<td>42 (82)</td>
<td>34 (90)</td>
<td>40 (82)</td>
</tr>
<tr>
<td>Met</td>
<td>5 (10)</td>
<td>2 (5)</td>
<td>5 (10)</td>
</tr>
<tr>
<td>Other</td>
<td>1 (2)</td>
<td></td>
<td>1 (2)</td>
</tr>
</tbody>
</table>
6.3 The Quantitative Findings

6.3.1 Are there significant changes in the frequency and severity of patients neurological functional status between surgery and radiotherapy? (n=49)

Introduction

Forty Nine of the 51 patients had an Edinburgh Functional Impairment Test (EFIT) score undertaken at two points within the study, post surgery (stage I) and at first follow up (stage vi). Two patients within the study were unable to have their functional status measured post surgery due to receiving their diagnosis within another study centre. The mean period between surgery and radiotherapy for patients was 41.2 days (SD 13.6 days). As it was more likely that patients will experience a clinically significant change as opposed to a group statistically significant change, it was decided by the researcher to apply a test of clinical significance to the EFIT. The statistical test applied to the data was as validated for the EFIT by Clyde et al (1998).

Post Operatively (Stage I)

From the study it was noted that most patients will have a degree of functional disability post operatively. Post surgical tests indicated that 45/49(92%) patients had an abnormal EFIT test (more than one test outwith normal limits). Only 4/49 (8%) patients had a normal EFIT test each of these patients had a diagnosis of malignant glioma (see Table 6.3)
Table 6.3  Characteristics of patients and tumours of those who had a normal and abnormal EFIT test post surgery. Figures are numbers (percentages) of patients

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Total Cohort n=49</th>
<th>Normal EFIT n=4</th>
<th>Abnormal EFIT n=45</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>28</td>
<td>4(14)</td>
<td>24(86)</td>
</tr>
<tr>
<td>Female</td>
<td>21</td>
<td></td>
<td>21(100)</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤60</td>
<td>34</td>
<td>2(6)</td>
<td>32(94)</td>
</tr>
<tr>
<td>≥61</td>
<td>15</td>
<td>2(13)</td>
<td>13(87)</td>
</tr>
<tr>
<td><strong>Hemisphere Affected</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Right</td>
<td>19</td>
<td>3(16)</td>
<td>16(84)</td>
</tr>
<tr>
<td>Left</td>
<td>19</td>
<td>1(53)</td>
<td>18(95)</td>
</tr>
<tr>
<td>Bi lateral</td>
<td>11</td>
<td>0</td>
<td>11(100)</td>
</tr>
<tr>
<td><strong>Tumour Site</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Occipital</td>
<td>3</td>
<td>2(67)</td>
<td>1(33)</td>
</tr>
<tr>
<td>Parietal</td>
<td>5</td>
<td>1(20)</td>
<td>4(80)</td>
</tr>
<tr>
<td>Frontal</td>
<td>9</td>
<td>0</td>
<td>9(100)</td>
</tr>
<tr>
<td>Brain Stem</td>
<td>2</td>
<td>0</td>
<td>2(100)</td>
</tr>
<tr>
<td>Temporal</td>
<td>12</td>
<td></td>
<td>12(100)</td>
</tr>
<tr>
<td>Parietal Occipital</td>
<td>3</td>
<td>1(33)</td>
<td>2(77)</td>
</tr>
<tr>
<td>Temporal Parietal</td>
<td>2</td>
<td>0</td>
<td>2(100)</td>
</tr>
<tr>
<td>Unknown</td>
<td>13</td>
<td>0</td>
<td>13(100)</td>
</tr>
<tr>
<td><strong>WHO Grade</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I&amp;II</td>
<td>3</td>
<td>0</td>
<td>3(100)</td>
</tr>
<tr>
<td>III&amp;IV</td>
<td>40</td>
<td>4(10)</td>
<td>36(90)</td>
</tr>
<tr>
<td>Met</td>
<td>5</td>
<td>0</td>
<td>5(100)</td>
</tr>
<tr>
<td>Other</td>
<td>1</td>
<td>0</td>
<td>1(100)</td>
</tr>
</tbody>
</table>

The most common functional test to be abnormal post surgery was the ten metre walk; 37/49 (75%) of patients were detected to have an abnormal score within this test of lower limb impairment. NHPT, WDRT and BASRS were less frequently abnormal.

Younger patients were more likely to have a functional impairment post operatively than older patients. 94% of the total cohort of younger patients (≤60) and 87% of the total cohort of older patients (≥61) had a level of functional disability measured post operatively. If patients had abnormal results in more than one functional test it indicated
that they had a higher level of functional disability. Interestingly, n=32 (71%) of the patients within the study had a functional impairment in more than one test post surgically (see Table 6.4), indicating that the majority of individuals’ suffer multiple functional impairments post operatively.

Table 6.4  Number of patients (%) demonstrating functional impairment in one or more tests by age segregation

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>4 Ab* Scores</th>
<th>3 Ab* Scores</th>
<th>2 Ab* Scores</th>
<th>1 Ab* Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients ≤60 n=32</td>
<td>5(15)</td>
<td>3(9)</td>
<td>13(38)</td>
<td>11(32)</td>
</tr>
<tr>
<td>Patients ≥61 n=13</td>
<td>2(13)</td>
<td>4(27)</td>
<td>5(33)</td>
<td>2(33)</td>
</tr>
</tbody>
</table>

Ab* = Abnormal

Change in Functional Status Detected Between Surgery and Radiotherapy

Younger patients as opposed (59%) to older patients (33%) improved in the period between surgery and radiotherapy (see table 6.5). Patients with a diagnosis of metastasis (80%) as opposed to a diagnosis of malignant glioma (57%), were more likely to improve functionally between surgery and radiotherapy. Older patients were noted more likely to deteriorate than younger patients. 13% of patients had an improvement in their lower limb function (Ten Metre Walk) and a 13% percentage of patients had improvement in their memory (Williams Delayed Recall Test) (see Table 6.5).
### Table 6.5  
Characteristics of patients and tumours of those with a clinically significant measure of improvement or deterioration between surgery and final data collection point. Figures are numbers (percentages) of patients

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Total Cohort n=49</th>
<th>Stayed Same n=13</th>
<th>Improved n=25</th>
<th>Deteriorated n=11</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
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<td>28</td>
<td>8(29)</td>
<td>14(50)</td>
<td>6(21)</td>
</tr>
<tr>
<td>Female</td>
<td>21</td>
<td>5(24)</td>
<td>11(52)</td>
<td>5(23)</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤60</td>
<td>34</td>
<td>9(26)</td>
<td>20(59)</td>
<td>5(15)</td>
</tr>
<tr>
<td>&gt;61</td>
<td>15</td>
<td>4(27)</td>
<td>5(33)</td>
<td>6(40)</td>
</tr>
<tr>
<td><strong>Hemisphere Affected</strong></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Right</td>
<td>19</td>
<td>5(26)</td>
<td>8(42)</td>
<td>6(31)</td>
</tr>
<tr>
<td>Left</td>
<td>19</td>
<td>3(16)</td>
<td>12(63)</td>
<td>4(21)</td>
</tr>
<tr>
<td>Bi Lateral</td>
<td>11</td>
<td>5(45)</td>
<td>5(45)</td>
<td>1(10)</td>
</tr>
<tr>
<td><strong>Tumour Site</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Occipital</td>
<td>3</td>
<td>2(67)</td>
<td>0</td>
<td>1(33)</td>
</tr>
<tr>
<td>Parietal</td>
<td>5</td>
<td>0</td>
<td>3(60)</td>
<td>2(40)</td>
</tr>
<tr>
<td>Frontal</td>
<td>9</td>
<td>3(33)</td>
<td>5(56)</td>
<td>1(11)</td>
</tr>
<tr>
<td>Brain Stem</td>
<td>2</td>
<td>0</td>
<td>1(50)</td>
<td>1(50)</td>
</tr>
<tr>
<td>Temporal</td>
<td>12</td>
<td>2(17)</td>
<td>6(50)</td>
<td>4(35)</td>
</tr>
<tr>
<td>ParietalOccipital</td>
<td>3</td>
<td>1(33)</td>
<td>2(77)</td>
<td>0</td>
</tr>
<tr>
<td>TemporalParietal</td>
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<td>0</td>
<td>1(50)</td>
<td>1(50)</td>
</tr>
<tr>
<td>Unknown</td>
<td>13</td>
<td>5(38)</td>
<td>7(54)</td>
<td>1(8)</td>
</tr>
<tr>
<td><strong>WHO Grade</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I&amp;II</td>
<td>3</td>
<td>2(67)</td>
<td>0</td>
<td>1(33)</td>
</tr>
<tr>
<td>III&amp;IV</td>
<td>40</td>
<td>7(17)</td>
<td>23(57)</td>
<td>10(25)</td>
</tr>
<tr>
<td>Met</td>
<td>5</td>
<td>4(80)</td>
<td>1(20)</td>
<td>0</td>
</tr>
<tr>
<td>Other</td>
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<td>0</td>
<td>1(100)</td>
<td>0</td>
</tr>
</tbody>
</table>

The impact of independent variables on frequency and severity of functional status between surgery and radiotherapy

The impact that the independent variables described in Chapter 4 had upon the changes in frequency and severity of the patient's functional state between surgery and radiotherapy were minimal. This is illustrated in the following sections;
• Length of Time Between Surgery & Radiotherapy (n=32): The mean length of time in days between surgery and radiotherapy for the patients was 41 days (SD 13.6 days) with the median length of time being 38 days. The level of functional improvement was not related to the length in time people waited between diagnosis and radiotherapy. Although not significant it is interesting to note that all patients who had radiotherapy within the recommended 28 days either remained functionally the same or improved between surgery and radiotherapy (see table 6.6).

Table 6.6: An overview of the relationship between the number of days patients (%) waited for radiotherapy and the change in functional status recorded between surgery and radiotherapy

<table>
<thead>
<tr>
<th>Clinical Change</th>
<th>≤28</th>
<th>≤35</th>
<th>≤42</th>
<th>≤49</th>
<th>≤56</th>
<th>≤63</th>
<th>≤77 days</th>
</tr>
</thead>
<tbody>
<tr>
<td>Functional Improvement</td>
<td>5 (17)</td>
<td>8(27)</td>
<td>5(17)</td>
<td>5 (17)</td>
<td>3 (10)</td>
<td>2 (7)</td>
<td>1 (3)</td>
</tr>
<tr>
<td>Stay Same (n=29)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Deterioration (n=9)</td>
<td>0</td>
<td>2 (22)</td>
<td>2(22)</td>
<td>3(33)</td>
<td>0</td>
<td>1(11)</td>
<td>1(11)</td>
</tr>
</tbody>
</table>

• Dexamethasone Dosage (n=51): The mean dosage of dexamethasone for all subjects over the transitional period was 4.2 mg daily. There was no relationship between an individual’s change in functional impairment and dose of dexamethasone administered. Table 6.7 indicates the mean dose of dexamethasone administered over the transitional period for all subjects in relation to diagnosis, age, tumour type, tumour site and change in functional impairment. The dose and impact of dexamethasone therapy administered to patients between surgery and radiotherapy will be further discussed in Section 6.3.3.
Table 6.7 The mean (mode) dose of dexamethasone administered to number (%) of patients and characteristics

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Mean (Mode) Post Surgery</th>
<th>Mean (Mode) Final Follow Up</th>
<th>Mean (Mode) Daily Dose</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>4.2 (2)</td>
<td>3.5 (2.0)</td>
<td>4.4 (2)</td>
</tr>
<tr>
<td>Female</td>
<td>4.2 (4)</td>
<td>3.3 (0)</td>
<td>4.0 (0)</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤60</td>
<td>4.4 (4)</td>
<td>3.6 (0)</td>
<td>4.7 (3.8)</td>
</tr>
<tr>
<td>&gt;61</td>
<td>3.9 (4)</td>
<td>3.0 (4)</td>
<td>3.4 (1.9)</td>
</tr>
<tr>
<td><strong>Functional Change</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Improved</td>
<td>3.6 (4)</td>
<td>3.4 (2)</td>
<td>4.2 (2)</td>
</tr>
<tr>
<td>Stayed Same</td>
<td>4.3 (4)</td>
<td>3.4 (2)</td>
<td>3.8 (3.6)</td>
</tr>
<tr>
<td>Deteriorated</td>
<td>5.8 (4)</td>
<td>5.4 (4)</td>
<td>5.2 (4)</td>
</tr>
<tr>
<td><strong>Tumour Site</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Occipital</td>
<td>4.0 (2)</td>
<td>2.2 (0.5)</td>
<td>4.6 (0.9)</td>
</tr>
<tr>
<td>Parietal</td>
<td>5.6 (2)</td>
<td>2.2 (0)</td>
<td>4.8 (4)</td>
</tr>
<tr>
<td>Frontal</td>
<td>4.0 (4)</td>
<td>2.3 (0)</td>
<td>3.8 (0.5)</td>
</tr>
<tr>
<td>Brain Stem</td>
<td>3.0 (2)</td>
<td>10 (8)</td>
<td>6.4 (4.8)</td>
</tr>
<tr>
<td>Temporal</td>
<td>4.3 (4)</td>
<td>3.3 (0)</td>
<td>3.7 (0)</td>
</tr>
<tr>
<td>Par. Occipital</td>
<td>4.0 (4)</td>
<td>5.5 (3)</td>
<td>5.8 (3)</td>
</tr>
<tr>
<td>Temp. Parieta</td>
<td>4.0 (0)</td>
<td>8.0 (8)</td>
<td>5.3 (2)</td>
</tr>
<tr>
<td>Unknown</td>
<td>4.0 (0)</td>
<td>0.0 (0)</td>
<td>2.5 (2.5)</td>
</tr>
<tr>
<td><strong>WHO Grade</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I &amp; II</td>
<td>2.6 (4)</td>
<td>1.5 (0)</td>
<td>3.5 (2.0)</td>
</tr>
<tr>
<td>III &amp; IV</td>
<td>4.1 (4)</td>
<td>3.4 (2)</td>
<td>4.3 (4.0)</td>
</tr>
<tr>
<td>Met</td>
<td>6 (4)</td>
<td>3.6 (2)</td>
<td>4.8 (2)</td>
</tr>
<tr>
<td>Other</td>
<td>4 (4)</td>
<td>0 (0)</td>
<td>1.4 (1)</td>
</tr>
</tbody>
</table>
• Offered or Not Offered Radiotherapy: One of the patients who did not receive radiotherapy did not have post surgical post operative tests undertaken (the diagnosis was given in another study centre). Analysis of the data from the n=12 patients who did not receive radiotherapy treatment indicated that being offered or refused radiotherapy could predict functional outcome;

  n=4 (33%) of them improved
  n=4 (33%) deteriorated and
  n=4 (33%) stayed the same.

• Tumour Site (n= 42): The change in functional impairment measured was not related to site of tumour (see table 6.7).

6.3.2 Are significant changes notable in the frequency and severity of the patient’s anxiety and depression level between surgery and radiotherapy?

Introduction

The Hospital Anxiety and Depression (HAD) scale scores of anxiety and depression were measured on 35 (69%) patients at two time points: post surgery and at final data collection point. Fewer patients 21/51 (41%) completed questionnaires three weeks after their surgery. It is assumed that this was due to the researcher not having face to face contact with the patients at this time point. 23/35 (65%) of these patients improved functionally over the period between surgery and radiotherapy and 3/37 (8%) deteriorated, 16/51 (31%) patients failed to complete the HAD scale. Patients were less likely to complete the HAD scale if they had clinically deteriorated, 6/11 (55%) of all the patients who deteriorated between surgery and radiotherapy did not complete the HAD scale. This finding indicates that these results may underestimate the frequency of anxiety and depression. The results discussed within this section can only be applicable to patients who improve or functionally remain the same between surgery and radiotherapy.

The data generated from the HAD scale within this study was analysed initially using a t test. Unfortunately, due to the small sample size and the small change in anxiety and
depression levels noted between patients and at two time points then no significant change in these scores could be measured using this statistical test. Simple descriptive analysis of the data did reveal some interesting findings.

Table 6.8 & 6.9 indicate the changes in the mean score of anxiety and depression over the 3 study time points (post operatively, two to three weeks post operatively and final point of data collection) all mean scores are all significantly below the level that indicates a case of anxiety or depression (score ≥ 11). Patients who improve or functionally remain the same between surgery and radiotherapy do not, according to results obtained from HAD scale, exhibit signs of anxiety and depression between surgery and radiotherapy.

Frequency & Severity of Anxiety between surgery and radiotherapy

The HAD scale detected that n=5 (13%) patients were anxious after their surgery, and 4 (11%) of these continued to be anxious throughout the period of time between surgery and radiotherapy. 8 (22%) patients were anxious prior to their radiotherapy. Five (13%) of these patients had not been significantly anxious post surgery. According to HAD scale there is a heightened level of anxiety in patients prior to their radiotherapy. Anxiety was more prevalent in younger patients between surgery and radiotherapy (see Table 6).

Overall 13 (35%) patients were detected to be suffering from anxiety by the HAD. 12 (32%) improved functionally between surgery and radiotherapy. 5 (39%) were not awaiting radiotherapy treatment. The level of anxiety that was detected by the HAD scale does not reflect the level of anxiety prevalent amongst all patients within the study that was apparent to the researcher from the qualitative findings. This will be discussed in Section 6.4.
Table 6.8:  Number (%) and characteristics of patients and their mean anxiety (MA) scores during the study period

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>MA* Post Surgery n=38</th>
<th>MA* Three Wks n=20</th>
<th>MA* Final n=35</th>
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</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>6.2 (n=22)</td>
<td>5.4 (n=16)</td>
<td>4.4 (n=20)</td>
</tr>
<tr>
<td>Female</td>
<td>7.3 (n=16)</td>
<td>9.0 (n=4)</td>
<td>7.6 (n=15)</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤60</td>
<td>6.8 (n=29)</td>
<td>6.8 (n=16)</td>
<td>8.4 (n=27)</td>
</tr>
<tr>
<td>&gt;61</td>
<td>6.1 (n=23)</td>
<td>3.5 (n=4)</td>
<td>4.2 (n=8)</td>
</tr>
<tr>
<td><strong>Functional Change</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Improved</td>
<td>7.2 (n=23)</td>
<td>7.3 (n=13)</td>
<td>8.1 (n=23)</td>
</tr>
<tr>
<td>Stayed the Same</td>
<td>4.8 (n=9)</td>
<td>5.0 (n=5)</td>
<td>6 (n=9)</td>
</tr>
<tr>
<td>Deteriorated</td>
<td>7.4 (n=5)</td>
<td>1.5 (n=2)</td>
<td>7.6 (n=3)</td>
</tr>
<tr>
<td><strong>WHO Grade</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I &amp; II</td>
<td>4.6 (n=5)</td>
<td>5.0 (n=1)</td>
<td>7.6 (n=5)</td>
</tr>
<tr>
<td>III &amp; IV</td>
<td>7.2 (n=29)</td>
<td>6.0 (n=16)</td>
<td>7.3 (n=27)</td>
</tr>
<tr>
<td>Met</td>
<td>5.3 (3)</td>
<td>4.0 (n=2)</td>
<td>10.5 (n=3)</td>
</tr>
<tr>
<td>Other</td>
<td>4 (n=1)</td>
<td>14 (n=1)</td>
<td>6 (n=1)</td>
</tr>
<tr>
<td><strong>Radiotherapy Treatment</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>6.9 (n=31)</td>
<td>5.8 (n=17)</td>
<td>7.7 (n=29)</td>
</tr>
<tr>
<td>No</td>
<td>5.5 (n=7)</td>
<td>8.0 (n=3)</td>
<td>6.3 (n=6)</td>
</tr>
</tbody>
</table>

MA* = Mean Anxiety Score

Changes in Depression

The HAD scale detected that only 5 patients had significant depression at one or more times between surgery and radiotherapy (see Table 6.9). Two (6%) patients indicated a depression level ≥11 post surgery and one (3%) of these patients continued to note a
high depression score pre radiotherapy. Four of the patients (80%) who were noted to have a heightened level of depression between surgery and radiotherapy had a past medical history of depressive illness. The other patient reporting a change or decline in depressive state deteriorated functionally between surgery and radiotherapy. Patients who clinically deteriorate less often completed the HAD scale and this may therefore be an underestimate.
Table 6.9: Number (%) and characteristics of patients and their mean depression (MD) scores during the study period

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>MD* Post Surgery n=38</th>
<th>MD* Three Wks n=20</th>
<th>MD* Final n=35</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>5.1 (n=22)</td>
<td>5.7 (n=16)</td>
<td>5.8 (n=20)</td>
</tr>
<tr>
<td>Female</td>
<td>4.8 (n=16)</td>
<td>5.2 (n=4)</td>
<td>5.7 (n=15)</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤60</td>
<td>4.8 (n=29)</td>
<td>6.0 (n=16)</td>
<td>6.1 (n=27)</td>
</tr>
<tr>
<td>&gt;61</td>
<td>5.4 (n=23)</td>
<td>4.2 (n=4)</td>
<td>4.7 (n=8)</td>
</tr>
<tr>
<td><strong>Functional Change</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Improved</td>
<td>5.8 (n=23)</td>
<td>6.3 (n=13)</td>
<td>6.0 (n=23)</td>
</tr>
<tr>
<td>Stayed the Same</td>
<td>4.0 (n=9)</td>
<td>5.2 (n=5)</td>
<td>5.0 (n=9)</td>
</tr>
<tr>
<td>Deteriorated</td>
<td>3.8 (n=5)</td>
<td>2.5 (n=2)</td>
<td>7.6 (n=3)</td>
</tr>
<tr>
<td><strong>WHO Grade</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I &amp; II</td>
<td>7.0 (n=5)</td>
<td>7.0 (n=1)</td>
<td>8.2 (n=5)</td>
</tr>
<tr>
<td>III &amp; IV</td>
<td>5.0 (n=29)</td>
<td>5.4 (n=16)</td>
<td>5.5 (n=27)</td>
</tr>
<tr>
<td>Met</td>
<td>2.3 (3)</td>
<td>7.5 (n=2)</td>
<td>4.5 (n=3)</td>
</tr>
<tr>
<td>Other</td>
<td>2 (n=1)</td>
<td>4 (n=1)</td>
<td>3 (n=1)</td>
</tr>
<tr>
<td><strong>Radiotherapy Treatment</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>4.9 (n=31)</td>
<td>5.8 (n=17)</td>
<td>6.0 (n=29)</td>
</tr>
<tr>
<td>No</td>
<td>5.2 (n=7)</td>
<td>4.6 (n=3)</td>
<td>4.6 (n=6)</td>
</tr>
</tbody>
</table>

MD* = Mean Depression Score
6.4.3 Is there an association between dexamethasone dosage and prevalence of side effects in patients between surgery and radiotherapy?

Introduction

The dosage of dexamethasone administered to patients was collated on 51 (100%) patients. The side effects of dexamethasone were reported by 43 (84%) patients between surgery and radiotherapy.

Dosage of Dexamethasone Administered

The dexamethasone dosage administered to patients within the study was not consistent. Dexamethasone dosage did not appear to be tailored to an individual’s functional state, age and/or diagnosis between surgery and radiotherapy. Over the study period the mode of daily dose of dexamethasone for all groups was between 2.0 mg and 4.0 mg (Table 6.7).

Eleven patients (22%) were prescribed a high dose of dexamethasone (≥12 mg) post operatively. All of these patients had an abnormal TMW or NHPT, post operatively. High doses of dexamethasone are administered post surgically to patients with visible functional problems. Patients with abnormal WDRT did not receive high doses of dexamethasone.

Frequency of Side Effects

The frequency of side effects that were reported by patients (n=43) each week is detailed in Figure 6.10. The percentage of patients experiencing the side effects of insomnia and gastric upset each week was significantly greater than the patients suffering ankle swelling and glycouria (see Figure 6.7). Insomnia was present on average in 33 (65%) patients and glycouria was only a problem for an average of two (4%) of patients. Gastric upset was present in an average of 15 (29%) of patients weekly. There was no relationship between the frequency of side effects and the dose of dexamethasone prescribed. Patients who suffered a side effect post surgically continued to do so throughout the study. Twenty six (75%) of the 35 patients who suffered insomnia in
week one continued to suffer it in week three and four. 85% of the 12 patients suffering gastric upset in week one continued to do so in week three and four. The impact that these side effects had upon patients and carers will be discussed in Section 6.5.

**Figure 6.10** The % of patients (n=43) indicating the frequency of the side effects of dexamethasone week by week

![Graph showing frequency of side effects](image)

6.3.4 Do patients and their carers encounter changes in their quality of life between surgery and radiotherapy?

*Introduction*

Post operatively 40 (78%) of patients completed an EORTC questionnaire (see Appendix 10). Three weeks after surgery 19 (37%) patients completed a questionnaire and pre radiotherapy 36 (70%) patients completed a questionnaire. Poor compliance with completion of EORTC questionnaires was associated with poor functional state or clinical deterioration. Only 3 (27%) patients who deteriorated compared to 33 (91%) patients who improved or remained functionally the same completed quality of life
questionnaires at two time points. These results, therefore, can only be generalisable to patients who improve or stay the same functionally between surgery and radiotherapy.

*Changes in quantitative measurements of Quality of Life between surgery and radiotherapy*

Using a RANOVA test the researcher analysed the post-operatively, three week post surgical and final follow up measurement of global health scores of the patients within the study. There was no significant change between the three time points.

Within the brain tumour module questionnaire patients reported insomnia, headache, motor, communication difficulties and concerns for the future to be having an impact on their lives. The quality of life scores indicate that patients who completed them experienced moderate disruption to quality of life. The data generated from the qualitative data, illustrates that the scores detected by EORTC questionnaires do not adequately reflect the impact that the diagnosis of malignant glioma has on the lives of patients and their families. This will be discussed further in Section 6.4.

6.3.5 How are patients and carers lives disrupted between surgery and radiotherapy?

*Introduction*

Thirty (59%) patients and 31 (61%) carers completed the level of life disruption questionnaires. Twenty six (90%) of these questionnaires were completed by the patients (and carers) who improved or remained the same functionally between surgery and radiotherapy. These findings can, therefore, only be applicable to this group. The disruption of life questionnaire asked about health, work, social life, family life, travel, future treatment and childcare. The responses generated from the closed questions will be summarised in this section. The open ended statements will be discussed in Section

---

10 The questionnaire asked both patient and the carers about the disruption they noted to their lives
6.5. It is likely that the results underestimate problems with level of life disruption in general, as patients with functional disability or who were deteriorating did not complete them.

*Health Problems*

In response to the question “Have you encountered any problems with your (your partners) health?” Twenty three (77%) patients and 20 (64%) carers responded yes. Interestingly, the range of problems noted by the patients was notably different from the range expressed by the carers (see Table 6.11). Patients noted the physical problems they were experiencing and the carers reported the personality and emotional changes they had witnessed within the patient.

---

11 This question within the questionnaire asked the patient about their health problems, the question to the carer asked them about the patients health problems
Table 6.11  The list of health problems noted by number of patients (%) and the number of carers (%) during transitional period

<table>
<thead>
<tr>
<th>Problem</th>
<th>No. (%) of Pts Noting Prob.</th>
<th>No. (%) of Carers Noting Prob.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n= 23 (77%)</td>
<td>n =20 (64%)</td>
</tr>
<tr>
<td>Anxiety</td>
<td>4 (17%)</td>
<td></td>
</tr>
<tr>
<td>Bladder Control</td>
<td>1 (4%)</td>
<td></td>
</tr>
<tr>
<td>Dizziness</td>
<td>3 (13%)</td>
<td></td>
</tr>
<tr>
<td>Headache</td>
<td>4 (17%)</td>
<td></td>
</tr>
<tr>
<td>Insomnia</td>
<td>1 (4%)</td>
<td>1 (5%)</td>
</tr>
<tr>
<td>Irritability</td>
<td></td>
<td>10 (50%)</td>
</tr>
<tr>
<td>Loss of Appetite</td>
<td>1 (4%)</td>
<td></td>
</tr>
<tr>
<td>Loss of Limb Power</td>
<td>2 (9%)</td>
<td></td>
</tr>
<tr>
<td>Medication Effects</td>
<td>1 (4%)</td>
<td>1 (5%)</td>
</tr>
<tr>
<td>Personality Change</td>
<td></td>
<td>10 (50%)</td>
</tr>
<tr>
<td>Seizures</td>
<td>1 (4%)</td>
<td></td>
</tr>
<tr>
<td>Tiredness</td>
<td>1 (4%)</td>
<td></td>
</tr>
<tr>
<td>Visual Problems</td>
<td>1 (4%)</td>
<td></td>
</tr>
</tbody>
</table>

Work Life

The questionnaire asked people about their work. Of the people who were working before diagnosis 18 (86%) patients and 21 (91%) carers had been unable to return to work between surgery and radiotherapy. It was anticipated that many of the patients would have been unable to return to work in the study period. However, the impact that the diagnosis had on the carer’s working life was found to be quite profound. It was also noted that some of these carers were not necessarily married to or living with the patient prior to diagnosis.

Family Life & Social Life

When asked to rank on a Likert scale, ranked from ‘not at all’ to ‘very much’, the level of disruption to family life that was being experienced, patients and carers responded
similarly. When ranking impact on social life patients reported a slightly higher disruption level than carers. Overall, the majority of patients and carers noted there to be middle to high level of disruption to their family and social life (see Table 6.12).

**Table 6.12** The Number (%) of Patients and Carers who Reported a Level of Disruption within their Family and Social Life

<table>
<thead>
<tr>
<th>Level of Disruption</th>
<th>Patient n= 30 (59%)</th>
<th>Carer n=31 (61%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Family Life Disruption</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not at all</td>
<td>3 (10%)</td>
<td>3 (10%)</td>
</tr>
<tr>
<td>A Little</td>
<td>9 (30%)</td>
<td>11 (35%)</td>
</tr>
<tr>
<td>Quite A Bit</td>
<td>12 (40%)</td>
<td>12 (39%)</td>
</tr>
<tr>
<td>Very Much</td>
<td>6 (20%)</td>
<td>5 (16%)</td>
</tr>
<tr>
<td><strong>Social Life Disruption</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not at all</td>
<td>2 (7%)</td>
<td>6 (20%)</td>
</tr>
<tr>
<td>A Little</td>
<td>8 (27%)</td>
<td>7 (22%)</td>
</tr>
<tr>
<td>Quite A Bit</td>
<td>14 (47%)</td>
<td>12 (39%)</td>
</tr>
<tr>
<td>Very Much</td>
<td>6 (20%)</td>
<td>6 (19%)</td>
</tr>
</tbody>
</table>

*Contact with Health Professionals*

During the period between surgery and radiotherapy 17 (57%) patients and 7 (23%) carers reported that they had contacted health professionals about the health of the patient. The type of professionals contacted is listed in Table 6.13. Only three (18%) patients and one (10%) carer had contacted specialised neuro-oncology personnel within the study centre.
Table 6.13 The health professionals contacted by patients and their carers during transitional period

<table>
<thead>
<tr>
<th>Health Professional Contacted</th>
<th>Patients n=17 (57%)</th>
<th>Carers n=7 (23%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>General Practitioner</td>
<td>11 (65%)</td>
<td>5 (50%)</td>
</tr>
<tr>
<td>Clinical Nurse Specialist</td>
<td>2 (12%)</td>
<td>0</td>
</tr>
<tr>
<td>Hospital Doctor</td>
<td>1 (6%)</td>
<td>1 (3%)</td>
</tr>
<tr>
<td>Psychologist</td>
<td>1 (6%)</td>
<td>1 (6%)</td>
</tr>
<tr>
<td>Dentist</td>
<td>1 (6%)</td>
<td>0</td>
</tr>
</tbody>
</table>

Detail about Future Treatment

In general, patients and carers did not report lack of knowledge about treatment options as a problem. Twenty Three (77%) patients and 19 (61%) carers stated they had enough information about their future treatment options.

Disruption of Travel Arrangements

The revocation of their driving licence was noted to have an impact on travelling arrangements for 11 (34%) patients and 8 (28%) carers. Worryingly, the impact that this had upon one patient could not be measured as they reported they were still managing to drive.

Disruption In Child Care

Disruption in childcare was reported by six (30%) patients and carers who had children (n=20). In retrospect the wording of this question did not capture the impact that a diagnosis of malignant glioma has upon a family when a parent is diagnosed with a malignant brain tumour and this will be further discussed in Section 6.5.

6.4 The Qualitative Findings

As described in Chapter 4 content analysis was used to analyse the data generated from the telephone interviews, semi structured questionnaire and unstructured interviews. The
priori categories used to analyse the data are fully detailed in Chapter 4. However, as the basis for the development of these categories were the main outcome measures of the study: anxiety, depression, quality of life and level of life disruption it is beneficial to discuss the findings under each of these headings.

6.4.1 Introduction

The researcher undertook weekly telephone interviews with 49 (96%) of the patients. Two of the patients within the study could not be contacted regularly as they were admitted to the local hospice and hospital after the first visit.

Four (7%) patients with a diagnosis of malignant glioma and their carers were interviewed after commencement of their radiotherapy. Some background details of each of these patients is provided in Table 6.14
### Table 6.14  Background Details of Patients & Carers Interviewed

| Patient & Carer A | This patient was a 38 year old women with two children aged 11, 7. The younger of the two children had cerebral palsy. From diagnosis this patient suffered a great deal of psychosocial problems. She was diagnosed with a right parietal glioblastoma multiforme for which she had full resection and waited 28 days for her radiotherapy. Upon meeting this patient the researcher could not undertake any of the tests required for the study as she was so distraught. From the telephone interviews it appeared that throughout the study this patient appeared to suffer no physical problems but this fact was superseded by her emotional reaction to the diagnosis. Her husband was the main carer and he left his work during the study period to care for this patient and the family. This patient and her carer were chosen for interview to try and gain some understanding of this patient’s experience. |
| Patient & Carer B | This 57 year old women had a diagnosis of a right frontal glioblastoma multiforme. This patient was functionally quite debilitated pre and post surgery but was offered full dose radiotherapy due to her age. At the neuro- oncology clinic this patient asked for time to consider her options as she was unsure whether she wished to undergo this aggressive treatment. Despite a poor functional state and tiredness this patient and her husband raised only one concern during the telephone interviews and this was the disruption that radiotherapy would cause to the husband’s work pattern. Once they had decided to undergo the radiotherapy treatment this issue was constantly referred to. For the researcher this was an interesting couple to interview as their coping between surgery and radiotherapy appeared to be solely affected by disruption caused to the husband’s work pattern. |
| Patient & Carer C | This patient was a 43 year old women married with three children aged 2,4 & 12. Her husband was the main carer throughout the study period. She was diagnosed with a right frontal glioblastoma multiforme, had a full resection of this tumour and waited 63 days for her radiotherapy. This patient had severe arm weakness post surgery that improved over the study period. During the telephone interviews Patient C reported a number of additional problems in the period between surgery and radiotherapy e.g. insomnia, gastric upset and had to be readmitted during this time for a scan as it was suspected that she was suffering from cerebral oedema. Patient C and her husband cancelled two holidays in the time period between surgery and radiotherapy due to delay in the commencement of radiotherapy treatment. The researcher chose to interview this patient and her husband as, despite all of these problems, these individuals appeared to ‘cope’ well in the period between surgery and radiotherapy. |
| Patient & Carer D | This patient was a 50 year old gentleman diagnosed with a left parietal malignant glioma that was causing headaches and a right arm weakness that did not improve between surgery and radiotherapy. He had a full resection of this tumour and waited 43 days for radiotherapy. His main carer during the transitional period was his wife. They had two sons aged 21 and 19 who both lived away from home. From the telephone interviews it appeared that this patient suffered from relatively few additional problems between surgery and radiotherapy. Patient C and his wife appeared to raise few issues or questions and coped remarkably well in the time period the researcher chose to interview them to gain insight into what helped them cope so well. |
6.4.2 Frequency and Severity of Anxiety & Depression

From the weekly telephone interviews it was apparent that there were a number of factors that were causing anxiety amongst the patients. From the data it was identified the one of the main sources of this anxiety was the impending radiotherapy treatment. People were anxious as they did not know when their radiotherapy would start. They also were unsure of what it would involve.

36 (75%) of respondents highlighted during the telephone interviews that the lack of information about their start date for radiotherapy was concerning them. The following extracts indicate some of the patients feeling in regards to lack of information about the start of their radiotherapy.

"Fed up waiting I am scared" Pt 63.

"no dates yet looking forward to them coming” Pt 54.

"I am desperate about some communication about my start date” Pt 15.

When this was further explored within the unstructured interview, Patient C whom the researcher knew from the telephone interviews was anxious about her start date when waiting for radiotherapy, required prompting to remember that this had been a source of anxiety.

**Researcher**" Did you think about the radiotherapy treatment when you were at home?”

**Patient C:** “No not really I didnae the last week before I got my card (appointment card) I started to think about it ... I got very anxious near the end (of the waiting period) if they did not start the treatment then it will come back you know the fact they had taken it out but if they did not hurry and start the treatment what would happen”.

**Researcher:** "Every week when I spoke to you kept asking about the card (appointment)”
Patient C: “I think I was just getting apprehensive. On the fifth week I started to wait on the card every day when is it going to come.”

The uncertainty of what radiotherapy would entail was causing 18 (35%) of patients to feel anxious about the whole experience. However, when this was further explored during the interviews it was interesting to note that some of the patients and carers who identified their need for more information about the radiotherapy sought it themselves from a number of sources.

Patient B: “a lady I knew had just finished radiotherapy although they said it was not going to hurt I had this feeling that it was going to be really sore. I phoned her and she calmed me down.”

Researcher: “Did you find internet helpful?”

Carer B: “Yes really the BACUP cancer research sites ... if we had been sitting here and we could not find anything then it would have been terrible.”

Patient D: “We got a video out of library on radiotherapy and it was free it takes you right through from start to finish.”

Researcher: “How did you find out about that?”

Patient D: “At the library.”

Many patients resolved some of their uncertainties about radiotherapy treatment by asking the researcher questions during the telephone interviews:

“will I lose my hair?” Pt17

“how many days do I come to the hospital?” Pt23

“am I in the hospital all day for my treatment?” Pt26

Three (17%) patients’ preconceived ideas about the radiotherapy treatment caused them to do and say things that raised some concerns for the researcher.

“my weakness is getting worse but never mind I will start my radiotherapy soon and I am looking forward to that as it will make everything better” pt 40.
"what will I do? I cannot get all my hair cut off prior to my radiotherapy, my hairdresser is on holiday and my husband is not here to take me to another one" pt16.

"I am very nervous about the simulator I get very sick at the fairground, I hope I am not sick when it is moving up and down like a fairground attraction" pt18.

In each of these instances the researcher had to inform and reassure the patient that their preconceptions relating to the radiotherapy and the simulator was unrealistic12.

Another source of anxiety expressed by 30 (58%) of the patients related to the diagnosis and the belief that the tumour in their head was growing and spreading and would continue to do so until the start of their radiotherapy. A few extracts from the telephone interviews illustrate some of these patient’s thoughts:

"I am not coping with the belief that cancer is spreading all over my body” pt29.

"I was petrified I thought the cancer had spread to my neck” pt C.

Eighteen (46%) patients mentioned to the researcher, during the telephone interview, that they were noticing changes in their physical state. When asked if they had reported these changes to anyone, their responses indicated that they were reluctant to do this as it would reinforce their fears that the tumour was growing. This lack of communication could have been related to the lack of contact that many of these individuals had with health care professionals.

Interestingly, throughout the telephone interviews many patients would describe problems that were obviously related to dexamethasone therapy. Although the

12 The patient with the weakness was referred to the Clinical Nurse Specialist, the patient attempting to get all her hair removed was assured that this was not necessary and the patient who had an inaccurate perception of the simulator was informed fully about what the simulator and the planning appointment entailed.
quantitative data generated within this study has clearly shown that the side effects of
dexamethasone are not associated to dosage of dexamethasone. The qualitative data
indicates that the majority of patients do not associate symptoms such as heart burn, oral
thrust, insomnia, night sweats, urine frequency and excessive eating with the
dexamethasone therapy.

"heart burn terrible taking 10 Rennie a day cannot eat as Rennie
making tongue sore (researcher what colour is your tongue?)
white tongue” pt8.

"thank you for referring me to have the times of my
dexamethasone changed, I am sleeping a lot better now and I
feel more normal, I thought it was the tumour” pt17.

"the Ranitidine you suggested has really helped the heartburn I
did not know what had caused it” pt16.

"I must be run down I have thrush in my mouth” pt19.

Forty Two (82%) of patients raised problems associated with dexamethasone therapy at
least once in their telephone interviews. With a little advice, and at times referral to the
CNS, the side effects of dexamethasone experienced by many of the patients between
surgery and radiotherapy were resolved. The resolution of some of these problems was
very beneficial for a number of patients; e.g. they could eat and talk without discomfort.

Some of the comments made by patients about their mood indicated that they could be
having depressive symptoms in the period between surgery and radiotherapy. When
speaking with the patients on the telephone the researcher would ask, ‘How are you
feeling? The common response from over half the patients on at least two occasions
during the study period was related to a feeling of ‘low mood’. Patients would state they
were feeling ‘low in mood’ or ‘fed up’. The cause of this low mood could only be
ascertained for a few of the patients but some associated their low mood with their hair
loss, weight gain, tiredness and/or poor functional state. In contrast from reading the
transcripts it was obvious that not all patients experienced this ‘low feeling’ between
their surgery and radiotherapy. Patient 60 a 64 yr old married man with a low grade
tumour stated whilst waiting for his radiotherapy that he ‘felt excellent’ one week and
‘felt physically and mentally very well’ the next. Although there are no quotes from patients who were diagnosed with high grade tumours stating they had the same overall feeling of well being as Pt 60 some did focus on positive things when asked how they were feeling:

“...feeling much better” pt 17.

“Appetite good so I am eating well” pt 38.

“...feeling a lot stronger” pt 18.

One patient within the study caused the researcher a lot of concern and appeared from the telephone conversation four weeks after her surgery to be suffering greatly from depression. Unfortunately, this was one patient whose HAD score was never recorded as she did not return the questionnaire. The following is the quote from the telephone interview transcript of Pt 16:

“Patient very low when phoned today. She has been told to get her hair cut, hairdresser on holiday, husband very angry he has to take time off work to take her for her simulator appointment tomorrow. Very upset uncontrolled crying on phone.”

Although this was an extreme example of some of the depressive behaviour witnessed by the researcher the impact of this on the one patient was extreme. This patient never did turn up for her simulation treatment the next day and despite the best efforts of the researcher and the CNS this patient was lost to follow up by the study centre. She was 41 years old, had a diagnosis of GBM, and her life was significantly shortened through her non attendance for radiotherapy.

Content analysis of the qualitative data demonstrated a frequency of anxiety in 36 (61%) of patients. The source of this anxiety was the forthcoming treatment and the brain tumour. Depressive thoughts appear to be less prevalent than anxiety. However, the transcripts confirm that when present these can be very detrimental for the patient.
6.4.3 Quality of Life & Life Disruption Issues

Introduction

Within the literature there are many discussions about what the term quality of life means, and how and by whom this concept can be measured (Fallowfield 1996). For the purpose of this study quality of life was a term used 'loosely' to interpret the views of patients and carers on what changes they perceived there had been in their every day lives between surgery and radiotherapy. At the outset of the study disruption of life was independent from quality of life but upon analysis of the qualitative data it became difficult to separate these two variables as they appeared inter related. Factors that were causing disruption in life were affecting life quality.

Throughout the data collection period the researcher witnessed an array of physical and emotional responses to the diagnosis of malignant glioma. Commonly, patients were experiencing altered physical and emotional states that appeared to be detrimental to the daily lives of themselves and their carers.

Physical & Mental Changes that Affected Quality of Life

Some of the physical complaints reported by patients in their interviews were having an impact on their quality of life. The following quotes from the researcher’s telephone interview transcripts illustrate this:

"the right arm weakness has started on his right hand, he has not contacted the hospital as thinks it will go away" pt29.

"the right arm weakness is deteriorating, seizures increasing in frequency, patient does not think he takes seizure medication however according to notes he was prescribed them on discharge from hospital" pt 7.

"having headaches all day" pt15.

"Having great difficulty swallowing and eating heart burn all the time" pt17.
"walking very slow not taking walks anymore" pt30.

'I've not been out much and I have never had the courage to go out myself yet' Pt B.

There were only 2 (4%) of patients who did not report some physical problem to the researcher during the study period. From the researcher's perspective it appeared that seizures and arm and/or leg weakness had the biggest impact on the quality of life for the patients and carers. The carers of patients who were not steady on their feet or were suffering from seizures were reluctant to leave the patients on their own in the house. Many of the patients were frightened to be alone and the carers were frightened to leave them in case something happened. This situation not only caused the independence of both the patients and carer to be taken away it also affected the dynamics of the relationships within the home:

**Researcher:** "Is it different, the two of you being in house all the time?"

**Patient D:** "More time I am here the more frustrating it gets at least I was away from her for 30 minutes on my bike. It is at the stage where she will not let me go out on my own" PtD.

**Carer Pt D:** "There is always a fear that if you leave him alone he may forget. When he is up through the night I hear him at the tablets and I am thinking how many has he had. At the same time he has to have your own independence but I am scared to leave him."

Physical changes had a large impact on both patients and carers but changes in the mental state of patients tended to have a greater impact on the carers of the patients. If married the impact of the physical and mental changes tended to be elicited within the patient’s spouses but when patients were widowed or separated it was their children who were affected. The daughter of one patient who was a 60 year old man with a frontal GBM took responsibility for the care of her father and moved him in with her husband and child. During the period between surgery and radiotherapy this patient’s mental state deteriorated and he was up wandering through the house and urinating on the carpets. Unfortunately, as the house was tied to the husband’s job they were informed that if this
behaviour continued the husband could lose his position. The moral decision for the daughter was very traumatic. She wanted to care for her father but could not afford for her husband to lose his job. For three weeks this patient's daughter stayed up all night to help her father and prevent any further upset.

Insomnia was a complaint that 70% of patients suffered from between surgery and radiotherapy and the tiredness that was associated with this impeded the life quality of many of these patients. A large number of patients were tired through the day so felt they could not go out and about with friends or family. Carers were also disrupted by patients over night and, therefore, were very tired at their work or at home. The cause of this insomnia could not be established through this study. The quantitative data illustrated that dexamethasone dosage was not related to this symptom and although many patients suffering from insomnia were instructed by the researcher to take their evening dosage early in the day this strategy did not always resolve the problem.

The emotional response to the diagnosis of malignant glioma elicited by patients was at times traumatizing for the researcher. The following from the researcher's notes of telephone interviews indicates that the diagnosis of malignant glioma was severely affecting the emotional functioning of individuals and consequently their family:

"patient very low on phone today, very upset trying to get hair cut off before start of radiotherapy, hairdresser on holiday, what should she do – devastated" pt16.

"not coping with the belief that cancer is spreading all over body" pt29.

"breaking her heart all week" pt36.

"sleeping all the time, crying all the time" pt40.

This was a note from a carer that was returned on the bottom of EORTC questionnaire:

"this past week has been very traumatic for us, he is having periods I feel (patient) is not coping with this and his illness and has had period of striking out at people verbally, I am really worried if anyone could phone me I would be grateful" Pt 26.
In one interview a patient reported she was doing ‘daft’ things during the study period to help her cope with her emotions. The following quote demonstrates the severe disruption of lives that is being experienced in the time between surgery and radiotherapy for some of the patients and their carers:

**Researcher:** To gain some insight into what patient A meant by daft things I asked for some examples “What do you mean daft things?”

**Patient A:** “Well I went to card shop and bought four years birthday cards, James and Shirley 8-12 age and 12-16 age ... Bought ribbon and tied it round the cards and wrote letters to people. Lists for Peter (husband) about insurance etc. Been to the cemtery crazy things. To other people these were all negative things but to me it was like taking control. That Saturday (at cemetry) I was distraught I walked out and my friend had to look for me but it was a need. I wanted to plan, there are loads of things I still want to do and tell them. I have to do them. Crazy things, after I had done them I would think what am I doing to everybody when I said to the insurance man. I needed to know when I do go everyone was Ok (crying) it sounds crazy but I needed to do it. Peter assures me the house is in order but I needed reassurance. I needed to see it at least the insurance man (part of the family) who was devastated. What else I have done. I have told my minister the hymns, the hymns I want”

Immediately after the diagnosis of a malignant glioma some patients and their carers are undertaking activities that could be described as ‘morbid’ by people outside of the situation. Three patients (6%) purchased their coffins and 10 (20%) purchased expensive jewellery that they could leave to siblings.

From the telephone interviews it was obvious that there were patients and carers who suffered greater impact on their quality of life than others. Patient C and her carer who were interviewed by the researcher had a number of physical and emotional problems to deal with throughout the study period. Each week this patient appeared to be coping and the family situation appeared from the outside to be adapting effectively to the patient’s diagnosis and impending treatment. Even when this patient and her family had to cancel their summer holidays due to a delay in radiotherapy treatment there was not a great deal
of upset witnessed. Within the interview the researcher attempted to explore how this family coped effectively:

**Researcher**: "Did your life change when you returned home from the hospital?"

**Patient C**: "No just the same"

**Researcher**: "Why do you think this was?"

**Patient C**: "Probably because I just got on with it, people wanted to help but as I felt well I just wanted to get on with it myself"

**Researcher**: "Do you think you were trying to make things as normal as possible for your husband and family?"

**Patient C**: "I never thought about it, the support was wonderful (crying) I just blanked it out until my hair fell out, I never thought I had cancer until my hair fell out."

Later on in the interview Patient C did say she was scared at times between surgery and radiotherapy but managed to deal with this effectively. When asked how she managed this she claimed that the researcher phoning her every week made a big difference. She appreciated the researcher phoning every week and asking her how things were. She felt she did not need to sit for weeks worrying about something as she knew someone would phone soon. Support and information helped Patient C and her family but other patients in the study who had the same level of support did not cope as ‘effectively’.

Physical and mental changes and the emotional reaction of the patient to their diagnosis appeared from the interviews to have a significant impact on the quality of life for the patient and the carer between surgery and radiotherapy.

### 6.4.4. Disruption to Life

**Dependency / Lack of Control**

The response from the level of life disruption questionnaire indicated that patients noted physical changes in their health and carers noted personality changes see Table 6.10. Some of the comments from the questionnaires demonstrated and confirmed that carers
are concerned about the emotional and personality changes they were noting in the patients;

"he feels he is a nuisance all the time"pt12.

"he appears more tense easily fazed by new or different situations, slightly panick"pt18.

"always had a great sense of humour now moody and very slow"pt10.

"very dependent upon my presence and inclined to feel anxious if I am not there"pt2

From the qualitative data it is apparent that the impact that this change in behaviour is having on the patient and the family is not being recognised and/ or acknowledged by the patient. The following quotes from the telephone interviews with the patients support this:

"I am getting confused at times and forget things however my husband is learning to take my BM and administer my insulin" pt 24.

"I am up three times a night to change my nightdress but I fall back asleep easily once my husband makes me a cup of tea"pt 39.

"I was anxious about being at home when my husband wanted to go back to work but I have asked my daughter to move back in"pt 57.

At times, the patient’s response to the impact that their change in health was having upon their family could have been described as inconsiderate. If the family was meeting the patient’s needs then this was satisfactory for the patient. Some of the patients appeared not to be able to envisage the impact that this behaviour was having upon the lives of others in their family. This concept was explored in the unstructured interviews.

Three of the patients who were interviewed were up through the night to go to the toilet or because they were anxious. They described this as not being problematic because their carer was there with them and provided them with the support they required at that
time to help them get back to sleep. The patient’s inability to drive was not described as inconvenient because friends and family would take them where they required to be; and if they could not ‘emotionally manage’ the number of phone calls and/or visitors, this was not a problem because the carer was there to deal with them. Interestingly, patients did not acknowledge the impact that this level of support is having upon the carer. They were focussed upon their own needs.

One of the patients who was interviewed, Patient C, did acknowledge the impact her disease and treatment was having upon other lives. She was worried about her husband having to take time off work to take her for radiotherapy as she could not drive. She forced her daughter to go on a holiday that she wanted to cancel. When asked if she felt her dependence on her family would cause any problems she acknowledged that it was not a major problem at that time but stated:

“I think in time it will become more of a problem than it is at this precise moment”

Patient C’s insight into the impact of her disease and her condition on her family was unique within the study. No other patient appeared to acknowledge the affect their diagnosis had upon other lives. Patient C was a nurse and this was the only factor upon which the researcher could base the difference in her attitude upon. Perhaps her experience of witnessing the effect of illness on other families gave her more insight into her own condition.
6.4.5 Change in Work & Home Life Routine

As described in Section 6.45, there was significant impact on the work lives of patients and carers. Although the researcher attempted to explore with the patients and carers the impact that not being able to return to work had upon the financial status of the family, this was not important to them at this stage. The financial implications of a diagnosis of malignant glioma were not considered important to patients and carers between surgery and radiotherapy. At no point within the telephone interviews and the unstructured interviews did patients or carers express any concern about financial difficulties.

6.4.6 Family & Social Life

Patients and carers acknowledged that the diagnosis of malignant glioma had affected both their family and social lives. Generally patients and their carers were content to accept the impact that the diagnosis of malignant glioma was having upon both their family and social life. Frequently, within the telephone interviews patients would say they were tired but would not complain about the impact that this would have on their lives. Patient A was physically very well between surgery and radiotherapy and managed to take a break with her husband to renew her wedding vows and Patient D and his wife went on a short break. Although it was positive that these patients and their carers were able to take time away together it was apparent that the reason for the break was ‘to get away’. They appeared to want to escape from things for a short while to gain some control of the situation. The support patients received between surgery and radiotherapy varied but for these two individuals the number of phone calls, letter and cards was overwhelming and, at times, difficult to handle.

Despite claiming they had a reasonable level of social support 15 (39%) of patients and carers felt they were very alone with their diagnosis.

"I mean I have all this wonderful family and friends but I still feel really lonely. Nobody knows how I am feeling” pt D.

Prior to interviewing Pt D the researcher and other involved in their care believed that Pt D and his wife were dealing very well with the diagnosis. However after the interview it
was apparent that Patient D's wife was very isolated and struggling to cope with her husband's diagnosis. Throughout the interview she sobbed and claimed she felt lonely, scared and just wanted someone to help her:

Carer: "We never got any sort of counselling"

Patient "X (wife) could do with support"

Researcher: "Would you like someone to come now? I can help organise this"

Patient "Yes I think so (husband) even once or twice it would help let her have a bubble"

Carer - "It would need to be locally so I do not need to go out and leave x on his own" (Pt and Carer D)

Patient D recognised his wife needed support but was not capable of organising this. The wife was scared to ask for support and did not know who to ask. The researcher had to intervene with this family and organise some support after the interview as the situation was very grave.

Although the level of life disruption questionnaire did not ask the patients about how useful they found the contact they had with the various health professionals, this data was generated from the interviews. When asked about their contact with their GP during the transitional period the patient and the carer were appreciative but not overly impressed with the result:

Patient C: "I did contact them on the Saturday morning but they did not really know what she was doing, she was vague about what was going on ... she did say ring but I had to understand it was only the doctors up here (study centre) who could only make the decisions"

Husband: "They are not specialised they do not know anything"

Patient B: "I have been down twice (GP surgery) and he always says if you need me give me a shout"

Researcher: "Does he provide you with the information you need?"
Patient B: "No I have the impression he is trying to find things out for himself and what it means"

There were at least ten instances during the research when the researcher had to use her professional knowledge to intervene in the patient’s care in order to prevent further deterioration or resolve symptoms. In these instances it was apparent that patient access to knowledgeable practical advice was limited. Although some patients seemed to be able to locate information about future treatment, many could not. A source of information was not readily available for the different problems that patients were experiencing daily.

Despite acknowledging that certain health care professional could not help them at the time, what was interesting was that patients did not question some of the delays in the health care system that were interfering with aspects of their lives, such as planning and going on holidays. Four patients cancelled holidays or deferred the date of going on holiday because they had not received the date for their radiotherapy when it was expected. One patient asked her parents to take the children on holiday as the date she received for radiotherapy was changed. There were many examples of this type of action being taken by patients throughout the study period.

6.4.7 Child Care

There were 20 (39%) patients within the study who had young children. The impact that the diagnosis of a parent (Patient A) with malignant glioma has upon these children is poignantly described through this quote from an unstructured interview.

"It has affected them (the children), the thing is we have always been honest with them, if they have asked they have been answered at their level. You cannot hide the obvious but I waited till they asked and the next day they asked what had the pathologist found from the pieces of skin, they had took. That was the way we were told to describe it pieces of skin so we could introduce the radiotherapy. CNS told us we could call it an X ray but I chose not too, because if you associate hair loss with X ray and she (my daughter) knows about X ray, I just said radiotherapy is a special treatment. She was the one that said, if it is going to dissolve the lump will it not dissolve your head and
your hair will fall out, I said that is exactly what it will do. I followed the kids and they have been great. Well James there has been more effect he has been distraught. He has said do not come into my room mummy without a hat on so I have respected that. Shirley is the opposite she wants to know all about it. Today she had a horrendous morning, but that had to happen, she cried and cried so much, I thought this had to happen this is a build up, Tom, Dick and Harry are taking her to School, her daddy has been taking her to school, picking her up. She has been asking I have been answering, so when I took her into school she asked am I bad for crying, sometimes I am crying and I don't know why and I said you know you have been coping with an awful lot and you are only seven. If you want to cry you cry because I can cry at the drop of a hat and she said OK. She said when I get to school you will not tell anyone what is wrong with me I said no but I will need to tell your teacher. So when the teacher came out she said I wondered where you were, of course I was bubbling…"

Although this extract obviously illustrates the impact that the diagnosis has had upon the younger children in a family, three of the children were the main carers because these patients no longer had a partner or spouse. Two of these children, (who were adults), had given up their work to look after the parent and one had moved back to live with her parent again. The impact of a parent being diagnosed with a malignant glioma is devastating for the children.

6.5 SUMMARY OF THE QUANTITATIVE AND QUALITATIVE DATA COMBINED

6.5.1 Introduction

The combining of both quantitative and qualitative methodologies has produced an in depth exploration of the functional and emotional issues that are experienced by patients and their families between surgery and radiotherapy. The following summarises the functional and emotional issues that patients encounter between surgery and radiotherapy.
6.5.2 Neurological Functional Status

- Most patients will have a degree of functional disability post-operatively.

- The most common functional difficulty after surgery was difficulty with walking (ten metre walk) (37 (75%) of patients).

- Younger patients were more likely to have a functional impairment post-operatively than older patients.

- Younger rather than older patients improved in the period between surgery and radiotherapy.

- Within this study patients with a diagnosis of metastasis were more likely to improve functionally between surgery and radiotherapy than those patients with a malignant glioma but as the numbers of patients with metastasis were small this finding needs to be further explored. Conversely older patients and patients with a malignant glioma were more likely to deteriorate between surgery and radiotherapy.

- A more significant level of global clinical deterioration than improvement in function was measured in patients between surgery and radiotherapy.

- All the patients who were treated with radiotherapy within 28 days n=5 (17%) remained stable or improved.

- There was no relationship between an individual’s change in functional impairment and dose of dexamethasone administered.

6.5.3 Changes in Anxiety & Depression

- Patients who deteriorated between surgery and radiotherapy 6/11 (55%) did not complete the HAD scale. The HAD scale was, therefore, not a useful measure of anxiety and depression for patients who have a poor or worsening functional state. This was due to non-completion.
• The majority of patients who improved or functionally remained the same did not exhibit symptoms of anxiety and depression on the HAD score.

• 13 (35%) patients were detected to be anxious by the HAD. 12 (32%) of these patients improved functionally between surgery and radiotherapy. 5 (39%) of these patients were not awaiting radiotherapy treatment.

• There was a heightened level of anxiety in patients prior to their radiotherapy. Anxiety was more prevalent in younger patients (see Table 6.2).

• The source of anxiety for patients was found to be related to aspects surrounding the diagnosis and radiotherapy treatment. The majority of patients felt;
  Uncertain about what the radiotherapy would entail
  Uncertain about when the radiotherapy was going to start
  Concerned about whether the tumour was growing and causing them harm.

• Four of the five patients who were noted to be depressed between surgery and radiotherapy had a past medical history of depressive illness.

6.5.4 Dexamethasone Dosage and Prevalence of Side Effects

• Dexamethasone dosage was not tailored to an individual’s functional state, age and/or diagnosis between surgery and radiotherapy (Table 6.6).

• High doses of dexamethasone were administered post surgically to patients with visible functional problems (weakness).

• There was no relationship detected between the incidence of side effects and dose of dexamethasone.

• Patients who suffered a side effect post surgically continued to do so throughout the study.
- The percentage of patients experiencing the side effects of insomnia and gastric upset each week was significantly greater than the patients suffering ankle swelling and glycouria.

- Patients did not associate common side effects of dexamethasone therapy e.g. heart burn, oral thrush, insomnia, night sweats, urine frequency and excessive eating with the dexamethasone therapy. This lack of knowledge caused patients to suffer unnecessarily between surgery and radiotherapy.

### 6.5.5 Changes in Quality of Life

- The EORTC quality of life questionnaire is a useful measurement of quality of life in patients who functionally improve or stay the same between surgery and radiotherapy. It's usefulness is limited amongst patients who deteriorate as amongst these patients there is a high non completion rate.

- The EORTC scores suggested that there was no significant changes in the quality of life scores of the patients who clinically improved or remained the same between surgery and radiotherapy.

- The EORTC scores suggested that on average these patients had a relatively low level of symptoms, an average global health status and relatively high level of functioning.

- The interview data noted that the diagnosis and the functional and emotional change associated with it were significantly impacting on the quality of life of both the patients and carers.

- Patients were anxious to go out on their own and carers were frightened to leave patients on their own in case something ‘bad’ happened to them.

- The morbid emotional behavioural response elicited to the diagnosis of malignant glioma was traumatizing for the patient and the families.
6.5.6 Level of Life Disruption

- Few patients with a poor functional state completed questionnaires between surgery and radiotherapy.

- Patients identified that they encountered physical problems that disrupt their lives between surgery and radiotherapy.

- Carers identified changes in the patient’s personality and behaviour.

- Patients appeared to be unaware of these changes and the impact that they were having upon the lives of others.

- A high percentage of patients and their carers did not return to work between surgery and radiotherapy, but the long term implications of this are not considered.

- Overall the majority of patients and carers noted middle to high level of disruption to their family and social life between surgery and radiotherapy.

- Patients readily accepted the inefficiencies in the health care system that disrupt their lives between surgery and radiotherapy.

- Patients required but did not receive, knowledgeable, practical advice between surgery and radiotherapy.

- The impact of a parent being diagnosed with a diagnosis of malignant glioma was devastating for the children. Coping with this was difficult for the patients and their carers.
CHAPTER 7
DISCUSSION

7 INTRODUCTION

"The best way to understand a symptom is to understand where the individual stands with his/her illness and to understand the context in which it occurs" (Leventhaul & Nerenz 1985 pp 43.)

Within this study it was identified that during the study period many patients diagnosed with a brain tumour after their surgery, receive steroid therapy (96%) and await radiotherapy treatment (75%). The length of time that patients waited for their radiotherapy varied (range 24-77 days) but according to the quantitative study findings, the length of time that individuals wait for their radiotherapy did not significantly affect their functional state, anxiety and depression levels, quality of life and/or level of life disruption.

The study findings concur with the findings from other studies that the majority of patients (92%) suffer a degree of functional impairment after their surgery (Davies et al 1996a,b, Salander et al 1996, Grant 2004). Younger patients and patients with a diagnosis of metastasis were shown to be the individuals who improved functionally within the study period.

The level of anxiety prevalent amongst patients during the study period was underestimated by the HAD measurement scale. Patients who deteriorated functionally within the study period did not complete the HAD scale and consequently only 69% of patients scores were analysed. Analysis of the HAD scores indicated that anxiety was
only prevalent amongst 13% - 22%, whereas, content analysis of the telephone and unstructured interview transcripts indicated that 75% of people were anxious about aspects of their radiotherapy and 58% were anxious about their tumour. These contrasting findings may help explain some of the discrepancies that exist within the literature regarding the prevalence of anxiety after a malignant diagnosis (Pringle et al 1999, Zabora et al 2001). Different measurement tools for the same dependent variable can produce significantly different results and this was highlighted throughout the data analysis stage of this study. Contrasting results were found within the measurement of all the dependent variables that were measured using a self completion questionnaire and a form of interview between the researcher and the patient.

The HAD scale detected a prevalence of depression amongst 2% - 3% of patients. However, depressive symptoms such as feeling ‘low in mood’ were detected in over half of the patient transcripts. The cause of these depressive symptoms could not be established for all patients from the transcripts but some patients did associate their feelings to their functional state, hair loss, weight gain and/or tiredness. People with a history of depressive illness were more likely to report a depressive state post operatively.

A quantitative measurement of patient’s quality of life was hard to establish during the study period, as many of the patients who deteriorated functionally did not complete the EORTC questionnaires. The individuals who did complete the questionnaires reported a relatively good quality of life throughout the study period. These findings conflicted with the findings collated from the other data collection tools used within the study.

The level of life disruption tool measured level of life disruption by asking patients and carers about changes in health, family life and social life. The questionnaire also asked patients if they had contacted any health care professionals during the study period and if they had sufficient detail about their future treatment. The majority of patients and carers reported some level of disruption in their work, family and social lives. Content analysis of the interview data allowed the researcher to establish why and how this
disruption to individuals' lives occurred. Physical changes, insomnia and dependency on others affected the role functioning of individuals in their work, family and social life. Emotional reactions, isolation, fear, dependency, lack of control and support contributed to changes in their personal and family life.

The majority of patients who were administered dexamethasone within the study period reported some associated side effects. Insomnia (65%) and Gastric Upset (29%) were the most common associated side effects reported but the prevalence of these side effects was not related to the dosage administered. The dose of dexamethasone administered to patients throughout the study period was arbitrary. There was no relationship detected between; dose, age, level of functional impairment or diagnosis.

7.1 DISCUSSION OF METHODS

This study found that using self completion measurement tools to collate data amongst brain tumours patients is problematic. Patients who are compromised physically and/or mentally are unlikely to complete questionnaires. This study and others have reported that the majority of patients with brain tumours are physically compromised (Davies et al 1996a,b, Salander et al 1996, Grant 2004) and therefore using these types of tools is not valid. From this study the researcher concurs with the belief of others that the findings from self measurement tools cannot be generalisable to the wider brain tumour population (Gupta & Sarin 2002); they can only be applied to patients who are functionally well. It is important for those undertaking research involving brain tumour patients to consider carefully the population they wish to investigate. If they wish to collate data on a complete sample, the data collection methods employed should be carefully considered.

This study utilised a mixed methods approach to collecting data on each of the dependent variables measured within the study. This approach proved very beneficial for this study as the content of the telephone interviews, the semi structured questionnaires and unstructured interviews contradicted some of the findings from the quantitative data,
added depth to the study findings and has allowed the author to provide some theoretical underpinnings for the findings. The used of mixed methods although difficult to manage provided more valid and reliable findings to be presented. It is acknowledged by the researcher that due to the limitations of the study (see chapter 4) other studies will have to be undertaken to ensure that the findings of the study are generalisable to the wider malignant brain tumour population.

7.2 DISCUSSION OF FINDINGS

From the literature review it was surmised that patients who encounter physical changes, anxiety, depressive symptoms, disruption in family, social and work life would be unlikely to be able to report a reasonable quality of life. Many studies have indicated that one or more of these factors diminishes the quality of life experienced by individuals (Weitzner & Meyers 1996, Lovely 1998, Huang et al 2001) and, therefore, one would expect that the presence of one or more of these factors would automatically be associated with a poor quality of life being reported. The findings of this study have illustrated that the reaction of each patient to changes in their physical and emotional state is unique. By discussing the study findings in association with the literature and the Framework of Illness Behaviour and Coping developed by Shaw (1999) the researcher will explain the functional and emotional issues witnessed amongst patients in this study.

7.2.1 Situation & Appraisal of Situation

From the results it can be concluded that the timing of events between surgery and radiotherapy for patients and carers is similar. After their surgery the patients were discharged home with dexamethasone therapy and waited at home for a mean period of 41 days until commencement of their radiotherapy treatment. During this time at home many patients had their spouse or children for support. Patients experienced some changes in their functional and emotional state. Each patient’s unique reaction to the situation was dependent upon a number of factors e.g. within this study there were
two patients A and B whose situation was very similar in regards to diagnosis, treatment, social support, age and gender. However, the response exhibited by them within the study was different. This finding can be explained using the Shaw (1999) framework as it indicates that there are a number of factors that influence an individual’s appraisal of a situation and it is their appraisal that influences their behavioral response.

7.2.2 Illness Representation - How do patients construct what malignant glioma is and what the outcome of this diagnosis is?

Illness representation is one of the factors that Shaw (1999) claims influences illness behaviour and coping. From the findings of many studies (Davies et al 1996b, Weitzner et al 1996, Fox & Lantz 1998, Huang et al 2001) the researcher assumed that the major component of illness representation amongst patients within this study would be related to the presence or absence of symptoms and/or the poor prognosis associated with the condition. However, from analysis of the findings the researcher proposes that it is the symptoms, information about diagnosis and treatment, and the uncertainly associated with this are the most influential in affecting the way an individual constructs what their diagnosis is and the likely outcome – illness representation.

Every week during the study period many of the patients within this study suffered symptoms from their brain tumour and side effects associated with their dexamethasone therapy that were reported to the researcher. The impact that the symptoms from the brain tumour and the dexamethasone therapy had upon individuals differed. The researcher identified that there were two categories of symptoms that the patients suffered from within this study;

- Problems that created a pragmatic response e.g. the side effects of dexamethasone
- Problems that created an emotional response e.g. limb weakness.

The common side effects of dexamethasone reported by patients in this study; insomnia and gastric upset caused patients ‘practical’ problems in their every day life e.g. they
were tired or they had difficulty eating. These types of problems did not appear to cause an emotional response within the patients. When reporting these problems patients would simply state the problem and not associate it with other effects.

The patients who suffered from limb weakness, unsteadiness and seizures within the study would associate their symptoms with a change to their daily activities that caused an emotional response. The patients who suffered limb weakness felt they could not leave the house alone and this made them feel like they had lost their independence. The carers of patients who were suffering from personality changes and mental deterioration also claimed loss of their independence as they felt they could not leave the patient alone. From many of the situations described by patients and carers within the study the researcher recognised that it was not the physical and/or mental symptoms that prevented patients and carers undertaking their normal daily activities, it was the fear of what would happen if they did. In this situation patients and carers were cognitively assessing the physical and mental changes associated with the illness, predicting the effect that this could have on the individuals if they ‘carried on as normal’ and creating an emotional response to this.

Shaw (1999) illustrates in her framework that there are two processes (cognitive and emotional) that patients use to create an illness representation and this was recognised amongst the patients within the study. Although at the outset the researcher believed that the presence or absence of symptoms would influence the patient’s representation of their diagnosis, she did not acknowledge that it would be the individual’s perception of a ‘potential’ as opposed to a ‘real’ outcome of these symptoms that would be a determining factor in their response. Shaw (1999) claims that all cognitive responses to a symptom result in an emotional reaction, however the researcher believes that within this study it was only the symptoms that caused an emotional reaction that had a negative impact on their lives.

The prognosis of malignant brain tumour patients is poor and the impact that this has upon patients has been examined in the past (Salander et al 1996, Adelbratt & Strang
2000). Unlike other patients few malignant brain tumour patients are open and honest about their feelings regarding their poor prognosis and to date research has not established why death is not discussed openly amongst this group of patients. Some authors have related this to patients not being fully aware of their prognosis (Davies et al 1996b, Salander 2000) and others have stated that the patient’s cognitive response to their prognosis has resulted in them dealing with the short term rather than the long term future (Salander 1996, Adelbratt & Strang 2000). Impending death was not directly discussed at length or mentioned by many patients within this study but some patients actions e.g. buying coffins (three patients) or comments e.g. ‘frightened cancer growing all over my body’ demonstrated to the researcher that there was some awareness in regard to prognosis. The reason people do not discuss openly their prognosis cannot be established from this study. However, it appears within the period between surgery and radiotherapy that many patients are dealing with the immediate future e.g. radiotherapy treatment and it is this that is causing them a great deal of fear and anxiety.

Adelbratt & Strang (2000) and Curren (2001) detected denial, anger, fear, anxiety and guilt within the first three months after diagnosis of a brain tumour. This study found that patients had anxieties and fears about their tumour growing (58%) and their radiotherapy treatment (35%). The source of anxiety and fear relating to the brain tumour growing and radiotherapy was associated to lack of information. 35% patients were found within this study to be asking questions about radiotherapy treatment indicating that they were unclear of what it would entail, its effects and response. Shaw (1999) states that the information people have or collect regarding their situation affects they way they construct their representation of it. It is known from the literature that in the initial stages of diagnosis patients require information about proposed therapy, sequence of future events, side effects of treatment, symptom management and prognosis (Adams 1991). According to the results of this study some (35% – 58%) patients awaiting radiotherapy do not have this information and this causes them heightened anxiety and fear.
The reason for patients not having adequate information between surgery and radiotherapy cannot be established from this study. From other studies it is known that patients do not always remember all the information they receive and others intentionally distract themselves from it (Butow et al 1997). Whether the patients had not received adequate information, forgotten the information given to them or were denying knowledge of the information, cannot be established. However, it is known from other studies that lack of information and support leads to heightened uncertainty (Mishel 1981). Patients within this study stated that it was the uncertainty about what their radiotherapy would entail, and when it was going to start, that caused them most concern. Mishel (1981) & Fox & Lantz (1998) have demonstrated that uncertainty amongst individuals initiates a feeling of threat and this ensures that patients cannot consider the cause of their uncertainty in a rational way. It is proposed that it was the uncertainty of patients in the time between surgery and radiotherapy that caused some of them to make irrational statements about their impending radiotherapy treatment during the interviews. The influence of uncertainty upon an individual’s representation of an illness is not incorporated within the framework developed by Shaw (1999). She places emphasis upon information but the researcher would propose that uncertainty is the more important element when a patient is constructing a picture of their illness. It is acknowledged that uncertainty can be minimised by information. However uncertainty should be a factor included within the framework as it is the uncertainty that causes the emotional response, not the lack of information (Mishel 1981, Northouse 1995, Fox & Lantz 1998).

Uncertainty about the start date of radiotherapy caused anxiety amongst 75% of patients within this study. This lack of information was due to lack of administrative infrastructure, lack of treatment machines, lack of staff and restricted planning dates. These issues also prevented radiotherapy being delivered within the recommended 28 days after surgery.
7.2.3 Social Support

It is acknowledged within the literature that families are the main source of support for patients during illness and that carers readily undertake this role (Oberst & James 1985). After initial diagnosis of an illness it is suggested that carers need information and support to care for their close relatives effectively. Within the study it was carers (77%), as opposed to patients (61%), who stated that they required more detail about treatment. The researcher proposes that this was because patients were depending on the carers to provide support, and carers were needing more information and support to do this effectively.

Quotes from the transcripts indicated that during the study many patients have a preoccupation with themselves while carers need to continually support and supervise the patient. Although this behaviour has been observed within other studies (Bergsma & Thomasma 1982, Oberst & James 1985, Radina & Armer 2001), it was interesting for the researcher to note that the dependency of some patients upon their spouse or carer was a major source of disruption for many families.

From some of the comments generated within the interview the scope of support offered to patients from their carers was immense. Three of the four patients interviewed acknowledged that the support offered was beneficial however they were not aware of the consequences of this support. According to the literature patients provide support to carers to minimise the physical and emotional disruption being experienced by the patient while coping with their diagnosis (Bergsma & Thomasma 1982, Oberst & James 1985, Radina & Armer 2001). Within this study some patients wished to take some control of their lives e.g. do their ironing or go for a walk (Patient C). Conversely, other patients depended and expected carers support when it was not entirely necessary. Shaw (1999) indicates within her framework that the bigger the change experienced within their lives, the greater the threat the diagnosis is perceived to have on the lives of the individuals involved. From this study and others it has to be acknowledged that social support is necessary to help an individual cope adaptively (Shaw 1999, Radina & Armer
However, the researcher proposes that the level of support provided has to be managed effectively, because if patients detect that their lives have been altered significantly, they will perceive that their diagnosis has a bigger impact than necessary and consequently this could lead to an altered response to their situation (Shaw 1999). Patient C within this study claims that it was her ability to carry on as normal that helped her immensely and allowed her to forget her diagnosis for some of the study period. Although some authors would claim that this was her exhibiting denial which is an emotional response to the diagnosis (Northouse 1989) others would state she was attempting to keep things as normal as possible which is a cognitive coping response (Hilton 1996). To the researcher whether it was an emotional or cognitive response was immaterial. What was important was that by attempting to keep things as normal as possible this patient’s coping response appeared to be more ‘healthy’ than the coping response of the individuals who allowed their carers to do more than they required. The researcher proposes that all patients require support from families and healthcare professionals after a diagnosis of malignant glioma. However, this level of support should be monitored as it may be that too much support is having a negative impact on the coping response of individuals. According to Shaw (1999) this is because patients when they perceive a bigger change in their commitments they see the diagnosis as being a bigger ‘threat’ to their lives.

### 7.2.4 Commitments

It is suggested that an optimum quality of life can be achieved when patients have achieved what is described as 'successful accommodation' of an illness into one’s life (Grossmann et al 2000, Koch 2000). Many patients within this study were not managing to integrate their diagnosis and its implications into their work, social and family lives during the study period. Over 2/3rd patients and their carers included within the study did not return to work and reported a disruption to their family and social life. The impact that this disruption had upon patients and their families varied. As reported within the results section, some people e.g. Patient A and D felt frustrated that they could not undertake normal daily activities and reported that this was distressing as the
‘normal pattern’ of behaviour within the house was affected. Some patients and carers (10%) indicated that they had not noted any effect at all on family and social life.

According to the literature it takes 1-2 months for families to adapt to a diagnosis and then ‘return to normal’ (Oberst & James 1986). This study was examining patients up to a period of 77 days after their diagnosis and would concur that in this time things were not ‘normal’ for many patients. From experience the researcher would anticipate that amongst malignant glioma patients the time period for things to ‘return to normal’ may be extended beyond that reported for other cancer patients. After a two month period many of these patients will have started an intensive course of radiotherapy treatment and will be suffering from the side effects of this treatment.

7.2.5 Group Differences

The age of patients has been indicated to influence the anxiety and coping behaviour elicited by patients in other studies and Shaw (1999) and others state that group differences e.g. gender, age, marital status influence an individual’s appraisal of their situation (Jamieson et al 1978, Morris et al 1981, Hughson et al 1988). At the outset of this study the researcher believed that marital status would be influential in the response exhibited by patients and carers as from personal experience it appeared that individuals with close spouses coped better. Northouse (1989) provided some findings to support this anecdotal evidence but within this study the only patient characteristic that statistically influenced any of the findings was age. It is suggested from this study that younger patients as opposed to older patients with a malignant glioma may report heightened anxiety between surgery and radiotherapy.

It is acknowledged by the researcher that the difference in anxiety levels reported within this study is not significant. However, as many of the patients who encounter a malignant glioma are aged ≤61 it is worth examining this finding further as it may provide the basis for future research. According to Shaw (1999) patients assess a situation by determining the threat they perceive the illness to have on their life commitments e.g. family role and work life. As many younger patients are more likely
to have an active work, family and social life than older patients the level of threat that an illness has on their lives is greater than perceived by older individuals (Shaw 1999). This study cannot conclude that younger as opposed to older patients within the study had a busier and more active social life and, therefore, it cannot conclude that the difference in the anxiety levels between younger and older patients was due to the ‘health threat’ of the illness. What can be concluded is that this is an area that requires further investigation.

7.2.6 Personality & Past Events

Within this study there could be no conclusions drawn that would indicate the personality and past events affected the way individuals coped with their diagnosis as this factor was not explored adequately. However, it was noted that people who had suffered from depressive illness in the past were more likely to exhibit a depression in the study period. This finding concurs with the findings of Maunsell et al (1992).

7.2.7 Health Threat

By interpreting the results of this study using the Shaw (1999) framework the researcher believes that it is, as the framework illustrates, a combination of factors that influence the way that an individual perceives their illness. It is not just the factors that health care professionals perceive will cause a problem to patients e.g. side effects of dexamethasone and functional weakness that affect their response to their diagnosis. It is how their assessment of how every aspect of their illness affects their life that determines their response. Patients look at themselves and those around them within their every day lives and assess the impact that the diagnosis of malignant glioma has upon all of these things and then they assess – What threat has this illness posed to my life? According to Shaw (1999) it is the assessment of the health threat and the amount of control that the individual perceives that they have over this threat that determines their response exhibited. The amount of control an individual perceives they have over a situation is termed ‘self efficacy’ by Shaw (1999).
7.2.8 Self Efficacy

According to Shaw (1999) 'self efficacy'; a sense of control over the situation, is very important when an individual is assessing their situation and creating a response to it. From the discussion so far we have identified that there are many things that individuals expressed were affecting their lives within the study period. However, throughout the study no patients stated that they felt they had no control over their situation.

The researcher suspected from her own experience that upon investigation people may feel trapped by the diagnosis and treatment of malignant glioma as their choices regarding treatment are so restricted. However upon reflection it would appear that individuals do not feel that this aspect of their treatment and diagnosis influences their experience between surgery and radiotherapy. Some studies have indicated that it is common for people to be happy for professionals to make decisions for them regarding their treatment (Butow et al 1997). Whether patients within this study fitted into this category of patients cannot be established.

Although patients within this study did not appear to feel a sense of low self efficacy about their treatment regime from the analysis of the results it could be presumed that some patients did indirectly suffer from some lack of control over their situation. Many patients within the study felt dependent on their carers and felt like the diagnosis had influenced many aspects of their lives. Although it was never stated by any of the patients that they felt out of control, the researcher suspects that it was their feeling of helplessness that led to the fact that they suffered, at times unnecessarily, from some aspects of their disease and treatment e.g. side effects of steroid treatment, delays in treatment. This feeling of lack of control could also have initiated the three patients who organised their funerals to take control of another aspect of their life that was within their control. Although this action may have been distressing for the family and the patient it could be assumed from the literature that this behaviour was a means of coping for these individuals.
7.3 THE OUTCOME

From the study findings we can conclude that the illness behaviour exhibited by individuals throughout the study period was varied. Every individual appeared to react and respond differently to their change in functional state, their treatment, the changes in their lives and their prognosis. The researcher believes there is no wrong way or right way to cope with the diagnosis of malignant disease. However patients need to have some support and advice whilst coping to assist them manage more effectively.

Patients within this study who were exhibiting morbid behaviour were attempting to take some control and this can be justified using the framework of coping developed by Shaw (1999). However, the researcher questions whether any action could have been taken to help these patients take control of their lives in an alternative way that could have been less distressing for the patients and the family.

From discussion of the study findings it can be concluded that although patients and their carers deal differently with the situation that they face, there is a need for health care professional to observe and interpret the behaviour exhibited by patients and their families to assist them during their time between surgery and radiotherapy. This process could ensure that the means of coping adopted by individuals was not adversely affecting their lives. Using a framework of coping and/or illness behaviour this assessment of behaviour could be easily undertaken by nurses and other health care professionals. This conclusion by the researcher has allowed the final research question of the study to be addressed. A framework of coping could be very useful in helping to interpret the behaviour exhibited by patients and their carers between surgery and radiotherapy. However the individuals utilising the tool have to gain a reasonable amount of knowledge and experience regarding coping theory and coping responses to ensure that the behaviour is interpreted accurately. With more emphasis on uncertainty being incorporated into the framework developed by Shaw (1999) this framework provides a useful basis for any health care professional aiming to interpret coping behaviour.
If, as stated within the literature, the overall aim of treatment for malignant brain tumours is palliative (Davies & Hopkins 1997, Gupta & Sarin 2002, Efficace & Bottomley 2003), the findings of the study raise a number of issues that should be addressed by nurses, medical staff and health care providers. The time period between surgery and radiotherapy within this study equated to 12% of the mean survival time of patients with malignant glioma. Hypothetically, in this time the majority of these patients should be: benefiting physically from the surgery and steroid treatment they have received, be comfortable at home with their family and friends and encouraged to enjoy their life prior to commencement of their radiotherapy. This study has identified that patients and their carers encounter a number of functional and emotional issues between surgery and radiotherapy that prevent each of these.

In the following chapter the researcher makes some recommendations that if implemented could benefit the majority of people between surgery and radiotherapy.
CHAPTER 8
RECOMMENDATIONS FOR CLINICAL MANAGEMENT, HEALTH CARE PLANNING & FUTURE RESEARCH

8 INTRODUCTION

The overall aim of this study was to explore the functional and emotional issues experienced between surgery and radiotherapy for patients with malignant brain tumours and their families. It was the intention of the study to provide health care professionals, specifically nurses, with information and recommendations that would allow them to optimise patient care between surgery and radiotherapy.

To ensure that patients and their carers optimise the quality of their lives between surgery and radiotherapy, they have to cope adaptively to their diagnosis and the symptoms of their diagnosis in this time. By implementing a number of practical and supportive measures the researcher proposes this can be achieved. From the results of this study the researcher offers the following recommendations for clinical management, health care planning and future research to ensure that optimal care is delivered to patients and their carers between surgery and radiotherapy.

8.1 RECOMMENDATIONS FOR CLINICAL MANAGEMENT

- This study has demonstrated that dexamethasone dosage is not tailored to changes in the patient's functional state, their diagnosis or age. However, for one week after their surgery patients with a visible functional disabilities, e.g. hemiplegia, are administered a high daily dosage of dexamethasone. This finding
indicates that the prescribers of dexamethasone therapy are aware of the benefits of administering dexamethasone therapy to patients with a poor physical functional status (Vecht 1994). However, perhaps because a cognitive clinical assessment is not commonly performed in neurosurgical wards, patients with memory, speech problems are not treated with as high doses of dexamethasone. Surgeons tend to use their 'visual measure' of functional status and determine the patients dexamethasone requirement. To prevent this inaccurate assessment of functional state affecting dexamethasone dose a regular neurological functional assessment should be undertaken on patients from the date of their surgery to commencement of their radiotherapy. This assessment should encompass all aspects of neurological function and should be receptive to clinical significant changes in the patient’s condition. The results of these tests should be recorded for the benefit of patients and the health care professional involved in the planning and delivery of care.

- The decision to offer radiotherapy and the type of radiotherapy offered depends upon the type of tumour, the patient’s post operative functional state and age (Rampling et al 2004). This study suggests that if patients wait more than 28 days for their radiotherapy, their post operative functional state will not remain stable until the commencement of their radiotherapy. If the period between surgery and radiotherapy is anticipated to be in excess of 28 days for older patients with a diagnosis of malignant glioma a regular neurological functional assessment would assure the appropriateness of the treatment offered to them post operatively. Additionally, these assessments may provide further reassurance to patients about their symptoms. Patients who perceive that they are experiencing a change in their functional state could refer to their previous assessments to verify if matters have changed. If a measurable functional deterioration was detected it would also ensure that patients were appropriately referred to the neuro-oncology team and a change in the patient’s treatment regime could be considered.
• The importance of neurological functional testing and the importance of reporting a significant change in these tests should be made apparent to patients and all health care providers.

• To ensure patients and carers participate as fully as possible in their work, life and family commitments when discharged they require some coaching about how they can manage their condition and its treatment at home.

• Patients with a past medical history of depressive illness should be closely monitored between surgery and radiotherapy, as they are at heightened risk of depression.

• Dexamethasone therapy should be tailored to the patient’s neurological functional state, which should be measured using a reliable and valid functional scale.

• Despite recommendations indicating that it is important for the dosage and prevalence of side effects of dexamethasone to be monitored closely (Gupta & Sarin 1992), patients are not routinely monitored in the time between surgery and radiotherapy. Generally, they are at home at this time with little or no professional support. The most common side effects of dexamethasone therapy detected within this study were gastric upset and insomnia. Interestingly, the presence of these side effects were not related to the dosage of dexamethasone administered to the patients. The only predictive factor that indicated that a side effect of dexamethasone would continue was if it was present in the first week after administration of dexamethasone. Consideration should be given to commencing a sliding scale of dexamethasone that adjusts the dosage according to side effects experienced and neurological functional status.

• Lack of routine monitoring and lack of information resulted in patients suffering from some side effects of dexamethasone therapy unnecessarily. As the patients did not associate heartburn, oral thrush and insomnia with the administration of
dexamethasone, they were unlikely to report suffering from these symptoms unless prompted by the researcher. The researcher recommends that by providing patients with more information about dexamethasone therapy, and asking patients about symptoms being encountered in the first week, simple measures could be put in place to alleviate the distress some of these symptoms cause. For example, if patients encounter gastric upset four days after their surgery and they require to continue their dexamethasone therapy, administration of an antacid should be considered. Antacids will most likely prevent the patient’s side effects worsening. Patients should be fully informed about the potential side effects of dexamethasone therapy between surgery and radiotherapy and these should be monitored by a health care professional.

- It is acknowledged that patients have to participate in a process of adjustment to cope with their diagnosis (Lazarus & Folkman 1984) and face the consequences of their illness. However, support strategies could be put in place to allow the patients to do this in an 'adaptive' rather than a 'maladaptive' manner. This would prevent the spiraling of negative events that could severely disrupt the time when patients and their carers should be encouraged to optimise their life quality (Mills & Sullivan 1999). Many of the emotional and practical issues that patients have between surgery and radiotherapy are a result of maladaptive coping. The behaviour exhibited by patients and carers between surgery and radiotherapy can be interpreted using the framework developed by Shaw (1999). Unfortunately, due to lack of professional support, specialised knowledge, advice and counselling, patients and their carers do not cope well with their diagnosis and its associated symptoms between surgery and radiotherapy. Support strategies should be put in place to ensure that patients and their carers ‘adaptively’ cope with the diagnosis of malignant glioma between their surgery and radiotherapy.

- In this study, between surgery and radiotherapy, patients were relatively unsupported and lacked the adequate knowledge they required to take some control of their condition, their symptoms and their treatment. To fulfil their need
to have some control, a number of patients decided to take control of what would happen when they died. This may have been an attempt by them to minimise the threat that the illness has upon their families (Shaw 1999). To an outsider of the situation this behaviour could readily be viewed as maladaptive but according to the patients it was behaviour that fulfilled a need - they had to take control of their lives at this time. Interestingly, the patients stated within the unstructured interviews that they could, in retrospect, identify that this behaviour had a negative impact on their lives at this time. To prevent the coping behaviour exhibited by individuals severely impacting on the lives of patients and their carers between surgery and radiotherapy it is recommended that the behaviour and adjustment of patients and their carers to their diagnosis and prognosis is monitored. The dependency that is created between patients and their carers between surgery and radiotherapy should be monitored closely and support mechanisms should be put in place to facilitate the carers to cope with this new role.

- The re design of the organising, planning and delivery of radiotherapy treatment cannot be resolved without additional resources. To ensure patients receive their radiotherapy within the recommended time scale, more treatment machines, more staff and more space would need to be provided. Implementation of effective computerised administrative process would take less resource, and this would ensure that patients could receive a start date for their radiotherapy at the time of their diagnosis.

8.2 RECOMMENDATIONS FOR HEALTH CARE PLANNING

- A prompt and direct means of reporting changes in the patient’s neurological functional state to the neuro-oncology team should be established. This would ensure that the treatment regime being implemented (dexamethasone therapy)
and planned (radiotherapy) for the patient was tailored to the changes occurring in their functional state between their surgery and radiotherapy.

- Most patients and their carers recognise that they need some professional support between surgery and radiotherapy. It was identified from the study that when seeking information and support between surgery and radiotherapy patients and carers tended to approach individuals, e.g. their GP, who were known to them prior to their diagnosis. The incidence of malignant glioma and uniqueness of the condition ensures that many health professionals in the community have limited knowledge about the diagnosis, the symptoms and treatment. Consequently, in the time between surgery and radiotherapy an individual with specialised knowledge who can establish a close face to face relationship with the patients and their families should be identified. Patients need readily available support and sources of information about their tumour type, their symptoms and, more specifically, the planning and delivery of their radiotherapy treatment in the period between surgery and radiotherapy. This information must be readily accessible after their discharge from the treatment hospital.

- The study findings indicated that patients with young families and their carers attempted to cope remarkably. The patients, whilst attempting to cope with their own diagnosis were admirably attempting to help their children. At times, this was emotionally distressing for the patients and their carers, and it was identified by the researcher that specialised support would have been extremely beneficial for these families in this time. Between surgery and radiotherapy the services available to help patients deal with the consequences of their diagnosis upon their children should be promoted.

- It is recommended that health care providers investigate more effective systems for organising the planning and delivery of radiotherapy treatment. Improved systems organisation would minimise the distress that is caused by patients waiting a prolonged length of time for their treatment and allow treatment
centres to meet the recommendations of various professional and government bodies (Davies & Hopkins 1997b, Joint Council for Clinical Oncology 1993, Scottish Executive 2001). More importantly, if patients could receive their radiotherapy within the recommended time scale it is possible that they may suffer less from the symptoms of their tumour and dexamethasone therapy. More effective systems for organising, planning and delivering radiotherapy treatment have to be investigated to ensure patients receive a start date for radiotherapy at their clinic appointment and to meet the recommendations of the professional and government bodies.

- With only limited knowledge for reference patients interpret their illness, symptoms, future treatment and future life to create their own perception of their illness, and the impact that this will have upon their lives. Whilst creating this perception patients face a great deal of uncertainty. This uncertainty heightens their irrational thoughts and encourages them to interpret their illness as a significant health threat. The greater the threat of an illness the more likely patients will maladaptively cope and the researcher believes that with adequate support and advice patients could cope more effectively between surgery and radiotherapy. The support and advice that is necessary to facilitate adaptive coping amongst patients and their carers between surgery and radiotherapy could all be provided by a nurse with the specialized knowledge and skills. The support services available to help patients cope with young families when diagnosed with a malignant glioma should be promoted to patients and their carers between surgery and radiotherapy.

- As discussed in Chapter 3, if all patients who have been diagnosed with a malignant brain tumour could have regular face to face contact with a neuro-oncology CNS after their diagnosis many of the above recommendations could be implemented effectively. The geometrical location and lack of resources ensures that currently many patients with a malignant glioma and their carers are struggling to cope between surgery and radiotherapy.
The development of a clinical network of nurses with an interest in neuro-oncology would also facilitate implementation of some of the recommendations above. If nurses throughout the treatment centre referral areas, with an interest in neuro-oncology, were offered a development package by specialised neuro-oncology staff they could gain the skills and knowledge they require to deliver the care recommended above in their local areas. These individuals would have a key point of contact at the tertiary care setting, and they would provide a face to face regular knowledgeable source of support for the patient in their home. With advancing technology the training required for these nurses could be delivered locally via CD Rom or WebCT which could be updated regularly with new information.

8.3 RECOMMENDATIONS FOR FUTURE RESEARCH

This study has re emphasised the difficulties of using measurement tools to establish the quality of life in patients with poor functional status (Weitzner et al 1996). There was a poor level of response to the questionnaires from patients who functionally deteriorated within this study. With increasing emphasis being placed on measurement of life quality amongst patients with malignant brain tumours (Gupta & Sarin 2002, Efficace & Bottomley 2003) it has to be highlighted that questionnaires are not always the most effective means to measure quality of life in this group of patients. When measuring anxiety and depression levels and quality of life amongst brain tumour patients, researchers should consider their data collection tools. Patients with deteriorating neurological functional state are unlikely to respond to questionnaires.

Further studies have to be undertaken to fully investigate the effect of age upon the coping response of malignant glioma patients. If age is a significant factor further investigation of the reason for this may help us understand the coping of patients.
• To ensure that implementation of the recommendations of this study would facilitate patients and their carers to receive an optimum level of support between surgery and radiotherapy, it is necessary for some of the recommendations above to be implemented and this study to be replicated. To provide an example of how this could be done the researcher proposes that another comparative study needs to be undertaken within two groups: malignant brain tumour patients receiving the current level of supportive care and malignant brain tumour patients receiving regular face to face contact with a specialised source of support between surgery and radiotherapy.

• From the study findings the researcher believes that the use of a framework of coping or illness behaviour may be very beneficial for nurses involved in the care of these patients. To test the benefit of such a tool for nurses and patients alike a study needs to be undertaken that compares and measures the influence of the framework upon nurses perception of the patients and carers coping response.

• Within neuro-oncology there is a need for more studies to be undertaken to investigate the experience of patients and their carers at various points in their illness. Until such times as the medical management for this disease dramatically changes prognosis the psychosocial issues of these patients have to be addressed to ensure that the care being offered is at the optimum level. Nurses involved in the care of these patients have the insight to generate good research questions that will address many of the research questions and with resources many of these could be developed into strong research studies that could significantly benefit the patients and care.

8.4 RESEARCHER CONCLUDING REMARKS

From the outset of this study the researcher believed that in the period between surgery and radiotherapy patients and their carers were isolated in the period between surgery and radiotherapy. At all other stages of their illness; during radiotherapy and
chemotherapy and upon recurrence patients seem to have established a reasonable network of support. However, after diagnosis of their illness and upon discharge prior to commencement of radiotherapy these patients appeared to be left in isolation to manage their illness and deal with their prognosis.

This study has not only highlighted to the researcher that there are physical and emotional problems experienced by patients and carers between surgery and radiotherapy it has also highlighted that without close communication and observation the coping behaviour of patients and carers cannot be assessed. It is hoped that the results of this study will:

- Inform health care professionals, especially nurses, involved in the care of malignant glioma patients about the experience of patients and carers between surgery and radiotherapy and give them some insight into how they can support patients and carers in this time.

- Encourage them to undertake more studies that investigate in depth the experience of patients and carers at different stages of their illness.

From the researcher’s knowledge of the literature the advancement in neuro-oncology care especially within the UK over the past decade has been very slow. The medical management of these patients has remained remarkably unchanged and the psychosocial care is being delivered, due to lack of an evidence base and resources, from a consensus base. Malignant glioma patients and their carers suffer from multiple problems from diagnosis to death and the insight that further studies examining the response of these patients and carers would provide to all health care professionals is invaluable. Further studies have to be undertaken within this area to ensure that these patients can be encouraged to make the most of their shortened lives.
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APPENDIX 1

THE KARNOFSKY PERFORMANCE SCALE
<table>
<thead>
<tr>
<th>Karnofsky Performance Status Scale Definitions Rating (%) Criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>Able to carry on normal activity and to work; no special care needed.</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Unable to work; able to live at home and care for most personal needs; varying amount of assistance needed.</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Unable to care for self; requires equivalent of institutional or hospital care; disease may be progressing rapidly.</td>
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<tr>
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<td></td>
</tr>
</tbody>
</table>
APPENDIX 2

THE EDINBURGH FUNCTIONAL IMPAIRMENT TEST
Williams Delayed Recall Test Instructions. Form C.

"Will you please have a good look at these pictures and see if you can remember them, in about 6 minutes I shall ask you what they were. Will you now tell me what you are going to call each one of them." When patient has named each object allow 1-2 sec. before removing sheet. Turn it over so that it can no longer be seen.

Test recall of first test saying:

"Will you now tell me as many of those pictures as you can remember, it does not matter in what order you give them."

Tick in column 1 all those correctly recalled.
When they cannot recall anymore use the prompts and tick in column 2 all correctly recalled.
If any picture not recalled after a prompt, show the 2nd sheet:
Ask

"Will you tell me which of these pictures was on the other page I showed you at the beginning."
Tick in column 3 those items correctly identified.

<table>
<thead>
<tr>
<th>Object</th>
<th>Prompt</th>
<th>1 Unaided</th>
<th>2 Prompt</th>
<th>3 Recogn</th>
</tr>
</thead>
<tbody>
<tr>
<td>Comb</td>
<td>May Have One In Your Handbag/Pocket</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clock</td>
<td>Some People Can't Wake Without One</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Key</td>
<td>To Get Back Into Your Home</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gun</td>
<td>Soldiers' Carry Them</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Flag</td>
<td>Seen At Tops Of Buildings</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Umbrella</td>
<td>If It Was Wet Outside</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cat</td>
<td>A Common Pet</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Iron</td>
<td>Usually Use It After A Washday</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Knife</td>
<td>Boy Scouts Carry Them</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Patient's Name ___________________________ Date ____________
APPENDIX 3

BARTHEL INDEX
# BARTHEL DISABILITY INDEX

## Feeding
- **2** = Independent
  - Able to use any necessary device: eats in a reasonable time; able to butter on his/her own
- **1** = Needs help
  - Cutting or spreading butter
- **0** = Dependant
  - Needs to be fed

## Bathing
- **1** = Independent
  - Able to wash self all over; maybe by using a shower, full bath or stable getting in or out of shower room.
- **0** = Dependant
  - Needs some help

## Dressing
- **2** = Independent
  - Includes tying shoelaces; buttons
- **1** = Needs help
  - Able to dress by self but needs help tying shoes; fasteners
- **0** = Dependant
  - Needs to be dressed

## Grooming
- **1** = Independent
  - Washing hands/face, combing hair, brushing teeth
- **0** = Dependant
  - Needs some help

## Mobility
- **3** = Independent
  - Can walk 50m; May use aid except roller; speed not important
- **2** = Needs help
  - Needs help of one person, including help standing
- **1** = In wheelchair
  - Independent
- **0** = Immobil
  - Including being wheeled by another

## Stairs
- **2** = Independent
  - Must carry walking aid if used; needs no help
- **1** = Needs help
  - Manages with help. Physical or verbal supervision, carrying aid.
- **0** = Dependant
  - Unable. Cannot negotiate stairs, needs lift.

## Toilet
- **2** = Independent
  - Able to handle clothes, wipe self, flush toilet, empty commode completely
- **1** = Needs help
  - Able to manage with minor help balancing, handling clothes or toilet.
- **0** = Dependant
  - Needs major assistance.

## Bed Chair
- **3** = Independent
  - Needs no help in moving from bed to (wheel)chair and vice versa. In wheelchair if necessary
- **2** = Minimal help
  - Verbal supervision, minor physical help from spouse
- **1** = Major Help
  - Able to sit unaided, but needs much help of one/two persons
- **0** = Dependant
  - Unable to sit. Needs hoist or lift by two persons

## Bowels
- **2** = No accidents
- **1** = Occasional accidents / help with enema
- **0** = Incontinent

## Bladder
- **2** = No accidents
- **1** = Occasional incontinence or device used
- **0** = Incontinent

Barthel: [ ]
APPENDIX 4

FORMULA FOR DETECTING SIGNIFICANT CHANGE IN EFIT
Formula for Detecting Clinical Significant Change in EFIT

\[
\begin{align*}
\text{NHPT change} & \quad \frac{\text{first test} - \text{second test} \times 100}{\text{first test} - \text{second test}} = \geq 0.2 \\
\text{TMW change} & \quad \frac{\text{first test} - \text{second test} \times 100}{\text{first test} - \text{second test}} = \geq 0.2 \\
\text{WDRT change} & \quad \frac{\text{first test} - \text{second test} \times 100}{81} = \geq 0.2 \text{ (change in score } \geq 16) \\
\text{BASRS} & \quad \text{second test} - \text{first test} = \geq 2 \text{ on the scale}
\end{align*}
\]
APPENDIX 5

THE HOSPITAL ANXIETY & DEPRESSION SCALE
Doctors are aware that emotions play an important part in most illness. If your doctor knows about these feelings he will be able to help you more.

This questionnaire is designed to help your doctor to know how you feel. Read each item and place a firm tick in the box opposite the one 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

<table>
<thead>
<tr>
<th>I feel tense or wound up:</th>
<th>I feel as if I am slowed down:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Most of the time</td>
<td></td>
</tr>
<tr>
<td>A lot of the time</td>
<td></td>
</tr>
<tr>
<td>Some of the time, occasionally</td>
<td></td>
</tr>
<tr>
<td>Not at all</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>I still enjoy the things I used to enjoy</th>
<th>I get a sort of frightened feeling like butterflies in the stomach:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Definitely as much</td>
<td>Not at all</td>
</tr>
<tr>
<td>Not quite as much</td>
<td>Occasionally</td>
</tr>
<tr>
<td>Only a little</td>
<td>Quite often</td>
</tr>
<tr>
<td>Hardly at all</td>
<td>Very often</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>I get a sort of frightened feeling as if something awful is about to happen:</th>
<th>I have lost interest in my appearance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very definitely and quite badly</td>
<td>Definitely</td>
</tr>
<tr>
<td>Yes, but not too badly</td>
<td>I don't take so much care as I should</td>
</tr>
<tr>
<td>A little, but it doesn't worry me</td>
<td>I may not take quite as much care</td>
</tr>
<tr>
<td>Not at all</td>
<td>I take just as much care as ever</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>I can laugh and see the funny side of things:</th>
<th>I feel restless as if I have to be on the move</th>
</tr>
</thead>
<tbody>
<tr>
<td>As much as I always could</td>
<td>Very much indeed</td>
</tr>
<tr>
<td>Not so much now</td>
<td>Quite a lot</td>
</tr>
<tr>
<td>Definitely not so much now</td>
<td>Not very much</td>
</tr>
<tr>
<td>Not at all</td>
<td>Not at all</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Worrying thoughts go through my mind:</th>
<th>I look forward with enjoyment to things</th>
</tr>
</thead>
<tbody>
<tr>
<td>A great deal of time</td>
<td>As much as I ever did</td>
</tr>
<tr>
<td>A lot of time</td>
<td>Rather less than I used to</td>
</tr>
<tr>
<td>From time to time, but not too often</td>
<td>Definitely less than I used to</td>
</tr>
<tr>
<td>Only occasionally</td>
<td>Hardly at all</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>I feel cheerful:</th>
<th>I get sudden feelings of panic:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not at all</td>
<td>Very often</td>
</tr>
<tr>
<td>Not often</td>
<td>Quite often</td>
</tr>
<tr>
<td>Sometime</td>
<td>Not very often</td>
</tr>
<tr>
<td>Most of the time</td>
<td>Not at all</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>I can sit at ease and feel relaxed:</th>
<th>I can enjoy a good book or radio or TV programme:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Definitely</td>
<td>Often</td>
</tr>
<tr>
<td>Usually</td>
<td>Sometimes</td>
</tr>
<tr>
<td>Not often</td>
<td>Not often</td>
</tr>
<tr>
<td>Not at all</td>
<td>Very seldom</td>
</tr>
</tbody>
</table>

A Count: 5
B Count: 7
Total: #Name?
Appendix 6

Level of Life Disruption Questionnaire
Patient
Carer
Patient Questionnaire

Patient Name
DOB
Date

PLEASE COMPLETE THIS QUESTIONNAIRE IN RELATION TO THE LAST TWO WEEKS

1. Have you encountered any problems with your health?
   NO    YES
   If yes give details_____________________________________________________

2. If relevant:
   Have you been able to return to employment?
   NO    YES
   Have you been in contact with your employer?
   NO    YES
   If yes give details_____________________________________________________

4. Have you suffered any disruption in your family life?
   NOT AT ALL   A LITTLE   QUITE A BIT   VERY MUCH

5. Have you suffered any disruption in your social life?
   NOT AT ALL   A LITTLE   QUITE A BIT   VERY MUCH

6. Have you contacted any health professionals?
   NO    YES
   If yes please indicate who you contacted_____________________________________

7. Have you felt that you have received enough details about your future treatment?
   NO    YES

8. Have you had any problems regarding travel?
   NOT AT ALL   A LITTLE   QUITE A BIT   VERY MUCH

9. If relevant:
   Have you had any problems with childcare?
   NOT AT ALL   A LITTLE   QUITE A BIT   VERY MUCH
Carer Questionnaire

Patient Name
DOB
Date

PLEASE COMPLETE THIS QUESTIONNAIRE IN RELATION TO THE LAST TWO WEEKS

1. Have you noted any problems with your relative/friend?
   NO YES
   If yes give details

2. If relevant:
   Have you been continuing to work?
   NO YES

   Have you taken any time of work?
   NO YES
   If yes give details

4. Have you had noted any disruption in your family life?
   NOT AT ALL A LITTLE QUITE A BIT VERY MUCH

5. Have you noted any disruption in your social life?
   NOT AT ALL A LITTLE QUITE A BIT VERY MUCH

6. Have you contacted any health professionals?
   NO YES
   If yes please indicate who you contacted

7. Have you felt that you have received enough details about your relative/friend future treatments?
   NO YES

8. Have you noted any problems with travelling arrangements?
   NOT AT ALL A LITTLE QUITE A BIT VERY MUCH

9. If relevant:
   Have you noted any problems with childcare?
   NOT AT ALL A LITTLE QUITE A BIT VERY MUCH
APPENDIX 7

PATIENT PROFORMA
<table>
<thead>
<tr>
<th>Patient Information</th>
<th>Dates</th>
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<tbody>
<tr>
<td>Name:</td>
<td>Date of diagnostic CT/MRI:</td>
</tr>
<tr>
<td>DOB:</td>
<td>Date of Surgery:</td>
</tr>
<tr>
<td>Address:</td>
<td>Date of Referral to Neuro Oncology</td>
</tr>
<tr>
<td>Marital Status:</td>
<td>Date of Consent:</td>
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<tr>
<td>Dependents:</td>
<td>Post Op Score:</td>
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<td>Occupation:</td>
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<th>EFIT Score</th>
<th>RNHPT</th>
<th>LNHPT</th>
<th>WDRT</th>
<th>BASRS</th>
<th>EORTC Score with Brain Supplement</th>
<th>HAD Score</th>
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<tr>
<td>At Consent</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>2 Weeks</td>
<td></td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td>Prior to Radiotherapy</td>
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<thead>
<tr>
<th>YES</th>
<th>DATE</th>
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<tr>
<th>Dexamethasone Dosage:</th>
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<tr>
<td>Gastric Upset:</td>
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<td>Hyperglycaemia:</td>
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<tr>
<td>Insomnia</td>
<td></td>
<td></td>
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<tr>
<td>Fluid Retention:</td>
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<tr>
<td>Hypertension:</td>
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<tr>
<td>Irritability</td>
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<td>Depressed immune response:</td>
<td></td>
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<td></td>
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<td>Other:</td>
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<thead>
<tr>
<th>NO</th>
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</table>

<table>
<thead>
<tr>
<th>Date of start of XRT:</th>
<th></th>
</tr>
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Appendix 8

Patient Information Leaflet
PATIENT INFORMATION SHEET

A STUDY OF PATIENTS AND THEIR FAMILIES TO EXAMINE THE PRACTICAL AND EMOTIONAL ISSUES IN THE TRANSITIONAL PERIOD FROM SURGERY TO RADIOTHERAPY

This study is being undertaken within the Western General Hospital, Edinburgh. The researchers are attempting to closely examine the effect that the transition period from surgery to radiotherapy has upon patients and their families. The study will run for 6 months and may indicate to the researchers important issues which are raised for patients and their families within the transitional period between surgery and radiotherapy.

Your participation in the study is non-therapeutic and will not alter any decisions regarding your future treatment. You will be asked to undergo an additional MRI Scan prior to commencing your radiotherapy and to complete some questionnaires in the period between your surgery and radiotherapy which will enable the researchers to examine the effect that this period has upon your quality of life, anxiety and extent of life disruption. The additional MRI Scan will require you lie flat and still for 20 mins in a cylindrical machine which will take detailed pictures of your head. You will during this scan be given some contrast which will make the pictures of your head clearer. There are some potential side effects of the MRI Scan eg claustrophobia, allergic reaction however the professionals involved in your care will ensure that you are at minimum risk of these and will prevent them as necessary. If you have any anxieties about the scan please do not hesitate to let any of the people involved in your care know.

Your participation within this study is entirely voluntary and you are under no obligation to participate. You are also free to withdraw at any time from the study without any detriment to your care. Your withdrawal can occur at any time before or after your consent is obtained for participation in the study. The information collated from you for the study will be confidential and will not be used for any other purpose. Your General Practitioner will be informed of your participation in the study but no information will be collated from him her.

If you wish any more information about this study please contact Ms Lynn Kilbride, Research Nurse, Edinburgh Centre for Neuro Oncology, Western General Hospital, Edinburgh, EH4 2XU on 0131 537 2657. Or if you wish more general information from a person independent from the study please contact Prof IR Whittle, Consultant Neurosurgeon, Dept Clinical Neurosciences, Western General Hospital, Edinburgh, EH4 2XU on 0131 537 2103.
APPENDIX 9

CONSENT FORM
CONSENT FORM

TITLE OF PROPOSED PROJECT

A Pilot Study of Malignant Glioma to Examine the Practical and Emotional Issues of the Transition Period from Surgery to Radiotherapy

NAME OF PRINCIPAL INVESTIGATOR

Lynn Kilbride, Research Nurse

ADDRESS

Centre for Neuro Oncology, Western General Hospital, Crewe Road, Edinburgh, EH4 1NW.

TELEPHONE

0131 537 2657

FURTHER INFORMATION IS AVAILABLE FROM

Prof. IR. Whittle, Professor of Neurosurgery, Western General Hospital, Edinburgh, EH4 2XU

PROCEDURES REQUIRED IN ADDITION TO STANDARD TREATMENT

MRI Scan

- I agree to participate in this study
- I have read the consent form and the information sheet and had the opportunity to ask questions
- I understand I am under no obligation to participate in this study and the decision not to participate will not alter the treatment that I the patient would normally receive.
- I understand that I have the right to withdraw from this study at any stage and that to do so will not affect my treatment
- I understand that this study is non-therapeutic research from which I will not derive any benefit

Name of Patient

Signature of Patient

Signature of Investigator

Date
APPENDIX 10

THE EORTC QUESTIONNAIRE
We are interested in some things about you and your health. Please answer all of the questions yourself by circling the number that best applies to you. There are no “right” or “wrong” answers. The information that you provide will remain strictly confidential.

Please fill in your initials: Your birth date (Day, Month, Year): Today’s date (Day, Month, Year):

Did you fill the questionnaire in yourself? Yes No (please tick box)

1. Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase? Yes 2
2. Do you have any trouble taking a long walk? Yes 2
3. Do you have any trouble taking a short walk outside of the house? Yes 2
4. Do you need to stay in bed or a chair during the day? Yes 2
5. Do you need help with eating, dressing, washing yourself or using the toilet? Yes 2

During the past week:

<table>
<thead>
<tr>
<th>Question</th>
<th>Not at All</th>
<th>A Little</th>
<th>Quite a Bit</th>
<th>Very Much</th>
</tr>
</thead>
<tbody>
<tr>
<td>6. Were you limited in doing either your work or other daily activities?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>7. Were you limited in pursuing your hobbies or other leisure time activities?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>8. Were you short of breath?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>9. Have you had pain?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>10. Did you need to rest?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>11. Have you had trouble sleeping?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>12. Have you felt weak?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>13. Have you lacked appetite?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>14. Have you felt nauseated?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>15. Have you vomited?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
During the past week:

16. Have you been constipated?  
   | Not at All | A Little | Quite a Bit | Very Much |
   | 1          | 2        | 3          | 4         |

17. Have you had diarrhoea?  
   | Not at All | A Little | Quite a Bit | Very Much |
   | 1          | 2        | 3          | 4         |

18. Were you tired?  
   | Not at All | A Little | Quite a Bit | Very Much |
   | 1          | 2        | 3          | 4         |

19. Did pain interfere with your daily activities?  
   | Not at All | A Little | Quite a Bit | Very Much |
   | 1          | 2        | 3          | 4         |

20. Have you had difficulty in concentrating on things, like reading a newspaper or watching television?  
   | Not at All | A Little | Quite a Bit | Very Much |
   | 1          | 2        | 3          | 4         |

21. Did you feel tense?  
   | Not at All | A Little | Quite a Bit | Very Much |
   | 1          | 2        | 3          | 4         |

22. Did you worry?  
   | Not at All | A Little | Quite a Bit | Very Much |
   | 1          | 2        | 3          | 4         |

23. Did you feel irritable?  
   | Not at All | A Little | Quite a Bit | Very Much |
   | 1          | 2        | 3          | 4         |

24. Did you feel depressed?  
   | Not at All | A Little | Quite a Bit | Very Much |
   | 1          | 2        | 3          | 4         |

25. Have you had difficulty remembering things?  
   | Not at All | A Little | Quite a Bit | Very Much |
   | 1          | 2        | 3          | 4         |

26. Has your physical condition or medical treatment interfered with your family life?  
   | Not at All | A Little | Quite a Bit | Very Much |
   | 1          | 2        | 3          | 4         |

27. Has your physical condition or medical treatment interfered with your social activities?  
   | Not at All | A Little |Quite a Bit | Very Much |
   | 1          | 2        | 3          | 4         |

28. Has your physical condition or medical treatment caused you financial difficulties?  
   | Not at All | A Little | Quite a Bit | Very Much |
   | 1          | 2        | 3          | 4         |

For the following questions please circle the number between 1 and 7 that best applies to you:

29. How would you rate your overall health during the past week?  
   | Not at All | A Little | Quite a Bit | Very Much |
   | 1          | 2        | 3          | 4         |

30. How would you rate your overall quality of life during the past week?  
   | Not at All | A Little | Quite a Bit | Very Much |
   | 1          | 2        | 3          | 4         |

EORTC: 71  
EORTC2: 40  
Total:  
EORCF: 100  
EORCSSI: 55  
EORCGH: 25  
EORCB20: 33  

FS-Physical functioning: 100  
FS-Role functioning(new): 33  
FS-Emotional functioning: 0  
FS-Cognitive functioning: 0  
FS-Social functioning: 67  
GH-Global Health status/Qol (new): 25  
SS/I-Fatigue: 44  
SS/I-Nausea and vomiting: 17  
SS/I-Pain: 50  
SS/I-Dyspnea: 0  
SS/I-Insomnia: 33  
SS/I-Appetite loss: 33
During the Week

<table>
<thead>
<tr>
<th>Question</th>
<th>Not at All</th>
<th>A Little</th>
<th>Quite a Bit</th>
<th>Very Much</th>
</tr>
</thead>
<tbody>
<tr>
<td>31. Did you feel uncertain about the future?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>32. Did you feel you had setbacks in your condition?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>33. Were you concerned about disruption of family life?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>34. Did you have headaches?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>35. Did your outlook on the future worsen?</td>
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During the past week:

<table>
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<tr>
<th>Question</th>
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<th>A Little</th>
<th>Quite a Bit</th>
<th>Very Much</th>
</tr>
</thead>
<tbody>
<tr>
<td>36. Did you have double vision?</td>
<td>1</td>
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</tr>
<tr>
<td>37. Was your vision blurred?</td>
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<td>4</td>
</tr>
<tr>
<td>38. Did you have difficulty reading because of your vision?</td>
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<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>39. Did you have seizures?</td>
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<td>2</td>
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<tr>
<td>40. Did you have weakness on one side of your body?</td>
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<tr>
<td>41. Did you have trouble finding the right words to express yourself?</td>
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<tr>
<td>42. Did you have difficulty speaking?</td>
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</tr>
<tr>
<td>43. Did you have trouble communicating your thoughts?</td>
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