The quality of survival of patients with malignant cerebral glioma following radiotherapy
Davies, Elizabeth

The copyright of this thesis rests with the author and no quotation from it or information derived from it may be published without the prior written consent of the author.

For additional information about this publication click this link.
http://qmro.qmul.ac.uk/jspui/handle/123456789/1664

Information about this research object was correct at the time of download; we occasionally make corrections to records, please therefore check the published record when citing. For more information contact scholarlycommunications@qmul.ac.uk
THE QUALITY OF SURVIVAL OF PATIENTS
WITH MALIGNANT CEREBRAL GLIOMA
FOLLOWING RADIOTHERAPY

PhD THESIS

Elizabeth Davies
Clinical Research Fellow
Department of Neurological Sciences
The Royal London and St Bartholomew’s Hospital
West Smithfield

July 1998
ABSTRACT

The quality of survival for patients with malignant cerebral glioma following radiotherapy

Objective - To describe survival, disability and morbidity after radiotherapy for malignant glioma and explore patient and relative experience.

Design - Home follow-up of patients and relative over up to 24 months and of relatives after bereavement.

Setting - Six London hospitals

Subjects - 92 patients receiving radiotherapy (83 recruited at diagnosis; 9 after radiotherapy) and 85 relatives. 56 bereaved relatives.

Main outcome measures - Survival, time free from disability, and changes in disability after treatment assessed, or deduced retrospectively, using interviewer observation, patient and relative reports, case note review and discussion with medical staff. A semi-structured interview designed for the study assessed awareness of the likely prognosis, distress, dissatisfaction with radiotherapy and perception of severe problems in everyday life.

Results - 6, 12 and 24 month survivals were 70%, 39% and 10%. Age, World Health Organisation clinical performance status, extent of surgery, and epilepsy each influenced survival. The Medical Research Council prognostic index was also significantly related to survival. Multivariate analysis showed that initial clinical performance status was the most important aspect of the index. Most (80%; 49/61) patients with a clinical performance status of 0, 1 or 2 lived at least 6 months before becoming permanently disabled. Of those with an initial good clinical performance status (0-2) who survived 6 months after radiotherapy 69% (36/52) experienced either clinical deterioration or severe tiredness after treatment. Severely disabled patients (clinical performance status 3 or 4) gained little benefit. 75 patients and 66 relatives were interviewed at diagnosis, 59 patients after radiotherapy and 27 after deterioration. As they began radiotherapy most patients understood that they suffered from a brain tumour (95%; 71/75), but only one quarter (19/75) seemed fully aware of the poor prognosis. Others were unaware (43%; 32/75) or only partly aware (32%; 24/75). The more aware patients were more distressed. Relatives were three times more likely to be aware of the prognosis (67%; 44/66) and were more distressed. Although 39% (29/75) of patients initially made negative comments about radiotherapy, only 17% (13/75) were completely dissatisfied. The decision to accept radiotherapy could be discussed directly with 19 fully aware patients. Twelve found radiotherapy acceptable if it were medically advised or if it improved survival. Assessed by their own reports of symptoms only 40% of patients improved or achieved a period of stability, yet dissatisfaction with treatment did not increase. Bereaved relatives' judgements about quality of life and the value of radiotherapy were strongly related to the patient's initial disability and distress. Short periods of survival between six and 12 months were felt worthwhile.

Conclusions - Severely disabled patients gain little benefit from radiotherapy and those not so disabled may experience considerable adverse effects. The lack of awareness of the prognosis, however, makes it difficult to explore with patients directly the possible trade off between quality and length of life. Relatives were more aware, more distressed and often concerned to protect patients from full awareness. However most aware patients accepted radiotherapy for the chance of improved survival and bereaved relatives valued relatively small periods of survival free from disability and distress. Conceptualising these questions as rational choices ignores therefore the social and emotional context of life threatening disease.
ACKNOWLEDGEMENTS

Charles Clarke and Anthony Hopkins employed me in the Department of Neurological Sciences in the former St Bartholomew's Hospital to work on the project on which this thesis is based. It was their original belief that both sociological and medical perspectives were necessary to study this situation. I am very sad that Anthony Hopkins died suddenly shortly after some of the papers based on this thesis were published. I will greatly miss his support and the clear-sightedness he brought to our many discussions about this work.

I am grateful to the consultants in Neurosurgery, Neurology and Radiotherapy at Charing Cross Hospital, the National Hospital for Neurology and Neurosurgery, Oldchurch Hospital, the Royal London Hospital, the Royal Free Hospital, St Bartholomew's Hospital, and University College Hospital who allowed me to study their patients. In particular Dr N Godlee and Dr PN Plowman explained radiotherapy techniques to me and gave me advice on the field sizes I should consider in relation to side-effects.

Maureen Bannon and Sue Hall were employed to help with data collection, and, as well as increasing the number of patients who could be seen, gave their enthusiasm and insight to the project.

Rachel Warrick and Valerie Pottinger transcribed most of the interviews with patients and relatives, whilst Laurence Letchford helped with the computer. Sally Stenning gave her time generously in checking the statistical analysis of survival and time free from disability.

Professor Sheila Hillier kept up her support throughout the project. Her comments and advice have been most welcome. I am grateful to my husband George W Brown for his advice on research methods and for all the other ways in which he has helped me find the time to finish this work. I also thank the examiners for their careful reading of this thesis.

My special thanks, however, are to the patients and relatives who agreed to be interviewed at such a difficult time, and who generally gave their help in the spirit that others might eventually benefit. All but a handful of the patients have now died. I hope therefore that the thesis does them justice.

This research was supported by the Cancer Research Campaign (Grant No CP/1017). I extend my gratitude to one relative whom I met whilst conducting this research who gave a generous donation to support me for a final period of concentrated work on the thesis.
CONTENTS

Abstract

Acknowledgements

1. The treatment of malignant cerebral glioma
   Introduction 1
   The incidence, aetiology and presentation of malignant cerebral glioma 1
   Table 1 - Classification schemes for the grading of gliomas 4
   Presentation and investigation 6
   Prognosis 8
   Figure 1 - The MRC Prognostic Index 10
   Approaches to treatment 11
   Surgery 12
   Radiotherapy 14
   Chemotherapy 22
   Methods of assessing patient function and "quality of life" 23
   Figure 2 - The Karnofsky Performance scale 24
   Figure 3 - The WHO Clinical Performance Status 28
   Summary 29

2. Debates about quality versus length of life
   Introduction 30
   Debates about the management of malignant cerebral glioma 30
   The wider context to debates about quality of life in medicine 37
   Formulations of the potential trade off between quality and length of life 40
   Figure 4 - Components of the Rosser Index of Quality of Life 42
   Studies of patient preferences for cancer treatments 47
   Psychological studies of how cancer patients cope with their disease 48
   Studies of doctor-patient communication 50
   The aims of this study of quality of life in malignant cerebral glioma 51

3. Survival, disability and morbidity following radiotherapy
   Introduction 54
   The recruitment of hospitals to the study 54
   The recruitment of patients and their relatives 55
   Table 2 - The recruitment of patients treated with radiotherapy from each site 55
   Initial patient assessments or interviews for the study 55
   Explaining the research to the patients and relatives approached for the study 56
   Figure 5 - Follow up of the patient cohort who received radiotherapy and definition of best follow up interview 58
   Initial interviews with relatives 59
   Follow up of patients and relatives 59
   Figure 6 - Follow up of patients' relatives during the illness 60
   Bereavement interviews with relatives 61
   The assessment of tumour grade 62
   Measurement of disability 63
Figure 7 - The assessment of disability, WHO Clinical Performance Status and score on the MRC Prognostic Index

Table 3 - Comparison of 83 ratings on the WHO Clinical Performance Status by clinicians and interviewers

Using the Barthel score to decide on the clinical performance status

Deducing the initial clinical performance status using retrospective reports

Definition of survival free from disability

The assessment of morbidity due to radiotherapy

Field sizes and radiotherapy doses

Statistical methods

Characteristics of patients and treatment

Table 4 - Characteristics of patients and tumours for those receiving radiotherapy or steroids alone

The relationship of the MRC prognostic index to survival

Table 5 - Prognostic factors and survival for patients receiving radiotherapy

Figure 8 - Survival for patients receiving radiotherapy or steroids alone

Figure 9 - Survival for patients receiving radiotherapy by initial score on the MRC prognostic index

The period of survival patients achieved free from disability

Figure 10 - Survival free from disability by initial WHO performance status

Figure 11 - Survival free from disability by initial score on the MRC prognostic index

Morbidity associated with radiotherapy

Table 6 - Brain dose, tumour dose and subsequent deterioration

Table 7 - Logistic regression analysis

Discussion

4. Approaches to studying quality of life in malignant glioma

Introduction

Previous studies of patients with cerebral glioma

Neuropsychological and neuropsychiatric studies

Questionnaire studies of patients with malignant cerebral glioma

Interview studies of patients with cerebral glioma

Sociological studies exploring the management of neurological and terminal disease

Potential problems of studying a life-threatening situation

Deciding on the methodological approach

Semi-structured interviews

Conclusions

5. Developing the interview and identifying themes for analysis

Introduction

Stage I - Identifying research themes from the pilot interviews

Stage II - The development of rating scales and a semi-structured interview schedule

Stage III - Managing data collection by three interviews - reliability

Table 8 - Inter-rater reliability study for 13 interviews

Table 9 - Scales where inter-rater reliability failed

Threats to the validity of semi-structured interviews and ratings scales

6. Patient and relative perspectives on the value of radiotherapy during the illness

Introduction

Demographic characteristics of patients and relatives

Table 10 - Demographic characteristics of patients and relatives

Awareness of the prognosis

Table 11 - Awareness of the likely prognosis and steroid dose at interview
Table 12 - Comparing patient and relative awareness of the prognosis shortly after the diagnosis 140
Distress experienced by patients and their relatives 140
Table 13 - Patient awareness of the likely prognosis and distress 142
Views about radiotherapy 143
Patient improvement, deterioration and subsequent dissatisfaction with radiotherapy 145
Table 14 - Initial disability, perception of disability and proportion of patients receiving a remission 147
Summary 148

7. The views of bereaved relatives about quality of life and the value of radiotherapy 150
Introduction 150
What new information might be gained from bereaved relatives? 150
Previous research on the views of bereaved relatives about medical care 151
The recruitment of bereaved relatives 153
Data collection at bereavement interviews 154
Do judgements about quality of life relate to the course of the illness? 159
Table 15 - The initial state of the patient and the views of bereaved relatives about quality of life and the value of radiotherapy 160
Table 16 - Aspects of the illness trajectory and the views of bereaved relatives about quality of life and the value of radiotherapy 161
Table 17 - The views of bereaved relatives about the quality of life and satisfaction with radiotherapy 162
Summary 163

8. Discussion and Implications for future practice and research 164
Introduction 164
Summary of the main findings 164
Shortcomings of this study 168
Study design 168
Potential biases in the selection of patients into the study 169
Problems with the assessment of morbidity 172
External validity of the results for morbidity 175
The rigour of the interview method and rating scales 176
Problems with assessing patients' awareness of the likely prognosis 178
The validity of giving weight to the views of bereaved relatives 180
Implications of the research findings for clinical practice 182
Deciding which patients might benefit from radiotherapy 182
Assessing and limiting morbidity from radiotherapy 183
Communication with patients and their relatives 184
Implications for future research 187
The possible relevance of the results to health policy 172

REFERENCES 190

APPENDIX (Bound separately)
Work based on this thesis already published


CHAPTER 1

THE TREATMENT OF MALIGNANT CEREBRAL GLIOMA

Introduction

In this first chapter I briefly describe the incidence, aetiology, classification and presentation of malignant cerebral glioma and discuss their investigation and prognosis in more detail. I then review studies of surgery, radiotherapy and chemotherapy treatment considering their design, the assessment of disability, morbidity due to treatment and analysis in terms of established prognostic variables. I conclude that although there is evidence that radiotherapy prolongs survival there is a surprising lack of data on either the palliation of symptoms or the morbidity due to treatment. These shortcomings and the overall short period of survival achieved have led some clinicians to doubt the value of treatment. These doubts have led to some debates about the quality versus length of life and the value of prolonging life which are considered in chapter 2.

The Incidence, aetiology and presentation of malignant cerebral glioma

Incidence

Cerebral gliomas are uncommon tumours which occur with an incidence of 4-6 per 100,000 individuals per year in the UK (Goldberg & Kurland, 1962, Barker et al, 1976, Grant et al,

1 Perhaps unusually for a PhD thesis I have chosen to write in the active personal tense. I have wished to make clear points at which I decided how the study should go. Sometimes the passive tense can obscure these points and denote a spurious sense of objectivity. I hope that the active tense is also easier to read.
1996a). Although malignant cerebral gliomas are the most common form of malignant brain tumour they do not possess a high public profile. This may be due to the absence of a screening test, an unclear aetiology, a short survival period, and the low prevalence of affected individuals within the general population. Grant and colleagues (1996a) further suggest that researchers within cancer medicine may have neglected the study of this disease.

Aetiology

Malignant gliomas arise from the supporting astrocytic cells within the brain, rather than from neuronal tissue. Their aetiology is unclear. Epidemiological studies show that gliomas are more common in caucasians than in black individuals and in males rather than females (Rosenfeld & Massey, 1991). They are more common with increasing age; the peak incidence occurring in the mid 50s age group (Rosenfeld & Massey, 1991), and therefore represent a significant cause of cancer amongst the working population (Grant et al, 1996a). Glioma are also more common amongst those working in the electronics-related professions including electricians and electrical engineers. Other professions associated with an increased risk of gliomas include anatomists, dentists and physicians (McLaughlin et al,1987). The highest risk, however, seems to be amongst those workers with the greatest probability of exposure to electromagnetic fields (Lin et al,1985), and this seems particularly so in relation to astrocytic tumours (Mack et al,1991). Farm workers are more likely to develop gliomas leading to the suggestion that organic pesticides may play a role in aetiology (Musicco et al, 1982). Another link has been made with radiation. Adults treated 20 or 30 years ago with low doses of radiation for fungal scalp infections as children have a higher incidence of brain tumours (Ron et al, 1988). All these associations have been replicated by case-controlled studies but the aetiological process is not understood in a manner indicating a preventative
strategy. Other established carcinogenic agents such as tobacco and alcohol do not appear to be significantly associated. Family studies show clusters of gliomas occurring in some families and genetic studies now suggest that the expression of the protein p53 is associated with malignant transformation (Iuzzolini et al, 1994). However, again, this finding does not yet point clearly to any preventative avenue.

**Histological classification**

The classification of cerebral gliomas is complex and a number of different schemes have been used which can make it difficult to compare the results of different studies. In general cerebral gliomas are classified for grade of malignancy according to the abnormal features shown by astrocytes and surrounding blood vessels when a specimen of the tumour is examined at microscopy. The features noted include pleomorphism, the number of mitoses, the degree of differentiation, endothelial proliferation and necrosis. Most usually the diagnosis is made on a biopsy specimen although it can be made later at post-mortem. Three schemes for classification are described in table 1. The original grading system was developed by Kernohan and Sayre (1952). Their scheme divided tumours into four categories depending on the presence of specific features with the more malignant features being assigned to the higher grades. However, the prognosis for tumours of grades III and IV did not differ and the usefulness of the distinction was questioned. By comparison the descriptive terms *anaplastic astrocytoma* and *glioblastoma multiforme* employed by the Brain Tumour Study Group (BTSG) (see table 1) distinguish tumours with differing prognoses; the difference being the presence of necrosis in glioblastoma multiforme.
Table 1 - Classification schemes for the grading of gliomas

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Grade I</td>
<td>Grades 1&amp;2</td>
<td>Astrocytoma</td>
</tr>
<tr>
<td>Grades II &amp; III</td>
<td>Grade 3</td>
<td>Anaplastic astrocytoma</td>
</tr>
<tr>
<td>Grades III &amp; IV</td>
<td>Grade 4</td>
<td>Glioblastoma multiforme</td>
</tr>
</tbody>
</table>

The World Health Organisation (WHO) scheme was subsequently developed, proposing three categories and giving specific criteria for each category according to the degree of malignant change. The categories are astrocytoma, anaplastic astrocytoma and glioblastoma; astrocytoma being equivalent to Kernohan grades I and II and glioblastoma to grades III and IV (Zulch, 1979). Yet another scheme attempting to simplify matters further is the Daumas-Duport Scheme (Daumas-Duport et al, 1988). This considers the same histological features of pleomorphism, mitoses, endothelial proliferation and necrosis, but does not assign more importance to any one feature. Instead any two features classify a tumour as grade 3, but three or four features constitute a grade 4 tumour.

With all these schemes it is recognised that the accuracy of diagnosis depends on the adequacy of the sample obtained at biopsy, the site in the tumour from which the biopsy is taken and the skill of the histopathologist making the diagnosis. For example, when panels of pathologists have been set up to verify the diagnoses for patients entered into large trials of treatment, significant disagreement between different neuropathologists has been disclosed.

In one study conducted by the British Medical Research Council (MRC Brain Tumour...
Working Party, 1990) one of the three neuropathologists in the panel disagreed 50% of the time with the other two. A consensus view was therefore taken for each diagnosis. In 5% of cases the panel disagreed with the neuropathologist at the collaborating centre which had entered the patient to the trial about whether the tumour was a glioma. In a further 5% of cases the three neuropathologists disagreed amongst themselves. Added to this variability in reporting of the tumour, a glioma may itself vary considerably in the degree of malignancy shown by different regions of the tumour. A sample taken by chance from a less malignant region could therefore lead to the tumour being misclassified as of a lower grade.

Different studies of patient outcome have tended to use different histological schemes and this can make comparisons of outcome difficult. For example, the American Brain Tumour Study Group which undertook the original and important trials of treatment, (Walker et al, 1978, Green et al, 1983) employed the descriptive terms (see table 1), whereas up until recently both the descriptive terms and the WHO scheme have been used in the UK. It is therefore often not feasible to compare the frequencies of different grades of tumours from study to study (Rosenfeld & Massey, 1991). For example, Revesz et al (1993) examined 419 stereotactic biopsy results from patients managed at the National Hospital, Queen Square between 1981 and 1989. Of the 160 confirmed supratentorial gliomas, one third were low grade, 36% were anaplastic astrocytomas (grade 3) and 31% were glioblastoma multiforme (grade 4) when classified according to the Kernohan system. When tumours were regraded using the Daumas-Duport criteria there was a considerable shift towards more malignant grading so that 24% were classified as low grade, 26% as grade 3 and 50% as grade 4. The authors found that both grading systems were highly correlated with survival. For the Kernohan system mean survivals for patients with low grade, grade 3 and grade 4 tumours
were 25.1, 9.9 and 7.4 months respectively (median survivals are not reported). The Daumas-Duport scheme, however, distinguished more clearly between grade 3 and 4 tumours. Using this scheme the mean survivals for patients with low grade, grade 3 and grade 4 tumours were 27.9 months, 14.8 months and 7 months respectively. The Daumas-Duport scheme may therefore be more useful in identifying a group of patients with grade 3 tumours who have a better prognosis (Resevz et al 1993). To date, however, most major studies have not used this classification.

Presentation and investigation

McKernan and Thomas (1980) reviewed the course of 653 patients with cerebral glioma treated between 1955 and 1975 at the National Hospital Queen Square. They found cerebral gliomas most commonly presented with epilepsy (38%), headache (35%), mental change (17%), and hemiparesis (10%). By the time patients reached assessment centres the frequency of these symptoms had increased; mental change was reported in 52% and epilepsy in 54% at diagnosis (McKeran & Thomas, 1980). The diagnosis is usually made by imaging studies - either computerised tomography scanning (CT scan) or magnetic resonance imaging (MR imaging) followed by biopsy or surgery. Although there has been some question about whether surgery is necessary once the diagnosis is strongly suggested by imaging, it is now generally recognised that imaging on its own will misdiagnose a significant amount of other intracranial pathology. Studies which have compared CT scan diagnosis with that shown by histology after surgery find that histological examination of lesions suggestive of gliomas reveals an infective, lymphomatous or metastatic cause between 5 and 13% of the time (Kendall et al, 1979, Todd et al, 1987, Choksey et al, 1989). There is also no correlation between the size of the tumour on CT scan and the prognosis (Reeves & Marks, 1979). The
same question posed in relation to MR imaging showed misdiagnoses 20% of the time (Christy et al, 1995). The risk of relying on imaging to achieve diagnosis is therefore that the patient could be treated inappropriately and, most seriously, that curable pathology such as infection could be left untreated (Porter & Thomas, 1997a). In addition without histological confirmation of the diagnosis valid comparison of outcomes following different treatment is not possible (Porter & Thomas, 1997a).

Until fairly recently one concern about the need for biopsy has been the potential harm caused by an open brain biopsy. The development of image-directed stereotactic surgery has now made the biopsy procedure much safer (Apuzzo et al, 1987, Thomas and Nouby, 1989). Under CT scan guidance, a fine needle is inserted into the tumour and a histological diagnosis can be obtained in up to 94% of cases (Revesz et al, 1993). Cook and Gutherie (1994) recently showed that the morbidity and mortality of the procedure varied with the area of the brain biopsied, but overall they found a complication rate of 6.5% with permanent problems remaining for the patient in 2.7% of cases. It is now generally recognised that in experienced hands the risk of biopsy is low for tumours in most parts of the brain (Porter & Thomas, 1997a). However, there is still debate about whether tumours of the brain stem or basal ganglia should be treated with radiotherapy without confirmation by biopsy because of the high risk of morbidity associated with surgery to these areas of the brain. In this respect Thomas et al (1988) have shown that CT and MRI directed biopsies via a transfrontal approach have produced a high rate of pathological diagnoses at the cost of relatively low morbidity and mortality. Such techniques, however, are best carried out only in specialist centres (Porter & Thomas, 1997a).
Prognosis

Malignant cerebral glioma are aggressive tumours and even after intensive modern treatment the prognosis for patients is poor. A large randomised trial conducted by the North American Brain Tumour Study Group (BTSG) was the first to show that the median survival after surgery for patients on steroids alone was only 14 weeks compared to 36 weeks after radiotherapy (Walker et al, 1978). A subsequent trial, which compared different radiotherapy regimes after surgery with radiotherapy and chemotherapy, showed that higher doses of radiotherapy improved survival (Green et al, 1983). Other groups have shown a survival following radiotherapy of around ten months (Kristiansen, 1981, Chang et al, 1983, Bleehan & Stenning, 1991). Chemotherapy increases the percentage of long-term survivors at 18 months, but despite the most intensive treatment few patients survive for long periods of time and the two year survival remains 5-10% (Walker et al, 1978, Green et al, 1983). The difficulties of influencing survival in this disease was considered by Salcman (1980) who showed that the exponential shape of the survival curve, particularly that for glioblastoma multiforme, resembles that of a disseminated slowly growing tumour. This would explain the observation that treatments succeed in pushing the survival curve to the right, so increasing the median survival without having a major impact on the proportion of long term survivors or achieving a cure. As already discussed the prognosis for patients presenting with the less malignant low grade gliomas is relatively good. A retrospective study using the Kernohan grading system reports the 5-year survival as more than 50% (North et al, 1989).

Although overall the prognosis is poor, some variability in survival does exist. After multivariate analysis this variation can be related to a number of factors which include the patient's initial performance status, their age and the grade of the tumour (Walker et al,
1980, Chang et al, 1983, Burger & Green 1987). Young patients with little disability who present with epilepsy and tumours showing less malignancy do best. The MRC Brain Tumour Working Party have recently developed a prognostic index incorporating some of these factors (MRC Brain Tumour Working Party, 1990). The prognostic index was developed with data on 417 patients, all of whom received radiotherapy within a randomised trial (MRC Brain Tumour Working Party, 1983). It has since been tested on an independent dataset comprising 443 patients entered into a subsequent MRC trial (Bleehan & Stenning, 1991). The index is based on four factors (age at diagnosis, WHO performance status before radiotherapy, history of seizures before diagnosis, and extent of neurosurgery) each within three categories. A score is attached to each category (see figure 1), and a patient’s index score is obtained by summing the scores for each of the four factors. A low score indicates a better prognosis.
Figure 1 - The MRC prognostic index

<table>
<thead>
<tr>
<th>Category</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years):</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>0</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

For example, in the first study of 417 patients, 41 (10%) fell into the best of the six prognostic groups defined by the index (scores 0-10). The median survival of this group was 53 weeks and 32% survived two years from the diagnosis. The second group (with scores of 11 to 15) fared almost as well and had a median survival of 51 weeks and a 2-year survival of 11%. Together these top two groups comprised 20% of all patients within the trial. By contrast patients within the bottom two prognostic groups (40% of the total) with scores of between 26 and 38 did poorly. The median survival for these groups was 16 or 23 weeks and the 2-year survival was only 1 or 2%. The middle two groups, comprising the
remaining 40% patients (scores of 16 to 55), had an intermediate outcome. The median survival for patients in these groups was 35 or 41 weeks respectively and only 4 and 7% survived to two years. When the prognostic index was tested on a second group of 443 patients within a further MRC trial the findings were broadly similar. However there were slightly more patients (30%) in the top two groups with scores of 0 to 15 and they also did slightly better than patients in the first trial. The median survivals were 80 or 76 weeks and two-year survivals 39% or 33%. No patient in the two groups with the lowest prognostic scores survived to two years (MRC Brain Tumour Working Party, 1990). These findings suggest that the index would be useful clinically in deciding which patients would benefit from treatment, although the index has not yet been tested in patients treated outside of clinical trials.

Hutton and colleagues (1992) have independently derived another prognostic index from a retrospective series of 560 patients. Their index, which incorporates the features of age, presentation with epilepsy, focal neurological signs, mental signs and CT scan features, appears to distinguish two groups with either good or poor outcomes. It has yet to be tested on another patient sample in a prospective fashion.

**Approaches to treatment**

I now review in turn the treatment options for patients, considering the kinds of studies that have been conducted and how palliation and morbidity due to treatment have been evaluated.
Surgery

Although patients entered into the initial radiotherapy trials of the American BTSG had mostly undergone extensive surgery rather than simple biopsy, there remains some debate as to whether surgery in itself adds significantly to survival. All studies of survival after surgery have been retrospective and have covered a number of years over which practice has changed considerably. For example, Jelmsa & Bucy (1967) reported 162 cases of glioblastoma multiforme treated between 1945 and 1964. They showed that post-operative mortality decreased from an initial 48% during this period to only 3% amongst the 35 cases treated once steroids had become available to control cerebral oedema. Most of these patients (58%, 92/162) underwent extensive resections and, comparing these to a much smaller group of 19 patients who had only partial resection, the authors describe a lower postoperative mortality, better post-operative function and longer survival after extensive surgery. It must be questioned whether these conclusions can be deduced from the small numbers not treated by surgery. None of their patients were classed as receiving biopsy alone and other prognostic factors were not considered. Weir (1973) later reviewed a sample of 248 patients treated between 1960-70. Twenty-eight percent of those treated with extensive surgery were alive at one year compared to 18% receiving partial excision and 12% biopsy. However, once other prognostic factors had been controlled for the apparent survival advantage due to surgery disappeared. The problem here is that patients selected for debulking surgery tend to be those who already possess good prognostic factors such as younger age, and good performance status (Punt, 1984, Nazaroo & Neuwelt, 1990, Quigley & Maroon, 1991). Subsequent prospective studies include those where patients have received some kind of surgery and radiotherapy but have been randomised to different chemotherapy regimes. These studies reach different conclusions over whether extensive surgery is an independent
prognostic factor for survival. A study by the European Organisation for Research and Treatment of Cancer (EORTC, 1981) found surgery did not have prognostic significance whereas the MRC Brain Tumour Working Party (1990) found that surgery was important and included this factor within the prognostic index already described. Given this uncertainty the possibility of mounting a trial in which all patients receive radiotherapy but are randomised between attempted maximal excision or biopsy was suggested more than ten years ago (Punt, 1984, Garfield, 1986). Such a study has not yet been attempted. A recent working group restated the possibility of such a trial where surgeons might randomise patients about whose management they were uncertain (Davies & Hopkins, 1997). At present, however, the survival benefit of resection cannot be ruled out (Porter & Thomas, 1997b). Garfield (1986) has made the interesting suggestion that whilst surgery may not in itself add appreciably to survival, it may, by removing dead tissue and decreasing intracranial pressure, put the patient in a better position to tolerate radiotherapy, and it is this latter treatment which has the greater influence on survival.

While it is therefore unclear whether surgery directly affects survival, it may have a palliative role. The removal of dead tissue can relieve distressing symptoms of raised intracranial pressure, and seems to lead to a functional improvement so possibly temporarily improving quality of life for the patient (Garfield, 1986). Against this positive effect, however, has to be considered the possible risk associated with extensive surgery compared to the more simple biopsy procedure. The mortality associated with surgery is low at about 3% (Jelmsa & Bucy, 1967) but significant morbidity by way of disability has been reported in 8 to 20% of patients (Fadul et al, 1988 Mahaley et al, 1989, Vecht et al, 1990). This compares to a persistent morbidity of less than 5% following stereotactic biopsy (Thomas &
A further problem has been of distinguishing the benefits of partial resection from a complete resection of the tumour. It is now clear that only early post-operative imaging (48-72hrs) can determine the extent of tumour resection, and frequently this does not tally with the surgeon's report (Garfield, 1986, Quigley & Maroon, 1991). Any future trial of surgical treatment would need to include post-operative imaging to measure the extent of tumour resection and compare this with outcomes such as survival, performance status and time to recurrence whilst taking into account different prognostic factors. If such a trial were not feasible it might still be possible to mount an observational study comparing surgical practice at different centres.

Radiotherapy

Trials of radiotherapy

The evidence that radiotherapy prolongs survival, unlike that for surgery, is derived from prospective randomised trials. As already mentioned large trials of radiotherapy were conducted in the United States by the BTSG in the 1970s. Although these trials are seen by some as providing indisputable support for treatment (see for example, Gregor & Cull 1996, Brada et al, 1997) some questions do remain. Large numbers of patients are required to demonstrate the efficacy of treatment, and one problem is that the very size of such studies make it difficult to co-ordinate the collection of accurate data on disability, morbidity and most importantly, on quality of life. Thus although survival does appear to be prolonged, the applicability of these findings to all patients groups can still be questioned.

Two randomised trials have included a group of patients managed conservatively after surgery and compared their outcome to patients treated with radiotherapy. The first of these
trials carried out by the BTSG included 222 patients randomised after surgery to either conservative treatment, chemotherapy alone, radiotherapy alone or radiotherapy and chemotherapy. Criteria for the study were a definite surgical resection, controlled use of steroids and a minimum life expectancy of two months. The median survival for patients was prolonged from 14 weeks with steroids alone to 36 weeks following six weeks of radiotherapy (Walker et al., 1978). Only 3% of patients receiving steroids survived to one year compared to 24% of those receiving radiotherapy. Patients were assessed every month using the Karnofsky performance scale. Those who had better performance status had a significantly better survival of 33 weeks compared to 25 weeks for those with a lower rating of 80-50. Those with very low scores of 40 or less had a poor median survival of 13 weeks. The authors suggest that the performance status might have considerable influence on survival although they do not show whether was evenly distributed between the groups. Furthermore the study does not report time free from disability nor does it supply any information on the palliation of symptoms or the morbidity associated with treatment. It must also be considered how representative the patients within the trial are of everyday practice and therefore, how generalisable the results are to UK practice. However, of the 303 patients entered, only 222 could be accepted into the trial because of protocol violations (incorrect histology or excessive use of steroids). The age range in this sample was very wide between 6 and 79 years, and it could be argued that data on children should have been analysed separately.

The second randomised trial was conducted by the Scandinavian Glioblastoma Study Group and found similar results when steroids and radiotherapy were compared (Kristiansen et al., 1981). In this study 118 patients were randomised to either conservative management, 

2 This scale is described in more detail on page 24.
radiotherapy or radiotherapy and chemotherapy (bleomycin). The median survival was 5.2 months amongst those treated by surgery compared to 10.8 months in the two radiotherapy groups. The age range of patients included in this study was more restricted (age 20-69), but again, patients had to have undergone a large tumour resection before they could be entered to the trial. In this study the authors report 66-75% of patients in all groups being able to take care of themselves at least for some portion of their post-operative survival. Overall this percentage was not that much higher amongst the irradiated groups but patients not receiving radiotherapy deteriorated more rapidly than the other two groups. There is no report of morbidity due to treatment; in fact all patients who had adverse effects interrupting treatment for 14 days or more were excluded from the trial.

Once the statistical significance of the survival benefit of radiotherapy had been established, further efforts were made to establish the effect of increasing dose of radiation. Retrospective analysis of the results for the BSTG trials showed that survival was longest after 60Gy of radiation (Walker et al, 1979). A prospective trial conducted later in the UK compared two doses of radiotherapy (45 and 60Gy) (Bleehen & Stenning, 1991). 443 patients aged 18 to 70 were included; 119 received 45 Gy and 299 60Gy. The study found that the increase between 45 and 60Gy corresponded to a 3 month increase in the median survival from 9 to 12 months and a 2 month increase in the time at which the patient began to deteriorate (Bleehen & Stenning, 1991).

One problem which has still to be addressed is the external validity of the results of these trials. It seems likely that the patients selected into trials are those who initially have a better prognosis. For example, as already discussed earlier in this chapter, patients who are selected
to have extensive surgery may tend to possess better prognostic factors, yet the requirement for entry to both these trials was to have had definitive surgery. In addition the age range in the largest trial was very wide including both child and adult tumours. The application of these findings to patients of all ages may not be appropriate. This is probably reflected in the questions that remain about the best management for patients aged over 60 who generally have a worse prognosis. A retrospective review of 80 patients aged over 60 treated at one centre in Scotland showed little relationship between the patient’s clinical state and their management (Whittle et al, 1991). Nine percent of the cohort survived to one year, yet survival at this point was not clearly related to any specific treatment. These authors concluded that prospective studies of different management regimes in elderly patients were needed to help resolve this uncertainty. The MRC Brain Tumour Working Group is now mounting a trial of best conventional care versus palliative radiotherapy amongst patients with poor prognoses to answer this question (Gregor & Cull, 1996).

Mode of administration

The large prospective trials of radiotherapy have mostly included patients who received whole brain radiotherapy followed by a boost to the tumour (Walker, 1978, Kristiansen, 1981, Bleehen & Stenning, 1991). Hochberg and Pruitt (1980) first questioned whether it was necessary to treat the whole brain when they pointed out that more than 80% of tumours appeared to recur within a 2cm of the initial tumour rather than in distant parts of the brain. There has since been a move away from whole brain irradiation towards the use of target volumes to cover the tumour as shown by imaging with an additional 2-3cm margin (Gregor, 1997). Treatment is usually administered in two phases - a first phase(I) of about 40Gy to the larger volume, and a second phase(II) of 20Gy which is administered as a boost to the
smaller tumour volume. Radiotherapy is also usually given in fractions of 2Gy and may be administered using opposed lateral or unilateral fields. The Radiation Therapy Oncology Group (RTOG) are now investigating the delivery of twice daily fractions of 1.2Gy up to a total dose of 72Gy (Nelson et al, 1990). Other techniques such as acceleration mean that treatment can be given more frequently than once a day. The technique does not show a survival advantage although it may be beneficial that treatment can be completed in a shorter space of time (Brada et al, 1995). Hypofractionation, where a few large fractions are administered to patients with a poor prognosis, can also decrease the time used up by treatment (Thomas et al, 1994). This method is currently being evaluated as part of a randomised trial mounted by the MRC Brain Tumour Working Party. The most modern technique is to give focal irradiation by external stereotactic radiotherapy (Brada, 1989). Other techniques such as interstitial radioactive implants have been used after recurrence. Here the regression of a recurrent tumour was reported in 18 of 34 cases (Gutin et al, 1984). Another larger study of 95 patients with recurrent tumours showed a further median survival of 81 weeks for patients with anaplastic astrocytoma and 54 weeks for patients with glioblastoma multiforme (Leibel et al, 1989). These patients are likely to be a highly selected group who had an initial good prognosis and remained in a good physical state even at recurrence. Furthermore 35% had to have further surgery to remove dead tissue after radiotherapy and this surgery may itself have contributed to improved survival (Brada 1989). It is therefore not yet clear how applicable these treatments are for the majority of patients with this disease.

Adverse effects of radiotherapy

The adverse effects of radiotherapy are classified as acute, early delayed, and late effects.
Acute effects include an encephalopathy presenting with headache, nausea and vomiting, fever, sleepiness and sometimes worsening of neurological signs. This encephalopathy is thought to be due to oedema caused by changes in the blood brain barrier due to irradiation. The symptoms and signs respond to steroids and it is not related to prognosis (Sheline et al, 1980). Early delayed effects present with lethargy, headache, nausea and vomiting or deterioration in clinical state a few weeks to a few months after treatment (Sheline et al, 1980). The syndrome is probably due to demyelination although this is unclear, and it is indistinguishable from tumour recurrence either clinically or by imaging (Graeb et al, 1982, Gregor 1997). Since this syndrome also responds to steroids, it is important that patients deteriorating after treatment should be followed up to distinguish those whose temporary deterioration does not indicate recurrence of the tumour. Potentially the most devastating morbidity following irradiation, however, are the late delayed effects. Patients experiencing this late morbidity present with worsening dementia, spasticity and seizures. Imaging studies show extensive white matter changes with periventricular hypodensity and extensive demyelinisation (Valk & Dillon, 1991). Patients may show serious neuropsychological deficits, and the severity of these appears to be related to the total dose of radiation, the volume of the brain irradiated and the size of the fractions employed (Gregor & Cull, 1996). For example, Hochberg and Slotnick (1980) described 13 patients who had survived several years after treatment with radiotherapy and chemotherapy. Despite no evidence of tumour recurrence, these patients had failed to attain their previous occupational function and neuropsychological testing showed that they possessed generalised problems with a range of cognitive skills rather than the specific problems that localised damage from the tumour might have caused. These authors suggested the possibility that radiation damage may have been the cause of a generalised cognitive decline. Subsequently Lieberman and colleagues
(1982) followed eight patients for two years and found a deterioration in cognitive ability occurring at about 11 months from the diagnosis. In another study Maire et al (1987) followed 49 patients after surgery and radiotherapy and confirmed that new learning skills deteriorated over time. Awaad et al (1990) described six patients with high grade glioma who survived five years from their diagnosis, and again found more cognitive problems than could be explained by focal tumour damage. This again suggested that radiotherapy may have been the cause. A later study, using single photon emission CT (SPECT) studies, confirmed widespread damage and showed that deficits on neuropsychological tests of frontal lobe function were associated with decreased tracer uptake (Ebmeier et al, 1994). The cognitive deficits revealed by neuropsychological testing could also be related to the time from treatment and to the volume of brain irradiated (Gregor et al, 1996). In a review of 29 studies, Crossen et al (1994) found evidence that the late delayed effects of radiotherapy were worse amongst older patients and when larger doses and fractions of irradiation were given. Twenty eight percent (213/748) of patients who had undergone total cranial irradiation and 27% (100/368) of patients who had undergone prophylactic irradiation showed evidence of encephalopathy that could be attributed to radiotherapy. These authors concluded that the true incidence of treatment-related adverse effects in adults surviving more than six months without recurrence may have been significantly underestimated. They proposed that in future more formal prospective evaluation of neuropsychological status should be carried out (Crossen et al, 1994). A further severe late delayed effect of radiotherapy is local necrosis and this is clearly related to the size of the fractions in which the radiation is administered (Sheline et al, 1980). All these side-effects of radiotherapy are more likely if the permeability and vasculature of the surrounding brain has already been altered by, for example, pre-existing cerebral oedema or another neurological condition. The prior administration of
chemotherapy can also potentiate the adverse effects of radiation (DeAngelis et al, 1991).

Although reviews of radiotherapy treatment recognise the acute and early delayed morbidity due to treatment they have generally concentrated on the late delayed effects which are regarded the more serious and irreversible effects of treatment. Because they are transient acute and early delayed effects are considered of less importance. Treatment trials have tended to report only the most severe reactions, and despite the fact that a somnolence syndrome has been recorded amongst children undergoing cranial irradiation, trials of treatment have not explored whether this morbidity occurs in adults. For example, in a trial comparing cranial irradiation of 45Gy versus 60Gy for malignant glioma Bleehen & Stenning (1991) reported that 83% of the 443 patients in either treatment arm reported no treatment morbidity. They do not, however, describe how information on side-effects was collected, and whether this was directly from patients or clinicians. Only 1% of patients in each treatment arm were reported as experiencing tiredness - a figure which seems surprisingly low compared to the changes in the clinical performance status that were also recorded after radiotherapy treatment. Here clinician assessment showed that 24% of patients had deteriorated by one point in the clinical performance status after treatment, although 26% of patients had improved (Bleehen & Stenning, 1991). It would be interesting to know whether morbidity reports were made more by clinician than by patient assessment since deterioration can be more easily observed and may have been more salient as a side effect to clinicians than tiredness.

A more detailed study by Faithfull (1991) simply followed seven patients for the six weeks following radiotherapy and documented the emergence of symptoms of excessive sleep,
drowsiness, lethargy and anorexia. This data was obtained using a visual analogue scale, a daily patient diary and semi-structured interviews with patients. She points to the dearth of evidence for this syndrome in adults within the literature and the need for more explanation and reassurance to be given to patients about these adverse effects. A similar argument was made by Choucair (1990) who pointed out that there is no prospective study evaluating the toxic effects of combined radiation therapy and chemotherapy on the brain itself. Studies of brain function have been mainly retrospective and involved selected patients, and, he argues, the threshold for including problems as proven adverse effects has been set very high.

Chemotherapy

Given the limited success of radiotherapy, further efforts have been made to improve survival by giving chemotherapy after radiotherapy. The most successful class of drugs to be investigated have been the nitrosoureas, and the most intensively studied example is 1,3-bis(2-chloroethyl)-1-nitrosourea (BCNU). One large randomised trial showed that it increased the median life expectancy from 40 to 50 weeks (Green et al, 1983). One meta-analysis from several further trials (Stenning et al, 1987) suggested that single agent nitrosourea probably increased survival at 1 year survival by 9.5% and survival at 2 years by 3.5%. A second meta-analysis by Fine et al (1993) showed a 10% higher survival rate amongst patients receiving chemotherapy at 12 months. However, in a recent comparison of these two meta-analyses Rampling (1997) points out that these survival gains are modest and only occur once the median survival for most patients has been passed. He also argues that patients who respond to chemotherapy after the diagnosis may be those who already possess a good prognosis and would respond equally well to chemotherapy after the tumour has recurred.

It is possible, therefore, that to give chemotherapy routinely as an adjuvant is simply to
expose more patients than necessary to adverse effects. At present studies have not identified which patients are most likely to respond to chemotherapy and again the problem here is that the treatment appears to be able to shift the survival curve only a little to the right without appreciably altering the proportion of long term survivors. The major factor limiting the effectiveness of chemotherapy is the problem of bypassing the blood brain barrier. Agents successfully used to treat tumours elsewhere in the body are water soluble and cannot therefore pass through the fatty blood brain barrier to reach the tumour. Current research efforts are to disrupt this barrier to allow more toxic agents through or to attach chemotherapy to monoclonal antibodies which have been raised to the tumour.

Overall the effects of chemotherapy are currently modest. Rampling(1997) also points out, along with other authors (Davies & Clarke, 1993) that no studies have addressed the issue of quality of life after chemotherapy. A British trial of combination adjuvant chemotherapy (Procarbazine, Vincristine and CCNU) conducted by the MRC will shortly report but this trial was not able to collect data on quality of life other than the clinical performance status.

Methods of assessing patient function and "quality of life"

Studies which have considered patient function in cerebral glioma have tended to use the Karnofsky Index (Karnofsky & Burchenal, 1949) or a modified version of this scale (see figure 2).
Figure 2 - The Karnofsky Performance scale (Karnofsky & Burchenel, 1949)

<table>
<thead>
<tr>
<th>Description</th>
<th>Scale (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Normal, no complaints</td>
<td>100</td>
</tr>
<tr>
<td>Able to carry on normal activities: minor signs or</td>
<td>90</td>
</tr>
<tr>
<td>symptoms of disease</td>
<td></td>
</tr>
<tr>
<td>Normal activity with effort. Cares for self.</td>
<td>80</td>
</tr>
<tr>
<td>Unable to carry on normal activity or do active work.</td>
<td>70</td>
</tr>
<tr>
<td>Requires occasional assistance but able to care for</td>
<td>60</td>
</tr>
<tr>
<td>most of needs</td>
<td></td>
</tr>
<tr>
<td>Disabled; requires special care and assistance</td>
<td>50</td>
</tr>
<tr>
<td>Severely disabled; hospitalisation indicated</td>
<td>40</td>
</tr>
<tr>
<td>although death not imminent</td>
<td></td>
</tr>
<tr>
<td>Very sick. Hospitalisation necessary</td>
<td>30</td>
</tr>
<tr>
<td>Active supportive treatment necessary</td>
<td>20</td>
</tr>
<tr>
<td>Moribund</td>
<td>10</td>
</tr>
<tr>
<td>Dead</td>
<td>0</td>
</tr>
</tbody>
</table>

This index was originally developed to assess nursing needs amongst oncology patients, the clinician deciding on a number between 0 and 100 guided by ten anchoring points (Karnofsky & Burchenel, 1949). It is popular because of its simplicity and speed of administration, but suffers from poor inter-rater reliability. Clinicians vary a good deal amongst themselves in rating the same patient, and clinic ratings tend to be optimistic in comparison to those made by visitors to the home (Yates et al, 1980). This might be because the scale gives no specific instructions for making a rating, mixes several dimensions such as neurological signs, activity and social resources (Hutchinson et al, 1979). Furthermore the instrument does not consider
distress, cognitive or psychiatric state, or the morbidity associated with treatment. Indeed it can reasonably be considered a scale about management and resource use. Many trials, however, have relied solely on this measure to assess "quality of life". In some other studies this measure, or a modified version, has been applied retrospectively to case notes, a procedure which must be of questionable validity.

As already discussed, however, the performance status, as assessed by the Karnofsky or by the WHO scale, is an important prognostic factor for survival. It might therefore be useful to consider what information it gives about the patient's level of function for remaining life. Trojanowski et al (1989), for example, studied 198 patients entered into a trial of chemotherapy in combination with radiotherapy and evaluated patients before surgery, after radiotherapy and every two months following treatment. For entry to the study patients had to possess a minimum Karnofsky score of 60. Although there was no difference between the group receiving chemotherapy and those not, overall Karnofsky scores increased six months after radiotherapy. Unfortunately Trojanowski and colleagues (1989) do not report the post-operative Karnofsky performance scores which would have shown the contribution of steroids and surgery to improvement before radiotherapy and provide a baseline against which the effects of radiotherapy could be compared. However, these authors also developed a battery of neuropsychological tests and scored patients depending on how important the lost function was for the patient's life, using this to calculate a quality of life coefficient. Unfortunately they give no specific details of this measurement but they report finding that six months after treatment the score increased by 6% on average and by 12 months by 10%. The maximum improvement was among the younger patients and the highest scores were amongst those patients with tumours of low malignancy.
Another study (Keim et al, 1987) compared two different administrations of radiotherapy in 133 patients. These authors found that neurological deficit improved slightly after radiotherapy. Definite or severe deficits diminished from 12% (16/133) to 4% (5/133) and paralysis from 23% (30/133) to 17% (23/133). Confusion showed most decline (from 30% to 18%). They provided no data on adverse effects although there was a suggestion that accelerated radiotherapy deteriorated earlier. The MRC trial of misonidazole with radiotherapy also found a gradual improvement in clinical state during radiotherapy, as assessed by the clinical performance status and neurological status (MRC Brain Tumour Working Party, 1983).

Other studies have considered patients undergoing chemotherapy. Shapiro and Young (1976) used the Karnofsky scale to show that quality of life is not altered by chemotherapy, although the scale does not in fact cover issues which would need to be considered in making the decision to prescribe chemotherapy. Such factors would include increased travelling time and hospital contact, the distress of nausea, vomiting, immunosuppression and its problems or indeed the dismay that may be the consequence of false hope. Shapiro and Young's (1976) findings that the post-operative Karnofsky score seems to reflect the patient's function for some 70% of time he or she survives, however, does suggest that chemotherapy, although prolonging life (in some cases), may not on average increase function, at least not to the extent that the Karnofsky measurement system is capable of picking up. Therapy may therefore simply keep the patient alive for longer with the same degree of disability.

Another study, this time a retrospective one of 74 patients who were well enough to receive BCNU (Hochberg et al, 1979) used a performance scale slightly different from the
Karnofsky, to evaluate the maximum functional status achieved and the absolute and relative time spent at this maximum functional level. The scale was applied retrospectively to case notes and the study found that patients maintained their postoperative functioning level for an average of 8 months. Some 40% had been able to perform some kind of work, and 70% to care reasonably well for themselves (Hochberg et al, 1979). It is not clear whether these patients represented a consecutive series or were selected into treatment, but the authors report that the majority had a notable improvement after surgery and radiotherapy. Another report of 110 patients with varying grades of gliomas treated between 1961 and 1977 applied a simplified Karnofsky score partly retrospectively and partly prospectively (Gibberd & Scott, 1983). These authors found that at five months from the diagnosis 29(41%) of the 70 patients who were still alive had either full function or were independent. Twelve months from the diagnosis 19(51%) of surviving patients were similarly rated. The authors also observed that once a terminal decline occurred it was usually rapid, and the patient did not typically remain dependent on carers for any length of time. They do not give specific data on this (Gibberd & Scott, 1983).

Trials carried out by the European Organisation for Research and Treatment in Cancer (EORTC) have used the WHO scale shown in figure 3 in preference to the Karnofsky score. This scale consists of fewer points, and defines different categories of disability more accurately without mixing this dimension with neurological symptoms. There is still the issue of how the clinician or observer is to decide in which category they should place the patient, for example, what kind of activity corresponds to "up about more than 50% of the time" as in the category 2. The recent MRC trials have also opted to use this scale rather than the Karnofsky scale and it is now included in the MRC prognostic index (MRC Brain Tumour

Figure 3 - The WHO Clinical Performance Status

<table>
<thead>
<tr>
<th></th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>Capable of all normal activity</td>
</tr>
<tr>
<td>1</td>
<td>No strenuous activity but able to carry out light work</td>
</tr>
<tr>
<td>2</td>
<td>Capable of all self care but no work; up and about more than half of the time</td>
</tr>
<tr>
<td>3</td>
<td>Limited self care. In bed or chair more than half of the time</td>
</tr>
<tr>
<td>4</td>
<td>No self care, confined to bed or chair</td>
</tr>
</tbody>
</table>

The data provided by these assessments of neurological state or simple performance status may show that for a proportion of patients their state remains the stable for some time after radiotherapy. However, the numbers of patients who are actually shown to improve with radiotherapy remain low, and this improvement has not been adequately analysed in relation to other prognostic factors. Furthermore, although Kristiansen et al (1981) report on the patients' ability to work, the impact on other areas of life has not been fully explored in any study. The result is a limited and one dimensional assessment of "quality of life". Studies have also not considered the potential unpleasantness of treatment, concerns over hair loss, nor have they directly questioned patients for their own views about the acceptability of this treatment or the value they place on the improved survival it achieves.
Summary

The treatment of malignant cerebral glioma is difficult. Although the diagnosis can now be made with considerable skill using computer assisted biopsy techniques, there is not conclusive evidence that more extensive surgery adds significantly to survival, or that it contributes to improved quality of life. Whilst radiotherapy is regarded as the main treatment option and two trials have shown that it prolongs survival, these studies have not answered questions about its benefit in terms of the palliation of disability compared to the adverse effects such as deterioration or fatigue. Finally chemotherapy adds only a little to survival and its usefulness remains doubtful. Research continues to hold out hope for new treatments, but it would be unrealistic to expect advances to be rapid. In this context it would seem important to consider carefully the benefits to be gained by intensive treatment. Over 15 years ago McKernan and Thomas(1980) noted:

"Although the clinical study of brain tumours may be regarded as the traditional approach to the subject modern approaches to treatment have necessitated a reappraisal of this area of study in attempting to answer such questions as meaningful survival and quality of survival".

In chapter 2 I discuss some of the debates about the value of radiotherapy treatment and place these within the more general setting of debates within medicine and health policy about the value of prolonging survival where cure is not possible.
CHAPTER 2

DEBATES ABOUT QUALITY VERSUS LENGTH OF LIFE

In the previous chapter I described limitations in current knowledge about the treatment of malignant cerebral glioma. Radiotherapy is the most effective treatment for this disease but only improves the median survival from three to about nine months. This modest effect and the absence of data on the adverse effects of treatment or about the palliation of symptoms raise questions about the quality of the extra survival achieved. In this chapter I consider how the literature on malignant cerebral glioma has considered the tension between quality and length of survival. I also cover shortcomings in the way in which quality of life has been perceived and measured, debates that have followed when radiotherapy treatment has been questioned and evidence that there may currently be considerable variation in management between different clinicians. I then set these problems in the context of wider debates within medicine about how decisions about quality versus length of life might inform health policy.

Debates about the management of malignant cerebral glioma

Most commentaries about the treatment of malignant cerebral glioma begin by stating the difficulty of the situation; some more dramatically than others. For example:

He who cares for patients suffering from brain tumours must bring to his problem much thought and stout action. There is also a need for formidable optimism, for the dice of the Gods are loaded! (Foster Kennedy quoted by Jennett, in Thomas DGT & Graham, 1980)

Kristiansen and colleagues (1981), reporting the results of their randomised trial of radiotherapy were careful to first note that they had established the statistically significant
effect of radiotherapy on survival before addressing whether this represented a "useful survival". In a later review Shapiro (1986), an American author set himself the task of answering the question of whether the trials of intensive treatment had been worthwhile. He concluded, however, that the improved survival made this self-evident:

Prospective trials over the last 15 years have demonstrated that median survival can be improved to a year or more and 25-30% of patients survive 18 months or longer. Newer therapeutic modalities have been suggested by recent laboratory investigations and hold the promise of improving survival further. It is evident that malignant neuroectodermal tumours should be treated vigorously using a multimodality approach.

Another review of the different techniques for administering radiotherapy, this time by a British author (Brada, 1989), encouraged optimism but placed more emphasis on quality of life:

Gloom about the current outcome of treatment of high grade gliomas may be justified but often leads to despondency which is unlikely to benefit either present or future patients with brain tumours. While we continue looking for new ways of controlling the aggressive proliferation of malignant glial tissue there is scope for sharpening the existing tools....However, any survival advantage which may be gained from new treatment must be accompanied by improved quality of life or the efforts will have been wasted.

Choucair (1990), however, whose concerns over the lack of data on brain toxicity I mentioned previously, cautioned the danger of optimism:

In the midst of our mixed enthusiasm and desperation for a cure, we have neglected a vital quality-assurance issue in clinical research - measuring the toxic effects on the target organ.

Other authors also suggest that the difficulty of the situation needs to be more freely discussed. Whittle & Gregor (1991), for example, criticised a consensus report produced by the Brain Group of the EORTC for failing to address "the important and controversial area of optimal clinical management of adult supratentorial gliomas".
The possibility of a minimum survival period worth treating for was explicitly discussed by Thomas (1988). He took the view that given radiotherapy treatment takes up six weeks of life and the patient is likely to spend six weeks deteriorating before death, less than six months’ survival did not seem worthwhile. Six month’s survival was proposed as probably worthwhile whilst 12 months or more was considered definitely worthwhile. Subsequently the MRC Brain Tumour Working Party developed the prognostic index described in the previous chapter (MRC Brain Tumour Working Party, 1990). In presenting this index they did not, however, question the merit of treatment in itself, but talked of identifying groups of patients for different treatment strategies without appearing to say that some groups of patients should not be treated. They suggested simply that:

...the use of the index to gain some broad indication of the likely course of the disease for an individual patient which may be of help in patient counselling.

However, a paper published several years previously which directly questioned the usefulness of any treatment had met an angry response (Wroe et al, 1986a). These authors reviewed the practice of two neurologists and two neurosurgeons at one regional neuroscience centre once a CT scan had strongly suggested the presence of a malignant glioma. Here 205 patients had been seen between 1978 and 82; 91 were initially referred to neurologists and 114 to neurosurgeons. Retrospective audit of the management showed that although the patients initially seen by each specialist did not differ clinically, those seen by neurologists were significantly less likely to undergo biopsy than those seen by neurosurgeons. The patients whom neurologists referred on for surgery tended to have signs of raised intracranial pressure, but when their tumours were confirmed at surgery, they were no more likely to be of a higher grade than those of the patients seen by neurosurgeons. At surgery pathology
other than a glioma was discovered in only 3% of cases. The study also showed that nearly all surgeons had referred their patients on for radiotherapy after surgery, whilst neurologists had tended to treat conservatively with steroids alone. Patients undergoing surgery had a wider range of outcomes being more likely to die, to leave hospital in a persistent vegetative state, or to be classed as having made a good recovery. Most (72%, 13/18) of the patients classed as having a good recovery were amongst the surgery group. On the other hand patients managed by neurologists were more likely to be classed as having slight or moderate disability on discharge from hospital. There was also only a trend for radiotherapy to increase survival, and, despite the different results of earlier trials, the authors used this data to conclude that treatment might have little effect on the overall survival. They argued that some of the poor outcomes for surgery might be so severe as to outweigh the limited positive effect of surgery and radiotherapy on survival, stating:

We agree with others that the effects of radiotherapy are unlikely to be great and treatment carries with it fairly considerable adverse affects that occupy an appreciable proportion of the patients’ short period of survival.

They concluded:

We would like to suggest from our data that a conservative approach to the management with steroids alone can be ethically justified. It would, therefore, seem reasonable that future studies could include a comparative control group of patients randomised to such management. We believe that it is only by adopting this approach that we will be able to improve the care of these patients (Wroe et al, 1986a).

This conclusion, drawn from a non-randomised retrospective report was strongly criticised for generalising too far from the practice of one centre and of not including sufficient numbers of patients undergoing surgery to validly compare outcome between the two treatment groups (Miller et al, 1986). These authors also disagreed that radiotherapy had little effect, pointing to the results of previous trials to say that radiotherapy was:

the most consistently effective treatment for malignant cerebral glioma doubling mean
survival time and increasing two year survival from less than 1% to 11%.

The more damming criticism, however, was of the way that Wroe and colleagues were seen as having interpreted their data:

Everyone knows that the outlook is poor for patients with malignant brain tumours. If a nihilistic policy of no diagnostic confirmation and no treatment is advocated this will always remain the case. Surely the public deserves something better than this from the medical profession (Miller et al, 1986).

In their response Wroe et al (1986b) argued back:

neurosurgeons should consider the need to prove that aggressive management policies which must inherently carry morbidity and mortality, give better results than "therapeutic nihilism".

They repeated the need for widespread collaboration in prospective randomised trials of management to help resolve these issues.

Although Wroe et al (1986 a+b) were trying to question management strategies using only retrospective audit data, they were making explicit the view that given the adverse effects and short-lived period of survival that treatment might simply not be worthwhile. Their report and the correspondence it provoked (Miller et al, 1986, Wilden, 1986, Davies et al, 1986, Wroe et al, 1986b) can be seen as important in disclosing the differences of approach to the palliative treatment of this disease existing between individual clinicians, and different specialties. There may also be differences of approach between countries. In the United States, for example, treatment by aggressive multi-modal therapy is preferred, whereas in the United Kingdom (UK) the effect of CCNU, vincristine and procarbazine on long-term survival only presently being evaluated by a Medical Research Council trial. The slow rate
of accrual to this trial\(^1\) also underlines the greater conservatism in the UK.

Another area where neurologists tend to be more conservative than their surgical and radiotherapy colleagues is in the management of patients with less malignant low-grade cerebral gliomas (Cairncross \& Laperriere, 1989). These patients may present with no neurological problems other than epilepsy and, once a CT scan suggests a lesion, neurologists may opt to manage these patients conservatively. A second retrospective study from the centre where Wroe and colleagues (1986a) conducted their study considered the outcome for patients presenting with epilepsy between 1975 and 1989 (Smith et al, 1991). The second study considered 164 patients for whom epilepsy was the only symptom and 396 who presented with additional neurological symptoms. As before, these patients were managed by two neurologists and two neurosurgeons. Multivariate analysis showed that the patients presenting with epilepsy were more likely to undergo extensive surgery, less likely to receive radiotherapy, and had a better survival than those presenting with additional symptoms. These latter patients were less likely to undergo extensive surgery but more likely to receive radiotherapy. When the authors divided the group according to whether surgical intervention came soon after the presentation of symptoms or was delayed, they found that the patients selected to have early surgery tended to have more neurological problems and subsequently had a worse prognosis. Smith and colleagues (1991) concluded that the uncertainty about management revealed by this study should be resolved by a randomised controlled trial. A trial was then devised by members of the MRC Brain Tumour Working Party to formally compare early versus late intervention. The trial was designed so as to leave it open to

\(^{1}\) Personal observation of discussions at MRC Brain Tumour Working Party Open meetings 1993-4.
participating clinicians to randomise only those patients about whose management they were uncertain and also to allow them to decide the extent of intervention. Despite this pragmatic design the trial ran into problems early on. It seemed that once the uncertainty of the situation had been explained, very few patients were willing to have their treatment randomised, with most preferring to undergo treatment earlier rather than later (Porter & Thomas, 1997a). The trial was abandoned, and it seems unlikely that this kind of information can ever be used to answer this clinical question.

Further evidence for variation in the management of malignant brain tumours comes from a large audit of the pattern of care for 439 patients in South East Scotland (Grant et al, 1996b). This study found that ten percent of patients with suspected malignant brain tumours were never referred to either a neurologist, a neurosurgeon or an oncologist. Another retrospective audit of the management of patients aged over 60, already mentioned in chapter 1, showed variation in the way clinicians managed their patients by either biopsy, surgery or radiotherapy and there was no clear relation between management and the patient's initial clinical state or their outcome (Whittle et al, 1991). This led the authors to suggest the need for prospective studies of treatment for patients with a very poor prognoses. A further trial by the MRC Brain Tumour Working Party is now under way attempting to compare quality of life after a short course of radiotherapy with that following a package of best supportive care only in this patient group (Gregor & Cull, 1996). Over the past ten years there has therefore been a re-evaluation of the value of treatment for older patients and others with a poor prognosis. The question of treatment for other groups of patients, however, revolves

---

around the issue of how much quality of life may be compromised by treatment and how worthwhile such relatively small extensions of survival are perceived to be. Presently there is little clearly established information about these factors.

The wider context to debates about quality of life in medicine

Reviewing the medical literature on malignant brain tumours, it seems somewhat surprising that these questions have not been more carefully evaluated. Given that radiotherapy treatment has been administered to the brain - the organ most central for human functioning - it is curious that there is no prospective data on the patient's cognitive and psychological function, or more broadly on their quality of life. In fact it seems to have taken over 15 years from the publication of the initial trials of radiotherapy (Walker et al, 1978, Kristiansen et al, 1981) and the initial suspicions of Hochberg and Slotnick (1980) about severe brain damage in long term survivors for this to have been confirmed more widely. It is now acknowledged that this damage is related both to the dose of radiotherapy administered and to the volume of brain irradiated (Gregor et al, 1996). A large review also suggests that deducing such effects only retrospectively will continue to underestimate their true incidence (Crossen et al, 1994). With the benefit of hindsight it is perhaps too easy to see that treatment should have been evaluated more thoroughly in a prospective fashion, but it may be useful to consider briefly why this was omitted and why the question of quality of life should now arise again.

The first and most obvious reason for the lack of data on quality of life is that when radiotherapy was first evaluated methods for assessing quality of life were not available. It would also have been a large undertaking to conduct neuropsychological testing for all
patients included within these large multi-centre trial and this was probably not considered feasible. At the time it was also not unusual for studies of "quality of life" to limit themselves to assessing the performance status. For example, Najman and Levine (1981) reviewed 23 studies which had evaluated other new medical technologies and showed that around this period assessments often lacked depth. Problems these authors identified included a lack of a clear definition of improved quality of life, the fact that clinician judgement was often used to assess "normal" functioning, and the absence of prospective measurement or investigation of the relationship between objective and subjective meaning for the patient. Clearly these last three criticisms can be applied to the literature on malignant brain tumour, as can the more general comment made by Najman and Levine (1981) of the contrast between the considerable investment in the technology for medical interventions compared to the lack of the development of quality of life assessments. To take a sociological perspective, medicine can be seen as having concentrated on rather narrow medical outcomes within the framework of the "medical model" at the expense of the more subjective view or social context of the individual patient. Thus, studies which purport to measure "quality of life" use performance scales which in reality stray only a short distance from clinical data obtained from the normal medical history and examination and assess "normal life" in a rather mechanical way. From these measurements, however, seems to follow a sense that because a measurement has been called "quality of life" that something more complex has been considered than is in fact the case (Fallowfield, 1990). Two further points are relevant. Traditionally medicine has seen many of the consequences of severe illness for the patient's psychological and social well being as outside of its control, reasoning that if the best available treatment is offered then other more personal consequences will follow for the patient. The assumption is made that it serves no purpose to record these personal factors in
any detail since, if treatment is not successful there is little anyone can do about these problems. At the same time, as far as research methods go, there are doubts about the possibility of tackling anything as "subjective" as quality of life in its full complexity, scepticism about the possibility of providing meaningful answers to any clinical question outside of a trial setting and doubt about the ability of much "soft science" to prove very much at all.

In understanding the apparent lack of concern with issues of quality of life in the initial trials of radiotherapy, it is also important to remember that over the last 20 years the kinds of questions that medicine is expected to address has changed radically. To recall the debate about conservative management discussed earlier: Miller et al (1986) completed their criticism of Wroe et al(1986a) with the comment:

surely the public deserves something better than this from the medical profession?

In fact the kinds of debates emerging within cancer medicine, and more generally, are one manifestation of just how much those outside of the profession have come to expect of medicine. A variety of other ways of looking at clinical problems have emerged which have increasingly questioned the ability of medicine to consider all factors relevant for patient experience. Research conducted from the standpoint of psychological and sociological disciplines, and by the nursing profession, present other perspectives on everyday medical reality, and, with the rise of consumerism the view has emerged that patients and their relatives are not always content to accept without question the medical perspective (Rigge, 1997). Hand in hand with this, to some extent creating awareness of these alternative perspectives, is academic interest in the quality of medical research and a re-evaluation of
which interventions can be offered within limited resources (See, for example, Royal College of Physicians, 1995). Not only is there perceived to be a broadening of the factors that medicine should take into account, but there is also a sense that any uncertainty facing the profession cannot now be contained amongst its members. One consequence of these trends has been a realisation of the potential medicine has to prolong life by technical means and increasing concern about the fact that the quality of life might be diminished. One response to these concerns coming from within academic medicine has been to try and formulate a model that will usefully express the kinds of decisions that might be made in situations where there is a tension between quality and length of survival. It is useful to consider the relevance of these formulations to quality of life in malignant cerebral glioma since one model has already been applied to this disease, and because these methods have had some influence in the field of health policy.

Formulations of the potential trade off between quality and length of life

The general approach of formulations which attempt to express the trade off between quality and length of life has been to first devise a means of representing health states using a single figure. The second step has been to decide what proportion of that score (or what proportion of the ideal) should be applied to different states. The third is to estimate (or measure) the effect that a given intervention might have on improving health status and the fourth to compare the numerical change in the score resulting from different treatments given for different conditions. Thus the relative ability of different interventions to achieve a given health gain can be expressed. The attraction of such schemes is that they hold the potential of deciding in a rational manner which interventions should or should not be used and which are cost-effective. For health policy makers they also give a possible means for containing
costs for the health care expenditure for any given population.

Three techniques can be used to represent the decision-making process - the Torrance time trade off (Torrance, 1987), the standard gamble technique (Capewell, 1988) and the distress/disability matrices described by Rosser and Watts (1972). In approaching decisions that might be made about whether to prolong life at a potentially reduced quality of life or whether to forego treatment, all formulations frame the choice in terms of comparisons between different states of health. I describe the Rosser scheme in detail since it has achieved most prominence, and its wider application to produce the concept of a Quality Adjusted Life Year (QALY) has caused most controversy.

Rosser and Kind (1978) developed eight descriptions of health status or disability by asking health professionals to describe how they assessed the severity of an illness in their patients without taking into account the diagnosis or prognosis. From these descriptions were derived the core elements of disability and distress each of which was the categorised according to severity (see figure 4). Descriptions of 29 possible combination of these categories were then given to a sample of 70 research subjects (including patients, doctors and nurses) who were asked to consider how they would rank these states in terms of the ratio of their desirability as if they were deciding how to use health care resources. This created a ratio scale which showed some interesting properties. Respondents did not class death as the least desirable outcome but instead placed unconsciousness or being restricted to bed by severe pain or depression at the lower points of the scale. The result was a ratio scale with a wide range over which individuals seeming to be to be willing to trade off between disability and distress.
Figure 4 - Components of the Rosser Index of Quality of Life

Disability

8  Unconscious
7  Not conscious but confined to bed
6  Confined to chair/wheelchair or able to move around the house only with support
5  Unable to work/carry out any education. Old people who can only go out if escorted.
    No Shopping. Housewives only able to do a few things.
4  Choice of work or performance severely limited.
3  Severe social disability and or slight impairment of performance at work
2  Slight social disability
1  No disability

Distress

Mental suffering                  Pain
4  Severe                        5  Agonizing
3  Moderate                     4  Severe
2  Mild                         3  Moderate
1  Nil                          2  Mild
                                   1  None
A utility was subsequently also derived for each state by assigning a value of 1 to freedom from disability and distress, zero to death, and by giving negative values to states worse than death.

Whilst the Rosser scale is innovative in combining different aspects of health into a global index of health and giving a possible model for comparing different conditions and their outcomes, it has been criticised on a number of counts. First, the assessment of disability and distress in the final categorical scale are made by professionals about patients, in a similar manner to the Karnofksy and other performance scales, rather than including the patient’s view. The Rosser scale is an advance on the Karnofsky performance scale in that it covers disability and some aspects of handicap more thoroughly and there is some rating of made of patient distress. However, factors such as personal meaning, sense of control or dependence are not considered. Furthermore the valuations of the different health states were made by people who did not have direct experience of these states or of the particular diagnosis to which they might be applied (Smith, 1987).

Although the way in which the Rosser scale is constructed has drawn some criticism, more has been directed at the derivation from it of the idea of a Quality Adjusted Life Year (QALY). The impetus to this has come from the realisation that, by comparing outcomes across different diseases, it might be possible to decide which interventions are the best value for money. Economists working at York University took the idea of gaining a full year free from disability and distress further to develop the Quality Adjusted Life Year or QALY as it is known for short. This involved considering how long patients might live free from disability and distress as a result of different interventions. The benefit of years was then
divided by the cost of treatment to produce the cost per QALY gained.

Although most would agree with this broad aim, many disagree with the particular assumptions built into the calculations and their application to cost-effectiveness. For example, the methods used to gain data on actual outcomes has been variable, and often estimates have been made of the potential gains rather than prospectively measuring them (Rosser, 1990). Williams (1985), for example, made a great deal of the possibility of economic evaluation of coronary artery bypass based on clinicians’ estimates of three possible illness trajectories. Another criticism is that QALYs combine quality and length of survival to create a summary figure and assume that individuals will trade off between the two to an equal degree. Rosser’s work showed that individual judges would trade off between disability and distress but she did not test assumptions about quality versus length of life (Smith, 1987). Rosser (1990) has since pointed out that although subjects may see disability and distress as important there are other aspects which have still to be incorporated into a new index (the Index of Health Related Quality of Life - IHQL).

There are a series of problems with assumptions that have been built into the overall calculations for QALYS. First, the calculations for the number of QALYS gained mean that different periods of quite separate individual survival are summed. This seems an insensitive and counter-intuitive method of dealing with individual gain, and one which will always be at odds with a clinical decision involving any particular patient. Second, in the calculation of cost health in the distant future is given less value than that in the immediate future. Thus time is said to be discounted in a similar way that cost would be in the financial world. The psychological parallel is taken to be the fact that in general individuals seem to avoid
immediate risks to early death even if their life expectancy might be increased by taking that risk. If the value of time gained in the future were not discounted in this way, interventions given to older patients would appear more expensive and therefore less effective than those for the young. This is because the old have fewer years ahead of them over which to spread the calculation of benefit. However, here a numerical correction has been built into the equation rather than properly testing this in an empirical manner. A third problem is the use of the data to rank groups according to their potential benefit to produce so-called QALY league tables. This approach does not encourage equity or equal right of access according to need rather than by diagnosis (Spiegelhalter, 1992). The tables will tend to encourage comparisons by diagnosis and do not therefore take into account differing prognostic groups within any particular diagnosis, but sum all potential benefits within that category. Spiegelhalter and colleagues (1992), have therefore observed that the problem with QALYs is that they aggregate data over uncertainty, over time and over groups of differing size to produce a single measure. Rosser (1990) who herself developed the underlying scale has pointed out that QALY advocates need to make these assumptions more transparent and spell out the implications more clearly.

Some of these problems are illustrated by calculations that have been made for the cost per QALY of treating malignant cerebral glioma. Here Pickard and colleagues (1990) examined the breakdown of the cost of neurosurgical services in West Sussex during 1985. Using patient case records they retrospectively examined survival and outcome and asked a panel of neurosurgeons their judgement of the outcomes that would have followed without neurosurgical intervention. This allowed the authors to calculate how may cases of severe disability or death had been averted by neurosurgery. Using simply the bed costs per length
of stay they calculated the cost of averting each severe disability or death and the cost per QALY gained for each diagnosis. At 1985 prices the cost per QALY gained by treating a patient with a malignant brain tumour was £68,694 compared to £310 for treating a patient with subarachnoid haemorrhage. The figure for the treatment of malignant cerebral glioma is amongst the most expensive interventions so far evaluated and the cost ten years later is over £100,000 (Robinson, 1993). The reasons for this apparently high cost include the fact that few patients with malignant cerebral glioma live longer than one year and very few suffer no disability during this time. Few patients therefore achieve a full year free from disability and distress and a large number of portions of different individual survivals need to be added before one QALY is gained. With only 5-10% of patients surviving two years from diagnosis the cost of the treatment cannot be spread over future years of survival and the cost for the group as a whole is high. In a resource-conscious NHS, this figure immediately suggests that it is inefficient to consider treating these patients and the fact that decisions might then be made on these measurements raises important ethical issues. As Rosser (1990) has pointed out, the calculations simply reflect the difficulty of the situation and avoid discussion of the fact that the context is one of terminal care and a different situation altogether from one where a curative treatment is available.

Although the QALY method may not take into account explicitly enough the peculiarities and uncertainties of any situation, the concept it incorporates of a trade off between quality and length of life would seem a useful one to explore. Clearly, as already discussed, some clinicians have recognised a tension between quality and length of life in the treatment of this disease. At present, however, these discussions are debates between clinicians about what they feel is in the patient’s best interests and nowhere has the role of the patient with the
brain tumour in this decision been raised. In the wider field of cancer medicine, the idea of quality of life has been explored more enthusiastically and the decisions that patients may make about other cancer treatments have been considered. Before setting out the aims of this study I briefly describe some of the key findings of psychosocial research which has covered preferences for treatment, psychological coping and doctor-patient communication.

Studies of patient preferences for cancer treatment

A number of studies have looked at the kinds of choices people make about different treatments, largely using hypothetical case scenarios. McNeil et al (1982) asked a group of patients and doctors to imagine they had lung cancer and to chose between surgery and radiotherapy. Surgery was preferred to radiotherapy when the treatments were named and when the information on probability was given in terms of survival rather than the probability of dying. In a study of 154 cancer patients O’Connor (1989) asked patients to indicate the risk they would take in terms of quality of life and survival following chemotherapy and compared their response to 129 well volunteers. She found that choices were influenced by whether risk was framed in terms of the probability of dying or surviving in both groups, but cancer patients preferred more toxic treatment.

Slevin and colleagues (1990) found similar findings when they presented different hypothetical cancer treatment and outcome scenarios to cancer patients and compared their views on the acceptability of treatment with those of a sample of doctors, nurses and members of the general population. Cancer patients were much more likely to prefer cancer treatments with very low odds for either palliation or cure and with more side-effects. Other studies have shown that patients with cancer and with other serious illnesses report the
quality of their lives in surprisingly positive terms. Breetvelt and Van Dam (1991) make the point that it is often difficult to find differences in scores on quality of life questionnaires between cancer patients and well individuals. An explanation of this effect has led to the idea of a "response shift" in that the experience of being diagnosed with cancer changes an individual's internal norm and therefore the way that the situation is perceived. After the initial crisis of the diagnosis there seems often to be an adaptation to the more negative aspects of the situation which are found less threatening and unpleasant.

The findings of all these studies thus suggest that patients facing the threat of death are less prepared to forfeit the possibility of cure or prolongation of survival, no matter how small this may objectively seem. This point is relevant to the validity of QALY-type calculations. If the judgements that well people make are very different from those who are ill, QALY values will not represent the quality of life which sick individuals are prepared in reality to cope with. Here the more detailed study of coping styles in cancer patients is relevant.

Psychological studies of how cancer patients cope with their disease

Research into psychological coping in response to the diagnosis of cancer sees this event as an example of a severely threatening attack on the concept of self, physical integrity, roles, relationships and future plans. Some workers have concentrated on studying the different coping styles that individuals adopt and others have attempted to relate these to perceived quality of life or to the length of time the patient actually survives. For example, Greer and colleagues (1979) studied women with breast cancer by looking at the coping strategies they adopted shortly after the diagnosis. Patients were characterised as coping by either stoic acceptance, denial, fighting spirit or anxiety and vigilance. This study found that patients who
adopted the strategies of either fighting spirit or denial lived longer than those coping by acceptance or anxiety and vigilance. Taylor (1983) looked at coping strategies in a slightly different way exploring the extent to which individuals could steel themselves against threats both in the present and in the future. She studied women with recurrent breast cancer and found they could maintain positive images of themselves despite the apparent seriousness of the situation. She described women employing coping strategies to resolve the issues of meaning, mastery and self-enhancement, one technique being that of downward comparison with others whom they could perceive as being worse off than themselves. Taylor (1983) describes some of this coping as the necessary creation of "illusions" - a way of looking at hard facts in a particular light. She saw this coping as the key by which individuals could keep control and she argued that it should be seen as an active and creative process rather than maladaptive simply because it diverged from how others perceive the situation. The strength of this coping is shown by studies of patients with terminal illness, although here studies have generally been keen to isolate what people fail to face rather than the benefits of the illusions they create. Kuebler-Ross (1978) identified a series of stages which patients may pass through before accepting their death - 1) denial and isolation 2) anger 3) bargaining and 4) depression and acceptance. These stages are not necessarily consecutive and patients could jump from stage to stage. Although the schema has been criticised, it is a useful way of understanding the process of coping. Overall Kuebler-Ross (1978) found that only 3 of her 200 patients maintained denial until death. Although patients may discuss dying within a research interview, this does not mean they will do the same with close relatives. Hinton (1980) found that only 6% of 80 married couple had been able to discuss the fact that the patient was dying although 80% were able to do so in separate research interviews.
As this study began there were no specific studies of the coping styles of patients with malignant cerebral glioma. However, one qualitative interview study has recently been published and described a range of coping strategies that patient used similar to those described above (Salander et al, 1996). I will consider the findings in more detail, and compare these with the interview results of this study in the final chapter.

Studies of doctor-patient communication

An important area related to the issue of quality of life is the quality of information patients receive about their diagnosis and treatment. If patients are to make informed decisions about their treatment and the quality of life they are prepared to tolerate they need clear information about their options. The situation is complex as it is possible that the way in which the patient copes i.e. possibly adopting an optimistic stance or avoiding bad news, may affect either their willingness to ask all necessary questions or their perception of the information they have been given. A study of patients being treated palliatively for cancer, for example, showed that as many as one third believed that their treatment was curative and the majority significantly overestimated the probability that treatment would prolong their life (MacKillop et al 1988). A large medical sociological literature, however, points to the fact that many patients would like more information about their disease and studies of patients with cancer have been no different. Fallowfield et al (1986) found that 51% of women with breast cancer wished they had been given more information about their disease. and further studies suggested a positive effect of women being in a position to decide how much they wished to be involved in decision-making about treatment. For example, in a trial of patients treated by surgeons offering choice between lumpectomy and mastectomy, patients offered a choice showed less depression at six months than those not given that choice (Fallowfield
et al, 1990). Tape-recordings of bad news consultations have also been found useful by patients (Hogbin & Fallowfield, 1989). However, these may work best for patients who have a better prognosis rather than those for whom there is a strong possibility of death (Fallowfield et al, 1995). Although the aim of much work on improving doctor-patient communication has been to approach honesty, it is becoming clear that this must be tempered by an appreciation that information needs have to be assessed in relation to what it appears that the patient wishes to know and that the wish not to know must also be respected. Thus this literature links to the work considered earlier on psychological coping strategies in that individuals may adapt to bad news or see unpleasant facts in a more favourable light. Equally it would suggest that the model of decision-making underlying formulations of a trade off between quality and length of life in which individuals consider all available information may not adequately represent the real life situations in which many such decisions are made.

The aims of this study of quality of life in malignant cerebral glioma

Clearly the treatment of patients with malignant cerebral glioma raises many issues. The literature I have so far reviewed suggests the need for more detailed studies of brain toxicity, disability and the palliation of symptoms. There needs also to be more general studies about the quality of life of patients with this disease. Gregor & Cull (1996) argue that assessments of quality of life should be undertaken within randomised controlled trials so that the information would be available for different treatments. Whilst such an approach is ideal, in reality the large size of trials tends to limit the number of occasions on which the patient can be seen and the quality of data that can be collected. It is also often not clear how representative patients recruited to trials are of patients presenting in everyday practice, and
therefore how far the findings of trials can be generalised. An additional problem is that trials attempting to answer some of the most critical questions, such as the merit of early versus late intervention, seem extremely difficult to carry out. In present clinical practice it would therefore seem unlikely that a trial of conservative treatment compared to radiotherapy could again be mounted.

One way around these difficulties is to consider using other kinds of studies to derive useful information. Prospective cohort studies recruiting a representative sample of patients undergoing usual treatment may be useful here. Ideally their sample size should permit an exploration, within a multivariate analysis, of the influence of different prognostic factors on outcomes. The measurement of disability can be made more accurate using standardised scales of disability considering a range of different functions. Better follow-up may also allow an evaluation of the possible morbidity due to treatment. Separate assessments can be made of the patient's subjective quality of life, and of the more personal meanings that patients may attribute to the situation. Here the extent to which patients wish for more information about their disease, the degree to which they conceptualise the situation in terms of a trade off between quality and length of life and how they appear to cope with the distress and threat of the situation can be explored. At the outset therefore the overall aims of the study were the following:

1) To study the clinical course of 100 patients with malignant cerebral glioma treated with steroids only, surgery and radiotherapy. To describe the disability and morbidity they suffered and gain information that may be relevant to an assessment of quality of life.
2) To explore patient experience of diagnosis and treatment and their views about the effectiveness and acceptability of treatment which might inform an analysis of the potential trade off between quality and length of life.

3) To interview a close relative or carer throughout the illness to see if their view differed from the patient, during either the illness or after bereavement.

In chapters 3 and 4 I describe how these questions were refined as a result of early interviews with patients and relatives, and how further issues emerged as the study progressed.
CHAPTER 3

SURVIVAL, DISABILITY AND MORBIDITY FOLLOWING RADIOTHERAPY

Introduction
In this chapter I describe the recruitment and follow-up of patients and their relatives to the study, and the methods I chose to collect data on patient survival, disability and morbidity. I then describe the characteristics of the patients studied, their survival, and the disability and morbidity they experienced before death. The results presented show that the patient's initial level of disability, as assessed by the WHO Clinical Performance status, was a good predictor both of length of survival and the time that the patient remained free of serious disability. However, one quarter of patients who initially had a good clinical performance status of 0, 1 or 2, and who survived six months after radiotherapy experienced clinical deterioration after this treatment. A further 40% experienced severe fatigue. These adverse effects were associated with increasing radiotherapy dose. I conclude by suggesting some reasons for the current disagreement about appropriate treatment and discussing the usefulness and limitations of such data in answering the question of whether it is justifiable to treat patients with radiotherapy.

The recruitment of hospitals to the study
Criterion for the recruitment of patients to the study was a first histologically confirmed diagnosis of high grade supratentorial glioma, age between 18 and 75 years, and radiotherapy treatment. The recruitment period extended between 1990 and 1992, beginning at one hospital and extending within six months to two others. It had been intended that 100 patients would be recruited from three hospitals but after one year of recruitment it became clear that three hospitals alone would provide insufficient numbers of patients. I therefore approached clinicians at six further hospitals to request that we include their patients. Clinicians at the three other hospitals agreed and these additional hospitals were brought into the study in a stepwise fashion.

1 The origins of the study and the responsibilities of the author: This study was originally conceived by Dr Anthony Hopkins and Dr Charles Clarke who gained funding for a 3-year period from the Cancer Research Campaign in 1990. The study was designed as a prospective observational study of patients treated at three London hospitals. I was employed as the principal researcher to carry out the work. My role was to decide on the methods to be used, to develop an interview to obtain patient and relative views, to liaise with medical staff at different hospitals, to interview some patients and relatives and to train and supervise two research assistants to interview others. Finally I was to analyse the data and write up the results.

2 At one hospital the neurosurgeons felt they saw too few patients to make recruitment worthwhile, at another hospital the neurosurgeons agreed but the radiotherapist to whom patients were referred for radiotherapy declined inclusion of his patients. In all, the study involved 12 neurologists, 17 neurosurgeons and 11 radiotherapists and I introduced the study to each by letter, telephone or personal visit. One neurosurgeon declined the inclusion of his patients. Recruitment was finally made from the following six hospitals where patients were treated with radiotherapy: Charing Cross Hospital, Oldchurch Hospital, the Royal London Hospital, the Royal Free Hospital, St. Bartholomew's Hospital and University College Hospital.
At each hospital the study was submitted to and approved by the ethical committee, and before recruitment began, the study was also explained to senior ward staff and radiographers.

The recruitment of patients and their relatives

At the beginning of the study consultants at the first three hospitals referred patients to the study themselves for a few months. They tended initially to refer patients who had recently finished their radiotherapy rather than patients waiting for radiotherapy immediately after their diagnosis. After the first few patients had been seen, and once consultant staff were happy with the study procedure, it was agreed that I could approach patients shortly after the diagnosis. Thereafter, to ensure that consecutive patients were approached the two other interviewers and I kept in contact with ward staff, junior doctors or radiographers, making weekly visits or telephone calls to obtain the names of newly diagnosed patients. We approached patients while they were on the ward or attending an out-patient clinic once the diagnosis had been confirmed and the decision had been made to refer for radiotherapy. At the three subsequent hospitals recruited it was possible from the outset to approach patients shortly after the diagnosis. However, I decided not to include patients who lived well outside the usual catchment area for each hospital, nor those who were not normally resident in the United Kingdom, since the home follow up of these patients would not be possible. Three patients who had their diagnosis confirmed as private patients but who underwent radiotherapy as NHS patients were included. The breakdown of patients recruited from each hospital site (coded as hospitals A to F) is shown in table 2. Because the hospital sites were recruited in a stepwise fashion more patients from hospital sites A, B and C were included in the final sample of patients receiving radiotherapy.

Table 2 - The recruitment of patients treated with radiotherapy from each hospital site

<table>
<thead>
<tr>
<th>Hospital site</th>
<th>Number of patients recruited</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>26</td>
</tr>
<tr>
<td>B</td>
<td>29</td>
</tr>
<tr>
<td>C</td>
<td>26</td>
</tr>
<tr>
<td>D</td>
<td>2</td>
</tr>
<tr>
<td>E</td>
<td>6</td>
</tr>
<tr>
<td>F</td>
<td>3</td>
</tr>
<tr>
<td>Total</td>
<td>92</td>
</tr>
</tbody>
</table>
Explaining the research to the patients and relatives approached for the study

Previous research, reviewed in chapter 4, shows that patients with cancer may cope psychologically with the prognosis for their disease in a variety of ways. Coping strategies may include avoidance and denial (Greer et al., 1979). Indeed there is some evidence that patients whom doctors are treating palliatively may sometimes believe their treatment is curative (MacKillop et al., 1988). Without knowing much of patients' perception of their situation, it did not seem appropriate to frame the research at the outset as a study of the potential trade-off between quality and length of life, but rather, to begin by talking to patients in general terms about their experience. I decided that we should approach patients explaining that we were interested in talking to people who were having radiotherapy after brain surgery. We explained that we wished to know of their experiences, the impact of the illness on their every day lives and their satisfaction with treatment and care. We also said that we would like to see a close relative separately in case they should have a different perspective, and, if possible, to see them and their relative several times over the following year. Finally we emphasised that the study was voluntary and that their care and treatment would not be affected should they decide not to take part. We gave each patient a letter restating these points, and, if a relative had not been present at our introduction, we asked the patient to discuss this with a close relative before deciding. We then telephoned a week later to hear their decision. We made our first visit within a week and explained all these points again before beginning an interview, and at each subsequent interview.

During the study periods at each hospital 105 patients receiving radiotherapy were identified and approached. A high proportion (88%, 92/105) agreed to take part in the study. All but three had a close relative, and of these 96% (85/89) also agreed to be interviewed. This represents a high acceptance rate to the study and I shall discuss some ethical aspects of approaching patients in such a vulnerable situation in chapter 4. The 13 patients who declined to be interviewed did not differ from those agreeing in terms of age, sex, or, as far as could be determined on these small numbers, tumour site. Most gave as their reason for not wishing to take part the fact that they or their families were too distressed. As patients were recruited to the study we wrote to their general practitioner explaining the study and stating when interviews would be due.

In addition to these patients receiving radiotherapy an attempt was made to study some patients who were being managed conservatively with steroids alone. These patients were very ill and often deteriorating rapidly. To make allowance for the fact that in this situation we needed to act quickly and find the right time to approach families, I limited recruitment of these patients
to hospital site A at which the study was based. Because of the severe disability of these patients, it was not possible to interview them all, but six could be seen briefly, and a relative of each of these six was also seen. It soon became clear, however, that limited information could be obtained from this patient group and that their physical state was so different from those receiving radiotherapy that they could not be considered as a control comparison group. Limited data on the patient's disability was collected using our observations, information from nursing records and relatives' reports. I therefore decided not to extend recruitment of patients managed by steroids alone to other hospitals. However, these patients treated with steroids represent one third (13/39) of all patients with malignant cerebral glioma studied at hospital A. Although not an adequate control group for patients receiving radiotherapy they may provide some useful information about the selection of patients out of treatment.

**Initial patient assessments or interviews for the study**

The diagnosis was dated from biopsy or surgery. A diagnosis contact was defined as an interview or assessment of a patient taking place up to 12 weeks from the diagnosis, and was usually carried out before radiotherapy or during the first weeks of radiotherapy. Nine patients were referred to the study too late after radiotherapy to carry out this initial interview or assessment (see figure 5) but 90% (83/92) could be seen for a diagnosis contact. Six of these nine patients were those referred by consultants at the beginning of the study, but the three other cases junior staff had not referred patients and they were discovered later by interviewers and included for completeness. Of the 83 patients who were seen for a diagnosis contact eight patients could make little more than basic responses to questions and were classed as 'too confused to interview' (see figure 5). Generally the full extent of the patient's confusion had not been apparent when initial agreement to the study was obtained, and in a few cases it was only once the tape-recording was reviewed that the paucity of patient comment, spontaneity or expansion became clear. In these cases data collection was limited to an assessment of disability using our own observations, reference to the nursing records and information from relatives. This was the same procedure as for patients being managed with steroids alone. Complete interview data for patients seen for the initial diagnosis contact is therefore available for only 75 of the 92 patients (see figure 5) and this is reported fully in chapter 6. Figure 5 also shows the numbers of patients who could be properly interviewed at any follow-up contact, and the point in time from diagnosis at which they made their best self report of function. Data from follow-
Follow up of patient cohort who received radiotherapy and definition of best follow up interview (the one at which the patient reported the least number of problems in everyday life)

Patient cohort

Interview shortly after the time of diagnosis

Could not initially be seen

Any follow up interview:

Patient died

At three months from diagnosis

Best self-report

At six months from diagnosis

Best self-report

At nine and twelve months from diagnosis

Best self-report

Alive at 24 months from diagnosis

Too confused to interview

Patient died

Patient died

Declined

Too confused to interview

Patient died

Alive at 24 months from diagnosis
up interviews are also reported fully in chapter 6 and used to deduce the number of patients able to report an improvement or period of stability after radiotherapy. The current chapter concentrates on data concerning patient disability and survival obtained using all other available sources of information. Thus data was collected from patient interviews, observation and assessment of patients, relative reports, case note review and discussions with medical staff and used to build up a picture of the clinical course. Patients did not therefore need to be able to give self-reported information on disability for this to be assessed and this explains why a larger number of patients are considered here than could be properly interviewed.

Initial interviews with relatives
Of the 85 relatives who agreed to take part in the study, 13 could not be seen for a first interview within 12 weeks of the diagnosis. Nine were relatives of patients who had been referred late to the study and 4 were relatives whom it had not been possible to contact or who had delayed an interview until after radiotherapy. Thus 72 relatives were interviewed in the first 12 weeks after the diagnosis (see figure 6). In 66 cases both a patient and a relative could be seen for an initial diagnosis contact and in all but 6 cases patients and relatives were initially interviewed separately.

Follow up of patients and relatives
Whenever possible visits were then made to the home at around 3, 6, 9 and 12 months from the diagnosis. Once a patient had been seen for an initial interview or assessment we would indicate to the patient or relative when we intended to see them again. Before writing to a family as this time drew near, however, we would check that the patient had attended for a recent clinic appointment, or if we were in doubt, we would telephone the general practitioner to be sure of any changes in the patient's state before writing or telephoning. Overall 270 visits were made to see patients. These visits were usually to the home. In a few cases, where it was acceptable, patients were visited in outlying hospitals or hospices with the permission of medical staff.

Taking first a chronological view of the patients who were alive and could therefore have been seen, 67% (56/83) were seen at 3 months, 77% (50/65) at 6 months, 60% (29/48) at 9 months, 72% (26/36) at 12 months and 89% (8/9) at 24 months from the diagnosis. The reasons for failure to see 28 patients at three months are as follows: in nine cases the diagnosis interview
Figure 6  Follow up of patients' relatives during the illness

Patient cohort

Relative cohort

Interview shortly after the time of diagnosis

Any follow up interview

After two years follow up

Carers bereaved after two years follow up

---

1 The number of relative interviews at follow up exceeds that for patients because of situations where only one party could be seen, or because patients were too confused to interview.
had taken place just a few weeks short of 12 weeks from the diagnosis and it seemed more sensible to delay a further contact until six months, six patients had not yet been referred to the study, six patients were too ill to be seen, three patients or relatives declined and in four cases the interviewer omitted to contact the patient. At six months 14 patients were alive but not seen, 2 patients had already declined and one further patient declined, four patients or relatives delayed interviews, three patients were too ill, one was abroad and in three cases the interviewer omitted to contact the patient. At nine months 19 patients were not seen. Two patients had already declined and a further three patients also declined, in four cases interviews were delayed until 12 months because patients had remained extremely well with no difference between interviews at three and six months. Two patients delayed because they felt unwell, five patients were too ill to be seen and three interviews were omitted. At 12 months ten patients were not seen - two patients had already declined, one further patient declined and the remaining seven were too ill to be seen. Finally at 24 months from the diagnosis of the nine patients alive one patient was abroad and could not be seen.

These figures show the difficulty of following a population of patients who are deteriorating over time. In particular at around nine months many patients were becoming ill and more declined or delayed interviews or were too ill to be seen at this point. Some relatives were happy to be interviewed themselves and for us to sit for a while with very disabled patients, whilst others found the situation too distressing to agree to our visit. In all 27 patients could be properly interviewed during a period of deterioration. However, we were generally successful in our overall follow-up rates when the data is considered in terms of achieving any follow up with patients as opposed to the success at particular months from diagnosis. Thus for those 83 seen for a diagnosis contact in 69 (81%) cases at least one follow-up contact with either patient or relative was possible whilst the patient was alive. Our approach was to use subsequent interviews to build up a picture of what had occurred since the last interview, to date any deterioration and if necessary to check this against medical records, as well as to collect information about the current state.

**Bereavement interviews with relatives**

Relatives were also seen for bereavement interviews four to six months and 13 months after the
death of any patient who had been studied. By 24 months of follow up, 71 relatives were bereaved (see figure 6) and by 36 months 73 were bereaved. Allowing for a delay of four to six months 69 of these relatives could be approached. Fifty-eight (84%) of these relatives agreed to a bereavement interview. At this time information was gathered about the final course of the illness and about relatives’ views about treatment and care (see chapter 7). All six relatives of patients who had been managed with steroids alone were also seen for bereavement interviews.

There were seven of the 92 cases (8%) where there had been only one contact with a patient or relative whilst the patient was alive, and where the relative declined both a follow-up interview or a bereavement interview. In these cases general practitioners or hospice staff provided information about the date of death and aspects of the terminal illness. In one case the date of the patient’s death was obtained from OPCS. Data for one and two year survival is therefore complete.

**The assessment of tumour grade**

As I discussed in chapter 1 there are several classification schemes for grade of tumour. Each hospital in the study graded tumours using different schemes. I explored the possibility of forming a panel of histopathologists to reclassify the histology obtained from the patients recruited to the study according to one single scheme, but this was not feasible. To achieve some comparability across the hospitals, I therefore chose to reclassify the tumours myself according to the Daumas-Duport definition (Daumas-Duport, 1988) using the histopathological reports. As already described this scheme considers four histological features: pleomorphism, mitoses, endothelial proliferation, and necrosis. Any two features constitute a grade 3 tumour, but three or four features constitute a grade 4 tumour. This re-classification exercise was possible in all but nine cases, in which the histopathologist had made the diagnosis of a “high grade glioma” without giving details of the histological features seen. I therefore excluded these cases when comparing survival between the two grades of tumour, but included these patients in all other analyses. This exercise overcame, therefore, the problem of comparability between different hospitals, but there remains the issue of the comparability of this study to others which have not usually employed the Daumas-Duport scheme. There is also the issue of the upward shift in malignancy observed by Revesz et al (1993) when tumours are reclassified using this
scheme. It is possible that some patients with grade 3 tumours on the Daumas-Duport scheme are missing from this sample since if such patients had originally been classified as having low grade tumours by histopathologists at each hospital they would not have been put forward for a study of patients with high grade glioma.

Measurement of disability

The emphasis in this study was on recording the disability that patients and relatives reported as resulting from neurological impairment rather than on the details that clinical examination might reveal. I suspected that patients might give optimistic accounts of their ability, and decided to give greater weight to their relative’s report of actual capability. Self care and basic mobility were rated using the Barthel scale (Mahoney & Barthel, 1965). This (see figure 7) is a widely used measure of disability covering primary activities of daily living including walking, transferring, maintaining continence, dressing, feeding, communication and bathing. This scale has been used successfully with patients suffering from other neurological diseases, such as stroke. A working group recently recommended that it should be used to record what a patient can do using the best available evidence, usually a synthesis of what the patient and relative say and observation of the patient (Royal College of Physicians and the British Geriatrics Society, 1992). Patients who have a high score may still have problems undertaking more complex tasks and these need to be assessed independently using an extended checklist. The same working group recommended the use of the Nottingham extended activities of daily living to assess other domestic and social tasks (Nouri & Lincoln, 1987). This gave more detailed information which could then be used to determine the World Health Organisation clinical performance status (World Health Organisation, 1979) which is a broad measure of disability included in the recently developed MRC Prognostic Index. The Barthel alone would not give enough information to allow the upper points of the clinical performance status to be rated. I chose the WHO clinical performance status (see figure 7) in preference to the Karnofsky scale (Karnofsky & Burchenel, 1949) because of the limitations of the latter scale which I have already outlined in chapter 1. The WHO clinical performance status provides a classification which is less ambiguous than the Karnofsky scale but still leaves some potential problems. For example, the rater has to decide what represents “normal” activity in the category 0, whether, for example, this is “normal” for the patient before they became ill, or “normal” in comparison to most
BARTHEL SCORE
Bowels 2  Transfer 3
Bladder 2  Mobility 3
Grooming 2  Dressing 2
Toilet use 2  Stairs 2
Feeding 2  Bathing 1

W.H.O. CLINICAL PERFORMANCE STATUS
0  Capable of all normal activity
1  No strenuous activity, but able to carry out light work
2  Capable of all self-care, but no work; up to and about more than 50% of the time
3  Limited self-care. In bed or chair more than 50% of the time.
4  No self-care, confined to bed or chair

NOTTINGHAM EXTENDED ACTIVITIES OF DAILY LIVING
Mobility
Walk outside
Stairs
Get in & out of car
Walk/uneven ground
Cross roads
Public transport
Kitchen
Feed self
Make hot drink
Walk with cup
Washing up
Make hot snacks
Domestic
Use money
Wash small items
Houswork
Shopping
Full washing
Leisure
Read
Telephone
Write letters
Go out socially
Manage garden
Drive car

MRC PROGNOSTIC INDEX
<table>
<thead>
<tr>
<th>Category</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>≥ 60</td>
<td>12</td>
</tr>
<tr>
<td>Clinical performance status</td>
<td></td>
</tr>
<tr>
<td>0-1</td>
<td>0</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>≥ 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 score = sum of scores for each factor

**Figure 7** The assessment of disability, W.H.O. Clinical Performance Status and score on the MRC Prognostic Index
people's lives. There is also a potential problem in deciding what "up and about more than 50% of the time" should mean in terms of diminished activity in category 3. However, this scale was already being used by clinicians to assess patients entered to the MRC trial of adjuvant chemotherapy and it therefore seemed sensible that the research should use a comparable measure. To check whether clinicians and interviewers were making these ratings in a similar way I first carried out a small inter-rater reliability study. Table 3 shows 83 ratings made by clinicians for patients either on the ward or at follow up clinic compared with those made by interviewers at home interviews. The inter-rater reliability as assessed by Kappa (Brennan & Silman, 1992) was good (Kappa = 0.66), and there was agreement in 62 out of the 83 ratings. It was notable, however, that in 18 of the 21 disagreements, the interviewer had rated the patient as more disabled. Nonetheless this reliability study does show that the research ratings are broadly similar to the ratings that clinicians would be able to make given the time restraints of normal ward or clinic practice. This means that the research findings using this kind of assessment could be said to have some external validity to everyday practice.

<table>
<thead>
<tr>
<th>Table 3</th>
<th>Comparison of 83 ratings on the WHO Clinical performance status by clinicians and interviewers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interviewer rating(n=83)</td>
<td></td>
</tr>
<tr>
<td>Clinician rating (n=83)</td>
<td>0-1</td>
</tr>
<tr>
<td>0-1</td>
<td>30</td>
</tr>
<tr>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>3-4</td>
<td>0</td>
</tr>
</tbody>
</table>

In the study, the assessments of patient disability using the WHO clinical performance status were made for the time at which radiotherapy began and repeated at each subsequent interview. Increase in disability or other evidence of clinical deterioration occurring between interviews was dated at any subsequent interview.
Using the Barthel score to decide on the clinical performance status

The identification of problems with items on the Barthel scale was used to make an important distinction when rating the clinical performance status. Patients with a clinical performance status of two are defined as capable of all self-care whereas those with a performance status of three can carry out only limited self-care. The Barthel score includes specific information on these items and a less than complete score of 20 would indicate potential problems. A patient with mobility problems would have a less than perfect Barthel score but this would not be sufficient to cause a patient to be rated as having a clinical performance status of three rather than two. However, if there were specific problems with self care such as eating, dressing, bathing or continence these would cause the patient to be classed as having a clinical performance status of three. The use of the Barthel therefore served to piece together evidence for the clinical performance status rather than this rating being based on an overall impression of the patient’s problems. It may have meant that the interviewer ratings were slightly more accurate. As can be seen from table 3, although there was broad agreement between clinician and interviewer ratings on the clinical performance status, interviewers did tend to rate the same patients as more disabled than clinicians.

Deducing the initial clinical performance status using retrospective reports

When patients had not been referred to the study until a significant period after radiotherapy any rating of the clinical performance status at the beginning of radiotherapy had to be made retrospectively. This was made after questioning both patient and relative about any possibility of disability after surgery, and by careful attention to the nursing and medical notes if necessary. Nursing notes were generally more useful here than medical notes since they usually contained a daily assessment very similar to a Barthel scale of what the patient could manage. Two of the nine patients who were referred late to the study appeared to have had such problems with self-care but this was largely evident from the relatives’ description of having to help the patient dress and bathe themselves after their discharge from hospital. In all these cases the patient’s state at the beginning of radiotherapy, and how they now compared was particularly salient to patients and relatives. In the following cases the use of the Nottingham extended activities of daily living scale and the Barthel is exemplified. For example, one
female patient (case 6) seen after radiotherapy described how she was unable to work in the family business, carry out any housework or discipline her children. She compared herself unfavourably to shortly after her initial surgery when although she had not been working she had been able to do much more around the home. For her state at interview she was rated as having a clinical performance status of 2 but she was rated as having had a clinical performance status of 1 at the beginning of radiotherapy. She was later judged by her radiotherapist to have deteriorated due to tumour growth which had not responded to either radiotherapy or chemotherapy. In another instance (case 13) a patient who at interview had significant problems with self-care and spent all day in his chair was given a clinical performance status for the interview of 3. However, his wife reported that shortly after surgery he had been able to manage all his self-care and whilst in hospital having his radiotherapy had been able to take short daily shopping trips with her to Oxford Street. This gave him an initial clinical performance status of 2. He was later judged by his radiotherapist to have deteriorated due to his radiotherapy treatment. Another woman described her husband (case 18) as initially having been able to carry out all his usual activities except work and in another instance (case 17) a father saw no change in his son since surgery. It seemed therefore that patients, and particularly relatives, were well able to remember the detail of various abilities after surgery and that their views could be corroborated. No attempt was made to assess the possibility of relative or interviewer bias in these ratings.

Increase in disability or other evidence of clinical deterioration occurring between interviews was dated at any subsequent interview. This dating was again based on the narrative accounts of relatives and patients, supplemented by careful questioning, case note review and discussions with medical or nursing staff.

**Definition of survival free from disability**

The duration of time free from disability was defined as the period of time that the patient had a full score on the Barthel of 20. This level of disability was chosen because the Barthel is widely used and this level of disability would therefore be immediately recognisable to those used to measuring disability. It also means that the results can be compared to studies of other patients with neurological disability. A Barthel of 20 also seems to be a level of functioning that
an individual contemplating treatment for this disease might be interested to know about in terms of what radiotherapy could be expected to achieve for them. Further it was a level of disability which could be identified relatively easily by questioning GPs or hospice staff when a patient or relative could not be seen for a first-hand account.

The same technique was used to date the point at which the patient appeared to have lost a complete Barthel score of 20 as was used for determining the initial clinical performance status. In giving accounts of the patient’s deterioration relatives tended to spontaneously relate the onset of problems with mobility, continence or self-care to clinic visits, holidays, visits from GPs or other dates of significance. These comments were used to date the time at which the patient first experienced problems. The total time (if any) that was spent free from disability could then be calculated.

**The assessment of morbidity due to radiotherapy**

Acute and early delayed effects of radiotherapy were the main focus of this study and were considered as three categories. The first category was that of a dramatic deterioration in the clinical performance status requiring medical intervention. The second was the experience of extreme tiredness without a sudden deterioration in the clinical performance status. The third category was a miscellaneous one including a number of other symptoms which were troublesome to the patient such as hair loss and sore scalp.

**a) Deterioration in the clinical performance status**

The assessment of morbidity due to radiotherapy needed some care. Deterioration and increasing neurological symptoms after radiotherapy could be a side-effect of treatment but, equally, could simply be an indication of tumour recurrence. As patients were followed some of the side-effects described in chapter 1 became apparent. For example, patients admitted with deteriorations in clinical state during or after radiotherapy at the treating hospitals were managed with high doses of steroids and mannitol on the clinical understanding that their problems might be due to radiotherapy. There were, however, two other groups of patients. First, those whose deterioration was managed by their general practitioner or a hospital other than that at which they were being treated. Second, were those patients who did not
immediately improve with steroid treatment. I observed that some of these patients improved gradually over a period of some six to 12 months, despite having sometimes been referred to a hospice for palliative care on the assumption that their tumours had recurred. At the end of the follow up period I reviewed the cases of all patients who had initially possessed a WHO clinical performance status of 0-2 and who had survived at least six months after radiotherapy treatment. I considered deteriorations in clinical performance status up to 8 weeks after radiotherapy and identified those which I believed to be acute or early delayed effects of radiotherapy if the following criteria were met:

1. The deterioration in clinical state had been fairly rapid developing over one or two days.

2. There was no evidence for another neurological cause of the deterioration such as hydrocephalus or another intercurrent illness.

3. There was at least a partial reversibility after high dose steroid treatment or a gradual improvement over the 12 month period after radiotherapy despite there being no further anti-tumour treatment.

Therefore, I made the assumption that if the deterioration had been due to tumour recurrence that the patient would not have survived so long after radiotherapy. By definition I would argue that patients whose tumours recur during or soon after treatment must have highly aggressive non-responsive tumours. The process by which I eliminated deteriorations that seemed likely to be due to recurrence of the tumour was therefore deductive, and an exercise which was only possible once the disease had run its course or the patient had survived a year from diagnosis. Allowing for the necessary follow up of the patients, I identified possible cases of deterioration in 1993. I then presented the research data, the patient’s case records and all available imaging studies to the patient’s radiotherapist for their opinion. At the time of the study magnetic resonance imaging was not routinely performed to confirm either radionecrosis or the delayed late effects of radiation described in chapter 1, and by the time of review most of the patients had died. The criteria for deterioration were therefore derived in a pragmatic fashion and could not be validated against neuroradiological evidence of later brain damage.
b) Deterioration involving tiredness but no change in the clinical performance status

As already discussed, studies of adults undergoing brain radiotherapy have not often assessed tiredness or somnolence. I decided to assess this side-effect based on the patient's level of activity during radiotherapy and the subsequent 8 weeks, and on their own account of tiredness. However, as for the assessment of disability, I gave priority here to descriptions of activity in the sense that weight was only placed on subjective reports of tiredness when there was no inconsistency with activity. If a patient complained of being severely tired, but nonetheless managed their usual activity or work, "severe" tiredness was not rated. Patients with this level of tiredness had to be incapacitated in some way. Tiredness was therefore rated within the following categories:

1. Absent
2. Present but not interfering significantly in the patient's usual activities
3. Severe and preventing activity which the patient would usually wish to carry out.

This data on tiredness was not presented to patients' radiotherapists for confirmation and was analysed separately from that for deterioration in clinical performance status.

c) Other morbidity due to radiotherapy

Some patients complained of hearing loss or in some instances their relatives observed this during treatment. We noted this and also recorded severe skin burns and the extent of hair loss and its regrowth.

Field sizes and radiotherapy doses

Before seeing all the radiotherapists to discuss the likelihood that deteriorations in clinical performance state might be due to radiotherapy, I decided how best to investigate the possible relationship of deteriorations to radiotherapy dose and administration. Different hospitals and sometimes different clinicians within the same hospital preferred different techniques of administration. Most typically, however, lateral opposed fields were used to treat the whole brain or a generous volume around the tumour. After 40Gy or four weeks of treatment, field
sizes were usually reduced so that the tumour rather than the surrounding brain received the remaining dose. Some clinicians treated their patients using lateral opposed weighted rather than unweighted fields and some used wedged unilateral fields. None of the patients received brachytherapy or stereotactic radiotherapy. Planning data were not always available to consider brain volumes or isocentric radiation curves. Because of the difficulty of comparing so many different techniques I approached two radiotherapists for advice. They suggested I look simply at the use of large field sizes, considering a large field to be around 8 or 10 cm square and use a threshold of “more than 40Gy to more than half the brain” (ie a transverse 8 by 10cm section of the brain). I therefore chose to make a simple estimate about the amount of treatment the brain and the tumour had received using two pieces of information. First, whether or not the tumour finally received more than 55Gy. Second, whether or not opposing lateral fields of 10cm by 8cm or larger had been used to administer more than 40Gy. I classed smaller, unilateral or weighted fields as delivering this amount or less. The use of either approach could result in a final tumour dose of 55 or 60Gy.

Statistical methods
The Kaplan-Meier method was used to produce event free curves which were then compared using the log rank (Mantel-Cox) test. When ordered categorical data were considered log rank tests for trend were incorporated. Multivariate analyses of factors associated with survival time were carried out using Cox's proportional hazards regression model and a forwards stepwise variable selection procedure. Ordered categorical variables were fitted assuming a linear trend across the categories, as in the original analysis from which the index was derived. I carried out a further multivariate logistic regression analysis to assess the importance of radiotherapy parameters on the end point of morbidity after radiotherapy.

RESULTS

Characteristics of patients and treatment
Most of the patients were men (69%; 72/105). The median (range) age was 52 (21-75). Each hemisphere of the brain was equally affected (see table 4). Frontal and temporoparietal tumours
Table 4

Characteristics of patients and tumours for those receiving radiotherapy or steroids alone

*Figures are numbers (percentages) of patients*

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Radiotherapy (n=92)</th>
<th>Steroids (n=13)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sex:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Men</td>
<td>63 (68)</td>
<td>9 (69)</td>
</tr>
<tr>
<td>Women</td>
<td>29 (32)</td>
<td>4 (31)</td>
</tr>
<tr>
<td><strong>Age (years):</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>21-44</td>
<td>24 (26)</td>
<td>2 (15)</td>
</tr>
<tr>
<td>45-59</td>
<td>34 (37)</td>
<td>5 (38)</td>
</tr>
<tr>
<td>60-75</td>
<td>34 (37)</td>
<td>6 (46)</td>
</tr>
<tr>
<td><strong>Hemisphere affected:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Right</td>
<td>48 (53)</td>
<td>3 (23)</td>
</tr>
<tr>
<td>Left</td>
<td>39 (42)</td>
<td>5 (38)</td>
</tr>
<tr>
<td>Bilateral</td>
<td>5 (5)</td>
<td>2 (15)</td>
</tr>
<tr>
<td><strong>Tumour site:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Frontal</td>
<td>20 (23)</td>
<td>1 (8)</td>
</tr>
<tr>
<td>Temporoparietal</td>
<td>18 (20)</td>
<td>4 (31)</td>
</tr>
<tr>
<td>Parieto-occipital</td>
<td>10 (11)</td>
<td>0</td>
</tr>
<tr>
<td>Temporal</td>
<td>9 (10)</td>
<td>2 (15)</td>
</tr>
<tr>
<td>Parietal</td>
<td>9 (10)</td>
<td>2 (15)</td>
</tr>
<tr>
<td>Corpus callosum</td>
<td>6 (6)</td>
<td>1 (8)</td>
</tr>
<tr>
<td>Frontoparietal</td>
<td>6 (6)</td>
<td>0</td>
</tr>
<tr>
<td>Thalamic</td>
<td>5 (5)</td>
<td>1 (8)</td>
</tr>
<tr>
<td>Frontotemporal</td>
<td>2 (2)</td>
<td>0</td>
</tr>
<tr>
<td>Occipital</td>
<td>2 (2)</td>
<td>0</td>
</tr>
<tr>
<td>Extensive</td>
<td>5 (5)</td>
<td>2 (15)</td>
</tr>
<tr>
<td><strong>Daumas-Duport malignancy:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Grade 3</td>
<td>21 (23)</td>
<td>0</td>
</tr>
<tr>
<td>Grade 4</td>
<td>62 (67)</td>
<td>13 (100)</td>
</tr>
<tr>
<td>Unclassifiable &quot;high grade glioma&quot;</td>
<td>9 (10)</td>
<td>0</td>
</tr>
</tbody>
</table>

72
were most common; 86% (83/96) were grade 4 according to the Daumas-Duport classification (Daumas-Duport, 1988). Fifty nine patients received biopsy and 46 surgery. Thirty six tumours were partially removed and 10 were classed as "complete" resections. Most radiotherapy patients (76%; 70/92) received 50-60Gy, the remainder 45Gy or less (24%; 22/92). Fractions of 1.8-2.0Gy were administered each weekday for four to six weeks. Twenty-five patients were randomised to the MRC trial of adjuvant chemotherapy and 10 received procarbazine, vincristine and 1-(2-choroethyl)-3-cyclohexyl-1-nitrosourea (lomustine). Eighteen others (20%) also received chemotherapy within one year for recurrence. By the end of 1995, 98 patients had died and the 7 remaining had a minimum follow up time of two years.

The relationship of the MRC prognostic index to survival

Figure 8 compares the survival of the group receiving steroids alone (median (range) survival 23 days (3 days to 5 months)) with all other patients (10.3 months (19 days to two years in 10%; 9/92)). The patients who were managed with steroids deteriorated rapidly and clinicians had clearly excluded them from radiotherapy treatment for this reason. Overall, 27 of the 92 radiotherapy patients died by six months and 56 by 12 months. The survival rate at six months was 70% (95% confidence interval 61% to 79%) and at 12 months was 39% (29% to 48%). Table 5 shows the distribution in this sample of the four components of the MRC prognostic index. There were significant differences in 6 month survival. Favourable factors included a good clinical performance status (this having the largest effect), age at diagnosis, history of seizures as a presenting feature, and partial or complete resection compared with biopsy alone. Lower tumour grade ($\chi^2_{1.9}; P=0.0006$) were also associated with improved survival.

Forty two per cent (39/92) were in the two poorest of the six MRC prognostic groups: a proportion similar to the samples from which the index was originally derived (Medical Research Council Working Party, 1990). Because of the smaller numbers in this sample, I chose to collapse the two best, intermediate, and two poorest groups to make three groups. Figure 9 shows survival curves for these three groups. The MRC prognostic index clearly identifies three groups with very different prognoses. To assess the contribution of the individual factors, however, a multivariate Cox analysis was performed. In addition to the four factors on which the index is based tumour grade and the presence of necrosis were included. Using a forward stepwise variable selection procedure the WHO clinical performance status
Table 5

Prognostic factors and survival for patients receiving radiotherapy

<table>
<thead>
<tr>
<th>Age (years)</th>
<th>No patients (N=92)</th>
<th>Median survival (weeks)</th>
<th>Survival rates (%)</th>
<th>Log rank ( x^2 )</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>21-44</td>
<td>24</td>
<td>53</td>
<td>83</td>
<td>54</td>
<td></td>
</tr>
<tr>
<td>45-59</td>
<td>34</td>
<td>42</td>
<td>71</td>
<td>32</td>
<td></td>
</tr>
<tr>
<td>60-75</td>
<td>34</td>
<td>35</td>
<td>59</td>
<td>35</td>
<td>11.6</td>
</tr>
</tbody>
</table>

| Clinical performance status at outset: | | | | | |
| 0-1 | 23 | 65 | 91 | 61 | |
| 2   | 38 | 42 | 84 | 59 | |
| 3-4 | 31 | 21 | 35 | 23 | |

| Extent of neurosurgery: | | | | | |
| Partial or complete resection | 45 | 50 | 79 | 45 | 1.78 | 0.18 |
| Biopsy | 47 | 36 | 60 | 33 |

| History of fits: | | | | | |
| >3 months | 15 | 96 | 87 | 60 | |
| <3 months | 22 | 49 | 86 | 50 | |
| None | 55 | 36 | 58 | 29 | 20.3 | <0.0001 |

| Overall prognostic score: | | | | | |
| 0-15 | 20 | 61 | 95 | 60 | |
| 16-25 | 33 | 49 | 79 | 45 | |
| 26-38 | 39 | 25 | 49 | 23 | 26.0 | <0.000 |

Note: All \( x^2 \) values are from tests for trend and 1 df
Figure 8  Survival for patients receiving radiotherapy or steroids alone

Numbers at risk:

- **Radiotherapy**: 92
  - Months: 0, 64, 36, 17, 8

- **Steroids only**: 13
  - Months: 0, 0, 0, 0, 0
Figure 9: Survival for patients receiving radiotherapy by initial score on the MRC prognostic index.
was first entered into the model (hazard ratio = 1.75; P<0.0001) followed by the history of fits (hazard ratio = 0.46; P = 0.0001), then extent of neurosurgery (0.49; P = 0.003), the prognostic importance of which increased after adjustment for the other two factors. Interestingly, age did not contribute significant independent prognostic information after the inclusion of the WHO status and history of fits (1.25; P = 0.13) and nor did tumour grade or necrosis (P =0.79 and 0.68, respectively). This suggests that in this data set the information provided by age group is replicating prognostic information provided by other factors in the prognostic index.

The period of survival patients achieved free from disability

Once the MRC prognostic index and the WHO clinical performance status had been defined as the most useful prognostic factors for survival, it seemed sensible to explore the relationship of these variables to the length of time the patient had been free from disability. I defined the onset of disability as the time at which the patient first experienced problems with mobility or self care and thus scored less than 20 on the Barthel scale. If the patient had presented with such problems and never improved, then they achieved no time free from disability. If they had improved for some time I included the point at which these problems re-emerged. Six patients did not have a deterioration in the Barthel score during the two-year follow up period. In each case this was a minimum of one year after the diagnosis. This calculation showed that the median time that patients survived free from disability was only four months. It also showed that the prognostic factors for overall length of survival were equally good at predicting the time that the patient was free from disability. Figures 10 and 11 show that the time free from disability varies according to the WHO clinical performance status and the initial score on the MRC prognostic index.

A WHO clinical performance status of 3 or 4 distinguished a group with a particularly poor survival. Of those 23 patients whose clinical performance at onset was 0-1, 74% (17/23) were free from disability for six months and 39% (9/23) maintained this for 12 months. Those scoring 2 also did well, but only 42% (16/38) lived for six months free from disability as defined by the Barthel scale and 18% (7/38) for 12 months. By contrast, only four of the 31 (13%) patients entering treatment with a clinical performance of 3 or 4 improved to the extent that they scored 20 on the Barthel scale. This small minority were all self caring and
Figure 10: Survival free from disability* by initial WHO performance status

Disability free survival rate

Months from diagnosis

Numbers at risk:

- grade 0 - 1: 23
- grade 2: 38
- grade 3 - 4: 31

*the onset of disability is a Barthel score of less than 20
and mobile at six months, and one sustained this for more than 12 months. Sixty five per cent (20/31) of this severely disabled group spent at least a month in hospital for treatment compared to 20% of all others. Here the clinical performance status performed better than the MRC prognostic index in identifying a group of patients who were unlikely to become free from disability.

Morbidity associated with radiotherapy

Fifty-two of the 92 patients treated with radiotherapy had an initial clinical performance status of 0-2 and a survival of six months after radiotherapy and data on their clinical course could be used to deduce morbidity due to radiotherapy. Using the criteria described on pages 68-70, I identified 17 patients who had deteriorations in clinical performance status which I suspected had been due to radiotherapy. In all but three cases radiotherapists agreed with this judgement. In these three cases the radiotherapist thought that the over rapid reduction of steroid drugs rather than radiotherapy had caused the patient to deteriorate. Of the 14 agreed cases (27%; 14/52), nine patients had required admission and five others either an emergency visit from their general practitioner or hospital attendance. All of the patients partially improved, but nine of the 14 (64%) did not regain their previous clinical performance status.

Table 6 shows that reaching each of a higher tumour dose and higher brain dose was associated with deterioration. Half of those with both factors experienced deterioration (7/14) compared with none with neither (0/8). Performing a logistic regression analysis showed that both tumour and brain dose are required to model the outcome (see table 7). In terms of odds ratios, brain dose had a slightly larger relative effect.

In addition to the 14 cases of deterioration, a further 42% (23/52) of patients experienced severe tiredness or somnolence sufficient to limit leisure or domestic activities severely during or after treatment. Again these symptoms were significantly associated with radiation dosage. In the sample as a whole all patients lost their hair, and 28% (26/92) developed a painful peeling scalp. Forty nine per cent (45/92) lived to see their hair regrow, but for two thirds of these (30/45) loss over the tumour site was permanent. One other possible effect which patients or their carers complained of was hearing loss or tinnitus(14%).
Table 6
Brain dose, tumour dose, and subsequent deterioration in 52 patients with clinical performance status of 0-2 who were given radiotherapy and survived at least 6 months after treatment. Figures are percentage deterioration (proportion of patients).

<table>
<thead>
<tr>
<th>Dose received by a 10 by 8 cm transverse section of brain</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Tumour dose</strong></td>
</tr>
<tr>
<td>-----------------</td>
</tr>
<tr>
<td>40-55Gy</td>
</tr>
<tr>
<td>56-64Gy</td>
</tr>
</tbody>
</table>

Table 7
Logistic regression analysis of brain dose, tumour dose, and subsequent deterioration in 52 patients with clinical performance status of 0-2 who were given radiotherapy and survived at least six months after treatment

<table>
<thead>
<tr>
<th>Model including</th>
<th>Coefficient</th>
<th>Standard error</th>
<th>P value</th>
<th>Odds ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td>Constant</td>
<td>-5.85</td>
<td>2.03</td>
<td>0.004</td>
<td></td>
</tr>
<tr>
<td>Brain dose</td>
<td>1.62</td>
<td>0.77</td>
<td>0.04</td>
<td>5.04</td>
</tr>
<tr>
<td>Tumour dose</td>
<td>1.37</td>
<td>0.73</td>
<td>0.06</td>
<td>3.94</td>
</tr>
</tbody>
</table>
Discussion

Before moving on to describe how I collected data on patient and relative perspectives about treatment, I will discuss how far the data on survival, disability and morbidity can be used on their own to answer the question about the value of radiotherapy. So far the study has confirmed many previous findings concerning the overall prognosis for this disease. The median survival of only 10 months, the survival curves for the group as a whole, the distribution of prognostic factors (age, a history of epilepsy and extent of surgery) within the sample and their relationship to survival are all very similar to those previously published. This suggests that although this sample is smaller than previous studies and was recruited across a number of different hospitals, it is one which is generally representative of patients treated with radiotherapy. Amongst the new information this study provides is the finding that the MRC prognostic index was a useful predictor of survival amongst a sample of patients treated largely outside of a trial setting. In this sample the clinical performance status was the most important component of the index. The classification of patients using the Daumas-Duport grading showed relatively few patients with grade 3 tumours, and this may account for why tumour grade was unrelated to survival in the multivariate analysis.

In recruiting patients to this sample I found that the small group of patients from the base hospital whom neurosurgeons decided to manage with steroids alone were already deteriorating rapidly. This strongly suggests that clinicians at that hospital were able to select those patients unlikely to benefit from treatment and it would therefore have been useful to have had more data on patients managed with steroids at other hospitals. Amongst patients receiving radiotherapy, the ease of defining prognostic groups using the MRC prognostic index suggests that it might be used more often in routine practice, particularly as it has proved useful in non-trial sample of patients. In this study the assessment of the patient’s prognostic group was made using formal checklists of disability to produce the clinical performance status. These provide for the first time accurate information about the trajectory for disability of these patients which gives potentially useful information about outcome dependent on the initial level of the patient’s disability. For example, on the basis of the data I have presented the clinician might discuss with a patient with the most severe disability (clinical performance status 3 or 4) that even with
treatment he or she stands only a 13% chance of substantial improvement in disability and a 23% chance of one-year survival. Conversely 74% of those who are initially free of disability may remain so for at least six months and 61% survive to one year. In fact in this study the clinical performance status performed better than the full MRC prognostic index in differentiating patients who faced the worse prognosis and had a low chance of becoming free from disability (when this is classed as a Barthel score of 20). In general the data suggest that the patients fall into two main groups. First, there are disabled patients with poor prognoses who are least likely to improve but spend longest in hospital receiving treatment. Second, are patients with least disability and better prognoses who undergo treatment as outpatients. Therefore, although radiotherapy prolongs survival it may not be successful in improving disability at least not to the threshold level set by a complete Barthel score.

The second main area where this study provides new information is in identifying possible adverse effects from treatment. It was necessary to limit consideration of these side-effects to this group of patients who were initially most well (clinical performance status 0-2) and who were alive 6 months after treatment. Amongst this group 27% experienced deterioration during or after treatment which the patient's radiotherapist agreed appeared attributable to treatment rather than progression of the tumour. Seventeen per cent of the group were left with permanent problems. In addition to this considerable increase in disability, a further 42% of those initially not severely disabled experienced severe tiredness. Both clinical deterioration and tiredness were related to increasing dose of radiotherapy. This incidence of adverse effects (69%) is higher than most previous reports, but these have generally concentrated on delayed brain necrosis or dementia which have been considered as producing the more important and irreversible consequences of treatment. Although the adverse effects I have isolated could be considered to be less severe I would argue that these involve larger numbers of patients and detract from the quality of survival that radiotherapy is intended to achieve. Whilst the presence of adverse effects could not be validated against neuroradiological evidence of brain damage, the data raises sufficient questions to merit further comparisons of the techniques currently in use.

The findings of this study show why debate has existed about the treatment of these patients.
There is evidence for both points of view - on the one hand some patients are treated for very little gain and on the other, some patients do reasonably well. Thus proponents of radiotherapy can point to the relatively good outcomes for young fit patients whilst critics of radiotherapy refer to the poor outcomes for those who are treated despite being already severely disabled. The data suggest, however, that proponents of radiotherapy may have underestimated the extent of adverse side effects amongst these patients. This may be due to a variety of factors. Patients may not complain of tiredness to their doctors, and when they do their doctors may not appreciate its severity. Clinicians may be more likely to explain neurological symptoms as being due to the tumour. Patients may also not be seen so frequently during the weeks after radiotherapy when these effects may emerge, and indeed some of these problems may be managed by clinicians elsewhere.

Returning to the original question of whether it is justifiable to treat patients with radiotherapy, this study provides data which might move on the debate. First, the formal assessment of prognosis using the MRC prognostic index will help distinguish patients with poor prognoses who should be considered carefully for treatment. Second, the study clearly identifies the need to investigate the range of adverse effects and their possible relationship to the administration of radiotherapy in other samples. Patients who are already severely disabled should also not be subjected to further morbidity. Although for logical reasons I could not consider the morbidity they experienced, it is unlikely that they are spared it. Given that the fit and generally young patients seem at risk from morbidity, the assessment of palliation in this setting is clearly complex. For the individual patient the decision about accepting radiotherapy involves considering whether these potential short term losses to quality of life are worth taking for the possibility of longer term gains. This decision can be expressed in terms of a trade off between quality and length of life. Although the clinician can supply patients with information about gains and losses, a critical factor must be whether the patient and their family judge radiotherapy to be acceptable or judge the gains to have been worthwhile. In the following chapter I describe how I decided to collect data from patients and relatives about their views on these decisions.
CHAPTER 4

APPROACHES TO STUDYING QUALITY OF LIFE IN MALIGNANT GLIOMA

Introduction
In this chapter I discuss how neuropsychological and questionnaire studies have approached the study of patients with cerebral glioma and aspects of this life-threatening situation which such studies have not addressed. I first consider the findings of a few small interview studies of patients with cerebral glioma and of some sociological studies of the management of other neurological or terminal diseases. I then describe the decisions I made about the methods best suited to collect data here on the experience of patients and relatives and their views about the value of radiotherapy. Finally I justify the use of qualitative methods to explore this situation, followed by the use of semi-structured interviews to collect data on issues related to quality of life.

Previous studies of patients with cerebral glioma
Apart from the clinical type studies described in chapter 1, three types of approach characterise studies of patients with cerebral glioma, mostly published since this study began. These are neuropsychological or psychiatric studies, questionnaire studies, and a small number of interview studies of patients with low grade cerebral glioma. Here I consider each in turn.

Neuropsychological and neuropsychiatric studies
Like clinical studies neuropsychological and neuropsychiatric studies place weight on
objective measures of patient function, but the emphasis is instead on tests of the mental state. To neuropsychology, patients suffering from discrete damage to one area of the brain such as the damage caused by a brain tumour have been seen as providing an opportunity to deduce the "lost" effects of that area. Similarly, studies in the area of organic psychiatry have concerned the possibility of identifying psychiatric syndromes related to damage to different areas of the brain. Gliomas are known to be associated with a higher incidence of mental change than meningiomas and this may be related to their faster growth rate (Lishman, 1987). Although it is difficult to isolate particular syndromes because of the large variation in the clinical picture, both between individuals and over time, early clinical studies gave rise to the classic descriptions of syndromes associated with localised tumours. For example, frontal tumours are recognised as causing intellectual deterioration, with those on the left leading to a greater loss of linguistic skills. Memory failure is often present together with profound apathy, lack of spontaneity and indifference. Personality change including irritability and lack of reserve are well-recognised with frontal tumours, and there may be an indifference to, or even denial, of the diagnosis. Temporal lobe tumours seem to be associated with the highest incidence of psychiatric disturbance and this may in turn be accompanied by epileptic phenomena. Emotional changes include blunting of affect, and occasionally psychotic states. Parietal tumours are associated with depression; tumours in the non-dominant hemisphere may produce disorders of visuospatial perception and body image disturbance, whilst tumours in the dominant hemisphere may give rise to dysphasia which makes the mental state difficult to assess. Occipital tumours seem less likely to be associated with specific mental syndromes (Lishman, 1987).

Most studies of the mental changes in patients with cerebral glioma, however, have been
concerned with mental state at presentation, and are the result of clinical observation rather than the systematic measurement of psychiatric, psychological or cognitive function. Many observations were made prior to modern brain imaging techniques, or the use of steroids to decrease oedema around the tumour. The psychological state of patients once intracranial pressure has been diminished have not therefore been documented (Davies & Clarke, 1993).

Once acute brain disturbance has been reduced it would seem reasonable to assume that the normal personality and coping of an individual will again emerge and may have more influence on their psychological response than the strict organic effects. Neither the psychiatric nor neuropsychological studies, however, have been concerned with the subjective view of the patient or their problems. Reviewing the organic psychiatry literature, Lishman (1987) points out that reactions to the diagnosis itself have so far been overlooked as a cause of mental change in patients with cerebral glioma.

At the time the study began most psychosocial studies of cancer patients had specifically excluded any patients suspected of suffering from brain disease and concentrated on understanding the responses of other cancer patients (see, for example, Derogatis et al, 1983, Greer et al, 1992). Studies concerning patients surviving several years from diagnosis (considered in chapter 1), have been concerned with neuropsychological function, and therefore with objective cognitive deficits rather than the patient’s subjective experience. Further, such studies have not considered the possible interaction between psychological coping and neuropsychological syndromes or deficits. The actual effect of brain damage on the individual or on their family had therefore not been charted.
Questionnaire studies of patients with malignant cerebral glioma

Given the general recognition that studies of treatment have for too long relied on simple measures such as survival, there has been a widespread move towards the measurement of quality of life within clinical trials. Ideally measures of quality of life should be made before, during and after treatment, and be easily interpreted and repeatable (Fayers and Jones, 1983). However, the large number of patients needed for trials and the number of collaborating centres usually involved means that simple easy-to-administer measures are required. One issue is whether it is possible for assessments to be made by clinicians in situations where the burden on patients is felt to be too great. An example of such a measure is the Q-L index (Spitzer et al, 1981). Slevin and colleagues (1988) explored whether doctors or relatives could adequately fill out these scales for patients by comparing their questionnaire responses with those of 108 patients. They found that the scores made by doctors and patients were poorly correlated for anxiety, quality of life and depression. This would seem to confirm the widespread finding in medical practice that doctors are not very good at picking up psychological distress amongst patients with physical illness (Goldberg et al, 1987). There was also a wide variability in the scores made by different professionals about the same patient. Although the Karnofsky scale showed the greatest reproducibility, even using this scale professionals agreed on their ratings only 54% of the time (Slevin et al, 1988). These findings show that if quality of life assessments are to adequately represent patient experience they need to be made by patients themselves. However, this may be more difficult than it initially seems.

There are a number of issues which relate to how researchers can be sure that a questionnaire is really picking up on all salient issues for the patient and presenting them in a manner that
the patient understands and identifies with. The problem here is that of assessing the validity of something like quality of life that is seen as inherently subjective (Fitzpatrick et al, 1992). There is also the issue of to what use the patient assessments are to be put, and how the scales might be used to justify future treatments. It must be clear what meaning should be attached to differences in the scores produced by patients and what level of concern patients refer to when they agree with items on questionnaire scales. Thus if two treatments differed by questionnaire scores which purported to measure aspects of quality of life, which, by definition doctors have been poor at rating, it is difficult to see how the difference in questionnaire score is to be interpreted, and how to translate that back into clinical practice. This is all the more difficult if the organisation of trials demands brief and simple measures which run the risk of omitting important areas.

There is currently no consensus about the best questionnaire measures or whether it might be possible to develop some core measures which can then be used to compare outcome across different conditions as opposed to the development of disease specific measures for a particular patient group. Fletcher and colleagues (1992) suggest a combination of the two approaches with a validated standard instrument supplemented by dimensions specific to any particular study. One example of this approach is the development by the European Organisation for Research into Treatment of Cancer (EORTC) of a general module covering issues of relevance for all cancer patients (QLC-C30) (Aaronson et al, 1993) and a series of short modules for patients with different cancers. Osoba and colleagues (1996) have recently reported the development and testing of a specific module for patients with brain cancer. Here a 28-item questionnaire was derived from a list of 80 issues suggested by patients and relatives attending a support group and by other health professionals. After testing the
questions for re-test reliability on a sample of 105 patients, the authors defined 24 items which clustered into five scales of three or four items. These scales were termed emotional distress, future uncertainty, visual disorder, motor dysfunction and communication deficit. There are seven other single items which cover headaches, seizures, drowsiness, leg weakness, bladder control, hair loss and itching skin. The statistical results for internal consistency showed that items in each scale tended to cluster together suggesting that the same construct was being tapped for different patients. The results for the re-test reliability provided further confirmation that patients filled out the questionnaires in the same way a week later. Both these findings suggested that patients interpreted the items in the same way on both occasions and that the questions tapped attributes or feelings that were themselves stable. However, most of the items (13/20) are directly concerned with physical function or symptoms. The ratings patients made on these scales showed the expected relationship with those made by clinicians about neurological status, motor deficit, dysphasia and confusion. Interestingly, however, patients' ratings on the emotional distress scale at baseline were also related to clinician's assessment of dysphasia and motor deficit. Patients later assessed as having deteriorated in neurological function also reported more emotional distress. This scale for emotional distress comprised questions about feeling frustrated, being on edge, agitated and angry but not the possibility of sadness or depression. However, a separate scale entitled 'future uncertainty' included the questions about uncertainty about the future, worsening outlook on the future and setbacks in the condition. Also included is an item concerning disruption of family relationships although this subject should perhaps have formed part of a separate scale.

Overall some items in this questionnaire appear to be measuring something in the emotional
sphere but nonetheless most of the items cover physical symptoms. To know that these are associated with clinicians' assessment of physical problems is important since it shows that patients are capable of recording their symptoms in agreement with trained observers. However, in terms of fully capturing health-related quality of life, the questionnaire scales tell us about perception of symptoms but nothing about the impact of these symptoms on the patient's roles, their life plans or their coping. In short it tells us nothing about the meaning of these symptoms to the individual, but rather tells us that the patient knows they have them. What we surely wish to do is to compare the responses of patients with similar symptoms to gain an idea of how different individuals react - thus keeping the measurement of symptoms distinct from the measurement of their impact on life in general. The problem of the questionnaire approach is shown by the fact that the authors of the questionnaire are left speculating why disability scores should be correlated with the uncertainty scale. They suggest that this might be explained by the two items which concern setbacks and disruption to family life since they say "these items could have a physical component". Similarly, the association of clinicians' assessments of neurological problems mentioned earlier with emotional distress led the authors to suggest that emotional problems may be "secondary" to physical symptoms (Osoba et al, 1996). These speculations show how, despite the apparent statistical validity of the exercise, the questionnaire approach has a long way to go before being able to capture the meaning of problems for the patient.

Some rather more interesting results emerged when Sneew et al (1997) compared the responses of 103 patients to the EORTC-C30 and the brain tumour module (QLQ-BCM) with the responses of significant others caring for the patient. In general there was moderate agreement between the patient and proxy scores (60% of scores agreed exactly, and 90%
were within one response category). When the mean scores were compared the proxies tended to rate patients as having more problems than the patients admitted to, particularly in the instance of fatigue. The lowest agreement was amongst patients who had been rated independently by clinicians as suffering from more disability and from cognitive problems, and also amongst those who had deteriorated over time. The authors make the important point, in relation to these disagreements, that discrepancies between responses should not be interpreted as evidence of proxy inaccuracy. Rather, the difference may represent a very real difficulty that impaired patients have assessing all aspects of their situation (Sneew et al, 1997).

*Interview studies of patients with cerebral glioma*

At the time this study began there were no studies of the experience of patients with high grade glioma immediately after the diagnosis, but interview studies had been conducted for patients who had survived some years from their diagnosis, or who had less malignant tumours. Such patients have fewer physical problems when their tumours present and, even without treatment, their prognosis is good (North et al, 1989). In an exploratory study, Koivukangas and Koivukangas (1988) interviewed four patients with low grade gliomas to elicit comments about their wellbeing after surgery with the aim of incorporating these concerns into a quality of life questionnaire. Their qualitative analysis of data from in-depth interviews suggested that quality of life should be conceptualised as the ability of the patient to take part in their usual social activities and roles. Thus, after the diagnosis patients could feel that their symptoms interfered with this activity and they could feel distressed because of this. At interviews one year later they felt more able to take part in usual activity, more at ease and adjusted to their situation. Koivukangas and Koivukangas (1988) saw their
approach to quality of life as contextual in that it needed to be considered in relation to the past and future roles of each patient.

Other work conducted while this study was in progress includes an interview study of 30 patients with malignant brain tumours by Salander and colleagues (1996). These authors report interview data from 19 patients whom they assessed as not suffering from severe cognitive problems or personality change. They used grounded theory techniques (Glaser & Strauss, 1966) to identify different coping strategies that patients used to create hope. They found that most patients were aware of the possibility that their tumours could be fatal but made this information less threatening by using a range of cognitive manoeuvres. They categorised patients' strategies as "trust in treatment", "downward comparison", "avoiding information", "finding meaning", and "creating a new future". After comparing their categories with psychoanalytic concepts they concluded that the processes they had identified were different means by which a frightening reality could be reconstructed or denied. In some senses the interview approach of Salander and colleagues (1996) was similar to the initial stages of this study although the final interpretations differ in emphasis. I will return to consider these differences in discussing the results in the final chapter.

Sociological studies exploring the management of neurological and terminal disease
This kind of work, which is usually based on in-depth interviews, asks patients in an open-ended manner about their experiences. Such work does not usually set out to establish statistical significance, but rather to unearth potential patterns to patients' experiences and is therefore referred to as qualitative rather than quantitative research. For example, a seminal study in the area of terminal disease was the study by Glaser and Strauss (1966)
concerning awareness of dying within a hospital setting. By a combination of interviews with ward staff and observation of their practice these authors found evidence that the terminally ill could die a social death sometime before their actual physical death. By this they meant that those around the dying patient could cease to discuss with them the reality of the approaching death. Glaser and Strauss (1966) defined a typology of patterns of interaction between dying patients and those caring for them which they termed closed awareness, suspicion awareness, mutual pretence awareness and open awareness. In situations of closed awareness they describe how medical staff who know that the condition is terminal fail to disclose this to a patient who does not yet realise he or she is dying. The authors argued that this kind of behaviour seems to be based on the belief that the patient will "go to pieces" if they knew the truth and that they would therefore prefer not to know. One consequence of this is that nursing staff and the patient's family, do not witness disclosure by medical staff of information and tend to continue to "guard the secret". Thus the patient has no "allies" to provide them with adequate information. Suspicion awareness represents a situation where the patient, previously in a closed awareness context, begins to ask questions about their prognosis. Here staff begin to wonder if the patient realises the severity of the situation but they remain unsure and continue to be careful in their interactions with patients so as not to give the truth away. Mutual pretence awareness describes a situation where patient and staff are both aware of the truth but silently agree not to speak openly of it. Finally the authors identify open awareness - a situation where patient and staff have freely discussed the situation so that each is fully aware of the other's knowledge. Although these categories do not describe how individuals cope with their own distress, they remain useful in understanding the wider context in which an individual may have to negotiate for information, and the response of those around if the patients does not appear to be fully
informed.

More recently Timmermans (1994) has redefined the concept of open awareness to take into account the fact that patients and relatives may sometimes have been told the medical truth of any situation but not yet *realised* or *accepted* the significance of what has been said. His analysis, significantly influenced by the experience of terminal illness in a close relative, proposes the addition of *suspended open awareness*, *uncertain open awareness* and *active open awareness*. In suspended open awareness he argues that the patient or relative is in a state of disbelief or shock leading them to block out the bad news. This may be a transient state or the individual may prolong this state further by denial. If the state becomes permanent, then those around the individual, after first attempting to hint at the truth will then avoid the subject. He defines uncertain awareness as a situation where the clinician has left the individual with enough uncertainty to maintain hope. Finally active open awareness is the situation where the patient and relative understand the full implications of the prognosis, acknowledge that death will occur and try to come to terms with this. While this classification is important in breaking down the work that patients and families have to go through in accepting the disease, it is not clear to what extent these states differ from closed awareness and suspicion awareness previously described by Glaser and Strauss (1966).

Timmermans (1994) has argued for a new subdivision of open awareness because from the medical point of view adequate information has been given. In fact the examples of medical disclosure he gives, including that of the case of his own mother whom his father was told had suffered a stroke and faced an uncertain future, do not I would argue represent a full statement of the prognosis. In this example the doctor has not explicitly stated that he expected the patient to die but has instead left this implicit. To the medical mind it may be
obvious that an uncertain future means likely death but a state of open awareness can only be said to exist if information is shared equally between both parties. This does not mean that there is nothing to be gained by exploring more fully the possibility of new states of awareness, but this needs to be based on a more detailed study of cases than Timmermans (1994) can report. However, a study recently published by Seale and colleagues (1997) used interview data from a sample of 447 relatives of patients who had died from cancer to deduce the awareness context in which the patient had died. They found a prevalence of open awareness amongst 84% of patients. This rate seemed higher for cancer patients than for those dying from other diseases, and also higher than in earlier studies. There is therefore the suggestion that changes in communication practice have had a significant effect on communication in families of patients dying from cancer.

Another classic study, this time of a specific neurological condition that may be relevant to the study of malignant cerebral glioma is Davis’ study of the management of polio (1973). This study followed 14 families in which a child contracted polio, exploring how medical staff and families coped with the uncertainty of this devastating diagnosis. Repeated interviews in the months following the acute illness led Davis to conclude that staff favoured the approach of fostering a "gradual dawning of realisation" amongst parents that their child was not going to recover fully from the disabling effect of the viral infection. Thus, rather than discussing early on in the illness the strong possibility that a significant level of disability would remain, staff allowed optimism to continue and this was often helped by the intensive efforts that were being made towards physiotherapy. It is not clear the extent to which staff could have predicted an individual’s outcome. Davis’ hypothesis, however, was that staff used the clinical uncertainty that there was to avoid giving parents the harsh truth....
of the situation for as long as possible.

One report which considered the disease of malignant cerebral glioma was the discussion of a case history of one patient given by Eisenbruch & Handelman (1990). These authors describe, from the perspective of medical anthropology, the case of a 16 year-old Cambodian refugee treated for an astrocytoma in Australia. They report how the family tried to come to terms with the fatal diagnosis, explaining the misfortune by the child's inheritance of a bad karma (demerit) from a previous life and their failure to placate the house spirits. Their efforts to deal with this included arranging a religious ceremony by which they could rid the house of these spirits and indicate to their son his need to acquire further merit in his remaining life. The ceremony served to tell him and their community of his poor prognosis and possibly, by way of the blessing, help to prolong his life. Eisenbruch & Handelman (1990) argue that the family's explanation of the disease by karma helped make the misfortune of the child's death more tolerable and offered them the opportunity to do something about the situation. Their belief in karma existed quite happily alongside an acceptance of Western medicine. This case also echoes the need to manage transitions between different awareness states. The family did not wish to directly confront their son with the truth of his prognosis, but rather allowed him to deduce this within the ritual of the ceremony. Even so some grounds for hope remained and the patient accepted both the religious blessing and the radical radiotherapy treatment. He also began a special diet and during a remission of one year came to believe that he had been cured.

These kinds of observations suggest that awareness of the prognosis, hope and uncertainty are all important components to the experience of cancer with a poor prognosis and may well
be relevant to quality of life. Indeed Muzzin et al (1994) refer to the experience of cancer as a "living-dying experience". The possibility of death and the struggle for existence through hope has been argued as involving individuals in much effort. This may result in tremendous attempts to control the disease, ignore or put to one side the enormity of the threat, comparing oneself favourably with those worse off, or concentrating on what remains of life. All these psychological manoeuvres are clearly linked to the psychological coping styles described in chapter 2 and would also seem relevant to the issue of quality of life.

So far I have discussed previous approaches to collecting information on quality of life in malignant glioma. I now consider some particular difficulties of approaching patients in this situation for research and describe the decisions that I made about the appropriate way to collect the data.

**Potential problems of studying a life-threatening situation**

A research method should reflect as accurately as possible the phenomena or experience under investigation. At the outset there seemed several difficulties in representing reality in this situation. The research question concerned the highly threatening issues of mortality and disability and to ask about these sensitive topics needed care and attention to the ability or willingness of patients and their relatives to discuss their situation in these terms. Indeed it was not initially clear whether this would be possible. The research was also sensitive in that it was an attempt to evaluate a treatment which was already being widely practised. It was therefore potentially confusing and distressing to patients and their relatives if research interviews were to raise questions about a treatment they had already agreed to, and in which they may have had considerable confidence. There was also the added complication that patients might be suffering cognitive or psychiatric problems due to brain disease, surgery
or drugs such as steroids and that these could affect their interpretation of the situation and their subjective experience. As well as ensuring that patients were able to understand and communicate during interviews this might lead to difficulties in representing their experience. All these issues needed to be considered carefully as the method was developed.

Another ethical issue raised by the fact that quality of life has not been studied is that there is no information about the ability of these patients to make informed decisions about their treatment. It is important that a treatment is recognised as effective in giving a period of adequate functional survival and any patient undergoing cancer treatment ought to be given the chance to weigh up for themselves costs and benefits of treatment. The question is whether patients with brain tumours are always in a position to make this judgement. Since it has not been conclusively shown that radiotherapy improves mental state, if an individual does not appear to understand the situation, doubts must be raised about whether it is the correct course to intensively treat that organ. These issues of informed consent have been considered in relation to the entry of patients into clinical trials in other conditions and the relevance of these issues to treatment decisions in everyday practice are increasingly recognised.

The justification for studying the subjective views of patients with malignant glioma was therefore first of all exploratory. There is an increasing expectation that patients should take part in decisions about their treatment and indicate the quality of life they will tolerate (Fallowfield, 1990, Bryne, 1992). It is therefore important to know how patients with malignant cerebral glioma understand their situation and whether they can make an informed decision about a treatment which aims only to prolong life. Finally in humanitarian terms it
is possible that understanding the experiences of patients and their families might help in the management of the situation in providing families with information and support.

**Deciding on the methodological approach**

Since little information existed on the experience of patients with malignant cerebral glioma and their relatives an initial phase of qualitative research was needed to identify issues that were relevant. Qualitative research methods are less familiar to a medical audience than survey methods, but it is increasingly recognised that they can be used to understand the experiences of patients, and are a prerequisite to good quantitative research (Pope & Mays, 1995). Such methods include in-depth interviews, focus groups, nominal group techniques, observational studies and case studies (Fitzpatrick & Boulton, 1994) Certainly it seemed unlikely that a survey approach using a standard questionnaire could address the kinds of sensitive issues required for this study. Equally it did not seem likely that individuals would necessarily feel able to discuss these sensitive matters in a group setting, nor did I feel comfortable attempting such a discussion. One-to-one interviews seemed a more confidential and comfortable setting to gain initial insight into the situation. It also seemed likely that the illness experience of patients with malignant cerebral glioma would be different from other cancer patients because the disease can immediately cause disability for the patient, and because of the singular threat that a tumour in the brain must pose.

In describing the qualitative interview approach it is useful to consider how it differs from the questionnaire style of research. Weiss (1994) clearly distinguishes a qualitative interview approach from a survey approach (using a questionnaire) to interviewing where questions are fixed. Here he sees qualitative interviews sacrificing uniformity of response for the detail of
a description that is guided by the respondent’s associations. As well as developing these
detailed descriptions, he also lists the functions of qualitative interviews as integrating
multiple perspectives, describing process, bridging intersubjectivity between participants and
the research audience, and in identifying variables and framing hypotheses for quantitative
work (Weiss, 1994). On a practical level interviewing allows respondents to convey in their
own words the issues which are important for them whilst leaving the interviewer scope to
explore as sensitively as possible other aspects of the situation. Second, both interviewer and
respondent can retain more control in clarifying the meaning of questions and responses.
The interviewer can repeat or re-word a question if it appears unclear, and the respondent
can elaborate on their view or point out other aspects to the interviewer. Interviewing also
allows for data collection about an overall experience, very often told as a story, rather than
the collection of data as a series of items in a pre-prepared format. Third, interviewing
supplies more data on which observations can be based. An interviewer can pick up on the
importance of a topic using cues such as the tone of voice, the frequency of repetition,
hesitation and the key part that it seems to play in the respondent’s life. By comparing
different respondents the interviewer gains an impression of common experiences.
Interviewing also keeps open the possibility of making some assessment of the degree to
which an individual suffers severe cognitive or psychological problems. Thus interviewing
was a method which was most likely to pick up on a patient’s subjective view but which
could also retain the possibility for the interviewer to make some of their own observations
on the situation.

The recruitment of patients to the study was described in chapter 3, but it is useful to
describe here how feasible it was to interview patients with brain disease. Of the 92 patients
recruited to the study, 83 could initially be seen. Most of these (90%, 75/83) could be interviewed without difficulty. Ten percent (8/83), however, were too confused or had language problems that were too severe to complete the interview. The conversation of patients with less minor problems was not necessarily perfect, but they could convey enough about themselves to give an impression of what was important. Unless language problems (aphasia) had been the presenting problem, it was often only in the last few weeks that patients lost all conversational skills. Problems with communication that emerged as the illness progressed could sometimes be overcome if an earlier rapport had been established. Inevitably, however, as the disease progressed the emphasis in data collection moved from interviewing patients in detail to observing the problems they had and, as the patient was less able to report their own view, an increasingly reliance on the relative for information about the situation.

**Semi-structured interviews**

Although qualitative data was necessary for an initial understanding of the situation and the experiences of patients and their relatives in this study I needed to be able to report some quantitative data such as the prevalence of particular points of view and their possible relationship to other variables, for example objective disability or reported distress. I aimed to do this by developing a semi-structured interview schedule and an accompanying series of rating scales. As a method, semi-structured interviews give the interviewer the opportunity to encourage respondents to talk freely about areas or issues that are important to them, but not in a rigid predefined sequence. Instead the interviewer takes their cue from the respondent in deciding what more they need to know to understand their perspective, and at what point it would be appropriate to raise other issues (Brown and Rutter, 1966, Brown
and Harris 1989). To conduct the interview the interviewer needs to retain a strong sense of the research questions being investigated and the level of detail that the ratings require. They need to direct the interview rather than to allow it to become open-ended and they must attempt to collect data in most of the areas of interest. Although the interview is not itself standardised, the aim is to collect data according to the same general principles in each interview, and to organise and rate the interview data in a standardised way. Tape-recording and transcribing the interviews allows for detailed questioning about different patients' concerns and eliminates recall or attention bias on the part of the interviewer. Patient and relative responses can then be coded at a later time according to clear standards which can be tested for inter-rater reliability. I reasoned therefore that this method would retain some of the "richness" of qualitative type data but allow for its coding into categories on which a quantitative analysis could be based.

Conclusions

In this chapter I have described how neuropsychological and neuropsychiatric studies fail to capture the individual meaning of illness to the patient and their family. Although questionnaire studies come nearer to recording some aspects of the individual perspective, there remains the issue of understanding questionnaire responses and translating them back into specific meanings for patients based on responses to particular situations. Questionnaire studies have, for example, shown that patients' assessments of their symptoms correlate with those made by their doctors, but that patients' relatives will tend to record more problems than patients, particularly as the patient becomes more disabled. Such studies cannot, however, address the issue of whether patients are in a position to make an informed decision about treatment nor ask them how they view undergoing radiotherapy for a relatively short
period of survival. Furthermore, questionnaires cannot address the specific meaning for each patient nor can they give information on the way that the situation is managed by patients and relatives. In this respect the small interview studies of patients with cerebral glioma suggest that it may be important to explore the impact of symptoms and disability on the roles and plans of the individual. However, the threatening nature of this diagnosis and its poor prognosis clearly needs to be taken into account. Here previous work suggests that the way in which an individual copes psychologically with the threat of death is important and that doctors and relatives may play a role in the development of the patients' awareness of the reality of the situation. In this chapter I have made the case that this exploratory study clearly needed to use interviews to collect information on these sensitive issues. In the following chapter I describe the qualitative and quantitative phases of the development of a semi-structured interview towards this aim.
CHAPTER 5

DEVELOPING THE INTERVIEW AND IDENTIFYING THEMES FOR ANALYSIS

Introduction

In this chapter I describe the different stages of the development of the interview and how themes for analysis were identified. In the first stage possible themes for the research were identified from pilot interviews with six patients and two relatives. The second stage was the development of a semi-structured interview schedule and rating scales to collect data on these issues. Here I give examples of the kind of data obtained, discuss how the scales were refined and report some preliminary results using data from the first 25 patients. The third stage of the work was managing data collection between three interviewers, ensuring that interviews with different patients covered the same areas, debating whether the scales covered relevant topics and achieving inter-rater reliability in their use. Once inter-rater reliability was achieved interviewers could use the results to rate data independently. I finish this chapter by discussing threats to the validity of the method, and how these might have affected the final results.

Stage 1 - Identifying research themes from the pilot interviews

Pilot interviews

I began developing the research interview by conducting exploratory interviews with six patients and two relatives and by discussing management with six members of medical staff caring for these patients. Of the six patients, three were recently diagnosed and three experiencing recurrence, having survived for 18 months or more after the diagnosis. One
relative of a patient was seen at diagnosis and the other at recurrence. It seemed useful to
interview patients whose tumours had recurred since they could give an overview of the
initial diagnosis, the experience of remission, and the problems of the re-emergence of
symptoms. In exploring the trade off between quality and length of life I initially wanted to
know how patients coped with the threat of the diagnosis, how they decided to undergo
treatment and what information they used to make that decision. I explained to these patients
and relatives that I wished to hear what they thought was important about the diagnosis and
treatment of a brain tumour in order to develop ideas for a future study. I asked them to tell
me what had happened from when they first thought that something might be wrong. I took
my cues from the story they gave and as this unfolded I asked in an open-ended manner
about the concerns that were mentioned and asked for their suggestions about others. There
was no interview schedule or prompt for these interviews - I was simply intent on hearing
what patients thought was important, to probe until I felt I understood their perspective, and
to see if there were patterns in the way that they described what had happened. I was also
exploring the acceptability of tape-recording and the first three interviews were not recorded
although notes were made shortly afterwards.

Data from pilot interviews
The analysis of these interviews was one of simple content analysis - identifying themes that
appeared to emerge from the situation together with supporting quotes or other evidence. I
was interested in comparing the concerns of different respondents and on deciding whether
their concerns could be linked to particular aspects of the situation. Here I give a brief
description of these interviews and of my initial discussions with medical staff about
management. These six patients were referred to me by consultant staff who told me what
they had told the patient, although this was not subsequently the case in the main study. The first three patients seen at the diagnosis gave a vivid picture of the range of difficulties patients could encounter.

Case 1 (pilot)
The first patient was a 44-year old woman with a large frontal tumour which had been diagnosed the week before. On the way to introduce me to the patient one of the senior doctors discussed the case with another who said that the patient had deteriorated so much since surgery that the decision had been made not to refer her for radiotherapy. The senior doctor took me onto the ward, where the patient was sitting by her bed, unable to walk. Beginning the conversation, the doctor observed that a lot had happened in the last week and asked the patient how she was. The woman had a rather distant, almost disengaged look and smiled at the doctor rather benignly. With what looked like a considerable effort she replied, "Oh alright". The doctor tried again; "How are you feeling?". The patient again smiled but appeared to look past her into the distance. Not getting any response the doctor persisted: "It must have been a shock for you?". Since the patient did not seem to be able to acknowledge the situation the doctor appeared to be skating around the obvious and not mentioning the word "brain tumour" or referring to the patient's disability. Again there was no response and it was unclear if she had understood the question. At some level, however, she might have done. She averted her eyes and even her face, as if by some curious reflex she might be trying to avoid the discussion. This left the doctor lost - unable to act on normal conversational cues and unsure of what was wanted or understood and able only to convey some words of comfort but no information. "Oh I expect you're a bit shocked now - I'll see you again later", said the senior doctor and turned to introduce me. The patient looked at me
with an air of quizzical interest. I explained that I would like to come back and speak with her about the research when her husband was there. She smiled again benignly. Unfortunately she continued to deteriorate over the next few days and died before the interview could be arranged, although I did hear that she had told her husband that someone would be coming to see them both.

This first case showed the shocking reality of this disease once advanced and the difficulty of assessing the patient’s point of view once the brain’s ability to comprehend the situation or to communicate has been overtaken. It seemed a daunting situation to study and the doctor commented to me, "well that was all psychologically very interesting. I wonder what was going on there". On a later date discussing management in general for these patients the doctor remarked:

I increasingly feel that people are going to be bitter for not curing them and the best you can do is just do lots for them, create activity and make them feel you’re doing your very best to give them a chance.

Case 2 (pilot)

The second patient I saw made the situation seem altogether much easier. I had been told his name and I introduced myself to him on the ward. He was the same age as the previous patient and warmly welcomed the idea of the research project only three days after having been told that his life expectancy was limited to a few years at most. He talked easily and in detail about the events he could remember before the diagnosis and how he was told about the diagnosis and prognosis. He said that he and his wife had talked openly about the situation and he talked warmly of her support. He said he was pleased to have been told clearly about his prognosis. He recognised that without surgery and treatment he would have died a week or so previously. He said he felt grateful for this, saying that he saw every extra
day as a bonus. In fact he seemed extremely positive, almost excited about the situation. He intended, he said, to use all possible means to fight his disease both those offered by medicine and alternative means. In discussing the management of this case with the doctor who had told this patient of his tumour, the doctor remarked:

I think it is important to try to be as honest as you can. Friends and relatives of mine have had gliomas and been told all sorts of things. It makes it worse. I have thought through what I tell people, and I usually do it over a series of interviews. There is way of saying it. I don’t, for example, say "you have the worse possible grade of glioma and you’ve got no hope...." In any case I find that although we think we would just wait for the injection in that situation, in actual fact people seem to find some hope to hang on to right up until the end.

The ease of discussion here contrasted with the difficulty in a third case.

Case 3 (pilot)

A man in his fifties sat with his wife in the radiotherapy department. Each looked strained and uncomfortable. The man, the patient, had dysphasia and English was not his first language. He stumbled in conversation as he told me how his symptoms had developed. When I asked how the diagnosis had affected his life he suddenly burst into tears. "I can’t compose my music", he said. "I don’t have the ability...". His wife interrupted, looking disapprovingly at him, and talking to me said, "I say to him that’s the least of your worries, you must concentrate on getting better". She explained, "You know they have told him and he thinks he is going to die and he keeps crying. I say don’t be silly you’re not going to die - it’s no use being depressed about it. You must think positive". The husband and wife seemed at odds with each other, one crying the other showing anger, both ashamed of the other and looking to me for support. I found it difficult to keep this interview going for very long since I felt I could not manage the tension between them, and the wife in particular wanted to treat the situation as a consultation.
These three early interviews showed the traumatic nature of the disease and the range of possible responses after the diagnosis. One patient was so affected by the tumour one could not be sure what she understood. A second appeared to understand the situation but remained positive about the time he had left and his ability to fight the disease, whilst a third understood the situation but could not feel positive at all. One talked of a warm and supportive relationship with his wife whilst another relationship showed signs of severe strain. As well as the threat of death, however, was the loss of an important aspect of self through disability. For one man the loss of his creative ability on his role as musician was disastrous. The next three interviews were with three patients who had survived over a year from their initial diagnosis and one relative.

Case 4 (pilot)

A single woman in her 30s had been admitted four years after her diagnosis and surgery with double vision. Scans had shown an expanding fluid-filled cyst within a frontal tumour. Although she had been referred quickly back to the neurosurgery centre she vividly described the anxiety of this admission. She described waiting some time before seeing a doctor, feeling very nervous before the operation when nobody came to explain what she should expect. Although it was clear that she was experiencing a recurrence of her tumour and she recognised that there were cancer cells in the fluid removed at operation, she complained that it was the radiotherapist rather than the surgeon who told her this news, and then not until several weeks after the operation. She felt very let down by the ward, commenting:

I think I class myself as a sensible person and I want to be told the truth. Maybe they didn’t tell me because they didn’t think I could handle it. I don’t know, but I’ve always felt very positive that I want to know what’s going on.
Apart from this she felt very well physically and was ready to return to her office job the next week. The way she spoke of her diagnosis was interesting. She spoke of this clearly and calmly and said that because of her faith in God she had been able to accept what had happened. When I asked her of the initial diagnosis she described the drama of her initial diagnosis after a grand mal fit whilst on holiday, the journey home, the unpleasantness of radiotherapy and her horror as all her hair fell out. I could not sense any anger or feelings of sadness or depression in her response and it surprised me that she should not feel great dismay at the seriousness of her situation. In fact she spoke at far greater length about other disappointments. She had a long term on-off relationship with a man whom she admitted did not reciprocate her love, but whom she felt unable to give up hope on. She was also disappointed in her career because the epilepsy she had suffered since her diagnosis had prevented her from fulfilling her vocation in a profession allied to medicine.

Case 5 (pilot)

A second patient who had survived 18 months from his diagnosis was a 46-year old waiter. I first met his man at a clinic I had been invited to sit in on. He and his wife had attended expecting to hear the results of a CT scan performed because he was becoming increasingly unsteady on his feet. One of the doctors had gone off to find the scan in the radiology department and the patient and his wife sat anxiously waiting for the doctor to return. I discussed the project with them and arranged to telephone them to confirm an appointment, but chose not to sit in on the consultation at which I expected them to have been told about the recurrence. A few weeks later I interviewed the patient on his own at home. He talked about the treatment he had received so far:

I had a new type of chemotherapy but it didn't seem to (make) any difference at all, probably because I had too much chemotherapy. I don't really know. You'll
have to ask the doctors that.

When I asked how his new scan had compared to the previous one, he replied:

It may have risen a bit as well. They’re not sure. They won’t know because they couldn’t find one of the scans, so they can’t say for definite.

Q: Did they describe what they could see?

They did yes. I think it’s more or less the same as what it was, yes. Because I’m taking the steroids and they’re to hold it, so whether it will or not I don’t know.

Some weeks later when the patient and his wife attended again a junior member of staff described the previous consultation to me:

His last scan showed that his tumour had recurred and well, we rather fudged the issue. Now he’s getting worse and I don’t know what we’re going to say now.

At this second consultation the doctors told the patient and his wife that the tumour had recurred and that there was nothing more that could be done. The patient’s wife later declined any further research interviews saying that I had heard what had been said and there was nothing more she felt they could contribute. She felt very angry and let down by the clinical team whom she felt had shown little interest in their problems. After this I decided not to sit in on clinic since it made my role as researcher too ambiguous.

*Case 6 (pilot)*

I saw a final patient for a pilot interview on the ward. He was a 50-year old man several years from his diagnosis. He was confined to bed and needed help with all self-care and even to sit up. He described the course of his illness from recurrence:

I said to Dr A, "at all times I like to know the estimate, you know, the starting price. And I think you can tell, or Dr A could tell. I came up here for the second lot of radium treatment and there was no improvement in my walking. If anything I was slightly worse. But I never said anything like, you know. I took full responsibility. I wouldn’t, no way, ever dream of blaming anyone in this hospital...They’re all diamonds as far as I’m concerned. They tried their best
and unfortunately their best wasn’t good enough. After I’d finished the treatment you could see straightaway that I wasn’t going to walk again and I couldn’t, it was impossible. And I said to Dr A, "what’s the bottom line?" So he said, "you’re going to be in a wheelchair for the rest of your life. How do feel about that?". So I said (I’m not exactly over the moon), "If that’s the way the cards will go, that’s the way you have to play them".

He then praised the community services he had received, described how long he had managed to work after his initial diagnosis, the difficulty he had found with not being able to work, and his luck in having kept his mental abilities and in having been able to remain at home despite his disability for so long. It was only finally when he began to describe the support he had received from his wife and the respect he felt for her that his voice began to waver. It was at this point that he requested we talk no more since he was finding it too upsetting.

His wife, whom I interviewed separately, also described his progressive disability and the various practical adaptations they had needed to make at home. She described how keenly he had felt the loss of his independence and the relief that the different aids and support services had brought at home. In hospital, however, she was distressed at the management of his incontinence but hoped that things might be easier once he was transferred to a hospice. When I asked if she worried how she was going to cope when he got there she dissolved into tears:

No. I just wish he would go now. I don’t want him to live any more. He doesn’t want to. He wouldn’t admit it to anybody else but he just doesn’t want to. When he knew he was coming in here he just kept asking me to give him his tablets. He always said he would do it, years ago in the beginning. He said, "if I became a burden to anybody ....but actually when it comes to the point where......I suppose he hasn’t felt he’s a burden. He has in a way, but he has accepted it much more. I always thought that he would be more suicidal than he is.....People cling onto every little bit of hope don’t they. I’ve seen it so often.
She then described how they had chosen the hymns for his funeral and some of her thoughts about her future alone.

Deductions following from these interviews

These interviews with patients at the point of tumour recurrence showed that the dawning of realisation that treatment had failed was not straightforward. There were stages to this process and it might take the patient and relative some time to realise what this meant. It also seemed possible, even at recurrence, that patients could be lulled into a false sense of security - if all had gone well up until now, it might be so again - in stark contrast to the perception of their doctors and myself as interviewer. The harshness of the situation was also clear. There was "no way out" except through the stages of severe disability. The agony of the relatives as this occurred and death approached was harrowing. There seemed therefore a similar range of awareness or coping as at diagnosis and, again, a lot seemed to depend, as far as the patient's experience was concerned, on the way that the carer (usually a spouse) and the patient talked about the situation. There was the hint that those who could speak openly were spared the additional tension of pretence about the situation and gained from the warmth they could convey to one another. Overall the themes I took from these first interviews were the following:

1) Apparent awareness of the reality of the situation (prognosis)

Here I divided awareness states into three - seeming not to know (cases 1, 4&5), trying not to know (relative case 3) and knowing (case 2, case 3(patient) and case 6 patient and relative).
2) Distress because of the situation

Here again there were three states - apparent absence of distress (in case 4 the patient showed religious acceptance and in case 5 the patient did not yet seem distressed), response present but suppressed or expressed in an unusual way (case 1 (failure to understand), case 2, (excited optimism) and relative case 3, (trying to be positive) and response present and expressed, case 3, (patient), case 6 (patient and relative).

3) Relationship with carer

Here there were two classifications - conflict about what should be acknowledged about the situation (case 3), and open acknowledgement of the situation (cases 2 and 6).

4) Impact of disability on different life roles

From the interviews emerged the idea of the range of different roles which could be affected for an individual. For example, the fourth patient felt unaffected and was well enough to work. The second patient was desperately unhappy at the loss of his creative ability whilst the sixth was completely unable to do anything for himself and abhorred his loss of independence.

5) Doctor-patient communication

The way patients recounted being told of their diagnosis and prognosis, and my own observations of management by clinicians, suggested that the situation could be led by either doctor openness or patient openness. For example, in the second and sixth case the doctor appeared to have taken a lead on disclosure, helped in one case by the
patient's frank manner. However, in the first and fifth cases the doctors had avoided discussing the issue of the prognosis. The fourth case was mixed in that one doctor appeared to have told the truth about the diagnosis after another team had given no information. The patient here argued that she saw herself as a person who wished to be told the truth although it was not clear whether she had been told of the prognosis. Whilst there is the suggestion that patients appreciate honesty the two doctors who avoided disclosure showed the personal difficulty they had in knowing what is best to tell each individual patient. Interestingly this clearly fits in with previous research Glaser and Strauss (1966) and Timmermans (1994) concerning different states of awareness amongst dying patients. Here I seemed to be observing the creation of some of these states. In a few cases doctors had not disclosed information about the prognosis which had led to periods for the patient of closed awareness for the patient. This unawareness was then broken by another doctor or by the progression of symptoms. One patient (case 5) may have been beginning to enter a period of suspicion awareness. Cases 2, 3 and 6 seemed to show open awareness between patient and doctor although in case 3 there was conflict between husband and wife about what should be acknowledged. There were thus two awareness contexts - that established between doctor and patient and that existing between patient and relative. The cases of closed awareness also seemed to fit well with Davis' observations (1973) of the way doctors could manage conditions of poor prognosis by allowing a "gradual dawning of realisation."
Stage 2 - The development of rating scales and a semi-structured interview schedule

Further interviews

The themes described formed the basis of further enquiry. Under each heading there was a rough description of the subject and a sketch of the scale covering the range of responses. These scales were developed more fully over the next 20 interviews. Here new data and examples were compared with the categories according to grounded theory (Glaser and Strauss, 1966). An example of an issue which emerged more clearly in this second set of interviews was that although patients varied widely in their awareness of the likely poor prognosis, relatives tended to be more aware of this than relatives (Davies & Clarke, 1993). Some relatives, for example, reported having asked the doctor directly about the prognosis and sometimes having decided what the patient should be told. For example,

I knew at once when he (the doctor) said it was serious, but I didn’t ask any more. I just want to take one day at a time. I don’t want to know what’s going to happen, and I’ve said to my children, I don’t want him to know either.

Relative case 1

Or:

He told me that if he operated she might have six months, maybe a year, so I told him that if she had that chance to go ahead. But no, I didn’t tell her that. I though if she got that chance she wouldn’t need to know.

Relative case 14

As more relatives could be interviewed separately it seemed in fact that at diagnosis few couples openly discussed for long the possibility of early death and that relatives often felt the need to protect patients from this knowledge. For example, an initial report, prepared for the Cancer Research Campaign was based on the first 25 patients receiving radiotherapy. These were mostly patients whom I had seen and the ratings were made once the rating scales had been developed but before they had been formally tested for reliability. Although most of these 25 patients seemed aware at diagnosis that their tumours were malignant, only
six were rated as giving a realistic account of their prognoses. By comparison two-thirds of their relatives or carers seemed to be aware of the poor prognosis for the disease. Most of the 25 patients felt well supported by their relatives or carers although it seemed that only six had actually discussed the prognosis together.

It seemed possible therefore to see the initial stage of the illness after diagnosis as one of coming to terms with the diagnosis and during this stage the level of awareness in a family about the prognosis might be set. This level of awareness could be influenced by either patient, relative or doctor, although it seemed that relatives and doctors more often took the lead. Once treatment had finished, however, the patient had to adapt to any change that had occurred. This involved coming to terms with a series of losses to their usual roles. I mentioned how patients seen for the pilot interviews talked of their inability to do things that were important for them and other examples of this were given. For example,

It's being at home all day with nothing to do - that really is the most difficult thing (50-year old man, pilot case 5)

Or:
I am a bit grotty because I can't do the things that I used to do (around the house). I always felt I did everything around here and now it's changed and I don't like it. It's very strange to me ....I appreciate what they're doing for me, still they don't do it as I did it....my control's all gone. (46-year old woman, case 6)

In the same group of the 25 initial patients I found that although most had been working before their diagnosis, only 40% were able to return to work in any capacity afterwards.

Finally as the tumour recurred there was a stage of deterioration and increasing disability, graphically described by the sixth patient seen for pilot interviews. Another man, as he entered this stage summed up his situation:

I felt so depressed this morning; I thought I've got to get out of this blasted bed,
wobble down to the bathroom, get downstairs and do the things of the day (59-year old man, case 7).

It seemed to make sense therefore to consider the interview data in terms of the phase of the illness trajectory rather than in terms of the exact time since the diagnosis. Thus I considered three stages in the analysis - coming to terms with the diagnosis, adapting to change during remission and a final stage of deterioration. As already mentioned, however, I planned that the research would go further than listing the themes which emerged, and that it would attempt to rate how common these were and whether some experiences could be related to others. Rating scales might therefore provide some quantitative data representing the frequency of different qualities of experience. This initial phase of the research can be summarised by the following stages:

1. Immersion in the experience under investigation, trying to understand its different aspects
2. Noting what seems to be important
3. Hypothesising what may be a causal process and pattern involved
4. Devising some way of representing the variable (in this case by a rating scale) so that causality or associations between different phenomena may be analysed later once more data had been collected.

**Development of the rating scales**

The development of rating scales is a step-wise process which feeds back on the development of the interview. A notion of a core component to an individual's experience is intuitively deduced from their account. In subsequent interviews further questions are asked with this
notion in mind. The observation may follow, for example, that a second patient mentioned the same notion but gave less significance to it, and that it was not at all relevant to a third patient. Both comments would be compared to check they related to the same dimension. A definition of the dimension would then be attempted including a statement of how it differed from other possible dimensions. When similar notions were mentioned in subsequent interviews the question would always be asked 'does it belong to the same dimension?'. The scale might then need to be altered when something new emerged that did not quite fit the previous conception calling into question the unity of the existing dimension. During this stage of the research there was a constant movement backwards and forwards between data, definition, and categorisation across dimensions and into categories in each dimension. In this research the process continued until the end of the inter-rater reliability study discussed later and involved the other two interviewers and I reflecting on the data.

The development and use of rating scales in this kind of research could therefore be described as both intuitive and classificatory. Intuitive skills are needed to understand the respondent's experience in their own terms, yet at the same time a facility to compare the experiences of different patients needs to be retained. Brown (1973) has argued that one way of describing this process is for the interviewer to see themselves as the measuring instrument employing their own empathic and classificatory skills. Using examples of scales for satisfaction with discussions with clinical staff I show how this process worked.

*Examples of developing scales for patient satisfaction with doctors' consultation style*

One of the main aims of the initial interviews was to explore how patients came to understand the poor prognosis, how they subsequently coped with and how this influenced
their decisions about treatment. However, it was immediately notable that patients could be very impressed with a doctor who had not appeared to tell them much at all about the poor prognosis. For example, the surgeon who had performed the biopsy could be thought completely honest since he or she had explained technical aspects of the operation in detail:

So they told me that an incision would have to be made and the hair would be shaved off. They peel the skin back and they don’t know whether they would actually have to take the bone away or whether they’ll drill into it....He doesn’t hold anything back. You know, to answer your questions and things like that. (Case 17)

Thus this patient saw the disclosure of information about technical aspects of the operation as indicating the competence and straightforwardness of the surgeon. He seemed to have found this reassuring and not "to realise" that information about the eventual poor prognosis was missing. However, whether or not the doctor tells the prognosis it is clearly important in the patient’s terms that their impression of the doctor has been good. Equally other patients, for example, pilot case 6 were very grateful for both technical expertise and honesty about the prognosis. One way of capturing this discrepancy was to record the patient’s general perception of the doctor as reassuring, concerned or open and to contrast this to what it appeared the doctor had told them. To assess how highly patients thought of their doctors I identified opposing statements representing the most positive and negative comments and used these to anchor the ends of 4-point scales ranging "marked", "moderate", "low" or "nil" for each of the areas of concern, reassurance and openness. A marked rating meant that respondents seemed pleased or impressed and a low rating that they were not. However, after 30 ratings of accounts of doctor-patient interaction I had found only one case where a patient felt that a doctor had shown concern but had not been reassuring. Since these two aspects could not be teased apart, I collapsed the two scales into one which I called "felt concern or reassurance". I retained "felt openness" as a separate scale with the aim of
picking up on the feelings of a patient who might have an idea that the doctor was not being entirely honest, but was pleased that he or she were not being blunt. For example,

I suppose all the time you really guess because Mr Y does...he gives you an inkling. 'He says I've taken a nice lot of material', you know, and you've got an idea. (Case 6)

In reality, however, it seemed too difficult for interviewers to agree in their ratings on this degree of subtlety and far easier to rate the difference between a patient who was clearly satisfied with how open the doctor had been compared to a patient who was dissatisfied and thought they should have been told more. For example,

I think I class myself as a sensible person and I want to be told the truth. Maybe they didn't tell me because they didn't think I could handle it. I don't know, but I've always felt very positive that I want to know what's going on. (Pilot case 4)

I then devised one scale called "rater's judgement about the ambiguity left by the doctor about the diagnosis" and a similar one for information about the prognosis. I wished to make a rating here, not of what the patient understood or wished to believe about the situation or of what they reported being told, but of what the interviewer thought it most likely that the doctor had said at the time. There were obvious difficulties with this kind of rating since the patient may not have been able or willing to recall the bad news consultation and this had not be observed. In the event the interviewers were only able to obtain moderate rather than good reliability on these ratings. Other studies have shown that it is possible to tape-record the consultation in which the news of the diagnosis of cancer is given so that patients can listen to the information later (Hogbin & Fallowfield, 1989). Access to such a recording would have helped clarify exactly what had been said in a consultation and it would theoretically be possible to carry out such a study in the future. In this study tape recording had not been planned so an attempt simply had to be made to estimate what it seemed likely had been said.

Although it was increasingly apparent that relatives or carers could often be relied upon to
recall what the patient had been told, that the scale could be no more than an approximation to what had actually happened remains a limitation of the study design. The final versions for all the scales are shown in the Appendix.

**Developing the interview schedule**

In developing the interview, questions that had appeared to tap a concern, or probes which had successfully provided clarification and seemed acceptable were also noted. For example, to determine what was understood about the prognosis I first asked the patient or relative to describe how they came to suspect that anything was wrong. As they recounted the "story" of their diagnosis I would ask questions like 'do you remember exactly what that doctor said?', or 'were they able to find out any more about the outlook in your particular case?'. This initially allowed the patient or relative to keep discussion of the diagnosis in the past tense so that they could distance any distress. Once the framework of events had been established, and it was clear what the respondent understood about the situation, I would move the discussion of reactions and implications into the present tense, for example, 'do you feel any differently about it now?'. Even though patients were being studied because they suffered from tumours with a particularly poor prognosis, I would never assume that they fully understood this nor would I volunteer information if it became clear that either patient or relative had an incomplete or false picture. The final interview schedule is also shown in the Appendix.

**Training for interviewing**

I came to this research project having studied both medical sociology and medicine. I had
worked looking after cancer patients including a small number of patients with brain
tumours. I had also attended a training course for the Life Events and Difficulties Interview
Schedule (LEDS, 1998) - a detailed semi-structured interview and accompanying set of rating
scales which can be used to identify life events and difficulties prior to the onset of
psychiatric disorder (Brown & Harris, 1978). My own training for this project was a series
of supervisory sessions by Sheila Hillier and George Brown, each professors of sociology.
They listened to some of the first interviews with patients and relatives and identified points
in the interviews where I could have elicited more information, where I had missed a non-
verbal cues or where I had been too direct or blunt in my questioning. They also suggested
themes that I should explore further and gave their own insights about the interview material.
I also discussed my initial ideas in some detail with Charles Clarke and Anthony Hopkins.
Both were neurologists who had looked after a large number of patients with malignant brain
tumours and they brought their own insights to the case material. They found my initial
impression that patients did not always appear to be told about the poor prognosis compatible
with their own clinical experience. They emphasised, however, the possibility of making
some assessment of what it seemed likely that the patient had actually been told and of
looking at the varying ways in which patients coped with this information.

Stage 3 - Managing data collection by three interviewers - reliability

During the second stage I had defined a large number of the rating scales in the manner I
have already described. Data collection for the main study, however, was shared with two
other interviewers, one with a background in sociology, literacy and counselling and the
other in psychology. The different perspectives that each interviewer brought to the interview
data meant there was the possibility of considerable variation in the interpretation of the interviews and in the way that these ratings might be made. There were two tasks to accomplish - first to ensure that we all collected relevant data in a similar but sensitive manner, and second, that all three of us rated this data in the same way. By the time the first interviewer was appointed I had conducted the first 20 interviews, prepared an interview schedule and collated a manual including definitions and supporting quotes for each of the 4-point scales. The second interviewer joined about a year later. Before seeing patients and relatives themselves, the interviewers read transcriptions and listened to tape-recordings of the interviews I had conducted. They made notes on these, read through the manual and asked questions. I used these discussions to explain the principles of the interview technique pointing out examples of the questions and probes which had been useful and acceptable. The interviewers then tried to rate the data within these interviews and we discussed any disagreements. After several weeks the interviewers felt confident enough to conduct an interview themselves. I listened to the interviews, noting their general sense of ease, the form of the questions they asked, the data they collected and made suggestions about how further areas could have been explored. In fact these first interviews often contained nearly enough data to rate most of the scales. A pattern to the work then emerged naturally, with the interviewers wishing to discuss an interview when they returned to the office immediately afterwards. This served several functions. First, given that the interviews covered such a distressing topic, they might want to be reassured that they had managed this well. Second, the interviews demanded a high level of concentration if we were to remain sensitive to the needs of the respondent whilst continuing to collect data in a thorough manner. Furthermore, the interviews could be emotionally demanding and, there was no escape from the fact that further interviews were likely to bring news that the patient was deteriorating or dying.
Sometimes interviewers would feel overwhelmed and feel they needed some respite, but with consecutive recruitment and follow-up interviews becoming due the pace of interviewing could not be slackened. Thus this discussion after the interviews, often quite detailed, served as a debriefing, allowing the interviewer the sense of having off-loaded some of the emotional content onto the others. The constant exchange of information about data and ideas sometimes revealed aspects which the manual had omitted, and it led to the refinement of some of the scales. It also meant that I could keep up to date with developments for all patients without needing to listen to each tape recording. In listening to the accounts given by interviewers I could ask questions about the amount of data they had collected and point out where I thought they could have asked more questions; in effect this served as an ongoing quality check on data collection.

**Establishing inter-rater reliability**

The constant discussion between the interviewers about the issues that seemed important for patients and relatives was the beginning of the process of achieving inter-reliability for data coding. However, finally obtaining this reliability formally was lengthy and not achieved until fairly late in the data collection period. There were two stages - an initial practise stage followed by a formal reliability study. In each stage the three interviewers independently rated 13 interviews - an exercise which generated 39 pairs of ratings which could be compared. Most scales required one such practice run where disagreements about the interpretation of the data or the scales could be discussed. These generally revealed ambiguities in the manual so that the definitions or points on the scale needed to be rewritten. if this occurred further transcripts were then rated, again independently by all three interviewers, to see if there were fewer disagreements. Once no major disagreement
emerged a formal reliability study of a further 13 interviews began. In this the ratings of different interviewers were compared an equal number of times for the level of agreement using Kappa (Brennan & Silman, 1992). A scale was not considered acceptable until a Kappa value of 0.6 was obtained (see table 8). For some scales the initial reliability of 13 interviews was poor, and a further period of practice was needed before another formal attempt at reliability was made. For some scales it proved extremely difficult to obtain even modest agreement even though the interviewers intuitively agreed that the particular areas was important and should be rated. This was the case for the topics of denial, uncertainty, seeking meaning and the extent to which we thought the patient and relative had discussed the prognosis (see table 9). Sometimes two interviewers would agree exactly and try and encourage the other to see their point of view. At worst ratings seemed to agree no more than by chance. In these cases I persevered through argument as much as through discussion until we had refined as far as possible what we thought we wished to measure, what we agreed on, and what we wished to measure, and explained why we had disagreed. If more than 100 pairs of ratings did not result in satisfactory agreement on a four-point scale, the scale was collapsed to two-points, and if this did not work then the scale was abandoned. For some scales the presence or absence of a concern seemed far easier to record than the degree of its presence. For example, this was the case for the scale "felt openness of the doctor" already described. By the end of this process, and before any rating of the interview data took place, there was good agreement (Kappa > .60) on 25 scales (15 with 4 points and 10 with 2, as shown in table 8). From start to finish the reliability study took four months to complete, considerably longer than I had expected. This exercise showed the bias that might have been introduced had the study relied on the decisions of one interviewer either for a conceptual analysis or for judgements about the way the ratings should be made.
Table 8 - Inter-rater reliability study for 13 interviews

<table>
<thead>
<tr>
<th>Detail*</th>
<th>Kappa**</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>4 point scale</td>
</tr>
<tr>
<td>Satisfaction with medical care</td>
<td></td>
</tr>
<tr>
<td>Felt concern of doctor</td>
<td>0.72</td>
</tr>
<tr>
<td>Felt openness of doctor</td>
<td></td>
</tr>
<tr>
<td>Felt support from general practitioner</td>
<td>0.72</td>
</tr>
<tr>
<td>Felt overall co-ordination in care</td>
<td>0.70</td>
</tr>
<tr>
<td>Felt coherence in information</td>
<td>0.62</td>
</tr>
<tr>
<td>Felt ability of the system to deal with distress</td>
<td>1.00</td>
</tr>
<tr>
<td>Awareness of the likely prognosis</td>
<td></td>
</tr>
<tr>
<td>Belief in the possibility of cure</td>
<td>-</td>
</tr>
<tr>
<td>Thoughts about the possibility of death</td>
<td>0.70</td>
</tr>
<tr>
<td>Satisfaction with treatment</td>
<td></td>
</tr>
<tr>
<td>Overall satisfaction with radiotherapy</td>
<td>-</td>
</tr>
<tr>
<td>Negative comments about radiotherapy</td>
<td>0.76</td>
</tr>
<tr>
<td>Overall satisfaction with surgery</td>
<td>-</td>
</tr>
<tr>
<td>Distress over hair loss</td>
<td>0.67</td>
</tr>
<tr>
<td>Coping strategies</td>
<td></td>
</tr>
<tr>
<td>Anger</td>
<td>0.75</td>
</tr>
<tr>
<td>Acceptance</td>
<td>0.60</td>
</tr>
<tr>
<td>Positive appraisal</td>
<td>0.70</td>
</tr>
<tr>
<td>Control</td>
<td>0.64</td>
</tr>
<tr>
<td>Avoidance</td>
<td></td>
</tr>
<tr>
<td>Problems caused by the illness in everyday life</td>
<td></td>
</tr>
<tr>
<td>Hobbies or interests</td>
<td>-</td>
</tr>
<tr>
<td>Household tasks</td>
<td>-</td>
</tr>
<tr>
<td>Social life</td>
<td>-</td>
</tr>
<tr>
<td>Self care</td>
<td>-</td>
</tr>
<tr>
<td>Cognitive ability</td>
<td>-</td>
</tr>
<tr>
<td>Social support</td>
<td></td>
</tr>
<tr>
<td>Perceived support from relative or carer</td>
<td>0.67</td>
</tr>
<tr>
<td>Perceived religious support</td>
<td>0.81</td>
</tr>
<tr>
<td>Overall distress</td>
<td>0.66</td>
</tr>
</tbody>
</table>

* I show here all the scales that were developed although in this thesis I report data concerning awareness of the likely prognosis, satisfaction with treatment, problems caused by the illness in everyday life, felt support from carer and distress

**I have listed Kappa for reliability on the 2 point scales only when it was not possible to achieve good agreement on 4 point scales.
Overall it seemed that the more subtle aspects of the situation were more difficult to rate. It is possible, however, that there may have been too many scales to learn how to rate in the time available, and a further period of concentrated training on the remaining scales might have improved their reliability.

Table 9 - Scales where inter-rater reliability failed (Kappa < 0.40)

<table>
<thead>
<tr>
<th>Detail</th>
</tr>
</thead>
<tbody>
<tr>
<td>Satisfaction with treatment</td>
</tr>
<tr>
<td>Positive comments about surgery</td>
</tr>
<tr>
<td>Positive comments about radiotherapy</td>
</tr>
<tr>
<td>Coping strategies</td>
</tr>
<tr>
<td>Felt independence</td>
</tr>
<tr>
<td>Denial</td>
</tr>
<tr>
<td>Seeking meaning</td>
</tr>
<tr>
<td>Felt uncertainty</td>
</tr>
<tr>
<td>Problems caused by the illness in everyday life</td>
</tr>
<tr>
<td>Work*</td>
</tr>
<tr>
<td>Social support</td>
</tr>
<tr>
<td>Discussion of the diagnosis with carer or relative</td>
</tr>
</tbody>
</table>

* The problem here seemed to be reaching agreement on whether the patient really wanted to return to work, and therefore whether they saw the loss of this role as important to them

Procedure for rating data for the main study

Before rating the main part of the interview data the manual was finally updated to include changes to scales made during the reliability study. All but a handful of the tape-recorded interviews were transcribed. This work was carried out by medical secretaries working on a part-time basis for the project. Usually transcription for social science research is costly
but by employing medical secretaries who were particularly skilled at audiotape work I could minimise the costs. Nevertheless the transcription of over 400 interviews was a major investment of resources. For the most part interviewers made their ratings alone using the transcriptions but where we felt uncertainty these were discussed as a group. In addition disagreements over ratings used for the reliability study were settled by consensus before being entered into the main analysis. All the interviews were re-rated using the scales for which inter-rater reliability had been achieved.

**Threats to the validity of semi-structured interviews and ratings scales**

So far I have concentrated on the number of checks included to make data collection and rating as systematic and reliable as possible. The fact that three interviewers were able to agree about the use of a rating scale suggests that the scales might represent to a reasonable degree one of the experiences under investigation, but the validity of the method still needs to be considered. There are several criticisms that could be made here. Some of these concern the method itself but others could be made about the way this study was conducted.

The assessment of rigour in research that incorporates a substantial amount of qualitative work, and relies on the interpretation of the researchers has been discussed (Mays & Pope, 1995). There is the possibly that during the development of the interview I gave particular attention to some issues in preference to others because of my own interests, background and personality. In doing so I may have made a number of false assumptions about what was actually important. Such potential biases are problematic since I would by definition be unaware of them. It is therefore only possible to report what initially seemed important based on the accounts patients gave. I chose not to check the validity of these decisions by
explicitly asking patients their views on the research categorisations I had made or to rank the importance of different areas being rated. Realistically it seemed insensitive to ask an individual whether, for example, it is more important to them to know that they are dying than the fact that they are severely disabled. Biases in the subjects chosen for rating scales may have been reduced by the iterative process of the development that when hand in hand with data collection, the fact that these appeared to make sense to my clinical and sociological supervisors, and that two other interviewers could work with them to the extent of obtaining a reasonable degree of inter-rater reliability. However, it could still be argued that we all simply came to agree as the easiest course to take.

There is then the question of the degree to which patient experience can or should be rated by an observer. Although the categories chosen for rating scales are informed by patient reflections, ultimately they are only a perspective on these experiences. The data from patient accounts is picked out as important because it looks as if it might be useful for answering a clinical question about the trade off between quality and length of life. This question is not one therefore that arose out of all patient accounts, although one could find evidence for it in some interviews. Rather, this research aims to provide insight into the situation using data from patient interviews. This kind of research is always open to the criticism that judgements are being made about respondents, categorising or fragmenting and therefore demeaning their experience. Research using interviews and rating scales, however, rests on the assumption that the complexity of patient experience can be adequately reflected in a categorical analysis because human intuitive and empathic skills work by way of understanding and classifying much of social interaction (Brown, 1973). The opposite argument is the position of relativism that the experience of others can never be entirely
known, and that the observations of researchers reveal more about current frameworks of knowledge and themselves than they do about the people that study.

A further criticism of this approach is that it erroneously mixes qualitative and quantitative approaches. For example, Weiss (1994), Plant (1996) and other writers describing interview research make the point that this method can only reveal insights into the processes at work and can never be used to prove causal links. Fitzpatrick and Boulton (1994) also distinguish between the conceptual analyses of qualitative research versus the numerate analyses of quantitative work and see the two as entirely separate. However, conceptual analyses are not possible without categorisation and this immediately raises the issue of how reliable these categories are. In other words what information can the categories give us about how well they represent the experience they purport to and how commonly that experience occurs? This gives an idea of how much significance to attach to that particular insight. Furthermore, without some implicit categorisation it is difficult to see how a researcher could communicate their findings. Mays & Pope (1995) set out criteria by which qualitative analysis should be judged and include the question of whether the analysis could be repeated by another observer using the same methods. Such an observer could, in this study, have access to all the data in the form of transcripts and could attempt to use the manual to rate this material. However, I did not document in great detail the iterative process of development, nor did I ask another researcher to repeat the quantitative analysis that was based on the categories that arose out of the qualitative analysis. Ultimately therefore the verdict on this research must lie in the coherence of the findings and how sensible or useful they seem in terms of the potentially understanding or diminishing suffering.
CHAPTER 6

PATIENT AND RELATIVE PERSPECTIVES ON THE VALUE OF RADIOTHERAPY DURING THE ILLNESS

Introduction

In this chapter I first describe the demographic characteristics of the sample. Results for ratings of patient and relative awareness of the likely prognosis shortly after the diagnosis are presented first. These ratings are then compared with the ratings for overall distress reported or conveyed in the interviews. Ratings for negative comments made by patients about radiotherapy, and ratings of their overall satisfaction with radiotherapy are then compared over the course of the illness. Ratings of whether or not the patient reported fewer problems due to the disease affecting their everyday life after radiotherapy are used to deduce the proportion of patients achieving an improvement or period of stability after treatment. These results and those presented subsequently in chapter 7 are discussed in the final chapter.

RESULTS

Demographic characteristics of patients and relatives

Table 10 summarises some demographic characteristics of the sample. Two thirds of the patients were male and 41% were from professional and managerial classes (OPCS, 1991). Sixty-nine percent of carers were female and most carers were spouses or partners (71/91, 78%). As explained in chapter 3 some of the patients who were seen and assessed for disability and included in this study were too confused to interview properly. Thus the 13 patients who received conservative treatment with steroids and eight of the 92 patients receiving radiotherapy could not be interviewed. A further nine of the 92 receiving

---

1 These figures for social class are comparable to those the data given by Social Trends (1995) for the United Kingdom.

133
Table 10 - Demographic characteristics of 105 patients 91 relatives. Figures are numbers (percentages) of subjects.

<table>
<thead>
<tr>
<th></th>
<th>Patients</th>
<th>Relatives</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>21-44</td>
<td>26 (25)</td>
<td>30 (33)</td>
</tr>
<tr>
<td>45-59</td>
<td>39 (37)</td>
<td>35 (38)</td>
</tr>
<tr>
<td>60-75</td>
<td>40 (38)</td>
<td>26 (29)</td>
</tr>
<tr>
<td><strong>Sex:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>72 (69)</td>
<td>29 (31)</td>
</tr>
<tr>
<td>Female</td>
<td>33 (31)</td>
<td>62 (69)</td>
</tr>
<tr>
<td><strong>Racial origin:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Afro-Caribbean</td>
<td>2 (2)</td>
<td>2 (2)</td>
</tr>
<tr>
<td>Asian</td>
<td>5 (5)</td>
<td>2 (2)</td>
</tr>
<tr>
<td>White</td>
<td>98 (93)</td>
<td>87 (96)</td>
</tr>
<tr>
<td><strong>Age leaving full-time education:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16 or younger</td>
<td>53 (58) *</td>
<td>49 (56)**</td>
</tr>
<tr>
<td>18</td>
<td>18 (20)</td>
<td>26 (30)</td>
</tr>
<tr>
<td>21 or older</td>
<td>20 (22)</td>
<td>12 (14)</td>
</tr>
<tr>
<td><strong>Social class (OPCS, 1991):</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I</td>
<td>12 (11)</td>
<td>12 (13)</td>
</tr>
<tr>
<td>II</td>
<td>31 (30)</td>
<td>27 (13)</td>
</tr>
<tr>
<td>IIINM</td>
<td>23 (22)</td>
<td>25 (27)</td>
</tr>
<tr>
<td>IIIM</td>
<td>25 (23)</td>
<td>17 (19)</td>
</tr>
<tr>
<td>IV</td>
<td>6 (6)</td>
<td>4 (4)</td>
</tr>
<tr>
<td>V</td>
<td>8 (9)</td>
<td>6 (7)</td>
</tr>
<tr>
<td><strong>Marital status:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>11 (10)</td>
<td>9 (10)</td>
</tr>
<tr>
<td>Married/Cohabiting</td>
<td>82 (78)</td>
<td>78 (86)</td>
</tr>
<tr>
<td>Widowed</td>
<td>6 (6)</td>
<td>1 (1)</td>
</tr>
<tr>
<td>Divorced</td>
<td>6 (6)</td>
<td>3 (4)</td>
</tr>
</tbody>
</table>

* Missing data in 14 cases, ** Missing data in 4 cases.
radiotherapy were referred too late to the study to be interviewed at diagnosis (defined as a contact within three months of surgery). Interview data is therefore available for 75 patients at diagnosis. The patients interviewed did not differ in demographic features from the full study sample of 105 patients. Fifty-nine patients receiving radiotherapy were seen for at least one follow-up interview and 27 could be seen again at a time when they had deteriorated after an initial period of stabilisation or improvement. Severe illness of or obvious confusion prevented further patients being seen at this stage of the illness (see chapter 3).

AWARENESS OF THE PROGNOSIS

The patients

As already described in interviews after the diagnosis patients were asked to recount in detail what they had been told in their medical encounters and what had been said by relatives and friends. Ratings of their accounts showed that most patients receiving radiotherapy understood they suffered from a brain tumour (95%, 71/75). Awareness of the prognosis, however, varied considerably. I defined three levels of awareness to represent the degree to which the patient conveyed a conscious knowledge of the situation that seemed to approximate the medical facts about their likely prognosis. Fully aware patients were therefore those who conveyed that they had a malignant brain tumour which carried a poor prognosis and that treatment was largely palliative. Partly aware patients were those who conveyed some idea that treatment might not be successful but who seemed to believe that there was a reasonable chance that their tumours could be cured. Unaware patients were those who did not seem to have considered the possibility that treatment would be anything other than successful and who saw cure as the most likely outcome. Patient were placed in these different levels of awareness on the basis of ratings from two separate scales - belief
in the possibility of cure and thoughts about the possibility of death. The psychological viewpoint to the development of these scales was to remain close to what patients and relatives said in the interviews or clearly implied, rather than what we felt they might unconsciously know. I was interested here in rating the level of awareness about the prognosis that they conveyed in an interview situation and which I therefore thought that a doctor might be able to elicit in conversations with them about treatment. This is because I was interested in the extent to which patients might consciously make a trade off between quality and length of life rather than inferences about what patients might "really know deep down". I would argue that knowledge at such an unconscious level is of little use to those around the patient unless the patient is clearly able to act on it or convey to others their wishes. In other words such knowledge is not "effective knowledge". I will, however, return to this point later in my discussion of the usefulness of the results. Thus to be classed as fully aware the patient had to have been rated as low on the scale belief in the possibility of cure and marked, moderate or some on thoughts about the possibility of death. To be classed as unaware a patient was rated as high on belief in the possibility of cure and nil on thoughts about the possibility of death. Judged by these standards, only one quarter (19/75) were fully aware of the prognosis, conveying that there was little chance of cure and expressing some thoughts or fears about the possibility that they might die. A 56-year old man with a parietal tumour, for example, spoke frankly about radiotherapy:

Well fundamentally it just delays the process. It doesn’t stop it. Wish to God it did but it doesn’t. We talk about it all the time that I’m going to die, that it’s going to happen after Christmas or whenever.

Just under a third of patients (24/75) were rated as being partly aware of the likely outcome. One 40-year old man with a frontal tumour, for example, remarked:

The family are still frightened that something might happen. Do you know what
I mean? Because you read about it in the papers everyday don’t you - this trouble? Cancer - person dies from brain tumour. So I suppose it’s at the back of your mind as well.

Such patients usually conveyed some fear of dying but also that they had a reasonable chance of cure (some thoughts about the possibility of death and high belief in the possibility of cure. However as many as 43% (32/75) of patients conveyed in the interviews practically no awareness that they might die. One 40-year old man with an occipital tumour, for example, when asked about the chance of cure said,

I didn’t specifically ask the surgeon. He spoke as if it were pretty certain. I can see that people who had only biopsy and growths in awkward places, that there would be a question mark over how complete treatment would be. But in my case, because it seemed to be something that was on the surface...then you should be able to wipe it out completely.

Did awareness of the likely prognosis relate to aspects of disease state?

I had initially thought that the optimism of some patients might be explained by the high doses of steroids they had been prescribed and obtained data on the patient’s dose at the time of the interview in 62 cases. A comparison of low dose (0-2mg) with moderate (3-8mg) and high doses (9-32mg) of steroid, however, showed this had no influence on the level of awareness (see table 11). It is possible that it was the dose of steroid that the patient was taking at the time that they were told of the prognosis that was critical here, but data on this was not available for analysis.
Table 11 - Awareness of the likely prognosis and steroid dose at interview for 62 patients
Figures are numbers (percentages) of patients.

<table>
<thead>
<tr>
<th>Steroid dose at interview</th>
<th>Fully aware</th>
<th>Partial awareness</th>
<th>Unaware</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>2mg or less</td>
<td>2(13)</td>
<td>6(30)</td>
<td>6(23)</td>
<td>14</td>
</tr>
<tr>
<td>3-8mg</td>
<td>10(63)</td>
<td>8(40)</td>
<td>13(50)</td>
<td>31</td>
</tr>
<tr>
<td>9-36mg</td>
<td>4(29)</td>
<td>6(30)</td>
<td>7(27)</td>
<td>17</td>
</tr>
<tr>
<td>Total</td>
<td>16</td>
<td>20</td>
<td>26</td>
<td>62</td>
</tr>
</tbody>
</table>

I then explored whether patient awareness of the prognosis was related to disease factors associated with the likely prognosis i.e. was it the patients who faced the poorest prognoses who had most awareness of this. In chapter 3 I showed that the initial clinical performance status was as good an indicator of the patient's eventual prognosis as the MRC prognostic index, and that this also gave an indication of the length of time a patient was likely to remain free from disability. I therefore chose to use the clinical performance status as an indicator of the likely prognosis and to relate this to the level of awareness about the likely prognosis that the patient had been rated as showing. Here I found that amongst those with the best prognoses and an initial clinical performance status of 0-1, 40%(8/20) of patients showed full awareness of the likely prognosis compared to 32%(7/22) of those with the worse prognosis (clinical performance status 3-4). Interestingly those with a intermediate prognosis - clinical performance status 2 - showed the lowest awareness of the likely prognosis. Only 15%(5/33) in this group were rated as being fully aware, but this difference did not reach statistical significance (X² 4.35, df 2, p < .2).
The relatives

Sixty-six of these 75 patients had relatives who could also be interviewed at diagnosis. Amongst these relatives full awareness of the likely poor prognosis was three times more common than amongst the patient group - 67% (44/66) versus 21% (14/66) (see table 12). The wife of the unaware patient quoted above said:

They told my husband it was a tumour, but they didn’t tell him about the prognosis or anything like that...I caught the surgeon in the corridor and he said that my husband could have been dead in a month if he hadn’t had the operation. He said that some people did well - it could be 18 months, or even 5 years but not really - 5 years was quite rare. It knocked me for six.

The implications of such news was also often spelt out. A 50-year old husband remarked:

From now on we’re living with a death sentence. The doctors said the tumour could come back quite easily and I got the feeling they were expecting it to.

Only 9% (6/66) of relatives were unaware of the likely prognosis. The agreement between awareness of patients and relatives was poor (Kappa=0.20). Moreover, there was a consistent tendency for patients to show less awareness (39 out of 66 comparisons between patients and relatives). On the whole relatives tended to see their role as one of remaining strong to protect the patient in the hope that they would be among the most fortunate. It was not uncommon for them to convey that to be explicit about the prognosis would be harmful:

If you say you’ve got six months or whatever, it does mentally act as a sentence to that person.
Table 12 - Comparing patient and relative or carer awareness of the likely prognosis shortly after diagnosis.

<table>
<thead>
<tr>
<th>Relative awareness of the likely prognosis (n=66)</th>
<th>Fully aware</th>
<th>Some idea</th>
<th>Unaware</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient awareness of the likely prognosis (n=66)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fully aware</td>
<td>13</td>
<td>1</td>
<td>-</td>
<td>14</td>
</tr>
<tr>
<td>Some idea</td>
<td>15</td>
<td>7</td>
<td>-</td>
<td>22</td>
</tr>
<tr>
<td>Unaware</td>
<td>16</td>
<td>8</td>
<td>6</td>
<td>30</td>
</tr>
<tr>
<td>Total</td>
<td>44</td>
<td>16</td>
<td>6</td>
<td>66</td>
</tr>
</tbody>
</table>

DISTRESS EXPERIENCED BY PATIENTS AND THEIR RELATIVES

Despite the seriousness of the condition patients were less distressed than I had initially expected. I chose to make a rating of distress which took account of all the concerns expressed and the degree of emotion that was conveyed during an interview. Patients or relatives constantly upset and overwhelmed by the situation were rated as highly distressed.

For example, a woman of 65 with severe disability said:

I feel sad all the time now. I think about whether I might die....I don’t want to be a burden to my children...It’s not a very nice thing is it? I thought it was upsetting because nobody seemed interested you see. (Case 19)

Another patient, in her thirties said:

I just can’t be bothered to do anything. I don’t know why, I’m not usually like that. I just leave things .. I think "Well, what’s the point?" Pathetic, really. I cry
about certain things, sometimes I have a snivel. I must admit I do feel anxious quite a lot... If I could relax, be less anxious, not be so paranoid... I don’t feel I’ve got much quality of life at the moment. (Case 80)

Patients or relatives who felt upset and anxious a good deal of the time but found pleasure in some aspects of life were rated as moderately distressed. For example, one patient in his forties (case 2) showed anger and paranoia and complained of poor sleep and lack of concentration. However, at the same time he was enjoying planning a holiday and future projects at work. In the analysis a dichotomy was made at this level between those patients showing marked and moderate and other patients who showed less distress. Those feeling only occasionally depressed, anxious or dismayed, or remaining generally cheerful were rated as showing little or no distress. For example, a man in his thirties remarked:

I was in a very sort of grim stage for quite a time about the whole business of dying possibly, how shall I say, yes, I don’t know, just I was dying very young or something, that sort of thing. I was scared of the actual disease. I suppose I’m not at all scared of it in a way these days. I’m just more at one with it (Case 99).

Another patient in his forties (case 12) described how he felt that his illness has reaffirmed his religious belief and given him a purpose in his community. He felt sad when he thought of the end of his earthly life and that this would mean parting from his family. He felt tearful but explained this as being is due to the steroids and said that in fact he felt great joy.

Of the 75 patients who could be interviewed within three months of the diagnosis, only 8% (6/75) were rated as highly distressed. These six patients appeared severely depressed or anxious and one expressed extreme anger. One fifth (16/75) showed a moderate level of distress, but more than two-thirds of the patients (53/75) felt only occasionally depressed, anxious or dismayed, and remained generally cheerful or confident. The level of the patient’s distress related to their awareness of the prognosis ( \( \hat{\rho}=0.53 \), table 13). Fifty-eight percent
(11/19) of the fully aware showed marked or moderate distress compared with one quarter of those partly aware (6/24), and 16% of those unaware (5/32) ($X^2$ for trend = 9.53, 1 df, $p < .01$).

Table 13 - Patient awareness of the likely prognosis and distress shortly after the diagnosis. Figures are numbers (percentages) of patients.

<table>
<thead>
<tr>
<th>Patient distress</th>
<th>No patients</th>
<th>Nil</th>
<th>Some</th>
<th>Marked/ Moderate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Awareness</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>of the likely</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>prognosis</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Full awareness</td>
<td>19</td>
<td>2(11)</td>
<td>6(32)</td>
<td>11(58)</td>
</tr>
<tr>
<td>Partial awareness</td>
<td>24</td>
<td>5(21)</td>
<td>13(54)</td>
<td>6(25)</td>
</tr>
<tr>
<td>No idea</td>
<td>32</td>
<td>14(44)</td>
<td>13(41)</td>
<td>5(16)</td>
</tr>
</tbody>
</table>

Although it was more likely therefore for patients to be more distressed the more they appeared to appreciate of their likely prognosis there was a sizable proportion of patients who were able to cope in a way with this information which kept their distress from overwhelming them. In clear contrast to patients, however, nearly two-thirds of relatives experienced a marked or moderate level of distress (64%; 42/66). In most instances, relatives were in fact more distressed than the patients they cared for (58%; 38/66); in only a few instances did the patient appear more distressed (14%; 9/66). Too few relatives remained unaware of the prognosis to explore whether this factor was associated with lower levels of distress amongst this group.
VIEWS ABOUT RADIOTHERAPY

Initial dissatisfaction with radiotherapy

A substantial number of patients (39%, 29/75) made marked or moderate negative comments about radiotherapy at the initial interviews, expressing their dislike of the procedure, adverse effects or doubt about its value. For example,

I found the radiotherapy quite unpleasant. I almost wish they'd operated rather than have to go through the radiotherapy....The department is a rather depressing place. I mean I can still smell it - a horrible acrid smell - and it seemed to linger afterwards...I'd touch my hair and literally a whole handful...and I'd put it in the bag for rubbish and I'd feel "Oh God", you know, "What are people going to think in the morning?" I knew it was going to happen but it was still a shock. (Case 4 (pilot))

Or:

My hand improves very slowly during the week. It improves rapidly at the weekend when I'm not receiving the radiation dose and then it slows down again during the week. I know what they are doing and it is quite horrendous. It is quite a horrendous dose, you know, which is something like ten and a half times what we work to in Administrative Health as a yearly dose. The first Wednesday of the radiation treatment I had a focal fit....I proceeded with the first treatment and I had another one when I tried to turn over for the radiation to the other side...I had another one so I abandoned the treatment. (Case 89)

Such negative comments about radiotherapy were more common amongst patients with marked or moderate distress - 59%(13/22) vs 30% (16/53) with little or no distress; (X²=4.33, p < .05), but such comments did not relate to awareness of the prognosis or initial clinical performance status. However, making negative comments about radiotherapy did not mean that at the same time the patient was not also positive in some way about the treatment. Given that only one quarter of the patients seemed fully aware of the likely poor prognosis, it would be misleading to interpret the fact that they expressed negative feelings about treatment as indicating overall dissatisfaction with the treatment. Instead, using a separate scale called "overall satisfaction with radiotherapy" a very high threshold for dissatisfaction
was taken to indicate serious dissatisfaction with radiotherapy with no positive statements such that had a patient realised that the prognosis was so poor it might reasonably be assumed that they would have doubts about undergoing the treatment. Only one fifth of the patient sample (17%, 13/75) was rated as being dissatisfied in an overall sense, however, since they showed considerable reluctance about undergoing radiotherapy. This level of dissatisfaction tended to be more common amongst patients who were fully aware of the prognosis - 32% (6/19) v 11% (6/56) of those partly aware or unaware (X²=3.17, 1df, p<.1) but this difference was not significant.

The fact that most of the patients in this study seemed to be unaware of the likely poor prognosis raises an interesting methodological problem. The initial research question was framed in terms of the potential trade off that patients might need to make about accepting treatment in this situation which might possibly diminish the quality of their life, and which carried a limited chance of prolonging their life for a short period of time. This question is in fact one framed from the perspective of the concerned outsider in full possession of the medical facts. What the analysis so far has shown is that the awareness of the likely prognosis possessed by patients does not approach that held by the medical profession when they debate the treatment of this disease. The views of patients about their treatment - the satisfaction or otherwise therefore has to be seen in the context of their orientation towards "the facts". Thus although overall I have shown that about one fifth of patients expressed a degree of dissatisfaction with radiotherapy which might have suggested that they regretted undergoing this treatment, this has to be seen in the context that only one quarter of patients appeared to share an appreciation of the prognosis with their doctors. We do not know whether if more patients had appeared to have full awareness of the likely prognosis, more
or less would have expressed dissatisfaction with radiotherapy. One rather forthright way around these difficulties would have been to have explained a little more of the prognosis to the patients in the interviews and then, or at a later date, asked for their views, but clearly this would not have been easy. Although a doctor caring for a patient may have raised these issues challenging the patient’s awareness within the context of a clinical consultation, such action by interviewers would, I believe, have been unethical with patients who showed little appreciation of their prognosis. It may be that they had not clearly been appraised of the facts of their case, but it always remained possible that "at some deeper level" they were fully aware and had chosen to deny or avoid this information, or had simply chosen not to share this within the interview. The possibility of such strategies needed to be respected. For these reasons I thought it appropriate that we should explore in a straightforward manner the decision to accept radiotherapy only with the 19 patients fully aware of the prognosis. Of these, six accepted treatment with reluctance because they saw no alternative but remained dissatisfied. Four accepted treatment as it had been medically advised and nine believed they could increase their survival by fighting the disease, having accepted radiotherapy for the chance of survival it brought:

I began to fight it, just began to start the battle... What I am doing is living for the future. I would like to think that I’ve got at least a year or so, or more. I’m thinking if you like of a strategy in that I’ve got to get planned what I can do.

Patient improvement, deterioration and subsequent dissatisfaction with radiotherapy

In chapter 3 I showed that the patient’s initial disability assessed by the WHO Clinical Performance Status (World Health Organisation, 1979) was an important prognostic factor. I have already compared this variable to the patient’s apparent awareness of their likely prognosis, and it therefore seemed sensible to compare this measure with patients’ own views
about their problems. Patients’ initial perceptions of problems in everyday life correlated, as
might be expected, with ratings of disability based on the WHO clinical performance status
(see table 14). In case dissatisfaction after radiotherapy related to the patient’s perception of
not improving after treatment, I first determined which patients could be classed, in their
own terms, as having improved or achieved a period of stability. I considered the number
of severe problems patients reported at all follow up interviews and found that less than one
half (40%, 34/85) of those patients treated with radiotherapy on whom I had follow up data,
had improved or achieved a period of stability. The most severely disabled patients, whether
judged by their own perceived problems or the WHO clinical performance status, were least
likely to achieve a period of stable or improved function (see table 14). Patients who had
achieved neither tended to make more negative comments about treatment - 50% (20/40) v
22% (4/18); X² 2.89; 1df; p < 0.10), although this difference was not significant; and patients
making such comments were more likely to be markedly or moderately distressed - 58%
(15/26) v 21% (7/32) X²=6.37, 1df, p <0.01.

As the illness progressed, slightly more patients became fully aware of the prognosis. Most
patients interviewed after deterioration were therefore aware that they were dying (52%,
14/27), although 26% (7/27) still conveyed no awareness of this possibility and the remaining
22% (6/27) were partly aware. At all stages of the disease most patients felt highly supported
by their relatives - 92% (61/66) at diagnosis and 77% (21/27) at deterioration. The proportion
of patients who were dissatisfied in an overall sense with radiotherapy, however, remained
stable at one fifth (21%, 12/58). Dissatisfaction at follow up did not relate to awareness of
the prognosis, distress over hair loss or level of distress.
Table 14 - Initial disability, perception of disability and the proportion of patients reporting an improvement or period of stability

<table>
<thead>
<tr>
<th>Initial level of patient disability*</th>
<th>Patients initially reporting at least one severe problem in daily life.**</th>
<th>Patients able to report an improvement or period of stability***</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>( %)</td>
<td>( %)</td>
</tr>
<tr>
<td>0-1</td>
<td>7/22 (32)</td>
<td>16/21 (76)</td>
</tr>
<tr>
<td>2</td>
<td>20/29 (69)</td>
<td>14/36 (39)</td>
</tr>
<tr>
<td>3-4</td>
<td>22/24 (92)</td>
<td>4/28 (14)</td>
</tr>
<tr>
<td>Total</td>
<td>75 (100)</td>
<td>85 (100)</td>
</tr>
</tbody>
</table>

* As assessed by the WHO clinical performance status
** "Severe" problems in everyday life refer to ratings made using the 2 point scales listed in chapter 5.
*** Here I considered all follow-up interviews and identified the one at which the patient reported fewest problems. I defined a period of stability as the same number of severe problems at diagnosis interview and at follow up interview; improvement was reduction in number of severe problems reported by the patient. The follow up result was based on 85 patients as six refused any follow up and data was missing for one. Those too confused to interview or who died before follow up are classed as not achieving a period of stability. Two patients reporting 3-4 severe problems at both points are included as having achieved a period of stability as although they continued to have many problems, lack of deterioration may have been attributable to treatment.

At deterioration, fewer patients made highly negative comments about radiotherapy (18%, 5/27) than on completion of radiotherapy (50%, 24/58; X2 5.55, 1df; p<01). Again, concentrating on those patients who appeared fully aware of their prognosis as they deteriorated, only one patient said he entirely regretted having undergone treatment. I cannot
rule out the possibility here, however that we were not so persistent in questioning patients at this stage of the illness for fear of precipitating a potentially painful realisation that rather than treatment being unsuccessful that they had undergone treatment on false pretences. However, given that caveat it was not possible to find evidence that most patients looked back over the illness feeling dissatisfied that they had undergone radiotherapy.

Summary

In this chapter I have described the results of interviews at diagnosis with 75 patients with malignant glioma and 66 of their relatives, showing how they appeared to view the prognosis for their disease, the problems they saw for the disease in their everyday life, and their satisfaction with radiotherapy. The findings show some of the difficulties of obtaining clear cut answers to questions about the trade off between quality and length of life. Detailed interviews with patients shortly after the decision to have radiotherapy had been made, showed that only one quarter (19/75) appeared to be fully aware of the strong possibility they would die from their disease and that the best they could expect from radiotherapy was some prolongation of life. Assessed by their own reports of problems, only 40% of patients improved or achieved a period of stability after radiotherapy. In chapter 3 I described the extent of adverse effects associated with radiotherapy, yet in terms of this, and the eventual outcome, relatively few patients conveyed that they regretted having undergone treatment. There was a suggestion that patients who had not achieved a remission made more negative comments about radiotherapy, but little more than one fifth of the sample were dissatisfied in an overall sense, and dissatisfaction did not increase with time. Compared with patients the relatives were three times more likely to be aware of the likely poor prognosis and often saw it as their role to protect patients from knowledge of the prognosis in the hope that the
patient would be amongst the most fortunate in living for a long time. These findings suggest that the concept of a trade off between quality and length of life may be a difficult one to explore with patients themselves. Reasons for this include the way doctors, patients and relatives cope with such information while there is still some hope of improvement. I discuss these issues in more detail in the final discussion chapter but in the following chapter I explore how relatives felt after bereavement about the quality of life and period of survival once it was clear what had been achieved. Such reflections cannot override or the circumvent the problem of the patient's own view about the trade-off but they do provide another perspective on the situation worth exploring.
CHAPTER 7

THE VIEWS OF BEREAVED RELATIVES ABOUT QUALITY OF LIFE AND THE VALUE OF RADIOTHERAPY

Introduction

In this chapter I finally present the results of interviews with relatives after bereavement and their views then about the quality of patients’ lives and the value of radiotherapy. I describe how these views related to the perception that the patient had been able to take part in their usual activities and the enjoyment or sense of purpose that followed from this. I explore how these judgements relate both to the initial level of the patient’s disability, as assessed by the WHO clinical performance status, and the initial ratings of the patient’s distress made at diagnosis. Finally I examine the relationship between satisfaction expressed by bereaved relatives about the fact that radiotherapy had been given, the length of time the patient survived and the time they remained free from disability.

What new information might be gained from bereaved relatives?

So far the data I have presented suggests that it is not a simple matter to obtain clear cut views from patients in the context of a life-threatening situation about a potential trade off between quality and length of life. The difficulties I encountered answering this question were that the patients had already developed perspectives on the prognosis shortly after the diagnosis which differed from that on which the concept of a trade off is based. Only a minority of patients who continued to view the prognosis in the same way could be directly questioned about the decision they had taken about treatment. Patients’ relatives had initially appeared three times more likely to be aware of this poor prognosis and during the illness they had often wished to protect patients in the hope that they would gain the most from
radiotherapy. However, it did seem possible that they might feel differently from the perspective of bereavement. When the short period of survival and the palliative nature of treatment was clear, they might begin to reinterpret these their initial hope as "false" and to feel that treatment was not justified.

**Previous research on the views of bereaved relatives about medical care**

There has recently been considerable interest in the possibility of using the views of bereaved relatives as a means of evaluating the care dying patients receive. For example, Seale (1991) reports the accounts given by those who knew a random sample of 639 patients who died in 1987. Using this interview data he deduces that of the 159 deaths from cancer, 44% of the patients had known that they were likely to die. Using the sample as a whole Seale and colleagues (1997) classified each death following Glaser and Strauss (1966) into the state of awareness in which they had died. They found that open awareness was more likely amongst patients of higher social class, those who died from cancer, those who did not suffer from mental confusion and who had relatives who had known that the death was likely to occur for several weeks before. Patients who died in such states of open awareness were also more likely to be reported as having said that they would have liked to have died earlier and to have been cared for in hospices. Thus, compared to the earlier findings of Glaser and Strauss in the 1960s the findings suggested the emergence of a group of patients who were more keen to maintain control over their death and that this might influence the kind of care they received. In an earlier analysis Seale & Addington-Hall (1995) had found that the non-spouse relatives were more likely to say in interviews after the death that it might have been better if the patient had died earlier, even if the patient had not said this, and to have perceived care as a burden. This finding had raised caution in accepting without question the views of
bereaved relatives since these could be at odds with the views of the person who died.

A few studies have looked at how the views of relatives compare to the views of patients to investigate not only whether there are frank differences, but also whether relatives' views might change over time because of the pain and distress of bereavement. For example, Higginson et al (1994) asked 35 bereaved relatives to rate the last week of the patient's life for family anxiety, symptom control, patient anxiety and pain control. When these retrospective ratings were compared to those made by staff during the illness there was poor agreement. A small sample of seven ratings made by relatives before and after the death suggested that relatives tended to polarise in their views after the death and rate problems as either more mild or severe after the death. A larger study by Hinton (1996) was able to explore this phenomenon in more detail using interviews with 71 relatives before and after the death. This study showed that patients' and relatives' ratings made before the death agreed better than relatives' later ratings. In particular pain appeared to be described as more severe from the perspective of bereavement whilst the patient's weakness, malaise and depression were under-rated. However, there was good or reasonable agreement on the items of patients' knowledge of diagnosis, awareness and acceptance of dying and immobility. Thus it would seem that there needs to be some caution in taking the views of bereaved relatives at face value (if one is looking on these ratings to represent in an absolute sense what occurred). This does not mean that the views of relatives do not in themselves have validity and indeed in some areas they do seem to reliably represent some aspects of the illness. If their views can be related to objective aspects of the illness trajectory then it would seem sensible to explore their views during bereavement to see if they present a new or useful perspective on the management of the illness.
The recruitment of bereaved relatives

Ninety-two patients with malignant cerebral glioma receiving radiotherapy and 85 of their relatives were originally recruited to this study. Eight relatives subsequently declined follow-up for the study. Of the remaining 80, 71 were bereaved by two years of follow up and 73 by three years. We sent these relatives a letter of condolence thanking them for taking part in the study and asking if we could see them again. Four to six months after the bereavement we sent a second letter explaining that we would like to hear any further thoughts about the illness or its management and treatment. We emphasised that these extra interviews were voluntary and telephoned relatives two weeks later to hear their decision. Allowing for this delay we could contact 69 of the 73 relatives and 58 (84%) agreed to be interviewed. Home visits were made in all but 4 cases where relatives were interviewed by telephone. Four relatives delayed the interview up to 12 months from bereavement. In all but a few instances interviews were carried out by the interviewer who had seen the patient and relative during the illness. To see whether their views changed with time, we approached 32 relatives again at 13 months from bereavement. More relatives declined at this point but we could interview 20 relatives (63%), one by telephone.

Characteristics of relatives

The relatives seen for an initial bereavement interview did not differ by demographic characteristics from those seen in the main study. There were 35 widows, 9 widowers, 4 parents and 8 other relatives. The median (range) age was 52 (24-75) years. Relatives who

---

1 This procedure was devised after a separate application to the Ethical Committee of St Bartholomew's Hospital and the Royal London Hospital. The Committee made useful changes to my suggested letter and proposed an interval of two weeks to allow bereaved relatives to consider fully the request for an interview.
described the quality of the patient’s life as poor in the first bereavement interview were more likely to refuse the second interview (59% (10/17) vs 13% (2/15), \( X^2 = 5.23, 1 \text{df}, p < .05 \)). In two of the 58 cases we did not collect sufficient information to rate the perceived quality of the patient’s life and I report results for 56 relatives at 4-6 months from the death and 20 relatives 13 months from the death.

**Data collection at bereavement interviews**

In gathering data in interviews after bereavement I gave particular attention to spontaneous comments relatives made about the quality of the patients’ lives’. Some relatives naturally mentioned the term "quality of life" or clearly spoke in terms of this being an issue. If relatives’ views appeared unclear direct questions were asked. For example: "Looking back on it now, how would you describe the quality of life? Do you think it was good enough? What do you think contributed to the quality of life? Do you think that the radiotherapy helped?" Commonly relatives who thought that the quality of life had been good would emphasise what the patient had been able to accomplish. For example:

*He was able to go back to work and was fairly strong in himself...He was a real fighter...that was him.*

Or they described how life had continued at a slower but acceptable pace:

*I do think that her life was prolonged - a) by the chemotherapy and b) by the radiation therapy. So that although she went downhill it was far slower going downhill. If nothing had happened she would, I think, have died probably within three or four months.....I don’t really remember any great improvement in her. I think it is probably more accurate to say that she stayed on that particular level for longer, because, well undoubtedly I made the assumption that a part of the reduction in her ability was due to the radiation therapy, you know, it was having a bad effect on her anyway. So it could have been that in at least holding back the progress of the tumour it gave her longer at that level, while in herself it was removing part of her energy....Right or wrong she had a relatively happy two years, or a relatively happy two years when she wasn’t upchucking (from the chemotherapy) or feeling knocked out by the radiation. She had a nice life with people coming to see her and chatting and sometimes she’d watch television although her attention wasn’t very long.*
Other relatives observed that the extent to which the patient had been well had itself given the impression that all was well. For example:

Yes, I think it was OK. It was just a shame that the wretched thing came back. Because up until the end of that month he was good - he was alright. He was almost leading a normal life....typing, writing letters, although he wasn't working ....There was almost hope at the beginning even though it was malignant. It was going to be....you thought it was going to be alright. He was so fit.

Or in another case:

For him it was worth it because he was very fit. He was able to take the children out for walks again, although it was very seldom. He was able to do things with us, go out with us. He was able to walk for a little while. If he wasn't able to do those things..... There are certain things that they could do to prolong life for a few more weeks. I wouldn't have wanted that - there was no point. He would have suffered more. His family would have suffered. I think for him, yes that time was worth it because he was able to be up and about and he was healthy for a while. But if he wasn't able to be up and about, no, because he would have just been lying there knowing he is going to die but having to live longer worrying about it....It (the radiotherapy) did give him "quality" life for a couple of months. He was really very well, to the point where he thought he was cured.

By contrast other relatives described the problems that the patient encountered and the change in their lives that had occurred:

I think if he had lived with those disabilities he would have found it very hard and so would we. It was like working with a child in a playgroup - doing everything, but making him think he was doing it himself - so I think it was better that he died than living with that poor quality of life. I think it was better for him and better for me and the boys. So maybe he was lucky to have the period of disabilities so short.

Or:

I half expected a change of character (from the treatment) to a degree. (But) no, to be honest, no I wouldn't have said there was much difference. Not when it was actually being done. I would have said the change was a week after, a couple of weeks after that she became ill. There was a tremendous change. But definitely, I would have said that while the treatment was on there wasn't a lot really.

Q: Do you think the treatment did improve the quality of her life?

A: No. That's when it all seemed to fall apart. Quality of life was just her family really. Once she seemed to lose her hair, if you like, that took it all away actually....The nurses
on the wards and that they all used to come and have a laugh and a joke with her. She was the life and soul of the wards. You see, it went from that, in such a short space of time, to an absolute cabbage. Dreadful.

Some relatives had very little to say about the patient's life:

He was in a terrible state. Oh he used to be so sickly. He used to be absolutely done in. It really took an awful lot out of him. I'm sure it was the radiotherapy that made him look so dreadful. He was always asleep. Everything got worse. The view was to reduce (the tumour) with a view to giving him an extended life-span which would have amounted to months...they stopped it because they could see it was having no effect at all. The tumour was just completely well advanced.

Or:

I mean I know of patients with tumours who are still alive and they are walking around with a frame and that's what I thought it was going to be. And she thought that as well. That's the sort of impression they gave us, that she would be mobile but that it would be poor mobility. I think the radiotherapy made it worse. That's my opinion. I think, I don't know, I just feel - she got so ill. There were times during that radiotherapy when I thought she was going to die....She really got very bad during that radiotherapy....I'd go and visit her and she'd be in such a state that it just upset me...then we'd have the priests coming and the nuns coming and giving her last rites, and they'd say such awful things that were upsetting for me...She really got very bad during that radiotherapy.

Q: So her quality of life was poor?

She was like a vegetable really...She was in such a bad state that she was better off dead.

To establish inter-rater reliability I and one other interviewer\(^2\) rated relative's comments from 40 interviews on a simple dichotomy of whether the relative felt that quality of life had been acceptable or unacceptable (Kappa 0.73). Differences of opinions were settled after discussion and I rated the remaining 16 interviews myself. Using this scale 39% (22/56) of relatives were rated as feeling that life had been of an acceptable quality but in most cases (61%,34/56) relatives were rated as feeling that the quality of life had been poor, and unacceptable.

---

\(^2\) Although all three interviewers were involved in data collection, by the time of analysis only one was still employed and available to check the reliability of the ratings.

156
In the bereavement interviews I and the other two interviewers also explored with relatives how useful they felt radiotherapy had been and how satisfied they felt that it had been given.

At this stage in the research, rather than use the simple 2-point scale as with patients, I wished to allow for the possibility that relatives might feel it impossible to make such a judgement. I therefore devised a 3 point scale - satisfied/uncertain/dissatisfied for radiotherapy. Inter-rater reliability between the same two raters on 40 cases was again good (Kappa 0.87). Using this rating a substantial number of relatives (46%, 26/56) were satisfied that radiotherapy treatment had been offered. These relatives felt that the patient had improved with treatment, had remained able to do things they enjoyed, or that their deterioration had at least been slowed. For example:

Yes definitely. It did give him time. Comparing what he was like before the operation to after radiotherapy - it was like a completely different person. There was a big improvement.

Other relatives placed value on the extra time the treatment had given the patient with their family and the hope it had brought for a better outcome. For example:

They were buying us time. I knew that at the time but I thought they should try and that maybe it would help...In a way you need hope and the only way he could have hope was to hope that things were not quite so bad...and they've had cases that have got through it. They told me they could cure one in ten and also that he had age on his side. You're got to have hope and he didn't give up. Radiotherapy was better than chemotherapy and it killed off some cells.

Eighteen percent (10/56) were less certain about radiotherapy, feeling the patient had improved less or survived for a very short period. These relatives tended to maintain that the patient had wanted to try radiotherapy and that this decision may have been correct for the patient, but, they wondered what had been achieved. For example:

He had to take that chance.
Q: Do you think the radiotherapy contributed to his quality of life?
A: No I don't think it did because the tumour was right under his brain. But it was a chance he was willing to take because he was told that if he didn't have the
treatment he wouldn’t live until Christmas. So he obviously thought it was worth the risk. I sometimes wonder if it was worth the effort because he died before Christmas with the treatment. So was it worth putting him through it?

Others felt, knowing what they now knew they would not now accept radiotherapy themselves faced with a similar situation. For example:

I think the most use was that he had an outing every day in that it was the most malignant kind of glioma. In a way the radiotherapy was cosmetic. I felt that it was his decision - it shouldn’t be my decision. As I say the radiotherapy was good because it gave.....a lot of people who took him there loved being with him and I spent a few hours recuperating. It was almost incidental that he went and had radiotherapy! You could have taken him to the park. I don’t know if it slowed it down or not. I’ve no idea. I don’t know which was doing what. I don’t particularly feel he shouldn’t have had it. I don’t think I would, and in a way I wish he had not had the last week. On the whole it went as well as it could... I am very grateful that he didn’t have to become totally disabled. He was very fortunate there.

Just over a third (20/56) of relatives, however, clearly felt radiotherapy had not been justified. They felt treatment had made no difference, that it had kept the patient alive in a damaged state, or worse, that it had detracted from the quality of life. Some described radiotherapy as an unpleasant procedure which had served only to use up precious time that could have been better spent enjoying other activities. For example:

They said without any treatment he would have three months. Well he got five months. If I’d have known he was going to die in this time...I wouldn’t have let him have it. I am sorry that he had it. He wouldn’t have lost his hair and the other brain cells wouldn’t have gone that quick if he hadn’t have had it.

Or If the radiotherapy wasn’t having any effect I would have liked that time to spend with him because all those times were just spent trailing in and out of the hospital and then sleeping in the afternoon. We had no leisure time or time to enjoy anything, there wasn’t any time left. We couldn’t have said we wouldn’t have had it because it was our only hope. I thought he died for the radiotherapy.

The stability of views about radiotherapy

In 50 cases I could compare the views relatives had expressed about radiotherapy during the
illness with those they expressed after the patient’s death. The rating of dissatisfaction with radiotherapy was 40% (20/50) whilst the patient was alive compared to 46% (23/50) after bereavement. Moreover only 2 of the 20 relatives who could be seen twice after bereavement expressed different views at the second interview. Views about radiotherapy were not related to demographic characteristics.

Do judgements about quality of life relate to the course of the illness?

In chapter 3 I showed that the patients’ initial disability, assessed by the WHO clinical performance status (WHO, 1979), was an important prognostic factor for length of survival, time spent free from disability. In chapter 6 I showed this was also related to whether patients reported an improvement or period of stability. It seemed sensible therefore to relate bereaved relatives’ judgements about quality of life to initial ratings of patient disability and distress and to relatives’ report of severe cognitive change (based on ratings made in the initial part of the illness). I then consider how aspects of the illness trajectory - time free from disability and length of survival - relate to satisfaction with radiotherapy. I also explore the usefulness of combining the two best predictors of views about quality of life into a simple index. I used the $X^2$ test and $X^2$ test for trend throughout.

The initial state of the patient

Table 15 shows that relatives’ judgements about quality of life were strongly related to ratings of the patient’s state made after the diagnosis. At most only one fifth of patients rated as being severely disabled, distressed or cognitively impaired were thought to have had an acceptable quality of life compared to most of those with mild problems. The two best predictors, however, of relatives’ judgements about quality of life were the patient’s initial
disability and distress. A simple index combining these factors slightly improved on the predictive power of each individual factor.

Table 15 - The initial state of the patient and the views of bereaved relatives about quality of life and the value of radiotherapy. Figures are numbers (percentages) of subjects.

<table>
<thead>
<tr>
<th>INITIAL PATIENT STATE</th>
<th>Relatives reporting unacceptable quality of life (%)</th>
<th>Relatives dissatisfied with radiotherapy (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disability*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>0/1</td>
<td></td>
<td>3/12 (25)</td>
</tr>
<tr>
<td>2</td>
<td></td>
<td>15/25 (60)</td>
</tr>
<tr>
<td>3/4</td>
<td></td>
<td>16/19 (84)</td>
</tr>
<tr>
<td>Distress**</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nil</td>
<td></td>
<td>3/16 (19)</td>
</tr>
<tr>
<td>Some</td>
<td></td>
<td>13/26 (50)</td>
</tr>
<tr>
<td>Marked/Moderate</td>
<td></td>
<td>12/14 (86)</td>
</tr>
<tr>
<td>Cognitive change***</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Some or nil</td>
<td></td>
<td>8/17 (47)</td>
</tr>
<tr>
<td>Marked/Moderate</td>
<td></td>
<td>12/39 (31)</td>
</tr>
<tr>
<td>Score on combined disability/distress Index****</td>
<td></td>
<td></td>
</tr>
<tr>
<td>0/1</td>
<td>3/16 (19)</td>
<td>2/16 (14)</td>
</tr>
<tr>
<td>2</td>
<td>14/20 (70)</td>
<td>7/20 (45)</td>
</tr>
<tr>
<td>3/4</td>
<td>17/20 (85)</td>
<td>11/20 (55)</td>
</tr>
</tbody>
</table>

* As assessed by the WHO clinical performance status (WHO, 1979)
** Three patients too confused at initial interview to rate their distress are excluded
*** As reported by the relative in the initial part of the illness
**** Based on the disability and distress scores, giving scores of 0, 1 and 2 to each 3-point scale
The illness trajectory

Relatives’ judgements about quality of life were also strongly related to objective aspects of the illness course - the length of survival and time spent free from disability (see table 16). Patients who lived more than six months (6-12 months) were more likely to be thought to have had an acceptable quality of life (53%, 9/17), but there was no evidence that longer periods of survival (12 months or more) influenced this judgement (58%, 11/19). In addition, patients experiencing at least 6 months free from disability were most likely to be seen as having an acceptable quality of life (65%, 11/17). However, neither survival nor time free from disability improved the prediction for quality of life above that which had been made by the combined disability/distress index.

Table 16 - Aspects of the illness trajectory and the views of bereaved relatives about quality of life and the value of radiotherapy. Figures are numbers (percentages) of subjects.

<table>
<thead>
<tr>
<th>ASPECTS OF THE ILLNESS TRAJECTORY</th>
<th>Relatives reporting unacceptable quality of life (%)</th>
<th>Relatives dissatisfied with radiotherapy (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Time free from disability</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6 months or more</td>
<td>6/17 (35)</td>
<td>3/17 (18)</td>
</tr>
<tr>
<td>1-5 months</td>
<td>10/18(56)</td>
<td>4/18 (22)</td>
</tr>
<tr>
<td>0 months</td>
<td>18/21(86)</td>
<td>13/21(62)</td>
</tr>
<tr>
<td><strong>Length of life</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12 months or more</td>
<td>8/19 (42)</td>
<td>5/19 (26)</td>
</tr>
<tr>
<td>6-12 months</td>
<td>8/17 (47)</td>
<td>2/18 (11)</td>
</tr>
<tr>
<td>Less than 6 months</td>
<td>16/20(80)</td>
<td>13/20(65)</td>
</tr>
</tbody>
</table>
Satisfaction with radiotherapy, perception of quality of life and the course of the illness

Satisfaction with radiotherapy was closely related to the perception that quality of life had been acceptable. Only one relative who thought quality of life had been acceptable (1/22, 5%) felt dissatisfied with radiotherapy compared to 56% (19/34) of those who perceived quality of life to have been poor (see table 17). Although this relationship was strong, approaching one half (44%, 15/34) of relatives judging the quality of the patient’s life to have been poor were not overtly dissatisfied with radiotherapy (8 of these 15 however were rated as being "uncertain" about the value of radiotherapy).

Table 17 - The views of bereaved relatives about the quality of life and satisfaction with radiotherapy. Figures are numbers (percentages) of patients.

<table>
<thead>
<tr>
<th>Satisfaction with radiotherapy</th>
<th>Relatives reporting acceptable quality of life (%)</th>
<th>Relatives reporting unacceptable quality of life (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Satisfied</td>
<td>19(86)</td>
<td>7(20)</td>
</tr>
<tr>
<td>Uncertain</td>
<td>2(9)</td>
<td>8(24)</td>
</tr>
<tr>
<td>Dissatisfied</td>
<td>1(5)</td>
<td>19(56)</td>
</tr>
</tbody>
</table>

Whether relatives were satisfied with radiotherapy was related to the same predictive factors as for quality of life although the associations were less strong (see table 16). Satisfaction more than doubled once the patient had survived longer than 6 months but then appeared to plateau and was no more strong when the patient lived 12 months than between 6 and 12 months (74% 14/19 vs 89%, 16/18 not significant).
Summary

In this chapter I have explored the views of 56 bereaved relatives about the quality of life following radiotherapy for malignant cerebral glioma. The judgements relatives made about the quality of patients’ lives were strongly related to a number of measures recorded at patient interviews within three months of the diagnosis. The strongest predictors were the patient’s initial disability and distress. Thus patients who were not initially severely disabled and distressed were judged to have lived an acceptable quality of life, whilst those who were severely disabled were considerably more likely to be judged as having had a poor quality of life. The perception that quality of life had been acceptable and satisfaction with the fact that radiotherapy had been attempted were highly related. However a significant group of relatives who judged the quality of life to have been poor remained broadly satisfied with radiotherapy, feeling it was a chance the patient had been willing to take. Relatives also judged relatively short periods of survival between six months and one year to have been worthwhile, and there was no evidence that longer periods of survival increased satisfaction with radiotherapy. Overall the judgements that relatives made about quality of life and their dissatisfaction with radiotherapy were strongly related to the important prognostic factor of initial performance status. I discuss the implications of these results in the final chapter.
CHAPTER 8

Introduction

In this final chapter I review the main findings of this research, consider possible shortcomings and published criticisms of this work and place the results in the context of previous research. I then discuss the possible relevance of the findings to clinical practice, considering decisions about which patients will benefit from radiotherapy, how to assess and limit morbidity from treatment and the relevance of communication with patients and their families. Overall the findings have several implications for health policy and suggest several issues for further research in diseases with poor prognoses.

Summary of the main findings

Survival and morbidity following radiotherapy

In this study detailed information was gathered on the clinical course of 92 patients with malignant glioma treated at six London hospitals. 83 patients were followed from shortly after the diagnosis and nine were referred to the study after radiotherapy and were followed from that point. Information on patient disability, morbidity and survival was collected by a combination of observation and assessment of patients, patient and relative reports, case note review and discussion with medical staff. These sources were used to define disability at the beginning of radiotherapy (retrospectively in nine cases) and to map out the history of disability and of any deterioration over the course of the illness.

Overall the findings confirm the poor prognosis for this disease. The six and 12-month survival for radiotherapy patients was 70% and 39% respectively. The study also showed the
importance of prognostic factors such as age, performance status, as assessed by the WHO clinical performance status (WHO, 1979), and the extent of surgery (Walker et al, 1980, Chang et al, 1983, Burger et al, 1987). A history of fits as a presenting symptom (Hutton, 1992) and the MRC prognostic index (MRC, 1990) were also important, although multivariate analysis showed that in this sample the clinical performance status was the most important component of the index. Most (80%; 49/61) patients with a clinical performance status of 0, 1 or 2 lived at least six months before becoming permanently disabled compared to only 13% (4/31) entering treatment with a clinical performance status of 3 or 4. There were relatively few patients with the less malignant grade 3 tumours, and this might account for why tumour grade was unrelated to survival in the multivariate analysis.

As well as considering different prognostic factors the study attempted to assess the morbidity associated with radiotherapy. Using the combined reports of patients and relatives and clinical evaluation in association with a radiotherapist, evidence was found for a high rate of adverse effects. Considering only those 52 patients who initially had a good clinical performance status and who were alive six months after radiotherapy most (69%; 36/52) had experienced either clinical deterioration (27%) or severe tiredness (42%) after treatment. In 17% some permanent loss of function remained. These adverse effects were associated with increasing radiotherapy dose as assessed by tumour dose of more than 55Gy and a brain dose of more than 40Gy. Severely disabled patients with clinical performance status of 3 or 4 gained little physical benefit from radiotherapy (Davies et al, 1996a).

*Patient and relative perspectives on the value of radiotherapy*

Given this short survival and the extent of adverse effects the study set out to explore the
experiences of patients and their relatives after the diagnosis and their satisfaction with radiotherapy treatment. Of the 83 patients seen shortly after the diagnosis, eight were too confused to interview and 75 could be interviewed properly. Semi-structured interviews with these patients showed that most understood that they suffered from a brain tumour (95%; 71/75), but only one quarter (19/75) seemed fully aware of their poor prognoses. Others were unaware (43%; 32/75) or only partly aware (32%; 24/75). The more aware patients were more distressed. Relatives were much more likely to be rated as fully aware of the prognosis (67%; 44/66) and were more distressed. Although 39% (29/75) of patients initially made negative comments about radiotherapy, only 17% (13/75) were rated as expressing complete dissatisfaction with treatment. The decision to accept radiotherapy could be discussed directly only with 19 fully aware patients after the diagnosis. Twelve of these patients found radiotherapy acceptable if it were medically advised or if it improved survival. Fifty-nine patients could be interviewed at follow-up and 27 could be seen again during a period of deterioration. Assessed by their own reports of problems only 40% of patients achieved an improvement or period of stability, yet dissatisfaction with radiotherapy did not increase over the course of the illness. This part of the study showed the difficulties of conceptualising the question of treatment in terms of a trade off between quality and length of life. It seemed that for a variety of reasons most patients developed an orientation towards the prognosis very different from that on which the concept of a trade off is based i.e. that to make an informed decision about the trade off the patient needs to be in full possession of the facts about the prognosis, the likelihood of improvement and the possible adverse effects of treatment. However, most of those who appeared to be fully aware of the poor prognosis they faced, said they accepted treatment for the chance of improved survival it brought even if some remained strongly critical of radiotherapy. Thus as well as the concept
of a trade off perhaps being perceived differently, it may be that the idea of preserving quality of life in such a situation is also seen in a different way. This suggests that the concept of "quality of life" as seen from the perspective of an observer on the situation might need to be rethought for some situations (Davies et al, 1996b).

The views of bereaved relatives about the quality of life and the value of radiotherapy

Since relatives had initially been more aware of the prognosis it was of interest to know whether they felt differently about treatment after bereavement. At this point the short period of survival would be known and the extent of the trade off that had been made might be more clear. Interviews with 56 bereaved relatives four to six months from the death of the patients showed that the judgements they made about the patients' quality of life were related to initial ratings of the patient's disability and distress made after the diagnosis. Relatives emphasised the importance of patients having been able to carry on with activities which had been important to them or given them pleasure. Most relatives of patients who had initially not been severely disabled or distressed were satisfied that patients had been treated with radiotherapy. This was the case even when patients had survived only relatively short periods between 6 and 12 months or had been free from disability for 6 months or less. Longer periods of survival did not markedly increase satisfaction with radiotherapy. These findings suggest that relatives were placing value on relatively short periods of survival of less than one year, particularly if life had not been too severely altered for some portion of the patient's survival. These findings may be of some relevance to current debates about the potential trade off between quality and length of life, but before discussing these possible implications, potential shortcomings of this work will be considered.
Shortcomings of this study

Study design

Although this study was prospective and based on more detailed and possibly complete follow up of patients than hitherto, it is essentially a descriptive observational study. Since large trials had established for some time that radiotherapy prolonged survival it would not have been possible at the outset to randomly allocate patients to radiotherapy and so compare quality of life following this treatment to that after another treatment or no treatment at all. It was also not possible to use patients for whom the decision had been made to treat with steroids alone as natural control subjects. These patients were already very ill and deteriorating when they were recruited and it was clear that they had been selected out of treatment. The deductions that can be made from this observational study must therefore be limited when compared to those that follow from an experimental study. Brada et al (1997), however, have argued that without comparative data it is not possible to say anything at all about whether prolongation of survival by six months with clinical deterioration in a small proportion of patients is worse than the alternative of progressive functional decline in all patients that will occur without any treatment. This is probably a rather extreme and limited view. Whilst this study may not supply all the data required to finally make that decision, it certainly provides relevant data. First of all, the study attempts to address continuing doubts about the value of treatment that have followed from the fact that trial designs have not adequately addressed the issue of quality of life. In such a situation other study designs have to be used to produce data that might help answer these questions. It should also be recognised that patients recruited to trials may themselves be a highly selected group of patients treated in specialist centres. In this study, for example, only 25 of the 92 patients treated with radiotherapy were recruited to the ongoing MRC trial of adjuvant chemotherapy.
It may therefore be useful to study patients being treated outside of a trial situation to gather information on outcome in everyday practice to ensure that trial data does indeed have wider applicability (Davies et al, 1997).

*Potential biases in the selection of patients into the study*

Another criticism made of this study by Brada and colleagues (1997) was that the number of patients recruited to this study was less than might have been expected. Basing their calculation on epidemiological figures they estimate that the centres studied would have seen 400-800 patients during the study period. They therefore find it difficult to believe that the 105 patients who were approached for the research (based on their figures, presumably one quarter to one eighth of all eligible patients) represent an unselected consecutive series of patients. In their calculations of the number of eligible patients, however, they seem to ignore the fact that the recruitment of centres to the study was made in a step-wise fashion. This limited the numbers of patients who could have been recruited so that only at the end of the study would all patients at all centres have been approached. Their suggestion, however, that the patients were unselected is important as this raises the possibility that the recruitment procedure was flawed or that biases may have been introduced into the study - something that would seriously threaten the validity of an observational study. The point has already been made with colleagues (Davies et al, 1997) that the interviewers were not aware of making any selections from the patients they were informed about. The procedure for obtaining the names of newly diagnosed patients was described in chapter 3 but it is possible that staff did not always inform us of patients whom they had decided should not be included. This bias might have been more likely to have occurred during the initial period of recruitment from a centre when consultant staff were referring patients themselves. However, once they had
handed this task over to other clinical staff, and we became familiar with the referral pathways, and were often present in the departments, it seems unlikely that large numbers of patients would have escaped us. Whilst no study can avoid the fact that some patients are inevitably missed when interviewers are absent or very busy the most important threat to the study would be if certain types of patients were systematically excluded. It is difficult to believe that this would be the case as it would have involved the co-operation of a large number of staff at different sites and on different occasions. However, if individual members of staff had independently decided to withhold the names of, for example, very frail or distressed patients then bias would have been introduced. Brada and colleagues (1997), however, were surprised at the significant number of patients who were severely disabled but who nonetheless received radiotherapy, and this would suggest that we were able to recruit this population of patients. Indeed the fact that the median survival time was 10 months and that the shape of the survival curve is so similar to those previously published suggests that the study was successful in recruiting a representative sample of patients with malignant cerebral glioma. Since these criticisms were published I have been able to compare the number of patients recruited at each centre with the numbers of patients which the centres reported to the Thames Cancer Registry (Personal communication, 1997) during the same recruitment period. During the period that 105 patients with malignant glioma were identified and approached for this study these hospitals reported 198 patients as having been treated with radiotherapy for primary brain cancer. However, the classification by the Registry of primary brain cancer includes not only patients with malignant cerebral glioma, but also

---

1 It may be relevant here that of the six patients whom consultants initially referred 4 were rated as having an initial clinical performance status of 0 or 1, and two patients a clinical performance status of 2. The three patients whom junior staff had not referred had clinical performance status of 2 or 3. There may possibly have been a slight tendency not to refer the most ill patients.
those with low grade gliomas, all meningiomas and other rare tumours who would account for some of the discrepancy. The Registry does not record individual diagnoses other than primary brain cancer so exact numbers cannot be checked further. Although these data cannot rule out the possibility that some patients with malignant glioma were missed from recruitment, it seemed unlikely that this approaches the high proportion suggested by Brada and colleagues (1997). These authors may also have assumed that all patients diagnosed with malignant glioma would have gone on to receive radiotherapy. This study concentrated on patients receiving treatment, but information on patients being treated with steroids at one hospital suggested that as many as third of patients were not treated with radiotherapy. In retrospect it would have been useful to have gathered some basic information on such patients at all hospitals. This might have shown how clinicians distinguished patients whom they thought unlikely to benefit from treatment or whether treatment policies varied between hospitals. Such a study would also provide information on the natural history of patients managed with steroids alone (Davies and Hopkins, 1997).

A further issue concerning the selection of patients, however, that was not raised by published criticisms is whether the patients represent a group with particularly malignant tumours. Assessed by the Daumas-Duport grade there were relatively small numbers who had grade 3 tumours. Given that the initial selection of patients into the study was on the basis of a local decision, according to which ever scheme was in use, that the patient suffered a

---

2 It might be relevant to note here that Charles Clarke and Anthony Hopkins who were closely associated with the project were also surprised at the smaller numbers of patients recruited compared to the numbers they had expected. However, it was because there were too few patients that recruitment had to be extended beyond the initial three centres. It may be that the workload and problems of these patients looms rather larger in the memory than their strict numbers.
high grade tumour, it is possible that patients with less malignant tumours were initially excluded. This would explain why there are relatively few patients with grade 3 Daumas-Duport tumours. Future studies should clearly attempt to address the issue of histological grading at the outset and the Daumas-Duport (Daumas-Duport 1988) and WHO (WHO, 1979) schemes were recently recommended in guidelines developed by a working group (Davies & Hopkins, 1997).

Another criticism of this study not yet made is that it involved relatively small numbers of patients in terms of defining the importance of the different groups within the MRC Prognostic Index. In this sample the six groups from the initial index were collapsed to make three groups. The size of this sample was limited by the intensive nature of the home follow-up and interview work, but in a future study it might be possible to look at limited factors on a larger sample. The strength of this sample was the greater attention given to the measurement of disability than is usual in large trials, and the fact that follow up data for survival is complete, something which trials can rarely achieve.

**Problems with the assessment of morbidity**

In this study morbidity due to radiotherapy was informed by patient experiences disclosed at interview but was largely assessed clinically. Deteriorations that might be due to radiotherapy were deduced by a process of elimination and the judgement was finally made by the patient’s radiotherapist. By the time of review most of the patients had died and, at the time of the study, MRI scans were not routinely performed to confirm radionecrosis or evidence of brain damage. Thus the definition of deterioration had to be pragmatically derived rather than being based on neuroradiological evidence of long-term brain damage.
Again Brada and colleagues (1997) criticised this method as flawed suggesting that without evidence from imaging nothing could be deduced about the cause of these deteriorations. Here these authors may be confusing the possibility of distinguishing radionecrosis rather than early delayed reactions from tumour recurrence. In fact "early delayed" reactions to radiotherapy are indistinguishable from tumour recurrence, and only careful follow up can distinguish these effects from tumour recurrence (Gregor, 1997). Radionecrosis is a later effect which might have been detected by MR imaging but is generally thought to affect a smaller proportion of patients. In this study there was a careful follow up of patients, and deteriorations were considered only amongst patients who initially had a clinical performance status of 0-1, and who were alive six months after treatment with no further anti-tumour treatment. The assumption was made that if a tumour had continued to grow during radiotherapy sufficient to cause such a sudden and severe deterioration, then that tumour was almost certainly highly aggressive, not responding to treatment and therefore highly likely to have caused the patient's death by six months after treatment. By excluding patients dying before this time, patients whose deteriorations after treatment were most likely to have been tumour recurrence were therefore excluded. Gregor and Cull (1996) make the important point that the assessment of possible morbidity amongst the remaining cases should have been made independently by clinicians rather than their being presented with the selected number of cases which I had judged most likely to be due to treatment. This would clearly have been ideal, but was limited by the perception that this would be too time-consuming a task to ask clinicians to perform. However, the rate of deterioration after radiotherapy deduced by this technique was the same rate as reported by clinicians in the recent MRC trial (Bleehen & Stenning, 1991) as pointed out by Burnet and Taylor (1997). These authors also point out that the concept of adverse effects being related to the volume of the brain irradiated is not
new and other authors (Gregor et al, 1996) have recently found evidence for the effect of volume of brain irradiated on subsequent brain damage in long term survivors. In some senses therefore there seems to be the suggestion that this study has done no more than restate what had long been recognised. The criticism seems to be more that the study should have raised the possibility that these adverse effects were too severe to justify treatment and framed the decision in terms of a potential trade off between quality and length of life. Indeed Brada and colleagues (1997) concluded their attack of the study by criticising the journal for having published it:

Yes we do need more effective treatments without morbidity, but to throw out a proved treatment on the basis of misinformation is a travesty to evidence based medicine, to which the BMJ claims allegiance.

The quality of the feeling shown here is reminiscent of that following the paper by Wroe et al(1986), also published in the BMJ, in which the authors concluded that a conservative approach to the management of these patients might be ethically justified (see chapter 2).

The assessment of tiredness due to radiotherapy in this study could have been improved. In a review of the findings Gregor and Cull (1996) recognise that up until now morbidity may have been underestimated, but they are circumspect that all the morbidity found in this study relates to treatment. They raise the possibility that some of the tiredness patients experienced may be due to the tumour affecting the frontal lobe rather than to radiotherapy. However, this seems unlikely since it would be expected that tiredness or lethargy due to a tumour in the frontal lobe would be a presenting symptom and would not become worse coincident with radiotherapy. Nevertheless it is clear that more detail could have been incorporated into the assessment. This could have included subjective data from patients collected each week, perhaps using diary assessments, as for example, carried out by Faithfull (1991). Clearly the
findings for morbidity both in terms of deterioration and tiredness should be explored on a larger sample in relation to different techniques of radiotherapy treatment and different tumour sites.

**External validity of the results for morbidity**

The main thrust of the criticism of the results of this study made by Brada and colleagues (1997) was that as well as the assessment of morbidity having been flawed, the radiotherapy practised in the hospitals studied was out of date and not carried out using the most modern techniques that would have been available in specialised centres. These authors therefore doubted that the findings were applicable to specialised treatment centres, in some sense questioning the external validity of these results. Gregor and Cull (1996) also pointed out that the study gave no information on the clinical reasons for the apparent variation in dose and administration between patients. This criticism seems to ignore the obvious interpretation that variations in treatment are common in medical practice. Indeed much of the thrust of the current interest in clinical effectiveness in the field of cancer care is to identify and limit this variation to improve outcomes for patients (see, for example, the recent Clinical Outcomes Group guidance for colorectal cancer (COG, 1997)). Gregor and Cull (1996) also raise the possibility that the step-wise inclusion of centres may have introduced some bias to the study. Here the problem might be that a hospital recruited at the beginning of the study and therefore contributing proportionally more patients, might have tended to give radiotherapy in a manner more likely to produce adverse effects and the effect of this would be to swamp the better results of other hospitals and so overestimate true morbidity. The spirit of this study was to deduce broad principles about quality of care rather than to compare data from individual hospitals. However, a look at the distribution of
adverse effects shows that they are not concentrated in one hospital. A further criticism is that some of the techniques, in particular whole brain irradiation, were outdated and toxic (Brada et al, 1997) and have now been superseded making the findings of this study irrelevant to everyday practice. However, even allowing for the delay in publishing the results and for some change in practice, it seems reasonable to suppose that such findings may be of use. The study of these hospitals does show that some variation in techniques existed between 1990 and 1993. The findings also show that adverse effects were associated with the volume of brain irradiated as indicated by the field sizes that were used. Indeed, Burnet and Taylor (1997) see the findings as not altogether new, but adding "considerable weight to the argument for using modern radiotherapy techniques to spare normal brain tissue". At the same time these authors appear to acknowledge that modern focused radiotherapy may still not be available for all patients by arguing that it is "time for the NHS to fund this treatment universally".

The rigour of the interview method and rating scales

The initial criticism of this study made by Gregor and Cull (1996) was that it lacked rigour. In their editorial which accompanied the publication of the findings concerning patient awareness they stated that the study showed many of the problems that can beset qualitative work as set out by Mays and Pope (1995). They pointed out that deficits in language and cognition may have affected the ability of patients to take part in an interview, although it is not clear how this would be less of a problem for the completion of questionnaires which they prefer. There is no doubt that some patients could contribute less to the interviews than others, but this does not seem a reason to exclude them entirely. Indeed it could be argued that there is all the more reason to interview patients with cognitive problems to try and
obtain some idea of their views. The approach was to give them time and the chance to express themselves affording a flexibility that questionnaire research cannot provide. Guerrero et al (1997) also describe the in-depth interviews as "non-validated subjective rating scale" which they argue are highly likely to yield a description of misery experienced by patients and relatives. The argument that the rating scales were merely subjective can be countered by reference to the developmental work and by asking how else it would be possible to record patient views. I have already made the point in chapter 5 that the ratings ultimately reflect only a perspective on these views and I have considered the shortcomings of questionnaire measures such as the EORTC module for brain cancer (Osoba et al, 1996) in chapter 4. Gregor and Cull (1996), however, see such questionnaire modules as providing a more systematic basis for evaluation of quality of life and argue that most assessments should be anchored in trials. Again this point ignores the fact that many patients are treated outside of such situations (BMJ, 1996).

I would argue that a more direct criticism of this study is of the time taken to undertake this research including that which was needed for developmental work, reliability studies and data coding. There is the point that a shortened interview and more limited ratings should have been undertaken at an earlier stage although repeating a study like this would need a fair investment of resources. Moreover to establish its validity over questionnaire research the interview findings should have been compared to an established quality of life questionnaire. Unfortunately the EORTC-QLQ - 30 was developed by another group working in parallel and only recently became available and could not have been used. However, validated measures of psychological distress, either in the form of questionnaires or interviewer-administered measures were available and should have been used alongside the interview. This would have
provided an opportunity to examine how the interview measure of distress developed here performed in relation to more widely used measures

**Problems with assessing patients’ awareness of the likely prognosis**

Social classes I and II are well represented in this sample. This may reflect the distribution of the disease in the population around London, or more probably differences in the referral of patients from different social classes to specialist centres. It seems unlikely that this bias reflects selective recruitment for the reasons already discussed. However, despite this, relatively few patients demonstrated the level of awareness that would have allowed an exploration of their thoughts about the kind of trade off they might have been making. Other studies have avoided this problem by asking patients about hypothetical situations rather than their own, and this indirect method has shown that cancer patients are prepared to consider more intensive treatment regimes than members of the general population (Slevin et al, 1990, O’Connor, 1989). That most of the patients whom we could directly question were prepared to undergo radiotherapy for the chance of longer survival is consistent with the results of such studies.

The possibility that the patients’ lack of awareness of the prognosis and their acquiescence to radiotherapy was directly due to their brain disease is made unlikely by the fact that severely confused patients were excluded from interview. The rest were interviewed at length and gave informed and interesting answers to many questions. Part of the explanation for limited awareness appeared to lie in the fact that many had been protected by relatives and medical staff. Patients’ relatives, for instance were three times more likely to be aware of
the probable outcome and showed more distress in the interviews. It is also possible that some patients had subtle neuropsychological deficits affecting the way they processed new information and attributing to it emotional significance which re-enforced their relatives' desire to protect them from distress.

A more specific criticism of the interviewer-based ratings in this study made by another group of workers is the definition of patients who were rated as "aware" versus "partly aware" of the prognosis. Salander and colleagues (1997) argued that the definition might need to be sharpened up. In their own work mentioned in chapter 4, they found that 11 of 19 patients were aware of the gravity of their situation. By this the authors judged that they knew it was possible that their disease might be fatal. The level of awareness counted as fully aware in the current study, however, was a level that approximating the awareness of an observer - i.e. that the treatment was palliative and there was a very strong possibility that the patient would die from their disease. This level of awareness was chosen to evaluate the extent to which the patient was in a position to make a trade off based on a similar level of information as would be available to an outsider, and if so, on what basis they were making that decision. Salander and colleagues (1997), however, point out that patients who were classed in this study as partly aware on the basis that they conveyed some fear of dying but also thought that they had a reasonable chance of being cured could have been demonstrating middle knowledge (Weisman, 1972). Such patients, they argue, are quite aware of the severity of their situation, but at the same time dealing with the psychological threat - individuals know and at the same time appear not to know. Salander et al (1997) argue that patients are aware of the knowledge but dissociate this from its personal impact and so create hope by this mental manoeuvre. Patients can therefore seem to be aware and unaware at the
same time. Salander and colleagues (1997) therefore argue that my assessment of awareness may be confounded by successful coping. In response I would argue that to measure awareness does not deny that the patient's coping could have been one factor influencing their awareness. However, here I have conceptualised awareness level as a measure of the outcome of a variety of factors which may be operating. These factors may include the patient's individual coping, and that of their family members and their doctors. This outcome - the orientation of the patient or relative towards that knowledge - can then be related to other factors such as coping strategy\(^3\), situational factors, distress and so on. It does not negate the need to look at coping strategies, but coping is a slightly different kind of variable and might be better conceptualised as a process rather than an outcome. In addition, by setting their own level of awareness as patients who knew that it was possible that their disease might be fatal, Salander and colleagues (1996) have probably introduced rather more possibility for confounding coping in the level of awareness set for their own study.

**The validity of giving weight to the views of bereaved relatives**

The finding that the views of bereaved relatives about quality of life and the value of radiotherapy related to observable aspects of the patients' initial disability and distress is interesting. That their views link so well to established prognostic factors makes it tempting to accept these without considering potential biases in their judgements or the dangers of relying entirely on their views. The earlier work of Higginson et al (1994) and Hinton (1996) suggests that bereaved relatives may retrospectively overestimate the patient's pain and underestimate their depression and malaise. However, these studies asked relatives about

---

\(^3\) Data on patients' coping styles is available and will help clarify these issues although it is not presented here.
single items and not their overall judgement about quality of life or the usefulness of
treatment. Relatives' perceptions of any specific problems the patient experienced in the final
weeks of life might well have affected their overall judgement about the patient's quality of
life, although the questions we asked were about the overall trajectory of the illness. Thus
we were asking whether the initial part of illness - the time gained after the treatment seemed
to have been good enough and whether this had offset later more distressing aspects of the
illness. We were therefore leaving it to the relative to weigh up these different aspects, and
although their quotes give an idea of the factors they thought were important the actual
weighting was left implicit. Here it might have been possible to ask more directly how
'worthwhile' relatives, or even patients felt radiotherapy had been. In this study views about
radiotherapy were conceptualised as 'satisfaction' or 'dissatisfaction' with treatment. In fact
many relatives answered the question in terms of how worthwhile they judged treatment had
been (see chapter 7) but the word 'worthwhile' was not included in the questions asked.
Rather relatives were asked how useful they thought radiotherapy had been or whether they
thought it had helped. There are, to my knowledge, no other studies of the views of bereaved
relatives about treatment which would allow these results to be put in context. What the
results do show is that those who had intimate knowledge of the patient's illness and who had
the least wish to lose the patient prematurely were able to assess the kind of trade-off that
had been made. Thus they could say that quality of life had in some circumstances been
poor, that radiotherapy had not helped or that short periods of survival had been worthwhile.
Given the difficulties of asking all patients directly about the potential trade-off between
quality and length of life, these relatives perhaps come as close as it is possible to being able
to explicitly explore a trade off which has been made, albeit with all the problems of
retrospective judgement. We do not know whether, had all patients been able to predict the
exact course of their illness, or looked back on it at its final point that they would have come to the same conclusion. They may have been more or less likely than relatives to disregard the possibility of treatment and felt that their lives had more or less quality. The views of bereaved relatives must therefore be seen as providing a useful perspective on the question of treatment for this disease rather than providing an answer for all its difficulties.

Implications of the research findings for clinical practice

Accepting these limitations of the design, the findings that do emerge from this study suggest several implications for the management of patients with malignant cerebral glioma. These are considered under the headings of deciding which patients might benefit from treatment, administering radiotherapy, and breaking bad news.

Deciding which patients might benefit from radiotherapy

In this study patients being treated with steroids alone had the worse survival. It could of course be argued that not providing any other treatment was a self fulfilling prophecy, but the steep decline in their survival curve suggests that the steroid only group were being separated out on valid clinical grounds. Among radiotherapy patients the MRC prognostic index was easy to use and appeared to differentiate quite different groups of patients in terms of outcome as did the WHO clinical performance status. For example, on the basis of the data presented here a clinician could inform any patient with an initial clinical performance status of 3 or 4 that he or she stands only a 13% chance of substantial improvement in disability. Conversely, 74% of those who are initially free from disability may remain so for at least six months. In this respect it is worth noting that although performance status is an important predictor of outcome, the most frequently cited trial did not report whether this
was evenly distributed between the groups randomised to radiotherapy or steroids alone (Walker et al, 1978) (see chapter 1). Another study showed that working capacity was improved in the radiotherapy arm, although this was based on mean performance scores for the groups rather than the proportion of patients improving based on their initial score (Kristiansen et al, 1981). A retrospective review of outcome after radiotherapy also suggests the need to consider the most appropriate package of treatment and support for elderly or disabled patients (Whittle et al, 1991). Not only do patients with a poor clinical performance status have the worse prognoses, they are less likely to improve, and in this study they also spent much longer in hospital receiving radiotherapy. This area is now being investigated by the Medical Research Council’s trial (BR 09) of best supportive care, with or without a short and simple course of radiotherapy (Gregor and Cull, 1996). A further implication of the study is the possibility that the routine use of checklists for activities of daily living such as the Barthel (Mahoney and Barthel, 1965) and the Nottingham Extended Activities of Daily Living (Nouri and Lincoln, 1987) might make easier the assessment of the patient’s prognostic group after the diagnosis.

Assessing and limiting morbidity from radiotherapy

The incidence of adverse acute and early delayed effects due to treatment (69%) found in this study is higher than in most previous reports which have generally considered delayed brain necrosis or dementia to be the more serious and irreversible consequences of treatment (Bleehan and Stenning, 1991, Wara et al, 1991, Freeman et al, 1973, Faithfull, 1991). This study has shown a relationship between these effects and the volume of brain irradiated. Although Burnet and Taylor (1997) argue that such volume effects are not new, data has not to my knowledge been presented that relates acute and early delayed effects to the volume
of the brain irradiated. Only recently did Gregor et al (1996) report these effects in relation to neuropsychological deficit in adult long term survivors of brain tumours. Despite the lack of published evidence about adverse effects there appears to have been a drift towards techniques which spare normal brain tissue. These results do raise sufficient doubt about the nature of the deteriorations isolated to merit further comparisons of the techniques currently in use. Future studies could compare possible adverse effects using more frequent assessments from patients during radiotherapy and in the following month. In terms of the clinical follow up of these patients the fact that side effects may continue to occur in the weeks after radiotherapy suggests that patients should be monitored for this period and warned of this possibility.

**Communication with patients and their relatives**

To convey the reality of this situation to patients newly diagnosed with malignant brain tumours is clearly no easy task. Not only is there the poor survival to disclose but there are the issues of current or future physical and mental disability, the absence of curative treatment and the possibility of serious adverse effects from radiotherapy. This is clearly a situation in which there needs to be careful attention to the ability of the patient to give informed consent to treatment. It is clear that issues of communication are important in this disease, particularly as it is now accepted that communication with cancer patients should be straightforward and open (Maguire and Faulkner, 1988a, Maguire and Faulkner, 1988b, Fallowfield, 1993). There may be obstacles to open communication if a patient is too confused to consider treatment options or if they genuinely do not wish to know the prognosis. However, without knowing what a patient understands it must be questioned whether those around the patient - either the patient’s doctor or the family can make the
decision about treatment on their behalf.

The findings of this study underline the fact that the consequences of the communication style adopted by medical staff need to be considered in terms of distress for both the patients and their families, particularly when many families seem to adopt a coping style which is not based on the continuous and explicit discussion of the truth (Hinton, 1980, Kuebler-Ross, 1978, Glaser and Strauss, 1966). The finding that patients who were fully aware of the prognosis were more distressed may provide one explanation of why some clinicians appeared reluctant to inform patients about the prognosis. Their experience with previous patients who had become very distressed may have led them to take the view that it was more important "not to take away hope" than to fully inform patients of the truth. However, being explicit about the diagnosis and prognosis is ethically justified on the grounds of gaining informed consent to treatment. If the patient's autonomy is to be respected then the issues of quality of life need to be addressed but if this is never set out clearly in discussions about treatment the framework within which the patient makes their decision will always be limited as appears to have been the case in this study. One way of dealing with this situation is to try to proceed very close to the patient's frame of reference, both in terms of the pace of information they seem able receive, and in terms of what it seems they would wish to achieve if they knew that time was limited. Thus a series of interviews should generally be undertaken in which the clinician and other staff gradually give warning of the possible diagnosis, confirm this and then disclose the prognosis, confirm how this information has been perceived, whether it needs to be reiterated and what more information a patient needs. In some situations, when, for example, a patient is confused after surgery relatives may approach doctors and need more information. It seems unlikely that this pattern of unequal
Disclosure should be allowed to continue indefinitely and a mixture of joint and single interviews may be appropriate. The results of this work have since been used to develop guidelines for communication practice (Davies and Hopkins, 1997) and their implementation is now being assessed as part of a randomised controlled trial in three neurosurgical centres in Scotland (Robin Grant, personal communication 1998).

Although honesty is to be recommended it does not follow that if all patients were fully aware of their likely prognosis large numbers would decide not to undergo treatment. Most of the patients who were fully aware of their prognosis were willing to accept radiotherapy for the chance of prolonged survival and saw this as a worthwhile aim. Even those aware patients who expressed dissatisfaction with radiotherapy nonetheless continued with the course, and did not seem willing to forgo treatment. It is possible that faced with the real threat of death, individuals in this situation were behaving in quite a different way to that a concerned observer might predict. The observer perspective seems to emphasise the possibility of a rational choice at the cost of largely ignoring associated emotions. In reality many of the patients appeared to have taken hope from the apparent element of clinical uncertainty and from the fact that some treatment was being attempted. Despite their increased awareness of the prognosis the relatives on the whole also supported the idea of treatment for the patient. The interviews with bereaved relatives suggested that rather than reinterpreting this hope as "false", some still saw that hope had provided real benefit in helping to maintain patients' morale and quality of life. This was particularly so if the patient had not initially been severely disabled but had been able to continue with activities and interests that were important for them. Here one can see a concept of quality of life emerging that emphasises the importance of hope or optimism and of maintaining key roles that give
an individual a sense of meaning, purpose and enjoyment.

**Implications for future research**

The way that the findings emerged in this study have implications for future research involving seriously ill patients. Given that only a quarter of patients appeared fully aware of the prognosis the standard gamble approach to decisions about treatment adopted by some researchers as described in chapter 2 would not have been justified. Such an approach would have required the interviewer to have been explicit about the poor prognosis these patients faced and the likelihood of treatment altering this future before questioning them about their decision. This would have meant potentially altering the awareness of the prognosis in three-quarters of the patients in this study. It is difficult to argue that this would have been ethically acceptable within the context of a research project. Certainly it is not what patients or clinicians would have expected when they agreed to the study. Future work with patients facing a poor prognosis should, at least initially, take a careful exploratory approach before asking patients in too straightforward a manner about their preferences for different treatment.

**The possible relevance of the results to health policy**

I began this exploration of the experience of patients with malignant cerebral glioma by suggesting the possible relevance of the concept of a trade off between quality and length of life. I described indices that have been used to develop the idea of the utility or value that may be attached to particular health states. In particular I described the Rosser Index which measures disability and distress and which has been used to derive the idea of a quality adjusted life year (QALY) (see chapter 2). Although the Rosser scale was not used here
measures of disability and distress were made over the course of the illness. The data I have presented so far suggests that the idea of a rational trade off that might be made on the basis of all available evidence may not be relevant to the decisions that individuals make in real life-threatening situations, or that the threshold at which the trade off is made changes shifts radically. Thus it might seem that faced with death individuals and their families are prepared to trade off the quality of life for the chance of increased survival. In this respect the aspirations of individuals caught in these situations may turn out to be at odds or certainly very different from the rational calculations of well individuals contemplating possible future states of disability. Here the idea that health policy decisions about the merit of different treatments to patient groups can be based only on such estimates therefore becomes questionable. It could be argued that the reference group should be those nearer by circumstance to those about whom the decision about resources is being made. Whilst there are obvious dangers to following what could be seen as the "emotion" of the situation, it might just as easily be recognised that the need for hope, to find purpose and to continue living are so universal and necessary that it would be deeply irrational to sweep these away in preference for more detached decisions. There is a sense in which the views of the bereaved relatives may begin to show the logic of the way in which such emotional decisions are in fact made. For example, the subjective comments about quality of life made by bereaved relatives did relate to the patient's initial disability and distress both of which are key dimensions to the original Rosser Index. This perhaps provides some validity for the idea of trying to attach some kind of utility to these states. The views relatives had about whether they felt radiotherapy had been worthwhile were also related to the length of time that the patient survived. Their views do not appear to be idiosyncratic but rather they are showing that they do at least value periods of survival greater than six months but often less than 12
months. There was no evidence in this sample that the fact that the patient lived longer than 12 months significantly increased relative's satisfaction with treatment. Therefore this study is providing evidence that people may value these relatively modest extensions of life and that to set the level of assessment for health care interventions as the attainment of one full year free from disability (one QALY) is simply to set the threshold too high. Again here there is evidence even in bereavement for a shift in the expectations so that quite small benefits can be greatly appreciated.

The results of this study could be seen as further evidence that although indices like that developed by Rosser have probably tapped important aspects of the situation that may relate to quality of life, the manipulation of such data into formulations designed to make difficult choices about treatment is ill-conceived. For example, the application of a QALY-type argument across the board to patients with malignant cerebral glioma will miss completely the issue of differing prognostic groups where some rather better outcomes might be particularly valued. Decisions made about treatments need to be more rather than less grounded in the realities of each disease. This study shows that there is a role for studying the responses of patients and their relatives to particular situations and that this can provide results that may be of real use. There is also support for the predictive and therefore assortative value of measures of the clinical performance status. These together with the interview data produce a means of achieving greater refinement and sensitivity in making clinical decisions.
REFERENCES


BMJ. Editor’s choice. The real world of brain tumours and mentally ill prisoners. BMJ 1996;313.


Burnet NG, Taylor RE. Modern radiotherapy techniques are needed to spare normal brain tissue (Letter). BMJ 1997;314:900.


Hinton J. How reliable are relatives’ retrospective reports of terminal illness? Patients’ and relatives’ accounts compared. Social Science and Medicine 1996;43(8):1229-1236.


Hutchinson TA, Boyd NF, Feinstein AR. Scientific problems in clinical scales, as demonstrated in the Karnofsky index of performance status. Journal of Chronic Disease 1979;32:661-666.


(LEDs) Life events and difficulties schedule. Royal Holloway and Bedford New College London 1988.


Sneew KCA, Aaronson NK, Osoba D, Muller M, Hsu M, Yung A, Brada M, Newlands ES. The use of significant others as proxy raters of the quality of life of patients with brain cancer. Medical Care 1997; 35:490-506.


Thomas DGT. Is conventional external beam radiotherapy beneficial for patients with supratentorial malignant glioma? 1988


Whittle IR, Denholm SW, Gregor A. Management of patients aged over 60 years with supratentorial glioma; lessons from an audit. Surg Neurol 1991;36:106-11.


THE QUALITY OF SURVIVAL OF PATIENTS
WITH MALIGNANT CEREBRAL GLIOMA
FOLLOWING RADIOTHERAPY

APPENDIX

(Interview schedule and rating schedule)

Elizabeth Davies
Clinical Research Fellow
Department of Neurological Sciences
The Royal London and St Bartholomew’s Hospital
West Smithfield

July 1998
CONTENTS

Interview Schedule i-iv

Introduction 3
Acknowledgements 4

RATING SCALES FOR MEDICAL CONTACT (Green pages) 5

Perceived care from individual doctors 6
1. Felt concern or reassurance conveyed by neurologist 8
2. Felt openness of neurologist 11
3. Rater’s judgement of ambiguity about diagnosis conveyed by neurologist 14
4. Rater’s judgement of ambiguity about prognosis conveyed by neurologist 17
5. Felt concern or reassurance conveyed by surgeon 20
6. Felt openness of surgeon 23
7. Rater’s judgement of ambiguity about diagnosis conveyed by surgeon 26
8. Rater’s judgement of ambiguity about prognosis conveyed by surgeon 28
9. Felt concern or reassurance conveyed by radiotherapist 31
10. Felt openness of radiotherapist 34
11. Rater’s judgement of ambiguity about diagnosis conveyed by radiotherapist 37
12. Rater’s judgement of ambiguity about prognosis conveyed by radiotherapist 40

Overall care 43
13. Perceived overall co-ordination in care 44
14. Felt coherence in information 47
15. Felt ability of the system to deal with distress 50
16. Felt support from General Practitioner 53
17. Felt support from specialist/community services 56
18. Felt need for or uptake of alternative type of support 59

Satisfaction with treatment effects 62
19. Overall satisfaction with steroid treatment 64
20. Negative comments about steroids 68
21. Overall satisfaction with surgery 71
22. Negative comments about surgery 74
23. Overall satisfaction with radiotherapy 78
24. Negative comments about radiotherapy 80
25. Overall satisfaction with chemotherapy 84
26. Negative comments about chemotherapy 88

RATING SCALES FOR COPING STYLES (Yellow pages) 94

27. Resentment/Anger 94
28. Rater’s judgement of subject’s ability to retain information 98
29. (Peak) Helplessness and despair 101
30. Acceptance 104
31. Cognitive avoidance 107
32. Seeking meaning 111
33. Seeking control 115
34. Positive appraisal or down playing 120
35. Belief in the possibility of a cure 125
36. Thoughts about the possibility of death 129
37. Getting life in order activity 133
38. Present uncertainty 137
39. Rater’s judgement of the lack of expected emotional response to the situation 141
40. Subject’s awareness of emotional tactics or lack of emotional response to situation 144

RATING SCALES FOR FAMILY RELATIONSHIPS (Orange pages)

41. Felt interference in relationship with carer 148
42. Subject’s satisfaction with support from carer 153
43. Rater’s judgement of subject’s family support 157
44. Subject’s satisfaction with family support 159
45. Subject’s perception of child’s difficulty coping 163
46. Perceived support from religious/spiritual belief or religious community 165
47. Rater’s judgement of subject’s social networks 169
48. Subject’s satisfaction with social support 172

FELT HANDICAP AND DISTRESS (Red pages)

49. Distress over hair loss 177
50. Frustration and interference from fatigue 180
51. Anxiety and impediment due to epilepsy 183
52. Present work status 186
53. Negative feelings about not being able to work 189
54. Felt handicap in work 192
55. Felt handicap in housekeeping/chores/odd jobs 195
56. Felt handicap in child care 199
57. Felt handicap in hobbies/interests 200
58. Felt handicap in social life 203
59. Felt handicap in self-care 205
60. Felt handicap in sex life 208
61. Felt loss of independence 210
62. Felt cognitive handicap 213
63. Felt handicap in communication 217
64. Overall distress 218

References 221
St Bartholomew’s and the Royal College of Physicians Study of Quality of Life in Malignant Cerebral Glioma

Interview schedule for the subject (patient)

Introduction

At the beginning of each meeting recap on previous discussions about the purpose of the interview and check on the use of the tape recorder:

As I explained at hospital X/in my letter, we are conducting a research project at several London hospitals concerning any problems people may have following brain surgery, of their feelings about treatment and of any concerns they or their families may have. We find it more useful to see people at home because there is more time and we are interested in your perspective. It is a research project and it is separate from the treatment but we do hope that it will improve things in the future. Everything that you tell me will be confidential.

A) Medical contact and attitude towards treatment

It is best to start off by letting each person tell their own "story" from first symptoms to diagnosis, rather than by directly asking what they think is wrong. Communication between family members can then be assessed as the story evolves, but initially the most important task is to ascertain the subject’s level of knowledge, and so avoid giving them new information they have not requested.

If an issue is raised spontaneously and seems important, probe at that point for the necessary details rather than covering the same ground later on. The interview should, as far as possible resemble a normal conversation with the subject being gently directed to cover various areas rather than being asked a series of standard questions out of the blue. This interview schedule serves as a guide for useful probes if the subject has not provided sufficient detail to make a rating.

It’s often useful to go over what was the first thing that happened and how you came to hospital X. Perhaps you could tell me when was the first time you thought there might be something wrong?

Record the date of the first symptom and the degree to which the illness was interfering with normal life by the time of diagnosis. Note which doctor raised the possible diagnosis and prognosis but do not refer to it before the subject does. Talk instead about "brain surgery" and "treatment".

Can you remember exactly what he/she said?
Note the language that has been used and the degree of ambiguity that has been left about the prognosis.

Did you feel reassured by Doctor X?
Follow the transfer to the tertiary centre. What was said before biopsy or surgery and how efficient did S feel the process was.
efficient did S feel the process was.

What about when you got the results of the biopsy, what did they say then? Again note the language that was used and the degree of ambiguity left about the prognosis.

Did you feel they were being straightforward with you or did you feel anything was being held back?

Did you feel you were being given enough information? What would you have liked to have known more about?

Did you get on with one of the doctors in particular or find one more reassuring? Why do you think that was?

How did you feel about the way in which you were told about the diagnosis? Would you have preferred it to have been done in any other way?

Were there any aspects of your hospital stay that you weren't happy with? For example ward rounds, nursing procedures or privacy and general feelings of being looked after.

Did your symptoms improve with the steroids? Probe for side effects - tearfulness, euphoria or weight gain. Record present dose.

How did you find the mask being made?

Do you find yourself getting anxious about having radiotherapy to your brain or while you'll having the treatment?

Does the radiotherapy appear to be helping?

Have the doctors been able in your case to give you an indication of the chances that the radiotherapy would work?

How have you coped with the hair loss?

(If relevant) How do you find the chemotherapy injections? Have you experienced much nausea or vomiting?

(If relevant) Does the worry of having a fit affect you? Does it stop you doing anything?

Have you felt particularly tired? When did that come on? What does it interfere with you doing?

How well organised do you think your medical care has been?

Have you seen your GP? How helpful have they been?

Have you seen a specialist nurse or social worker?
Have you consulted any other practitioners?
Probe for faith healers and alternative practitioners

B) Coping and Psychological Response

The Comprehensive Psychopathological Rating Scale can be administered here or at the end of the interview. However, if the subject talks about feeling depressed or anxious assess severity at this point rather than leaving it until the end.

Do you remember what your reaction was to finally being told the diagnosis?

Sometimes people have really black moments when they can't see the point of it. Did you have any times like that?

Keep the discussion in the past so that it can initially be distanced. If the subject is able to talk, ask how they feel now. Do not pursue if the subject is obviously defended but return a few times later on until you are sure that they are either ignorant of the implications or else strongly denying them. Evidence of this kind of avoidance is usually easy to pick up. The subject may avoid eye contact, change the subject or else become restless. They should not have to tell you verbally that they do not want to discuss it. If it becomes obvious that the subject cannot or does not wish to discuss their reactions, continue with the interview but concentrate on the more physical aspects of the illness such as treatment, disability and practical problems.

How would you say you have coped with all this?

What sort of strategies do you use? What do you find helps?
For example, keeping busy and trying not to think about it, putting to the back of the mind or else trying to control the situation or the disease.

Do you ever find yourself going over in your mind why it should have been you who got the tumour or what could have caused it?
Probe for anger, rationalisation and acceptance. Does the subject feel they have any psychological control over the tumour, or any theories on its cause?

Have you learnt anything about yourself or life in general? Do you feel you've changed in anyway?

Has there been anything positive that has come out of this?

Do you have a religious faith? Has that helped at all?
Probe in what way, increased church attendance.

Do you have any worries for the future?

Sometimes people feel the need after a serious illness to get their papers in order, to get things sorted out. Have you felt that?
How many plans and what has actually been done.
What about wanting to talk to other people in your situation? Would you have found that helpful?

C) **Emotional support from family and friends**

Was your relative there when you learnt the diagnosis? Did they see the doctors?

How do you think they have coped?

Have you talked about the illness a great deal with them?
How often, who brought it up, does the subject have any worries for the relative. What does the subject feel the relative worries about.

Have you tended to talk about things a great deal in the past?
Has there been a particular difficulty in discussing the illness or have the subject and relative tended not to openly discuss major issues in the past.

Is there anything you feel you need to protect your relative from?
This may throw up fears of dying or of physical incapacity.

Sometimes people notice a change in their relationship when something like this happens, or a change in their feelings. Have you noticed anything?
Probe for increased closeness, resolution of past problems, comforting each other and talking about the future. Does the subject feel the relative is over-protective or is not disclosing certain facts about the illness.

How have your children (if relevant) coped with all this?

What have you been able to tell them?

Do you have any close friends who have been useful? In what way? Have you been able to talk things over with them?

D) **Handicap in home life, social life and employment**

Obtain a clear picture of the subject’s life before the illness including employment, home life and hobbies or interests.

Employment: Are there plans for going back to work. What does work entail and can they foresee any difficulties on return. What payment is the subject receiving at the moment.

Is there anything around the house that you are having difficulty doing?
Quickly probe difficulties with stairs, dressing, using public transport, using money, reading, writing, using telephone and going out. If there are any problems proceed to more extensive Nottingham Extended Activities of Daily living and the Barthel Scale.
Is there anything around the house that you would normally do that your relative is now doing for you?

Do you have any hobbies or things you normally do in the evenings or at weekends?

How do you feel about not being able to do those things at the moment?

What about your social life?

What for you has been the most difficult aspect of this illness to cope with?

How do you feel this illness has changed the quality of your life? How could it be improved? What gives you your quality of life? How would you describe it now?

Generally be careful about introducing the issue of quality of life as some people equate this with terminal illness and of course may not yet see their own illness in these terms. This question is best approached at the second or third contact with the patient once they have had some time to take on board the implications of their illness.

I would just like to finish off by asking you some questions about your memory. Sometimes people notice changes in memory after surgery. Have you noticed any problems? Probe for forgetting names of acquaintances, dates of appointments or doses of drugs.

What about getting yourself organised; thinking about the order in which you have to do something?

Have you noticed any problems finding the right word in conversation or remembering what day of the week it is?

I would now like to do a routine test used in hospital which involves remembering a few simple things.

Administer the Mini-mental state examination. Minimise any sense of failure the subject may feel if they make a lot of mistakes saying, for example, that it is more difficult than it initially seems.

Finishing the interview

How have you found talking about your experience during the past hour? Is there anything we have not covered which you think is relevant?

If the subject feels upset spend some time winding down, reassuring and talking about more mundane issues. Emphasise the value of their views.

Thank you very much for taking the time to talk to me. We are learning a great deal and we do appreciate it. Give some idea of the next meeting and ask them to fill out the Nottingham Health Profile making the point that some of the questions may not seem relevant to them.
Subsequent interviews

Follow the same basic format particularly if there has been a recurrence. In general later interviews should be less detailed since a good deal of the background information will already have been collected. Follow-up interviews are mainly concerned with documenting how much more information the subject receives about the condition and how their state changes at three and six months from the diagnosis. Does, for example, distress change over time or do expectations become lower.

Physical disability, except when it involves severe dysphasia, is no impediment to interviewing. Even subjects with moderately severe cognitive impairment, for example, disorientation in time, may still be able to say quite a lot if the questions are simplified and proceed at a slow pace. When there is frank confusion tape recording may be inappropriate but an assessment should still be made of distress and physical disability.
Introduction

This manual contains instructions for the use of rating scales, and rating sheets for an interview designed to record information about the diagnosis of malignant cerebral glioma.

The research from which this interview is derived followed a tradition of research which uses an investigator-based approach to measurement. This method is exemplified by the Life Events and Difficulties Schedule (LEDS) developed by Brown and colleagues at Bedford College (e.g., Brown & Harris, 1978). Rather than using preformed standard questionnaires, an investigator-based method is based upon the careful interviewing of research subjects to gather data. Interviews are usually tape-recorded and the interviewer rates this verbatim material, together with some non-verbal cues in comparison to the range of responses given by other subjects. A series of rating scales give anchoring standards showing the level of detail that needs to be obtained to make a rating, and how material should be rated.

It is essential with this kind of method that the interviewers are trained in interviewing and understand the use of the rating scales. It is not sufficient for an interviewer to ask a standard list of questions in the hope that the relevant data will be supplied, nor should the interviewer simply follow the respondent’s train of thought carefully avoiding topics that appear difficult. Interviewers need to know how to probe at sensitive points in the interview to get more specific data, how to encourage the respondent to expand and how to move on to cover all areas of research interest. The interviewer also needs to know when it is not possible to collect data in all areas.

This method is not one that can be used by a single investigator working alone (unless they have a dedicated and energetic supervisor). This is because the method is based on the idea that there is some kind of underlying team agreement to the manner in which interview data is interpreted. The interviewer needs to know therefore that they are rating data in a similar way to other interviewers and in any new study with a new research team the inter-rater reliability has to be established. This is to show what was possible, but we are not arguing that the scales will behave reliably in all circumstances. After exhaustive interviewing of patients, reflection on the experiences we were told about, and many hours of discussion, three interviewers with different backgrounds were able to agree to an acceptable level on how to rate the data. We felt that we had managed in these areas to operationalise a theme of patient concern and hoped that we were picking up on something "real". We take this as some evidence for the validity of the method, but it is difficult to argue for the essential validity of a method that tries to represent another individual's experience. Ultimately one can only judge this kind of social research on whether its findings make sense or can be used to make predictions. The same criticisms can be made of a questionnaire-based method.

Some of our ratings may seem rather crude and encompass several different aspects of an experience. This we found was a drawback of trying to reach some standard of inter-rater reliability. We found that there were some aspects of the experience that we wished to measure that we simply could not agree despite our experience in interviews that the issue was important for patients. We list some of these scales in the appendix. Particular culprits were denial, uncertainty and seeking meaning. The difficulty we had with some of these more "interesting" issues makes us wary of the research based on the interpretation of single
researchers. We are therefore aware that not all possible themes have been covered. However given that the development of these scales was a lengthy business we wish to make them available for other researchers considering this kind of work. They may find them useful as they stand or they may wish to use them as a starting point for more detailed work in any particular area. We will be happy to help here in any way but we request that the scales should not be adapted for interview or questionnaire use without prior discussion.

Acknowledgements

This research was made possible by a generous grant from the Cancer Research Campaign Grant no CP1017. The data could not have been collected without the collaboration of the patients who agreed to talk to us at such a difficult time in their lives. We owe them a debt and hope that the insights and knowledge that stem from this work may begin to repay this.

Important notes

The examples we have given have been chosen for the clarity and insight they convey. These quotes however often represent the reflections of individuals on their considerable suffering. All names and places have been omitted but it is possible that some individuals or their doctors could be recognised. We therefore request that nothing in these manuals is cited without our permission.

Throughout the manual the term "subject" is used in preference to "patient". Although our subjects were patients at hospitals, we saw them mostly in their own homes and preferred the term research subjects. At times subject has been abbreviated to "S".
MEDICAL CONTACT
RATING SCALES FOR MEDICAL CONTACT

The ratings scales for medical contact cover the subject's satisfaction with their medical treatment and care. This section also allows the interviewer to make some assessment of what the subject has been told or understands about their disease and its management.

PERCEIVED CARE FROM INDIVIDUAL DOCTORS (Scales 1-12)

Although many staff are generally involved in making the diagnosis, there are usually a few key clinicians who have spent time explaining the meaning and outcome of the investigations to the subject. The first 12 ratings cover the subject's satisfaction with the care given by these key representatives of each specialty.

Whom these clinicians were should be apparent as the story of the diagnosis unfolds.

The interviewer should try to identify which doctor said what, and if it is not spontaneously volunteered, probe as to how concerned, open and reassuring the subject perceived each doctor to be.

The rater should also try to judge what each doctor has actually told the subject.

These ratings of felt concern/reassurance, felt openness (about information) should be repeated for the representative of each speciality who was most involved in the case. Ideally this should be a senior clinician, but if a junior member of staff has explained more than anyone else he or she should be the subject of the rating.

If it appears that doctors on the same team have given inconsistent or conflicting information, give preference to that from the more senior clinician. Rate the subject's overall view about conflicting information in the later section covering coherence in information.

If there is a mixture of senior and junior clinicians where information has not clashed then rate the "team" in general using all available doctors rather than leaving the categories out altogether.

It may not always be possible to make all these ratings, especially if the patient was initially confused, in a state of shock and unable or unwilling to remember exactly what was said.
PERCEIVED CARE FROM INDIVIDUAL DOCTORS

NEUROLOGIST

1. [ ] Felt concern or reassurance conveyed

2. [ ] Felt openness

3. [ ] Rater’s judgement of ambiguity conveyed about the diagnosis

4. [ ] Rater’s judgement of ambiguity conveyed about the prognosis

SURGEON

5. [ ] Felt concern or reassurance conveyed

6. [ ] Felt openness

7. [ ] Rater’s judgement of ambiguity conveyed about the diagnosis

8. [ ] Rater’s judgement of ambiguity conveyed about the prognosis

RADIOThERAPIST

9. [ ] Felt concern or reassurance conveyed

10. [ ] Felt openness
11. Rater's judgement of ambiguity conveyed about the diagnosis

12. Rater's judgement of ambiguity conveyed about the prognosis
RATINGS FOR INDIVIDUAL DOCTORS

1. Felt concern or reassurance conveyed by neurologist

This is the degree to which the patient feels that the neurologist manifested his or her concern by their actions. This may have involved taking their initial problems seriously and arranging for an urgent transfer, coming back to see them as promised after an investigation, making a special effort to explain procedures, taking the time to explain the diagnosis or the general warmth that they conveyed.

Rating

1. Marked S is extremely pleased with the neurologist.

2. Moderate S is pleased and satisfied, but not exuberantly so.

3. Some S feels that there was just about enough concern shown. They may express some dissatisfaction that more attention could have been given but they are not extremely concerned. This rating could be seen as the doctors just about passing.

4. Nil S has very little positive to say and indeed has to be extremely negative for this rating to be made.
1. Examples of felt concern or reassurance conveyed by neurologist

**Marked**

2. I was very impressed with the way things were handled. I felt it was well co-ordinated. My wife was told about it in the nicest possible way, and I was led gently stage by stage. I don't think it could have been done any better.

30. She was very nice. She gave me ... I thought a very good set of tests ... I was in there a long time and then Dr B came to see me she was very nice too. In fact I was suspicious then because people aren't normally as kind as they were. They were very caring and said they were going to send me straight to St C's.

35. That chap is brilliant. There's no way I'll ever say anything against him. It was he who said he wanted me to come up here.

**Moderate**

10. Luckily I'm under a neurologist at Hospital C and I saw him I had some very worrying symptoms, and he, bless him, as he went up to Hospital X the next day, arranged for me to have a bed and I heard literally within a couple of days. (Rated moderate due to comparison with another clinician)

26. I think he did pretty well really ... It was a bit tricky but I think he did pretty well in retrospect. It's hard trying to tell someone ... So he left me with a bit of hope as it were - a very nice man I thought.

He was very sort of sympathetic and I think pretty cautious in the way that he broke the news. It's a very difficult thing to tell someone.

17. They got me right into hospital the next day, a scan was done that day and they told me in the afternoon I had a tumour. It was very quick but a bit sudden. I wasn't expecting it at all. Then I had to wait one whole week for the surgery - but, no, I was satisfied with the whole thing, getting the results so quickly.
1. Examples of felt concern or reassurance conveyed by neurologist

Some

121. Dr. X. came in and he said, "Oh, Mr. B. you're a very sick man." So I said, "I've just come out of hospital, I've just been given clearance." He said, "Half your brain's not working" and it was as blunt as that. There was no beating about the bush. ......... And he started talking down to me and I won't have that at all. I said, "You might be the specialist and you've read all about it and you're a good man as far as I'm concerned, but I'm still the patient." I said, "You can't talk from my experience."

57. We went two weeks ago to see him. Nothing. It was a waste of time going. You sit there for about an hour and a half (waiting) and then, "Hello Mrs O, how are you?" and I say "I'm not too bad" and he says, "See you in three months."

99. Now he was quite, I wouldn't say sneering, but quite dismissive that I should think or connect these two things (fits and steroids) and he said he would write to Mr S to sort it out... So that was it. I got this rather odd sort of interview with this doctor ....

Nil

6. He used some word, I can't remember what it was, but he was so abrupt he must have been because I said to him "You've gutted me." I didn't like his attitude at all. He was awful... his bedside manner is really awful... I didn't mind seeing the students but it was the way he put it over you know "They're going to be GP's in 5 year's time."

12. He said the whole thing very suddenly. I know in these days of litigation doctors have to be careful what they said and not withhold anything but he didn't give any hope at all, and he didn't seem to realise that it was important.

96. He was a bit sarcastic, he really was. He said to me, "Oh, there's no need for you to come here, you can see me as a National Health Patient at the R." So I thought I don't want to .... you know... because we were anxious to get it sorted out. If you have never had it before you do sort of worry. But I did go for the NHS appointment and he kept me waiting three months before he let me even go and see him. I was really annoyed.
2. Felt openness of neurologist

The aim here is to elicit how open the patient feels each doctor has been. This is rated separately from felt concern and reassurance because it seems that people do not always mind some economy with the truth if it allows them to come to terms gradually with the initial diagnosis. Indeed, they may see the planned and gradual disclosure of information as indicating care and concern on the part of the doctor. The aim of rating openness is therefore to show that it is the way in which things are handled in relation to the patient's personality and coping skills that is important, and that telling the whole truth all of the time is not what is desired. For example, two men appreciated that they had not been told the whole truth at the time of diagnosis whilst feeling that everything was handled extremely well. One woman was very clear that she had been told the truth but felt that her experience of surgery had been mismanaged and her feelings and worries ignored.

Again, repeated ratings over the year will allow a doctor to be re-interpreted as 'dishonest' for failing to mention the possibility of a recurrence, even though he or she might have originally been perceived as extremely open.

Rating

1. Marked  S feels that the neurologist has been very forthcoming and truthful about the diagnosis.

2. Moderate  S feels that the clinician was able to tell them most things but has held back some facts or else suspects that there may be more to the story, although they are not particularly dissatisfied with this. Rate here when subject knows they are not being told everything but are quite happy about this.

3. Some  S feels that the clinician has been non-committal, did not expand in the manner they would have expected, or used only non-verbal language to convey that things were serious. They show some perplexity at the way that things have been managed.

4. Nil  S feels that the clinician was purposefully avoiding them or else never made themselves available to answer even the most basic questions. They are definitely critical of this.
2. Examples of felt openness of neurologist

Marked

5. He said it might possibly be a tumour. I said to my aunt that's just what I didn't want to hear.

2. I was told it was a tumour with a cyst in it although I was a bit disorientated.

125. I asked him what was the bottom line, and he told me straight, he said, "You’ll be in a wheelchair for the rest of your life." He's always been honest with me oh yes. Oh he's been right down the line with me. No pretence with him and that's how I wanted it.

30. She asked me through to her office and asked if I had any idea what was causing my problems. I said then, "I've got a brain tumour?" She said, "Well, they have just telephoned the results through and it seems to be that you have got something like that.

Moderate

2. I realise now that the biopsy had no bearing on the course or prognosis although in hospital I attached great significance to this. (S is not dissatisfied).

22. He was being very frank. He’s been very frank all along. I have to see how I do... He’s not told me any lies. They have established that it's a brain tumour and they are going to deal with it with radiotherapy.

73. They took me into hospital, gave me a brain scan, found a tumour. They told me that they had found an abnormality. I was happy with that because I am an ex-soldier. I have always wanted to know what the bottom line is.

100. Q: Do you feel you got enough information from him? A: Yes, I think so. Although, I don’t suppose they can tell you everything from the start.... can they, until they start to do tests.

81. They all explained to me then and there. They said, "You’ve got a tumour. It's not a great big thing, we don't know the actual size of it yet. We are going to take it out. It is not a difficult operation, we are doing them everyday."
2. **Examples of felt openness of neurologist**

Some

2. For example, it was the first time I'd seen my scans. They said there was a chance of cure, that the tumour was quite close to the surface and that they were all good things but I hadn't heard any of that before. (ie; rating of previous doctor)

26. I don't think he told us it was an astrocytoma which would have been useful to know.

32. Well, now, I know what I'm looking for, so to speak (on the scan). It showed a smallish patch up here on the brain and a bigger patch on January 13th. And they said, "Oh, we had better find out what is causing this." They never sort of, you know, told you that you could have a brain tumour, cancer, or any of these things.

Nil

32. I am very sorry, I'm afraid I have to say that I haven't found him very helpful. I personally don't think that I have had a very good opinion from him. I found him not a person I wanted to explore at all. He didn't seem to know what the problem was or to explore the opportunities.... I am afraid he didn't help me.

96. I went and saw him and he examined me and he said, "Well, I can't find anything wrong with you." And when I had had the tests done and everything he said to me," Mrs X there is nothing wrong with you. You can get in your car and go back to work." I was so confused. I really should have gone to somebody else because at the time the girl who was doing the EEG she almost said it, spluttered out to me, you know, that they had found something wrong.
3. Rater's judgement of ambiguity about diagnosis conveyed by the neurologist

This scale is an attempt by the rater to judge what kind of information the subject has actually received from their doctors. Since the subject's perception and recall of this information may be different from that of their doctor, this scale allows the rater the freedom to decide what it seems most likely that the subject was told, even if this contradicts what the subject themselves reports. It is important that some effort is made to rate what information has been presented to the patient so that their coping styles can be seen as being in response to certain kinds of information. Subjects who have been told different information can, quite literally, be coping with different situations.

In deciding on this rating take account of the credibility of the subject’s own account, including tone of voice and willingness to discuss it, as well as what the relative reports that the subject has been told. The latter’s account can be invaluable. They may, for example, clearly describe an occasion when they witnessed the subject being told that the tumour was malignant, but that this information was subsequently not recalled. Clear information from the notes can also be used in some situations.

In this scale, therefore, the term 'cancer' must leave least room for ambiguity, whereas the term 'lump' or 'cyst' leave most. The subject may still believe that cancer and malignancy are worse or better than each other but this is a separate issue. A doctor who has told a patient they have a malignant brain tumour, has, in their own terms, been as clear as possible about the diagnosis.

**Rating**

1. **Marked** It seems that the doctor used a fair degree of euphemism to describe the tumour such as ‘cyst’, ‘swelling’ or ‘growth’.

2. **Moderate** It seemed that the doctor described a tumour that was not too serious or was of a benign kind.

3. **Some** It seems that the doctor gave an indication that the tumour was serious in so far that it needed to be treated with radiotherapy, but he or she did not make clear that it was a malignant brain tumour or a cancerous tumour. The doctor doesn’t have to mention radiotherapy as long they say the tumour is serious.

4. **Nil** It seems that the doctor made it clear the tumour was of a malignant kind or cancerous. The doctor can still be rated as nil for ambiguity about diagnosis if they implied that was cure was possible, but this later information should be covered separately in ambiguity over prognosis.
3. Examples of rater's judgement of ambiguity about diagnosis conveyed by neurologist

Marked

26. He said there was a cyst on the right side of my brain that was how he put it.

7. He told me there was a swelling - that's the language he used of course that didn't mean very much to me then - I didn't realise it was swelling into a confined space.

6. He called it a lesion at one point.

96. I told him exactly all the symptoms and .. I mean the first thing that came into my mind was "Oh, don't tell me I've got a brain tumour." When I went back to him and he had all the tests he said to me, "Mrs X there is nothing wrong with you." ... and later I met a woman who had been to see the very same man and he told her there wasn't a thing wrong with her either. Well, she was a lot worse of than me. She had cancer everywhere.

32. (I had) an ultrasound and an X-ray of the lungs.... just to.. I think it was to identify whether it was secondary or primary. But I don't think he ever said "tumour", he just said, "I want to know what's wrong with you." No one really told me what they were looking for until they came to see me in intensive care.

17. Dr S said there was a dark shadow but didn't actually relate it to being a tumour. He just put it down to being, as I say, a shadow but he didn't actually specify you know whether it was a mass there or just a shadow on the brain. He didn't call it a tumour at the time.

Moderate

3. He told me I had a tumour in my brain but he told me not to worry that it wasn't a bad one, that it was benign.

43. They've done a lot of different tests but nobody actually came through with anything for some time. When I was taken into hospital for more tests, that's when they came up and said I had a lump on the left side of the brain. He didn't tell me then that they actually found what it was. When I went to his outpatients I had to ask. He was not straightforward at that point.

81. They all explained to me then and there. They said, "You've got a tumour. It's not a great big thing, we are going to take it out. It is not a difficult operation, we are doing them everyday."
3. **Examples of rater's judgement of ambiguity about diagnosis conveyed by neurologist**

Some

5. I don’t think they told me it was cancer. I think I read that in a book.

29. Yes, well, they’ve done a lot of tests..... found out I had a bad head.... tumour which was caused ....a couple of years. Well, when they found out about it they thought it was just as big as a pea but they done these tests and they found out that it was a very big lump which they had to take out.

30. I can’t remember exactly what she said but I said then, "Have I got a brain tumour?" and she said, "Well, they have just telephoned the results through and it seems to be that you have got something." I don’t know what she said then but she indicated what it was and again she was very, very nice.

Nil

25. They said it was a malignant tumour of the brain.

35. I was virtually told it was cancer that was burning my head.

121. When we went in he said to me, "You’re a very sick man, you have got a tumour on the brain, and it will kill you, that’s as simple as that." He said, "That’s how ill you are." And he said, "It is going to be major surgery to get it out and you have to decide if you want the operation." He said, "It will kill you anyway or you can have the operation and your chances of pulling through with all your faculties are about 10%.

99. And he came round in the afternoon and he said he had found a very big brain tumour and just sat down.... I mean he told me in a very good way like he said "It's very bad news", just said... just spit it out really. Well, I can’t think of another way to do it to be honest... I mean how do you tell someone something like that!
4. **Rater's judgement of ambiguity about prognosis conveyed by the neurologist**

Despite the diagnosis having been clearly explained, the prognosis may be left unclear or discussed in terms of the best possible outcome. The rater's judgement must be made using all the available information. The manner in which the subject discusses this, the coherence of their account and conflicting information from the relative are all important here. Evidence from staff who have witnessed the interviews can be used if available.

Ambiguity left by the doctor about the prognosis should be assessed by reference to information that it is clearly established i.e. that more than one half of patients with this grade of tumour will be dead in one year. The doctor, however, may not have mentioned a possible fatal outcome, may have talked only in terms of an implied cure, and this would be rated as "marked ambiguity". A "moderate" rating is one in which a recurrence at an unspecified future date is mentioned but in general an optimistic picture is given. "Some ambiguity" is a less optimistic scenario with more emphasis on the fact that it would come back in the medium term or that there is no guarantee that treatment will be successful in treating the disease. A situation of no ambiguity is one in which the patient is told that the disease is probably fatal, that it is highly likely that it will come back within the year and that the aim of radiotherapy is to delay rather than to cure the disease.

**Rating**

1. **Marked**  It seems that the doctor has implied that a cure is possible, for example, that the radiotherapy will finish off the tumour or that the scan is "fine" or "clear" without an added caveat.

2. **Moderate**  It seems that the subject has been told that there is only some possibility of recurrence, for example, that the radiotherapy should stop the tumour coming back or that the doctor has seen cases of people who have survived a long time. Some slight inkling of doubt may have been introduced.

3. **Some**  It seems that the doctor has said that there is only a very small chance of a cure or that it is uncertain whether the radiotherapy will achieve a remission. There has to have been some measure of doubt introduced into the situation for this rating to be made.

4. **Nil**  It seems that the doctor has explicated a scenario in which treatment merely delays but does not cure the disease and there is very little uncertainty about the situation.

0. **Zero**  No evidence that the prognosis has been discussed.
4. Examples rater's judgement of ambiguity about prognosis conveyed by the neurologist

Marked

22. No they never have given me any information about prognosis but I haven't asked.

26. They suggested I should have radiotherapy and went into some of the practicalities of that... I didn't really get any clear sense of the prognosis at Hospital X.

88. He showed me the scans .... and said that there are different ways that they can deal with it.... Am, they told me that the brain tumour wasn't very dangerous to my brain right now.

43. He said it was a tumour and he said it was very small and whether it would come to an operation they wouldn't know exactly because there's drugs and everything that they can use beforehand. I was happy with being told because there's nothing worse that not knowing.

17. And he just basically gave me a run through of what... of what actually happens, I think I asked him. And he said that I would be given a biopsy and that was that.

Moderate

5. They said mine was a slow-growing one.

23. I said, "Would it get better of it's own accord?" and he said he didn't think so. No that's not quite true. He did say that there was a 50/50 chance of full recovery.

29. Well, he said I had a bad thing growing in my head ... and he said if it wasn't taken out it would just get bigger. He said one of these things is not good in any case but he said if it saves your life... why you have it done and then you'll get better.

84. Oh, he just said, you know, that there was something in there and it would be growing, he said, like your hair and your nails, it would be at that sort of pace, so therefore we have got to get on with the treatment very quickly.
4. Examples of rater's judgement of ambiguity about prognosis conveyed by the neurologist

Some

23. I asked him at the beginning if it would get better and he said he didn't think so.

15. He told me straight. He said you'll be in a wheelchair for the rest of your life.

22. He's not saying "You're going to live." He doesn't say that. I haven't asked him to. I wouldn't expect him to.

They've established that it is a primary brain tumour and that they'll try and deal with it with radiotherapy. They say they'll have to see how I go.

35. Saw Dr. C, my life may last a while but he could not say how long. I must enjoy every moment. I asked him how long my life would last but he couldn't tell me. He couldn't say whether it was going to be six months, twelve months or ten years. So it was obvious that there was something in there that he was worried about to a degree, but where he thought it could be mastered.

Nil

2. I realise now that the tumour will come back quite soon, probably within two years I will not be here.

99. He said it would be non-curable and he said.... he used the phrase, "Keep you as comfortable as possible." I thought immediately that I would be some sort of vegetable quite soon. You know, "We'll keep you as comfortable as possible". Well, they can't give you a straight answer to, like, "How long?" because every patient is slightly different.
5. Felt concern or reassurance conveyed by the surgeon

This is the degree to which the patient feels that the surgeon manifested his or her concern by their actions. This may involve taking things seriously and arranging for an urgent transfer, coming back to see them as promised after an operation, making a special effort to explain procedures, taking the time to explain the diagnosis or the general warmth that the surgeon conveyed.

Rating

1. Marked S is extremely pleased with the clinician.

2. Moderate S is pleased and satisfied but not exuberantly so.

3. Some S feels that there was just about enough concern shown. They may express some dissatisfaction that more attention could have been given but they are not extremely concerned. This rating could be seen as the doctors "just about passing".

4. Nil S has very little positive to say and indeed has to be extremely negative for this rating to be made.
5. Examples of felt concern or reassurance conveyed by the surgeon

Marked

9. Do you know him? He's a lovely man. He’d found my notes and was waiting for me up on the ward. He couldn’t have done it better. He has a good doctor-patient attitude.

11. I felt he really understood me, that he was my doctor since he had been the one who saw me in casualty... He came back and told me after the operation that things had gone well and that they had been able to go ahead and do the full operation. And he had come to check that I was OK before I went down, to tell me why there had been a delay.

6. It wasn’t until we saw Mr J that he had a different sort of attitude - nicer attitude. He put it very subtly ... Well you’re getting the soft sell along the line aren’t you? So it’s letting you down gently. It’s quite nice. I shouldn’t say that should I, but that’s how it came over. It was quite psychologically done.

99. He just sort of sits down and talks to you in a nice way. And he is very positive about it all, explains, you know, what he is going to do. He just reassures you where you are.

Moderate

8. You’re not just being told, "Right that’s it, you’re in the dustbin - cheerio", you’re given a chance with the treatment. You’re told in one breath, but you’re told in another that there is still a chance.

26. Mr C's team were pretty good I thought.

25. They came to see me every day. It did me so much good to be there. They told me about the tumour in a good professional way.

32. I mean as a surgeon he’s absolutely brilliant. As a sort of human consultant I wouldn’t want to be with him too often because he was very clinical.
5. Examples of felt concern or reassurance conveyed by surgeon

Some

21. He did go out of his way because he seemed to think Dr A was the man for it. But I don’t think he wanted it. It was he who told me we’re putting you under Dr C. I thought he was trying to do his best.

10. I saw somebody - I don’t know his name. I had to wait ’til 2.15 in the morning because they were operating. I mean that’s not their fault and he did a full history taking. He did ask me how I was feeling... I didn’t get his name you see I think I’m bad at remembering names but when you’re in that situation, you don’t, you remember faces. He didn’t say “I’m Dr So and So.” In that sort of situation you don’t always remember names so I can’t blame him.

24. I suppose looking back on it - they didn’t spend a huge length of time telling me all about this - the pros and cons of this that and the other ... I don’t recall more than the basic amount of time being given.

Nil

10. It wasn’t as well handled as last time. Nobody told me what to expect, nobody came to talk to me, and I didn’t find out until later that there were tumour cells in the fluid.

5. He started off by saying “I’m very sorry but I’ve got some bad news for you.” Well this isn’t the right way to go about it, you should say, “Now listen mate you’ve got a problem and we know how to deal with it.” You shouldn’t get people all depressed from the start because I just switched off and didn’t hear all the rest.

60. A: I didn’t think much of Dr X at all.
Q: What didn’t you think much of?
A: Well he just comes in: “Oh hello Mr B, how are you?” You know, “Can you move your foot? Can you move your arm?” “Yes, that’s fine, OK, bye.”
Q: So he didn’t give much information or show concern?
A: No, he didn’t give much.

78. So it wasn’t until a week after the operation that the doctor came and said they’d operated and I was so angry! I was angry. As far as I was concerned somebody had yanked me in and he had decided that he was going to operate and I had no idea. How on earth could he come to the conclusion I was ill when I was totally well. I told him that he wasn’t much of a doctor and I was very angry with him, really angry. I thought, this is against civil liberties that anybody should do that when there was no need. As I say I was really angry.
6. Felt openness of surgeon

The aim here is to elicit how open the patient feels the surgeon has been. This is rated separately from felt concern and reassurance because it seems that people do not always mind some economy with the truth if it allows them come to terms gradually with the initial diagnosis. Indeed, they may see the planned and gradual disclosure of information as indicating concern on the part of the doctor. The aim therefore of rating openness is to show that it is the way in which things are handled in relation to the patient’s personality and coping skills that is important, and that telling the whole truth all of the time is not what is desired. For example, two men appreciated that they had not been told the whole truth at the time of diagnosis whilst feeling that everything was handled extremely well. One woman was very clear that she had been told the truth but felt that her experience of surgery had been mismanaged and her feelings and worries ignored.

Again, repeated ratings over the year will allow a doctor to be re-interpreted as 'dishonest' for failing to mention the possibility of a recurrence, even though he or she might have originally been perceived as extremely open.

Rating

1. Marked S feels that the surgeon has been very forthcoming and truthful about the diagnosis.

2. Moderate S feels that the surgeon was able to tell them most things but has held back some facts or suspects that there may be more to the story, although they are not particularly dissatisfied with this. Rate here when subject knows they are not being told everything but are quite happy about this.

3. Some S feels that the surgeon has been non-committal, did not expand in the manner they would have expected, or used only non-verbal language to convey that things were serious. They show some perplexity at the way that things have been managed.

4. Nil S feels that the surgeon was purposefully avoiding them or else never made themselves available to answer even the most basic questions. They are definitely critical of this.
6. Examples of felt openness of surgeon

Marked

7. We were told there was an element of risk in the biopsy itself that it could make things worse or that I could die.

9. He’s a man who understands. He talked to me normally and explained everything.

30. They told me I might have to have two operations. I might have to have a biopsy and then another bigger operation to remove the tumour. He said, “What you’ve got is very common and you’ll just need one operation” and then he said, “Maybe you’ll need some radiotherapy afterwards.”

73. The surgeon came to me and he told me what he was going to do. He said he had seen the x-rays and it was a tumour which was in a good part of the brain. He told me he would open my skull and take out the tumour, as much as he possibly could. He told me I could come off the table dead. I asked him for the bottom line and he was good enough to give it to me.

99. He talked about the radiotherapy and the chemotherapy afterwards. He talked about the operation and what he was going to do very clearly. And they talked about possible risks and things in the operation. They were very up front about that... it was good to hear that and good to talk.

63. I mean, obviously, they have to be very Joe Blunt on what they find and I do find that they don’t beat about the bush, they tell you what is wrong with you.

Moderate

11. I think it was half and half. He told me some himself and I asked him as well, but the nurses explained to me so I didn’t have to wait for the doctor. Anytime I thought of something to ask I should make a note of it so that when the doctor came I could ask him.

28. I wouldn’t say they were evading me, no way, obviously if I ask any questions or ask to see somebody they must oblige and see me.

7. I suppose all the time you really guess because Mr. B. does... he gives you an inkling. He says “I’ve taken a nice lot of material” you know and you’ve got an idea.

2. I realise now that the biopsy had no bearing on the course or prognosis although in hospital I attached great significance to this. (S is not dissatisfied).
6. Examples of felt openness of surgeon

Some

9. I thought they could have told you earlier (that it was malignant) but I suppose they don’t want to worry you.

26. I have a biological background as does my wife and I think it would have been useful to have explored our background as we could handle information that perhaps other people couldn’t ... I’ve dissected the head so I’ve a fair bit of knowledge and I think that means you can jump some of these things and maybe concentrate on the other bits of information. I think I would have liked to have known a bit more about what my options were.

88. He was the one who showed me the X-rays, and I can’t remember his name. He was a bit more upper class well-educated doctor who spoke words that you didn’t understand and kind of washed over things a bit and then I went to somebody else and asked for an explanation. So, you know, if you’ve got someone else to turn to I don’t mind that because I realise they’re in surgery and when you’ve got patients put under you don’t have to worry about communicating with them.

Nil

10. I think I class myself as a sensible person and I want to be told the truth. Maybe they didn’t tell me because they didn’t feel I could handle it. I don’t know but I’ve always felt very positive that I want to know what’s going on.

19. Q: What makes you think it might be malignant
A: He kept avoiding me you see, and I had to keep asking him and he saying, "It’s still in the lab, it’s still in the lab." So eventually I said, "You’re not telling me but I think it’s malignant." He said, "Didn’t I tell you?" Perhaps they were testing it all those weeks I don’t know ... Perhaps he thought it might upset me.

11. I don’t like all this my wife knowing things and them not telling me. I didn’t know that there would be any after effects from the surgery such as fitting (epilepsy) g and that it would interfere with my job.
7. **Rater's judgement of ambiguity about diagnosis conveyed by the surgeon**

This scale is an attempt by the rater to judge what kind of information the subject has actually received from their doctors. A subject’s perception and recall of this information, can of course, be very different from that, for example, of their doctor. This scale therefore, allows the rater the freedom to decide what it seems most likely that the subject was told, even if this contradicts what the subject themselves reports. It is important that some effort is made to rate what information has been presented to the subject so that their coping styles can be seen as being in response to certain kinds of information. Subjects who have been told different information can, quite literally, be coping with different situations.

In deciding on this rating assess the credibility of the subject’s own account, including tone of voice and willingness to discuss it, as well as what the relative reports that the subject has been told. The latter’s account can be invaluable. They may, for example, clearly describe an occasion when they witnessed the subject being told that the tumour was malignant, but that the subject subsequently failed to recall this. In this scale, therefore, the use of the term 'cancer' must leave least room for ambiguity, whereas that of 'lump' or 'cyst' leave most. The subject may still believe that cancer and malignancy are worse or better than each other but this is a separate issue. A doctor who has told a patient they have a malignant brain tumour, has, in their own terms, been as clear as possible about the diagnosis.

**Rating**

1. **Marked** It seems that the surgeon used a fair degree of euphemism to describe the tumour, for example, as a 'cyst', 'swelling' or 'growth'.

2. **Moderate** It seems that the surgeon described a tumour that was not too serious or was of a benign kind.

3. **Some** It seems that the surgeon gave some indication that the tumour was serious in so far that it needed to be treated with radiotherapy, but he or she did not make clear that it was malignant or cancerous brain tumour. The surgeon doesn't have to mention radiotherapy as long they have conveyed that it was a serious tumour.

4. **Nil** It seems that the doctor made it clear that the tumour was of a malignant or cancerous kind. The doctor can still be rated as "nil" for ambiguity about diagnosis even if they implied that was cure was possible. Information about the prognosis should be rated separately in the following section covering the prognosis.
7. **Examples of rater's judgement of ambiguity about diagnosis conveyed by surgeon**

**Marked**

11. He told me I had a lump in the back of my brain and it was the pressure that caused my headaches.

10. They told me they were going to drain off the cyst in my head.

26. They said there were cysts on the scan which they wanted to biopsy.

28. An earlier team did say... oh I can't remember now... some sort of pressure which was removed - a nasty thing or something. I didn't ask what they meant.

**Moderate**

11. He said this tumour has roots which spread out.

9. Nobody told me anything until I went to outpatients... All the time I kept asking for the results and they never told me. In the end it was not until I was actually out of hospital they told me it was a **malignant** brain tumour.

81. They said, "You've got a tumour, it's not a great big thing.... We're going to take it out, it's not a difficult operation, we're doing them every day."

**Some**

9. He explained that it was a tumour. He said it appears the tumour is growing....He said it was a slow-growing one. He said it had taken 9 years to grow to the size where you could see it and take it out.

30. They said it was a brain tumour, that they'd taken away as much as was safe to, and that I needed radiotherapy to get rid of any that was left... nobody actually said I'd got cancer. That slowly dawned on me, that I wouldn't have radiotherapy unless I had it.

17. They told me I had a tumour.

**Nil**

25. They said it was a malignant tumour of the brain.

24. He said it was a tumour, that it was a glioma a good way up the scale of malignancy.

60. Just that they would make a hole in the skull and make a little trap door and go in with ultrasound to find the exact spot and remove the tumour which he did and unfortunately it's cancerous which he told me.

47. And then they decided they had to operate to find out what it is. They have given me a needle biopsy and then they decided what it was. Then they said it was a tumour, definitely tumour. A grade IV glioma.
8. **Rater's judgement of ambiguity about prognosis conveyed by the surgeon**

Despite being fairly clear about the diagnosis, the prognosis may be left unclear or discussed in terms of the best possible outcome. The rater's judgement must be made using all the available information. The manner in which the subject discusses this, the coherence of their account and conflicting information from the relative are all important here. Evidence from staff who have witnessed the interviews can be used if available.

Ambiguity left by the doctor about the prognosis should be assessed by reference to information that it is clearly established i.e. that more than one half of patients with this grade of tumour will be dead in one year. The surgeon, however, may not have discussed the possibility of a fatal outcome, and may have talked only in terms of an implied cure. This would be rated as "marked" on ambiguity. A "moderate" rating is one in which a possible recurrence at an unspecified future date is mentioned but in general an optimistic picture is given. "Some" ambiguity is a less optimistic scenario with more emphasis on the fact that it would come back in the medium term or that there is no guarantee that treatment will be successful. A situation of "nil" ambiguity is one in which the patient is told that the disease is probably fatal, that it is highly likely that it will come back within the year and that the aim of radiotherapy is to delay rather than to cure the disease progression.

**Rating**

1. **Marked** It seems that the surgeon has implied that a cure is possible i.e. that the radiotherapy will finish off the tumour or that the scan is no 'fine' or 'ok' without an added caveat.

2. **Moderate** It seems that the subject has been told that there is only some possibility of recurrence of the tumour i.e.; that the radiotherapy should stop it coming back or that the doctor has cases of people who have survived a long time. Some slight inkling of doubt may have been introduced.

3. **Some** It seems that the surgeon has said that there is only a very small chance of a cure or that it is uncertain whether the radiotherapy will achieve a remission. There has to have been some measure of doubt introduced into the situation for this rating to be made, eg: We have to see how it goes.

4. **Nil** It seems that the surgeon has explicated a scenario in which treatment merely delays but does not cure the disease and there is very little uncertainty about the situation.

0. **Zero** No evidence that the prognosis has been discussed or even implied.
8. **Examples rater’s judgement of ambiguity about prognosis conveyed by surgeon**

Marked

11. He told me that I would be cured by the radiotherapy. They explained it as if you removed the root of the tree, because the tree has so many tiny branches, it’s very possible that some roots of this lump cause serious trouble. The treatment is to kill these roots, to guarantee it won’t grow again. He reassured me it would cure me.

24. A: He’d taken out 90% and there were dangers of trying to get more out with surgery and I needed radiotherapy.
Q: What about the actual prognosis, was he able to say the chances of the radiotherapy getting rid of the 5-10%?
A: I didn’t specifically ask him. He spoke as though it were pretty certain.

30. But they explained very fully about radiotherapy and what it would do and how it would help to get rid of anything that was left. They said it would take away anything that was left and there was no other way it could be done.

60. ....but he is pretty confident that with therapy and everything else it will be clear.

Moderate

6. (He) told us that a certain number of people will not do so well, and then he told us that his mother had gone on for 15 years with the same as what I’ve got, and that was why he went into neurosurgery.

9. They said that as far as they know they would give the radiotherapy treatment, but there was no guarantee it would not come back again. If it shows any sign of growing back we’ll just go straight back to the radiotherapy department. I’ve had what they call a quite miraculous recovery.

47. ...I am not sure that I am going to die soon. They said it was a possibility when I asked them really. He did say most people can recover. Some don’t. And you try and be positive. So, he sort of said try and be positive. Some people do die but try and think positive. He said most don’t.

90. They said...it might not grow back for the rest of your life, or there is 5% where it could grow back within a few years. So there’s 90% where it does come back in 10 years, but in 10 years time, there might be a cure for it.
8. Examples of rater's judgement of ambiguity about prognosis conveyed by the surgeon

Some

25. They said it would probably get worse but they hoped, they couldn't say, but they hoped that the radiotherapy would reduce the inflammation...

13. A: He said, "We've taken it out or we've taken quite a lot of it out but it will come back again, I think."
   Q: Did he give you any idea of how long before it came back, or what to expect?
   A: No, in fact, I've been given no real details of prognosis. I mean, I don't know how long this is going on for or what to expect.....they told me it would, it might respond to treatment.

100. Oh, he did say I would have radiotherapy. He said it was inoperable because it was in a sensitive spot, but they were going to try radiotherapy. He said it was a fast-growing one.

80. He said, "We've had the results back and we've suspected this already" and then he sort of... you know... said, "You've got this medical thing" and I said "What's that?" and he .. sort of going round and round. I said, "Right I've got brain cancer, alright?" and he said, "Yes, you have." So of course I said, "I'm going to die, am I?" and he said, "No, well, I can't answer that." That's what he said. Then he sort of went on to explain what sort of cancer it was...And I said to him, "Well, how bad is this news?" and he said, "Well, a lot can be done, you can have radiotherapy and there are other things if necessary." And that was it. I didn't understand it was incurable. I don't know if I'm thick or what. He didn't say incurable or anything like that.

Nil

7. ... the radiotherapy simply delays the progression, it doesn't actually stop it, wish to God it did, but it doesn't.

25. The surgeon looked at my scans and said there's nothing we can do. I said "Well what are you telling me?" He said "I give you three to five months."

74. He just sat there and looked at me and he went, "It's not good." So I said to him "Well, it never has been good, has it?" and he said, "It's not good at all." And I just felt like hitting him... I felt like hitting him, really, so I said, "You've made me sit here all day to tell me that it is not good and that's all you're saying!" So I said, "Well, how long have I got then. Six months to two years?" and he went, "Yes".
9. Felt concern or reassurance conveyed by the radiotherapist

This is the degree to which the subject feels that the radiotherapist manifested his or her concern by their actions. This may have involved taking their initial problems seriously, arranging speedily for the radiotherapy treatment to begin, explaining the procedures and allaying fears. It may cover the general warmth and reassurance the subject feels was demonstrated by the radiotherapist during consultations.

Rating

1. Marked Subject is extremely pleased with the radiotherapist.

2. Moderate Subject is pleased and satisfied but not exuberantly so.

3. Some Subject feels that there was just about enough concern shown. They may express some dissatisfaction that more attention could have been given but they are not extremely concerned. This rating may be seen as the radiotherapist just about passing.

4. Nil Subject has very little positive to say and indeed has to be extremely negative for this rating to be made.
9. Examples of felt concern/reassurance conveyed by radiotherapist

Marked

35. The doctor who's in charge of this lot he's a great fella. He's a great fella he is always smiles and says 'hello' and when he decides to have a good look at you there's not a lot he misses.

100. He is a very good doctor. He actually put my mind at rest. When I said, "It's cancer isn't it?" he said, "Well don't worry about it, it can't go anywhere in your body. It can't go anywhere, don't worry about it.

30. I think he was very straightforward and straight to the point which we liked better than someone who hedges round or someone who lays it on the hard line. He was in the middle of that, very good, we liked his approach.

10. I can talk to him, I find him fine. ... The first time I met him he seemed a little bit negative... he seemed to dwell on the aspects of, you know, it might not work, but the second time I saw him I got on with him much better and we talked about the positive aspects of the situation as well as the negative ones. I felt immensely reassured.

Moderate

22. Oh he was good. A nice guy.

26. I think they've been very good from the radiotherapy side - very cheery and helpful. They've always been willing to talk to us and very informative. But he was very sort of sympathetic and I think pretty cautious in the way that he broke the news.

71. He's good, he's good there. Doctors, they are usually busy. They can see you quick. Dr D. is not bad who looks after me but for how long? Five? Ten minutes?.... the doctor is busy....he's got his job to do.......(this patient felt satisfied overall with the approach)

78. Yes he was very gentle and he spoke very clearly.... now I have to say in his honour that I wasn't taking anything else in... I was stunned and I couldn't eat my dinner and he took me, he dragged me downstairs and I had various things.
9. Examples of felt concern/reassurance conveyed by radiotherapist

Some

12. I don’t feel that to the same extent (as the surgeon) I had a relationship with any particular doctor.

99. I thought this man is a ... there is maybe a genius pugged in here. I felt very safe in his hands but at the same time I felt very rushed. I mean, it is rather a conveyor belt, you know, the man has so many things to do. As one is opening the door to leave he’s dictating stuff on his dictaphone straightaway. And there’s no chance to sit down and talk things really through in length.

74. I wish that before they started the radiotherapy that somebody would have sat down for an hour or half an hour, I know they haven’t got much time, and explained what I could expect, what the affects I have, because after the first lot of therapy I left there and I didn’t feel well and it frightened me and I was walking down the road and I was everywhere, all dizzy, and the next day the RT’s said, "Well, it shouldn’t have made you feel like that."

Nil

72. And he started on about radiotherapy and that was alright and he started on about what it would be and trying to reduce and all this, that and the other (and he said) "But you won’t understand it, my dear." So I said, "Well try me" (and he replied) "Oh no, there’s no point." So I said, "Try me, I’ve got a degree in physics." And "Oh dear, you’ll know more than I do," and off he went!

47. I saw him yesterday and we were talking and suddenly he said, "Right that’s it, time to go now," and he sort of pushed the "ward round" out of the room and "Goodbye" and I don’t really feel that the conversation is finished. I think he is of the old school, you know.

2. I had a disconcerting meeting with Dr. X in the radiotherapy department. (At) one of his clinics he decided to tell me the worst that could happen, I thought, "Why is he telling me these things, why on earth is he telling me these things, what is going on that I don’t know about?" It upset me and so I became worried.

61. I don’t know who he is, I don’t know his name. I don’t see much of him. I feel unclear about what’s going on. I want to get out of here.
10. Felt openness of radiotherapist

The aim here is to elicit how open the subject feels the doctor has been. This is rated separately from felt concern and reassurance because it seems that people do not always mind some economy with the truth if it allows them to come to terms gradually with the initial diagnosis. Indeed, they may see the planned and gradual disclosure of information as indicating concern on the part of the doctor. The aim therefore of rating openness is to show that it is the way in which things are handled in relation to the subject’s personality and coping skills that is important, and that telling the whole truth all of the time is not what is desired. For example, two men appreciated that they had not been told the whole truth at the time of diagnosis whilst feeling that everything was handled extremely well. One woman was very clear that she had been told the truth but felt that her experience of surgery had been mismanaged and her feelings and worries ignored.

Again, repeated ratings over the year will allow a doctor to be re-interpreted as 'dishonest' for failing to mention the possibility of a recurrence, even though he or she might have originally been perceived as extremely open.

Rating

1. Marked S feels that the clinician has been very forthcoming and truthful about the diagnosis.

2. Moderate S feels that the clinician was able to tell them most things but has held back some facts or suspects that there may be more to the story, although they are not particularly dissatisfied with this. Rate here when subject knows they are not being told everything but are quite happy about this.

3. Some S feels that the clinician has been non-committal, did not expand in the manner they would have expected, or used only non-verbal language to convey that things were serious. They show some perplexity at the way that things have been managed.

4. Nil S feels that the clinician was purposefully avoiding them or else never made themselves available to answer even the most basic questions. They are definitely critical of this.
10. Examples of felt openness of radiotherapist

Marked

10. He explained to me what had been done. He made it very clear which I was very grateful for.

2. I got a lot more information from him that maybe it wasn't appropriate to give in the first place (other doctor). It was very useful questions came out - it was very helpful ... When I saw him it was the first time I'd seen my scans.

73. He told me that he would offer me radiotherapy to kill off what was remaining. Unless the cells were neutralised there was a possibility that they would grow back. And, yes, I asked him what my chances were if I didn't have the RT and he said, "Well, I have known people live without it."

88. Yes, he told me about its side effects and that helped with this therapy. He explained that it would be a grade of tumour that I had, that it would help shrink it and that after the therapy they would do a scan to see how it reacted, so he explained it all. I was so well informed.

30. He was very straightforward. He answered any questions we wanted answering without any messing about.

93. Well, asked him to tell me exactly and he did. Which was the thing I wanted. I mean, as far as I'm concerned it was perfect. I mean, it may not be good for everybody else, I mean people sometimes don't want to know these things, but I asked him, and I insisted to be truthful. I said, "I want to know, I am entitled to know, and I want to know" and he told me. Which you can't ask for no more than that.

Moderate

28. Very well, very well, they was very co-operative and answering questions and that and the doctor was quite good.

69. Basically, I don't really know much about it. All I know I ask when I go down and have my treatment exactly what they're doing. He (the radiotherapist) seems to have an awful temper, shouting at all the staff and everything. I was terrified. I was really upset... but anyway, he has changed his tune and he has been very nice to me... All I can gather is that it's these rays or whatever and it is supposed to be going to eradicate it.

77. He can't say anything. He said,"You've got to do the course of treatment" and "that's all there is to it." (He is) trying to shrink the tumour. I said to him,"How am I doing?" and he said, "I think you're doing alright". The man can't answer me until he knows what the tests are.
10. Examples of felt openness of the radiotherapist

Some

100. Well, I think actually they only give you the information that you ask for. I suppose they have got lots of people to see haven’t they. Unless you specifically ask they don’t really tell you a lot. He seemed to be a bit evasive.

99. He said, "You know it’s a tumour?" and I said, "Yes, well, I know it’s a tumour but what do you mean by that?" He said, "Well, we don’t want that coming back, do we?" And I said, "too right." I thought that was a funny sort of phrase. So I think we were rather skirting round the issue there. I think he could have bitten the bullet a bit harder that time. I could have done with more information there I think, really. I thought he was rather evading the issue.

26. Just occasionally I think we could have done with a bit of information such as the effects of radiotherapy. We had to seek it out ourselves. We got the Backup book ....

80. I went to an organisation called Backup and they sent me leaflets so before I went to see them (the radiotherapists) I’d read up a bit. Unfortunately, the day I saw him he was in a rush, it was really packed. I took some questions with me but unfortunately I didn’t have the opportunity to say anything because he sort of jumped up and left.

78. When he’s spoken he gives you the minimum.... His information has been very sparse.

Nil

21. He never said anything at all. He just said he’d taken me over, that’s all. I don’t think he’s happy.

74. Yes, nobody..... just haven’t told me anything. See, I think I’m getting worse because nobody has still told me about this treatment. ...... nobody has ever sat and explained anything to me. No, nobody has even told me what will happen if the radiotherapy does shrink it. Nobody. What the next course of action (will be).... nobody ever said anything.

47. I think doctors should talk to their patients. He was very, you know, I’ve seen him three times in five weeks. I mean, the junior doctor was much better and she will talk to you. He just sort of stood up and walked out of the room. He was trying to usher you out of the premises. We asked a few questions that he didn’t really answer.

43. They haven’t actually spoken to me in a couple of words. If I ask a question you get answered, you know, you just get an answer. I have spoken to Dr B (radiotherapist) and you don’t get straight answers. I have spoken to Dr E, don’t get straight answers. You just don’t seem to get anywhere.
11. Rater’s judgement of ambiguity about diagnosis conveyed by radiotherapist

This scale is an attempt by the rater to judge what kind of information the subject has actually received from their doctors. A subject’s perception and recall of this information, can of course, be very different from that, for example, of their doctor. This scale therefore, allows the rater the freedom to decide what it seems most likely that the subject was told, even if this contradicts what the subject themselves reports. It is important that some effort is made to rate what information has been presented to the subject so that their coping styles can be seen as being in response to certain kinds of information. Subjects who have been told different information can, quite literally, be coping with different situations.

In deciding on this rating take account of the credibility of the subject’s own account, including tone of voice and willingness to discuss it, as well as what the relative reports that the subject has been told. The latter’s account can be invaluable. They may, for example, clearly describe an occasion when they witnessed the subject being told that the tumour was malignant, but that the subject subsequently failed to recall this. In this scale, therefore, the use of the term 'cancer' must leave least room for ambiguity, whereas that of 'lump' or 'cyst' leave most. The subject may still believe that cancer and malignancy are worse or better than each other but this is a separate issue. A doctor who has told a patient they have a malignant brain tumour, has, in their own terms, been as clear as possible about the diagnosis.

Rating

1. Marked It seems that the doctor used a fair degree of euphemism to describe the tumour, for example, a 'cyst', 'swelling' or 'growth'.

2. Moderate It seemed that the doctor described a tumour that was not too serious or was of a benign kind.

3. Some It seems that the doctor gave some indication that the tumour was serious in so far that it needed to be treated with radiotherapy, but he or she did not make clear that it was a malignant brain tumour or cancerous. The doctor does not have to mention radiotherapy as long as they said the tumour was a serious one.

4. Nil It seems that the doctor made it clear that the tumour was of a malignant kind or cancerous. The doctor can still be rated as nil for ambiguity about diagnosis if they implied that was cure was possible. Information about the prognosis, however should be rated separately in the following section on ambiguity covering the prognosis.
11. Examples of rater’s judgement of ambiguity about diagnosis conveyed by the radiotherapist

Marked

80. I mean he doesn’t really explain much. Last time I was here he had my CAT scans up on the screen and I saw my name and I was looking at them and I said to him, "Well, what does this mean?" sort of thing. And he said, "Oh, don’t you worry about that, you let me do the worrying" after I’d already heard him say "I think she’s got a cyst" you know, so of course I was worried. (this was on recurrence)

64. A: Because this is.... I don’t know why this has come. I don’t know really.
Q: What don’t you know?
A: Well, what’s wrong with me up here, you know.
Q: Have you asked anybody?
A: Oh, yes, I have been asking, but I just don’t know.
Q: Who did you ask?
A: The doctors.
Q: And what did they say?
A: Well, they just say it’s alright.

5. He said everything’s fine... he said there’s no pressure there. He said everything looks fine so that’s just as good as saying (that the treatment’s worked)... I’ve just got to take it steady.

Moderate

28. Q: So do you remember who first said that you needed to have radiotherapy, or why you needed to have radiotherapy?
A: The team, as I was just saying, did tell me but why I don’t know. I am not so sure why I had the therapy. I don’t think it was exactly explained to me. I mean, I took confidence in them telling me I needed it, but why?
11. **Examples of rater’s judgement of ambiguity about diagnosis conveyed by radiotherapist**

Some

88. He told me about the side effects ..... that it would be a grade of tumour that I had that it would help shrink it and that after the therapy they would do a scan to see how it reacted, and, so, he explained it all.

35. Yes, he told me it was cancer and there was no way that they were going to do anything that wasn’t warranted to affect my brain.

57. I felt so fit, you know, but since I’ve been having the radium I’ve really gone I think down, you know.

Q: Have you had a chance to talk to the radiotherapists about this? What did they say when you told them?

A: Once the radium’s finished I shall be alright.

Nil

25. They said it was a malignant tumour of the brain.

10. It turned out not to be a benign tumour, it turned out to be malignant.... He said did I know that it wasn’t a benign tumour, it was a malignant one, and it had quite a high degree of malignancy.

1. I asked her what the trouble was, what I had. I knew it was a cyst on the brain. I knew that much. I said, "Can you tell me how bad it is, or what it is?" And she said, "Think of 4, and what you have is 2. She said it and I didn’t really catch on. But I caught on in my own sort of way. You’ve got 4 and on the 2 you’ve got 2 and it's chances and you can go a month, you can go 6 months, you can go a year or you can go for longer than that... it’ll go from the 2, it’ll move to the 4 and it could be terminal. That’s what she said.

80. I said,"Right, I’ve got brain cancer, alright?" And he said, "Yes you have."
12. Rater's judgement of ambiguity about prognosis conveyed by the radiotherapist

Despite being fairly clear about the diagnosis, the prognosis may be left unclear or discussed in terms of the best possible outcome. Again the rater's judgement must be made using all the available information. The manner in which the subject discusses this, the coherence of their account and conflicting information from the relative are all important here. Evidence from staff who have witnessed the interviews can be used, if available.

Ambiguity left by the doctor about the prognosis should be assessed by reference to information that it is clearly established i.e.; that more than half of patients with this grade of tumour will be dead in one year. The doctor however may not have discussed the possibility of a fatal outcome. They may have talked only in terms of an implied cure, and this would be rated as "marked" ambiguity. A "moderate" rating is one in which a possible recurrence at an unspecified future date is mentioned but in general an optimistic picture is given. "Some" ambiguity is a less optimistic scenario with more emphasis on the fact that it would come back in the medium term or that there is no guarantee that treatment will be successful in treating the disease. A situation of "nil" ambiguity is one in which the patient is told that the disease is probably fatal, that it is highly likely that it will come back within the year and that the aim of radiotherapy is to delay rather than to cure the disease progression.

Rating

1. Marked  
   It seems that the doctor has implied that a cure is possible i.e. that the radiotherapy will finish off the tumour or that the scan is 'fine' or 'clear' without an added caveat.

2. Moderate  
   It seems that the subject has been told that there is only some possibility of recurrence of the tumour i.e.; that the radiotherapy should stop it coming back or that the doctor has cases of people who have survived a long time. Some slight inkling of doubt may have been introduced.

3. Some  
   It seems that the doctor has said that there is only a very small chance of a cure or that it is uncertain whether the radiotherapy will achieve a remission. There has to have been some measure of doubt introduced into the situation for this rating to be made.

4. Nil  
   It seems that the doctor has explicated a scenario in which treatment merely delays but does not cure the disease and there is very little uncertainty about the situation.

0. Zero  
   No evidence that the prognosis has been discussed or implied.
12. Examples rater's judgement of ambiguity about prognosis conveyed by the radiotherapist

Marked

11. He said the chances of it coming back are always very small, in fact nil after the radiotherapy...He wasn’t definite about it. He just said it's not a guarantee but 9 times out of 10 there's no recurrence.

2. He told me that the tumour's quite near the side - well that's good news. It's apparently better than being stuck in the middle and that it's very small. Then that the radiotherapy tends to have a 30% success rate. He said what I'd been told was broadly true but there are exceptions.

57. He just said he thought I should have it (chemotherapy), you know. So I said, "Alright" and started it. Mainly he hoped it would take all the swelling down.

88. I went in. He said, "Any fits, fainst, bumps or bruises?" Something like that. I said, "Everything's fine." He said, "Well it looks like you're a perfect success, then."

Moderate

10. A: He told me that he wouldn’t do anything for the moment until I have recovered. There is an operation of putting in these radioactive needles but even that they wouldn’t think about at the moment. Just sort of let well alone.
Q: Does he know or has he said whether the treatment that they decide on is going to affect whether it comes back?
A: No he just said "The fluid may return and we would have to drain it again."

26. We had to dig a bit for information on prognosis. In the end we got 5 years with the radiotherapy.

25. They said they could probably destroy some of the tumour but at the same time they could possibly destroy some of your brain. They hadn't enough information yet to decide how it would affect me. I asked Dr. G specifically, "Does this shorten my life span? Can it affect other organs?" He said, "Your liver, kidneys and heart are alright but we must tell you, you have to face it, that it might shorten your life span. But it will be months. We don’t know enough about it and that is why we are doing research. We don’t even know what a cancer is."

28. I asked her what it was doing, this therapy, and I didn’t know exactly what it done. Just sterilising the area as far as I know. ....... There's a possibility of a recurrence.

41
12. Examples of rater's judgement of ambiguity about prognosis conveyed by the radiotherapist

Some

99. I had been told at the start of it that it was incurable and he said, "I still think we are still sort of missing each other if you like." He said, "Think positive, it is a very powerful treatment." So, I thought, "Right, fair enough."

30. Oh yes, I asked him what were the chances of people who had radiotherapy, what were their life chances, and he said that they had a 60% survival rate after a year and that included people who died of anything, like being run over by buses or heart attacks or whatever. Well, I think that's fair enough.

Nil

73. I live in the full realisation that I have had maximum surgery. There is no more in my brain they can remove. There is no more radiotherapy they can offer me when this course is finished. The only help they can give me after that is help to die and I was told that yesterday. I can handle it. I wanted the direct approach. I have insisted on it all along......and they have given it to me.

63. Twice I've been there on my own when they have told me bad news. That lady was talking about somebody coming home and speaking to the family. And I said, "What are you trying to tell me? That I'm dying?" So she said, "Well, I'm saying that you have got to prepare yourself for later on." So then I said to Dr. P., "Am I dying?" and he said, "Well, yes." I felt gutted.
RATINGS FOR OVERALL CARE

13. | | Perceived overall co-ordination in care

14. | | Perceived coherence in information

15. | | Felt ability of system to deal with distress
13. Perceived overall co-ordination in care

Although the subject may be very impressed with the attention given by any of the individual doctors, they may not be so happy with the overall planning of the care. A range of aspects may be rated here including:

Perceived communication (or its lack) between different departments or doctors involved in the care of the patient.

The perceived efficiency of arrangements made to attend different departments for investigation, treatment or out-patient appointments. This may include a perceived disparity between what the subject has been told will happen and what has actually happened.

Do not include for rating comments about the hospital food, shop or general cleaning.

Rating

1. Marked The subject feels that everything has gone very smoothly.

2. Moderate The subject feels that for the most part things have been smooth and straightforward, but there can be some small reservation. Include here difficulties with travelling that are due to poorly co-ordinated hospital transport if the subject thinks that these are severe.

3. Some The subject feels that several areas needed extra effort but that there were some redeeming features. They are not overtly dissatisfied.

4. Nil The subject has strong misgivings about the package of care, and continues to feel that the situation could have been dramatically improved.
13. **Examples of perceived co-ordination in overall care**

**High**

22. They're a great team. I couldn't wish for a better one.

2. I was impressed with the speed and the quality of the care.

7. It was all very swift and well-organised.

122. I mean... a lot of people knock the National Health Service but I've got nothing but praise for it. No, you know, the treatment I've had, you know... Oh no, I've got no complaints about it at all.

55. Oh yeah, I was quite happy with everything in hospital X: doctors, consultants, nurses...... Everything. They wrote fairly quickly really (to the GP) so that's all taken care of and there has been co-ordination there.

**Moderate**

9. Well when I got to clinic they couldn't find my notes, well it's a big hospital I thought.

43. The overall care has been really good. I couldn't go against it. But you know they had me in for about 4 weeks before they got around to operating.

17. Well everybody I see seems to move out. I originally saw Dr A, then Dr B, and one time I saw Dr C. The last couple of times it's been Dr D. He's been sitting in with Dr B because he's going back to surgery I think. I was told because I just phoned to find out to all these people because they keep disappearing you see...! So I'm seeing Dr D, he 's the consultant that I'M seeing at X....I want to see Dr E though because he's the man who diagnosed it sort of thing.

30. I've been going up to (the hospital) a few times to see, not to see anyone in particular, but to see anyone from his department (radiotherapy) who will see me and also to see the surgical team as well. Now they've decided not to bother to go to both of those and just go for the radiotherapy. .... it was a nuisance, we were going up there practically every week, it was a real drag going on the tube.

38. I don't know what to say about the hospital. I can't fault it. The medical staff were absolutely brilliant. The surgical team.... I couldn't fault anyone. The food, I kept going on about the food.... the food was absolutely brilliant. But the only thing I found... a bit distressing is the fact that you were moved around so much. Yes, I was moved around about four times and I found that distressing.
13. **Examples of perceived co-ordination in overall care.**

Some

2. These scans seem to go missing quite a lot. Perhaps there is some kind of competition between the departments to see who can lose the most!

8. They never tell you what time the radiotherapy is going to be. They just tell you any old time. And although the treatment may not take a long time you might have to wait an hour for the porter to bring you back. Sometimes they just let you sit there while they have a chat.

11. I went to see my GP and asked if the hospital had been in contact. She said "No." I told her what had happened, that I had been taken in and had an operation. So the link between the two was not made in my mind.

57. I've got to go up every month (to Hospital X) but I said, "Well, I don't see any point in going next month (when) I've got to go to Hospital Y." It seemed a bit pointless.... especially when it's just like to answer questions.

Nil

32. It seems to me that there ought to be a top man in charge. There isn't a super-chap I mean who takes on the whole deal. I am critical of the way the whole system is running. I am getting different skills and different people come to me and they chip away at me. I mean ... no one seems to be in charge, why not? And I find medical, on these matters, seem to be slightly odd in that you get one bit of expertise and you get another little bit of expertise but you don't get them brought together as a package.

19. He kept avoiding me you see, and I kept asking about the biopsy. He kept saying it's still in the lab, it's still in the lab. He never told me straight out. He (the surgeon) wanted me to go under Dr A for the treatment, but I don't think he (radiotherapist) wanted it you see. ..He just looked at me asked my age and walked off. I don't think they like to treat old people, that's the impression I got. He hardly spoke to me.....He just said he'd taken me over.

60. We turned up for the appointment at the proper time, ok. - waited til 2 o'clock, fine, and they had to send up for the actual chemo, I don't know, the drugs, and am, they sent us up to the ward and we sat there in the corridor of the ward for about a half to two hours, right, when eventually a doctor came to administer the treatment. The treatment was administered in the corridor with the doctor kneeling on the floor with the tray of his needles and stuff on the floor..... so, well, I was annoyed about that.
14. Felt coherence in information

This is a rating of whether the subject feels that they have received enough information about the illness including treatment effects and advice on activity and about whether this seemed coherent to them. Sometimes subjects may complain that they receive noncommittal replies or conflicting information that make little sense to them. This seems more likely to occur when the doctors involved in the case hold different perspectives or when the doctor is avoiding full disclosure. However since the subjects tend to hold onto the 'best' piece of information, this rating may be of more relevance to the carers who puzzle more openly with differences of opinion. It should however be a rating that is made from the subject's point of view and not one of how 'correct' their understanding is. Do not include conflicting information about the timing of treatment or appointments since this should be included in the category for co-ordination in care.

Ratings

1. Marked  S feels they have obtained a clear as possible picture of the illness and its management given present knowledge.

2. Moderate  S feels they have a reasonably clear idea but has some unanswered questions which they wish to get sorted out although they may be uncertain about there are exact answers to be obtained.

3. Some  S feels they have some idea of what might happen, but is still at a considerable loss about areas which they consider important.

4. Nil  S feels that there is very little that has been made clear. They may perceive contradictions in what they have been told or feel unsure about what they consider to be the most basic aspects.
14. Examples of perceived coherence in information

Marked

22. They've all been marvellous. I couldn't really fault them.

81. A: I spoke to the doctor yesterday and he said to me "It's a long drawn out process but you will get back to normal".
Q: Did he give you any idea of when you would be better?
A: I didn't ask him that because they're only human anyway aren't they? They're not bionic. They can't say one week, two weeks or three weeks. That I know. I've been told it's been cut out completely and the reason that I'm having the therapy is to help the confusion and to make sure it has all gone.

35. Well, all the things I have been given, all the problems they have tried to help me with -it has been done right as far as I am concerned.

88. I told them I wanted to know everything. I felt they were very honest. ... All along I asked, so I was well informed all along. Nothing really came as a shock.

Moderate

10. The only thing that did rather surprise me was that the surgeon did come and see me before I was discharged. He had seen the first scan and it reminded me that he had talked about this operation and drawing off the fluid then, but obviously didn't feel it was the time to do it then. It just crossed my mind that the fluid has been there all the time. I didn't actually ask that and I don't see there is any way of finding out, and why should I suddenly get the effect in the last month.

78. And also, at that stage, nobody told me what the steroids did because they kept saying about 'treatments' and what have you and I thought I was going to have more operation or more things on my head and I didn't realise that the steroids were actually a method of giving you whatever it is they give you. I don't know, anyway...... nobody, as I say, told me.... they know what it is, but they don't always tell you. So, I thought I was going back to have a bit more treatment, instead of the steroids which are the treatment!

90. Then there was, like, the operator who done the operations, then there was ah, another type of doctor who came round, who gave you the paperwork and you had to sign, and then there was another one who came round with, they used to come round in the morning, ...... he was the one who came round and told me the result of it.
14 Examples of felt coherence in information

Some

2. With hindsight I can see that the information I got was right at the time, but in clinic it's necessary to build up. (S told 1 year by neurologist and then told 30% success rate by the radiotherapist)

26. I didn't feel we got more than the basics as regards side-effects. I would have liked to have known a bit more about what my options were... You know that way you would have had a choice and you can make up your own mind and feel more in control of your body and your illness. I think that sort of information about actions, consequences and side-effects is very important.

80. .....because I just keep getting different opinions. It's like one week I'm thinking "My God I'm dying" and now this week I'm thinking it's not going to be like that. And they can't say to you "Well, look, you've got so and so time." I thought they could, because of the films and all that.

Nil

30. I did have a lot of intensive questioning by the doctors. One would speak to me and another would then say to me "What did so-and-say? Would you repeat it?" and then another would come along and ask me what that doctor had said. So it seemed I was being tested in some way. One said to me "I think there has been a misunderstanding, you've misunderstood something". I said "I don't think so", and he said "Well if I haven't misled you than someone in our team has".

43. I don't know what the practice is... how they actually pass things on because they never really told me anything... The doctor must have known there was something wrong with me but he didn't seem to take anything as serious as other people I had seen, and he disregarded one letter the GP sent that she wanted checked out.

32. No one has ever discussed with me what the other options are. We haven't talked about chemo at all, as to whether that is available or whether you merely wait to get to a stage one fail before you talk about other options. I think that ought to come from the medics, possibly from somebody who is not one of the doctors involved. There should be somebody...it's medical advice, someone who can bring it all together and bring in alternatives and statistics.

74. .....different people say different things and that's another thing that quite annoys me. I wish they wouldn't. Nobody has told me from start to finish what I've actually got, what will happen, and what it will end up as definitely.
15. Felt ability of system to deal with distress

Again this rating deals with the subject's experience of the medical system at a suprah-individual level. It may not be any particular person's responsibility to deal with the emotional needs of either the subject or the carer, but in some instances one member of staff, or the sum effect of several friendly interactions has given the subject a feeling of being supported and cared for. At present this can be an ad hoc affair, depending more on chance and the personal characteristics of individual staff than on any institutional policy. By specifically addressing the perception of the 'system' we can see how much need is un-met.

In this rating distressing situations such as incontinence or hair loss are included as well as emotional shock. Do not include comments relating to specific doctors since these will already have been covered, but do rate the if the subject complains about nobody talking to their relatives or about nobody seeming particularly interested in their case. Do not rate tea ladies and cleaning staff.

Rating

1. Marked  The subject feels that every possible attention has been paid to their needs.

2. Moderate  The subject feels that for the most part they have been attended to, but there can be some small reservations.

3. Some  The subject feels that several areas needed extra effort but that there are some redeeming features. They are not overtly dissatisfied.

4. Nil  The subject has very strong misgivings about the lack of interest they have received, and continues to feel that the situation could have been dramatically improved.
15. Examples of felt ability of system to deal with distress

Marked

7. That young man (a nurse) was very helpful in listening to someone who has just been told that he’s only got six months or at most 18 months to live. He talked about his father who was in the ministry worked in a hospital and the kind of work that we both did.

2. Apparently my wife had been told in the nicest possible way about it and I was led step by step through it.

1. It really and truly is a marvellous hospital.. It’s the people, even the tea lady. They really are very nice people and you couldn’t wish for a better crowd... You never feel on your own. You know you always feel there’s someone there to dry your eyes for you and do the rest of that.

11. It was a nurse, one of the charge nurses who came and explained everything. He used simple words like an ordinary person.

56. The nursing care was marvellous. They were all marvellous. I had no problems, nothing at all, they were just marvellous.

Moderate

78. Oh yes I feel very relaxed...... I have no queries about anything else....... And that is really good, and the nurse who comes in, I don’t know quite what, he’s a professional, he’s in charge as it were. He comes in. And he’s a smashing lad. And he talks about what’s what.... (but) ... if there was something to comment, it would be that it is all standardised. They come round with the trolley and everything, sleeping tablet, painkiller? Oh, yes, I’ll have that. ... you know without really thinking.

95. Yes I had no complaints with the actual hospital treatment as such...... except for the fact that now, I mean, the way life is outside now, sort of years ago a doctor you seemed to be personal to everybody and now you seem just another number in passing like. You know the whole attitude in hospitals has really changed. It is probably new to what I’ve been used to, you know.

88. I trust everybody here...Actually, I’ve been really happy with everything except for my last scan, you know, it was the most upsetting thing I’ve had happen to me the whole time .... they just seemed a bit rough and too occupied with themselves or something.
15. **Examples of felt ability of system to deal with distress**

Some

26. The one thing I felt I could have done with is more physical contact. Sometimes in the middle of the night I just wanted to hold one of the nurse's hands, more than having my blood pressure taken. I felt that physical contact was something I required and wanted more than anything else, I was in this low patch and I wanted human contact.

24. I suppose looking back on it they didn't spend a huge length of time telling me all about this - the pros and cons of this that and the other. I think they probably had fairly full schedules...I don't recall more than the basic amount of time being given to sort of go round cosseting me...

25. The first time I woke up on the ward on arriving from X I thought I was in the lower gun deck of the Victory at the Battle of Trafalgar. The screams of "I'm dying, Oh God, let me die" at 3.20 every morning. It's almost criminal, not criminal but very unwise to put orthopaedic recuperation together with radiotherapy. One needs extreme rest and the other extreme care. ... I felt that living in the same ward was too much. You need to rest your brain and they were screaming their heads off!

Nil

10. Can I just speak on behalf of some of the people on my ward? Because it wasn't just me. I just thought there was a job there for somebody to go round and speak to people who were worried. ...there were a lot of staff but there wasn't anyone that you could sort of rely on...I know it was a busy ward but...I didn't know who was in charge. It seemed that they sort of did their bit and went off without really seeing who was biting their nails or was a bit anxious.

32. I am sad at the moment that I am not hearing from anybody about whether I am getting better or worse and no one will tell me. I protest to everybody this question and it is passed over. Why don't they tell us? They don't seem able to tell me what it is doing.... or do they know something and they won't tell me?

85. "What's the problem?" that's all she knew. "What's the problem?" Four or five times she asked me. So I said, well I'll tell you the problem, I'll tell you my medical history. That was disgraceful, asking me what the problem was.

80. They don't want to hear you saying, "Look I'm really miserable and fed up, you know I don't understand all this." Do you know what I mean.... they didn't, they're not really interested in that. They want you to say "Life's wonderful, life's great" and I wouldn't because that isn't how I felt.
16. **Felt support from General Practitioner**

This is a rating of the subject's attitude towards the care they have received from their General Practitioner (GP). They may, for example, be pleased that their GP has paid a visit shortly after the diagnosis or continues to make regular calls. On the other hand they may be surprised that this has not occurred and feel that they simply sign repeat prescriptions for them. The rating does not separate concern or reassurance as is simply to reflect the overall feelings of confidence that the carer feels in the GP.

**Rating**

1. **Marked**  
   S is extremely satisfied with the care from the GP.

2. **Moderate**  
   S is satisfied, with a few minor reservations.

3. **Some**  
   S feels the GP has done a reasonable job but can suggest several areas which could have received more attention.

4. **Nil**  
   S is extremely dissatisfied with and critical of the GP.

If S is changing GP, or if they have not seen their GP throughout a critical period rate as not relevant except in cases where the subject feels that the GP should have contacted them to find out the diagnosis from the hospital.
16. Examples of felt support from General Practitioner

Marked

19. Oh Dr Vac they call him, he's been to see me in hospital - lovely man.

26. Our GP was very good. It was her original diagnosis either a brain tumour or meningitis. She tried to get me straight into the neurosurgical unit and when they won't buy it she said well let's try for the meningitis because I was slightly photophobic.

7. My GP was very good. She said just take three months off. I was so relieved that someone told me to do it - you have to have someone in authority like that to let you off.

55. Well, it was an emergency situation and they reacted to it really, I mean he came round, he was in surgery seeing his patients, just dropped his surgery and came straight away. And the hospital wrote to him almost immediately and I've been to see him since I've come out. No, I haven't got any complaints. They all acted as I would hope.

88. You know they've been very interested in not only us as patients but as people. And I really appreciate our GP's even down to our doctor's secretary. You know everybody has been just really impressive.

Moderate

89. Well, my wife has worked for him for ten years, although he's not a particularly, how can I put it, particularly nice character. He is very helpful as far as we're concerned. So I would say there is no problem there.

77. I've got a good GP, I'm not complaining about the man, I mean a man can only try, he's given me all the tests he possibly could but even on my blood tests they didn't show up - it's an amazing thing. I even had my eyes tested and they didn't see it. No, I will say this, he tried everything. He's a very caring man.

85. I went around and told him about this giddiness and, ah, he never said what it was. I don't know whether he said, no, it wasn't a Chinese flu. Oh yeah, that's right, he said I was down a bit, yeah, that's what he said, and the daughter don't reckon him at all.

37. I mean, me own doctor, he gives me all the information that he knows. Q: Have you talked to your own doctor about how you're getting on? A: No, he comes round and perhaps I might stand up and he says, "You look well, anyway" (chuckle), which I do, I feel great in myself, it's just that I've got to get moving.
16. Examples of felt support from General Practitioner

Some

66. Well, I only see him when I want tablets, you know, medication. Well, he’s not my kind of doctor.

57. I don’t think that’s right (GP has not been to visit). He says (to daughter), "How’s your mum getting on? Tell her to come and see me." I thought, why can’t he come and see me? I think he should pop in and see his patient.

11. I went to see my doctor and asked if the hospital had been in contact. He said no! I said it was severe and he said "What?" and I told him what happened that I was taken into hospital and had an operation. That link between the GP and the hospital was not made, in my mind.

37. I think my doctor should have sent me up to see the specialist before he did, really. I mean, (it) was from Christmas to March 3rd - two whole months!

Nil

6. Our GP comes in, "Have you put your whatsit, your affairs in order?" I thought "Oh lovely", there’s you trying to think positive and she comes in like that.

5. He gave me tranquillisers on prescription and he said have 1, 2 or 3 a day. I mean is that 1, 2 or 3? If you take 3 a day you’ll get hooked on them. I’ve read about tranquillisers. They’ve got a lot of women in doors hooked on them so I didn’t take one. I’ve still got the bottle.

73. My first symptoms were deep penetrating headaches which I took to my GP who was a complete waste of space. She diagnosed stress, gave me painkillers. They began to be more painful and increased in frequency. I went back to her and she diagnosed migraine, gave me tablets, no better. By this time I was in a terrific amount of pain. I was in bed. I couldn’t get out of bed. In the end she told my wife that there was nothing wrong with me and that she was fed up with coming out. She was very reluctant.

63. I noticed that I was dropping things in the shop like scissors, combs. When I went to wind a perm I never had the strength. She (GP) said, "There’s nothing wrong with your hands. It’s stress". Well I was very cross with Dr G because she told me there was nothing wrong with my hands..... was very cross, I could have smacked her in the mouth.

98. My doctor is not very co-operative. Unfortunately......somebody said it might be a clash of personalities or something, I don’t know.
17. **Felt support from specialist nurse/ community services**

This rating covers care provided to the subject from specialist nurses based in primary care, local hospice services, hospital palliative services, social work care and physiotherapy. The nurses might provide basic everyday care, night nursing or counselling as, for example, in the care of the MacMillan service. Social workers might offer assistance with the patient’s living circumstances, such as, re-housing needs and benefit entitlements.

The rating should relate to those who come to the subject’s home, but not to care received whilst an in-patient in hospital or hospice. The rating should take into account both the adequacy of the care (as perceived by the subject) and the support the subject receives from this.

**Rating**

1. **Marked**  
   S is extremely pleased with the care they have received and cannot fault it.

2. **Moderate**  
   S is generally satisfied but there may be a few areas they have minor reservations about.

3. **Some**  
   S feels the nursing services have been just about adequate but there are several areas that could have been improved.

4. **Nil**  
   S is extremely dissatisfied and critical of the help (or lack of it) that they have had.
17. **Examples of felt support from specialist nurse/community services**

**Marked**

6. I get a MacMillan nurse come in. She's very good. She comes in and just has a cup of tea. She doesn't force her views, might sort of ask has anyone said...more caring whatever. She's quite good, and she's good in the fact that she's got a spastic boy and she has to cope with a lot of fits and she's good like that...

26. The people from the North London Hospice Group have been round two or three times. They've been very helpful.

89. I collapsed twice and the situation has been such that it meant quite a kerfuffle to get me up to X hospital which would have been unnecessary if we had had access to the MacMillan nurses at this end. Then after that they suggested that we get in contact with them and this is what we did and one of them came round to talk to us. I think we will find it useful if I collapse or anything in the future... somebody who is familiar with you and your circumstances.

57. Q: And how is it at the hospice? (patient attends hospice day centre)  
A: Yes, it's lovely. A very nice place. The people are lovely. We just sit and talk, mind you, we had a young couple come in playing the piano.

**Moderate**

80. I don't see the social worker on a regular basis or anything but I know that she is there if I want her. No, I don't see the point in seeing the social worker every month. I've decided to put it to the back of my mind and get on with life.

96. Well, I have a nurse that comes but she hasn't been now for about two months. The thing about it is they're really short up there because about seven or eight of them are off with different things, but, she will pop in now and again and obviously if I want her I would ring her, but I don't, you know, I don't really want her.

100. Yes, I have (a physiotherapist) but I've not had her round for a couple of weeks because I have been too weak to move.... but I will have her this week if I can.
17. **Examples of felt support from specialist nurse/community services**

Some

74. ...they refused to see me at R because the lady there, the MacMillan nurse at the R, was seeing me while somebody else was seeing me. Isn’t it ridiculous? Same as the social worker. The social worker won’t get involved until that one stops getting involved at the R..... I mean, like I said to the social worker the other day I don’t care whether you help me or the woman from R. or the one from W. I just want somebody who I can ring up who deals with me.

77. They’re (the social worker) just starting now. I went over today and had a discussion with the girl and she’s going to start it off and they’re going to bring somebody over or I’m going to see somebody. They’re going to get it alright. I told them I don’t want no charity and I don’t want anything that I’m not entitled to.

Nil

86. One of these district nurses came round. Oh, he was useless. He phoned and said he’d be here at twelve o’clock. He came about quarter to one. He was a senior man. He don’t do nothing, he just organises. That’s the trouble, too many organisers and nobody working.... Well, he said, I can’t give you a bath, it’s not my job.
18. **Felt need for, or uptake of alternative type of support**

This scale is for the few subjects who contact cancer support groups or any other kind of support group, or who feel that they would very much like that kind of contact.

This scale is also relevant for those who have visited practitioners such as homoeopaths, faith healers, reflexologists and those teaching visualisation techniques. Do not include healing services that have taken place in the places of religious worship the carer and subject normally attend regularly. This scale will only be relevant to a proportion of patients.

**Rating**

1. **Marked**  S is extremely pleased with the practitioner and has gained considerable relief from the consultation.

2. **Moderate**  S is generally satisfied although there may be some areas of minor reservations.

3. **Some**  S feels the consultations were just about adequate, but there are several areas that could have been improved on.

4. **Nil**  S is extremely dissatisfied and critical of the care.
18. **Examples of felt need for, or uptake of alternative type of support**

**Marked**

26. The fact that I’m interested in the holistic side as well. I would have been interested to know their views on the complimentary approach - not to do one or the other. I feel that talking those things through would have been quite helpful. I think that few doctors I’ve met in this process have really been interested in getting into that aspect of it. We’ve occasionally given them the opportunity to. I can understand, why, after all, they’re sort of brought up in a certain paradigm and have to operate within that and therefore it is more difficult to stray away to where you feel less confident. So I can understand it but, I think, given the interest in mind-body medicine these days it would not be unreasonable to have it as part of the armoury for people who are seeing patients like myself.

80. I was looking for a group because, I mean, I do think it would help. I don’t know anyone who has had a brain tumour and all this sort of stuff and I wish I had been in a group or something...... a group of people where we can all sit and talk about it. ...... I went to an organisation called Backup as well. I got loads of leaflets to read up on it.

63. My faith healer told me that the tumour would be practically gone. She told me that on the Thursday and then I saw one of Dr P’s team on the Friday. So she already told me that it would be gone. She's marvellous, she really is. I go to her once a week.

23. I very much believe in healing and felt if I gave that up I think I would be gone. I’ve always been involved in it in a Pentecostal way...... God can heal this, um, physically.. yeah.

**Moderate**

2. I’ve been in contact with Backup about psychoimmunology. They’ve been quite good.

26. I find quite a lot of help from some of these organisations like Cancerlink...I’ve felt there was a lot of support there but that’s really at the practical level.

24. I found the healing quite useful. I just have to see how that turns out.
18. Examples of felt need for, or uptake of alternative type of support

Some

5. The first time I went it was useful but the second time it was just the same old thing and it didn’t make me feel any better. And anyway how can you possibly think that thoughts can kill cancer cells?

100. Well I didn’t think it would be helpful at first (to talk to other patients) but I suppose, really, you know, if anyone is the same as me it would. I suppose, to talk about it and see how they’ve got on. And...(pause) ... talk things over. I don’t know if it would make things any better but....

74. I went once with D’s mum who is quite religious and he went absolutely mad. D is a complete atheist and will not discuss faith healing or anything. She was a nutter. She was an alcoholic. She kept touching my head and saying, "Which side is the tumour?" And I said to her, "Well, if you’re a faith healer you’d know!" D’s mum felt really terrible taking me to a nutty one. I thought it was quite funny. Well, I mean I’ll try anything. I am going to see another one in S. He specialises in people with tumours and he’s wrote a book saying how many people he’s cured. As long as D doesn’t find out because he is completely against anything like that.

Nil

55. There’s a chap down the road, so I’m told had a similar complaint some years ago; he seems alright but you can’t compare - it’s not exactly the same. (This man does not see the use in seeing or knowing about other people in the same situation as him.)

96. Q: Have you ever thought about any alternative medicines, is that something that you were ever interested in?
A: I don’t really know if whether they would be any good or not because I never... I never....
Q: Were you never interested?
A: Well, no not really because it is only in these last few years that they started talking so much about it, isn’t it?

30. Somebody lent me a self-healing tape which I don’t really know if I’ll bother with. I’m not really into that sort of thing.

5. That holistic doctor I was seeing I just don’t trust him. It’s alright for them saying, "Oh, you can make yourself better." I mean, I’ve tried the tapes... but you don’t get rid of the fact that you’ve got problems.
SATISFACTION WITH TREATMENT EFFECTS

There is some considerable difficulty in obtaining the subject's 'objective' satisfaction with treatment when they are not always in possession of information about what the treatment can realistically be expected to achieve, or which symptoms are actually side-effects of the treatment. For example, it is not uncommon for clinicians to say that disability, tiredness or fits are late effects of radiotherapy in an attempt to try and forestall the realisation that the tumour is growing again. Similarly, neurological deficit can be put down to the effects of surgery or of 'withdrawing the steroids too quickly' rather than an honest discussion of the actual damage caused by the disease. On the other hand, the subject may in fact be willing to undergo any side-effects in order to have some chance of cure or of living longer, and so welcome treatment because of the hope that it brings.

By attempting different kinds of rating scales it became clear that it was necessary to rate the subject's overall satisfaction with the treatment separately from their negative comments about side effects. We found that a subject may have several critical things to say about the treatment procedures or effects while at the same time feeling satisfied in an overall sense with the treatment. The patients were thus able to hold conflicting views about the treatment. On the one hand, they may have disliked what they were going through, while at the same time they welcomed and were generally pleased with the chance treatment offered to them. Although we could agree whether a subject was satisfied in an overall sense, we could not agree on the extent to which a subject was positive about treatment.
RATING SCALES FOR SATISFACTION WITH TREATMENT EFFECTS

SATISFACTION WITH STEROIDS
19. Overall satisfaction with steroid treatment

20. Negative comments about steroid treatment

SATISFACTION WITH SURGERY
21. Overall satisfaction with surgery

22. Negative comments about surgery

SATISFACTION WITH RADIOTHERAPY
23. Overall satisfaction with radiotherapy

24. Negative comments about radiotherapy

SATISFACTION WITH CHEMOTHERAPY
25. Overall satisfaction with chemotherapy

26. Negative comments about chemotherapy
19. **Overall satisfaction with steroid treatment**

This is the degree to which the patient is generally satisfied with the steroid treatment he or she has received. In making this assessment the rater takes into account both positive and negative comments about the treatment overall as well as about particular effects or side-effects.

Overall satisfaction with steroid treatment is rated using a 5-point scale.

**Rating**

1. **Marked satisfaction**
   
   S has several positive things to say about the steroid treatment and is very pleased indeed. S is content and happy with the treatment.

2. **Some satisfaction**
   
   S has several positive things to say but is not so impressed. S may have some minor misgivings about some aspect of the treatment.

3. **Neutral**
   
   S is matter of fact, ambivalent, or has no strong feelings about the matter

4. **Some dissatisfaction**
   
   S has some definite negative views but still retains some positive feelings about the treatment.

5. **Marked dissatisfaction**
   
   S has nothing favourable to say about the steroid treatment and in fact is highly critical of it.
19. Examples of overall satisfaction with steroid treatment

Marked satisfaction

45. Q: In what way was there an improvement?
   A: Because I get stronger...I walk good. Now everyday I'm walking better...I had a bath alone yesterday.
   Q: Did you notice that they affected your mood in any way? Did you feel more cheerful or less cheerful?
   A: More cheerful...yes I feel...
   Q: Just better?
   A: Yes.
   (S does not say a great deal about much because of her frontal disease and this is therefore rated contextually as high on satisfaction.)

30. They're to reduce the inflammation round the tumour...they do make you feel very well as well. You feel instantly good. I think that's been a factor in me feeling so well.

95. I think the only things I'm on is them steroids. That's the only tablets I take. Whether they do that I don't know. But that...the general mood is mostly sort of high and the feeling that I can fight anything and take on anything...I mean in my mind that's a big plus.

35. I haven't a clue what they are all for but if you get told you need to take them to do you good then as far as I am concerned I'll take them and that's it.

Some satisfaction

22. The steroids actually helped me in the early days. They stopped me being so emotional.

89. Q: Have you had any problems with that?
   A: None whatsoever...they reduced me on that and that's what produced the fits with my arm and hand and when he realised what was happening he put me up again.
   Q: And you seem to be alright on that dose?
   A: Yes I have no side effects that I know of on that...as you can see my face isn't fat and not muscled up. They give me a stomach coat of Ranitidine with it and I always try to eat something before I take it.

21. And then gradually, day by day I really felt a lot better and they started to reduce my steroids. You know how you imagine if you are reliant on steroids and you have had them for the last....God knows what is going to happen to your body but I didn't notice anything really much happening.
19. **Examples of overall satisfaction with steroid treatment**

**Neutral**

49. I was offered Dexamethasone, you know, as a treatment merely to, I suppose, keep down my pressure.....I have responded to treatment.

63. I mean they did try and reduce them when I first came home a couple of weeks ago but I had to go back to the hospital because the swelling started again. So I was falling asleep, didn't know who was who, calling my husband all names and trying to bite him.

73. I have pressure but that, they tell me, is the result of the redness that you see on the outside of the skull, is much if not exceeded by the redness inside. Therefore, that creates pressure which is balanced by the steroids. It is just a twinge. It is just nothing compared with the headaches. What I have now is nothing, it is just no way.

55. Q: Have the steroids had any noticeable kind of effects?
   A: Made me hungry, apart from that it's alright.

**Some dissatisfaction**

77. So I couldn't sleep 'cos of the steroids and I was running round because of the steroids and I began losing about two kilos a week. But I'm still 14 stone three, so..
   Q: .... you're not worried about that?
   A: Well as long as it don't affect what I've got, I mean I'm piling food in, I don't care.

43. Well, I'm just swelling all over just now. I think it's the drugs and I'm eating a lot, eating far to much, can't stop eating. Even the doctor says it's the drugs. I'm hoping they might be able to cut them down a bit.

25. I've got to lose weight because I've put on a hell of a lot of weight in the hospital. I don't now have this intense hunger, when I was in hospital I couldn't get food quick enough into my mouth. I was making a disgrace of myself.
19. Examples of satisfaction with steroid treatment (cont)

Marked dissatisfaction

74. The weight. I’ve put on so much weight. They say it’s all due to the steroids. I’ve put on three and a half stone. I can’t get up and down the stairs properly. I caught an infection. They said it was because I was on the steroids, that my resistance is low and that’s why I caught the infection. (And) I’ve been having trouble with my knees. Pain, yes. I just lay and cry all night. That’s just the steroids. I mean, I’m covered in bruises. My nails started to fall off and go yellow. (Shows stomach covered in sores and stretch marks) That’s all over my stomach and back and under my arms and they just bleed all the time. They say it’s where the steroids, like, I have naturally stretchy skin and it has made them rip inside, everywhere though. Absolute agony.

40. I hallucinated, yes, they told me afterwards it was a very rare event.... I told my son, I said, "Look, don’t think I’m potty" I said "Something is going on that I don’t understand and I’ve got to get to the bottom of it." .... I said, "They shouldn’t put you on these drugs unless you are prepared for what happens." Completely by surprise I was, I think that should not have happened in the first place. I don’t think I should have been subjected to that. Some of it was quite frightening.

63. Oh, I feel like I’ve swallowed a load of salt but that could have been the steroids. I think the only thing that really bothered me, and I didn’t panic, but, because I was putting on so much weight my face was blowing up like a balloon and when they put the mask on me I used to feel they were cutting my hair off (it was too tight).... Yes, and I have been a bit down when I think of how ugly I look now. The weight, the double chin and bloated cheeks and the facial hair. Obviously from the steroids.

30. All I’m doing now is taking loads and loads of tablets... I’m taking 28 mg a day and I’ve got to cut them down because when you take too many you get all these side effects. You puff up like this and having these fits and makes you overactive and you want to eat too much. So it’s not a nice thing. I would prefer to take less but I can’t cut them down very quickly, if you do you make yourself ill.
20. **Negative comments about steroids**

Rather than feeling positive, subjects may feel worried by the general reputation of steroids and if not by the possibility of side-effects, then by the reality of experiencing them. For women weight gain around the face and the trunk can be particularly distressing. Acne and stretch marks can bother either sex, as can loss of strength in the legs and the more severe weaknesses that can sometimes occur with prolonged use.

**Rating**

1. **Marked**  S has 2 or more negative things to say about the treatment and is very distressed about it.

2. **Moderate**  S mentions several negative things to say but does not appear extremely distressed. Alternatively there is one thing that the subject is very distressed about.

3. **Some**  S does not really see the benefit or has only one negative thing to say. They have experienced some distress because of it.

4. **Nil**  No negative things, is matter of fact or has only positive things to say.
20. **Examples of negative comments about steroids**

**Marked**

116. I developed a constant hunger which I now know is associated with the steroids. I put on 4 stone. Unfortunately that didn’t help my arthritic joints, and as a result I needed a second hip replacement. The trouble is I keep on putting on weight. It’s an awful hunger they give you.

43. I spoke to them about that, they said it was the steroids. Says you keep suffering from headaches, you’ve got to keep the steroids up. I said, "But can’t you treat the legs or do something with them, instead of leaving them open like that?" I would say just about a week after the treatment started my legs started coming up, the skin would break so easily because it got so tight. I can walk, I can’t walk far. I couldn’t stand it, couldn’t stand it any more. They weren’t helping me.

60. ... my foot has been swollen, I’ve had to buy these larger shoes. I don’t know if it’s a side-effect of the tablets or what. On Sunday morning I woke up in absolute agony with my calf muscle, it just seemed to close right up really tight. The doctor said we were reducing the steroids too quickly and I said to him that I had been following the reduction chart... I have this excruciating pain which felt as if it was in the stomach and it goes right through your back and every time... just breathing was absolute agony, and if I coughed, God, that was chronic!

**Moderate**

63. Swelling up. I think that’s just with the steroids. the tummy is a-lot larger. The face. At the end of the day I have a little swelling, not very much, around the ankles.

30. They said today that they would start reducing the dose because they’re not a good thing to be on for very long because you have to have other tablets to kind of counteract the effect of the steroids.

Q: What effects have they had on you?
A: Face has puffed up...It’s not normally puffed up, but it has. It is the steroids. They do make you have a kind of indigestion pain. I’ve mentioned that today that I get this sharp pain here and she said "That’s the steroids as well". I have to carry a card with me saying I’m on steroid treatment because if you withdraw, stop taking them can make you quite ill.

80. I wanted to eat all the time. I just couldn’t understand it. I just had this ravenous appetite. Yes, I’m pretty worried about the steroids now. My face is definitely swollen...now it’s sort of round. I was fairly attractive before and now it’s dreadful.
20. Examples of negative comments about steroids

Some

45. Yes a little bit. The pills were too bitter. It’s only the tablets. Too bitter. I cannot stand it. They stop in the stomach. I must drink something warm.

49. Well, I’m told by Dr A that Dexamethasone alters the reflective index of my eyes....So he says that whereas I can read that, things over there he says that your accommodation goes. It’s not as good as it was.

6. I eat fruit and that sort of thing. I can take a bowl of fresh fruit salad and eat the whole lot myself! I hide it in the fridge and hope that nobody sees its. We all put it down to the steroids.

2. I’m conscious of putting on weight and of taking it from elsewhere. I could do without that.

12. I know I am weaker in the thighs and across the legs. I’m not particularly pleased with that.

Nil

89. Q: Have you had any problems with it at all?
   A: None whatsoever.

71. These are the new steroids, the new packet. That’s the old packet and the new ones I got last week. These are for headaches. I only take them when I have a headache.

82. Q: Do you notice any effects from taking the steroids?
   A: No, not really, no.
21. **Overall Satisfaction with Surgery**

Generally subjects seem to be impressed by neurosurgery although they are not always aware of the diagnostic rather than therapeutic nature of a biopsy. It is also sometimes difficult to separate out the subject's satisfaction with the technical aspects or improvement from the whole experience of becoming ill and of having the situation seem to have been brought under some kind of control. It seems, therefore, that surgery, because it is at the beginning of the illness career, is inevitably seen in a more positive light than later interventions.

**Rating**

1. **Marked Satisfaction**
   S has several positive things to say about the surgery and is very pleased indeed with the operation.

2. **Some Satisfaction**
   S has several positive things to say but is not wholly impressed by the operation and may have some minor misgivings about having surgery.

3. **Neutral**
   S is matter of fact and does not have strong views on the matter. S may be genuinely ambivalent about the surgery.

4. **Some Dissatisfaction**
   S has some definite negative views about the surgery but still retains some positive feelings about having the operation.

5. **Marked Dissatisfaction**
   S has nothing favourable to say about the operation and in fact is highly critical of it.
21. Examples of overall satisfaction with surgery

Marked Satisfaction

73. The surgeon came to me and told me what he was going to do. He said he had seen the X-rays, it was a tumour which was in a good part of the brain and he told me that he would open my skull and take out the tumour as much as he possibly could. He didn’t know at that stage anything else. Ah, I asked him what my chances were, of the operation. He told me I could come off the table perfectly alright, I could come off the table paralysed, I could come off the table dead. I asked for the bottom line and he was good enough to give it to me.

30. That seemed to go very well. I didn’t have a problem. It was fine ... they got me up quickly and I was soon walking about again. I regained all the senses I’d lost immediately, straightaway and I began to feel extremely well. I could get dressed, I could do all the things I couldn’t do before. It was marvellous. We were quite happy about everything and very happy with the treatment that I’d had here.

5. They explained that it would mean taking a small part of the tumour away for examination. They said the risk was like any operation. They couldn’t guarantee 100% success but the chances are they’ll be no problems and there wasn’t. But it was a risk, obviously, working on your brain must be. They came and told me afterwards it worked out perfectly.

Some Satisfaction

89. The actual operation was very well done. I was under for 3 and one half hours. It was not a simple operation. What they do is put a steel cage over your head. They screw it into your scalp at the back and the front. They then put you in a CT scanner which is the computer tomography scanner and find the right place to do the penetration. They slit the scalp and put a self-tapping screw with a hole in it through the scalp and they put a whole needle in and extract a bit of brain. They then take the self-tapping screw out and the skull, the bone material, collapses you see, it recovers and self-seals but your only connection is the actual stitching in your scalp. I didn’t even have a headache after it and I was completely lucid.

63. Well, they obviously had a scan and the surgeons were going to do whatever. They said they were going to do a biopsy first. They explained to me. They said they were going to take a small piece and do a biopsy to find out what it was. They came on Thursday evening to say I would be going down next morning at 8.30am for this biopsy operation. He said, "You could wake up with your left side completely gone" and I didn’t take any notice of that..... Well, I mean, he told me what I was having done and what could happen.
21. Examples of overall satisfaction with surgery

Neutral

49. The biopsy was done with great skill and Mr H. kept coming in, you know, just to sort of keep me on the straight and narrow as it were and inform me about these things.

90. There was the operator who done the operations. He came round and told me it was a medium thing, not a small one. He says it could come back in ten years time after you have had the operation. That doctor was the best doctor.

Some Dissatisfaction

45. A: They did the operation.
   Q: Did they explain to you how they were going to do the operation?
   A: No.
   Q: How did you feel when you came round from the operation?
   A: I feel funny. I had a lot of pain. For about 3 nights.
   Q: Did he (surgeon) say how successful the operation had been?
   A: No, he told me nothing.
   Q: Did you ask him?
   A: I haven’t asked him.

78. Next thing I remember was I woke up.... I thought, "Why am I here?" It wasn’t until a week after the operation that the doctor came and said they had operated and I was so angry.

10. Eating was more difficult because I got this numb patch which they said was because they had to clamp the nerve across here to keep me completely still during the operation and it hasn’t really recovered. I can’t close my teeth right the way across and that’s caused me some discomfort.

Marked Dissatisfaction

71. I got really frightened, even before, when they had me on the bed and I saw the doors of the operating theatre, all the things on top of the ceiling, all the machines. I got frightened and I said to myself, "They’re going to operate on my brain, what’s going to happen to me. Am I not going to wake up, am I going to become blind?"

80. (My eyesight) has got worse since the op. I’ve got pain here, down my leg, and pain in my chest. I’ve got a hole in my chest but I don’t know why. I’ve got a hole where a pipe.... I don’t really understand what’s going on and I feel, like, you know I haven’t really got much choice.
22. Examples of negative comments about surgery

Subjects may make a range of negative comments about their experience of surgery. This may include criticism about the way the operation was performed, the information or lack of it received, the physical effects of brain surgery and the general care they received both before and after the operation. The surgery is taken as a whole experience and negative comments about any aspect of it are rated here.

Rating

1. Marked  S has two or more negative things to say about the treatment and is very distressed about it.

2. Moderate S mentions several negative things to say but does not appear extremely distressed. Alternatively, there is one thing that the subject is very distressed about.

3. Some  S does not really see the benefit or has only one negative thing to say. They have experienced some distress because of it.

4. Nil  S has no negative things, is matter of fact or has only positive things to say.
Examples of negative comments about surgery

Marked

19. They gave me a local not a general. It was dreadful. He injected me to deaden the pain but you could hear everything - the sawing on the bone. He took me down at ten to two and finished at about half past two. He put me under some sort of contraption, rubber ring or something like that.

92. Up until the biopsy I really felt OK. It was only post - biopsy that the symptoms started to begin to show themselves. It was only after the biopsy that I started hallucinating. And then my eyesight started slowly deteriorating. .... Oh yes, definitely (I was confused after the operation) I mean, how can you not be when you've had your skull plummeted with drills!

47. I just couldn't move it forward (his leg) and it was an effort to get it to move forward. It was worse since the operation. I could walk before the operation. And now I can't, not at all.

Moderate

89. Before the operation I had 40-50% control of my hand. I could just write. Immediately after the operation I lost that completely. All I could move was my thumb slightly. My hand was a sort of useless claw. Dr. G voiced the opinion that there must have been some minor complications. So I was an unfortunate one. It is a very considerable loss.

49. Don't get me wrong I'm not being critical here but I wasn't terribly well informed. I wouldn't like to look gift horses in the mouth but I think before a definite diagnosis had been made it was some 10 or 12 days .... so it was about two weeks before we were really put in the picture........... and you know, I was left with the feeling, particularly from Mr H. (surgeon) that the die was cast, that I hadn't a chance.

2. The surgery mucked up my jaw enormously. I have to speak a little slurred and my mouth doesn't move in the same way and it's a damn nuisance. I can't open it fully this way. I can't eat a sandwich. Every time I ask about this I'm told it will come back.
22. Examples of negative comments about surgery

Some

73. Having an anaesthetic is a shock to the system and it takes an awful long time to come out of the system. My body has been grossly insulted.

63. I felt fine after the operation. I just wanted them to take the thing out of my arm because I am very squeamish to needles. Each time I looked at that awful needle in my hand I became a little bit faint. Anyway, eventually it came out, thank God, and I was up and walking.

45. I felt funny (after the operation). I had a lot of pain for about three nights.

Nil

90. He says we have got to give you an operation. (He gave good explanations) That doctor was brilliant to me.

60. (He said) that they would make a hole in the skull and make a little trap door and go in with ultra sound to find the exact spot and remove the tumour which he did.....but I must say, after the operation I feel a completely different man. Now I am calmer, much more laid back, don't seem to worry about anything.

66. Q: Was there anything about the operation itself that worried you or you didn't like? A: No, I didn’t even know I was operated on to be honest with you, don’t remember a thing. When they operate do they cut you open?
23. **Overall satisfaction with radiotherapy**

As with the ratings for satisfaction with steroid treatment and surgery this rating relates at how generally satisfied the subject feels with the radiotherapy treatment he or she has received. The rating is made on the basis of all the comments made by the subject about the experience of having radiotherapy.

Include:-
- a) Relief that there is still hope.
- b) Glad that no side effects seem apparent.
- c) Glad that it seems to be quick.
- d) Pleased with an improvement.

**Rating**

1. **Marked satisfaction**
   Subject has several positive things to say about the radiotherapy treatment and is very pleased indeed.

2. **Some satisfaction**
   Subject has several positive things to say but is not wholly impressed by the radiotherapy and may have some minor misgivings about the treatment.

3. **Neutral**
   Subject is matter of fact, ambivalent or does not have strong views about the radiotherapy treatment.

4. **Some dissatisfaction**
   Subject has some definite negative views about the radiotherapy but still retains some positive feelings about having the treatment.

5. **Marked dissatisfaction**
   Subject has nothing favourable to say about the radiotherapy and in fact is highly critical of it.
23. Overall satisfaction with radiotherapy

Marked Satisfaction

49. they’re very pleasant, I’m most impressed with the servicethat they give......and get treated very promptly which I think is really tremendous. I’ve had my treatment, I’m able to walk better, I’m able to grip better, I’m able to generally well......you can talk to my wife about this, I mean, she’s noticed a tremendous difference.

45. It’s nice, it’s good.........but it’s good.
Q: Do you find yourself getting anxious when you go down to have treatment?
A: No.
Q: And do you find them particularly helpful down there?
A: Yes. Everybody help, putting stool, I climb up.
Q: So you really sound very satisfied?
A: Yes, I am.

21. I thought I’d adapted to that (hair loss) incredibly well and I’ve got used to my wig, I love my wig. .... I mean they were very attentive, I felt very sort of monitored, which was very very good. And then I just gradually day by day really felt a lot better.

Some satisfaction

30. None of the treatments have been painful.... I was almost wanting to get back here to get on with the treatment, I was quite keen to get back.... They said that it would, said that it would take away anything that was left there, there was no other way. I want this (radiotherapy), I’m happy with what I’m getting. You didn’t think of it as a harmful ray that was killing you, you looked on it as a healing ray, a healing light.

63. I feel that the treatment is working and they will burn it out and they will get rid of it. And obviously the roots will start growing again if they’re not burnt off with this radium.... Lovely, Yes, fine.....I’ve been less scared than when I’ve been at the dentist.

73. I regard this tumour as an enemy.Intent on the takeover bid, ah, it crept in there and began to grow....it gave me headaches. So, we have had the heavies in, the bombers and the heavy artillery. And we have taken his command centre out. During the process we cannot destroy the battlefield. ... part of his headquarters was left and there are one or two of his troops scattered about. So, we start the radiotherapy which for me is an infantry. Guards, possibly the Kings Own 0 am, everyday I come here for radiotherapy and more paras are flown in. And they sweep the area and clear it gradually. Never taking too much at a time, back to First World War principles.
23. Examples of overall satisfaction with radiotherapy

Neutral

28. I've had about 8 sessions and I haven't noticed any side effects.

90. ......that is a good thought to me (having radiotherapy) that it's, I mean basically I don't know what it is doing but what I think it is doing is burning the part away that is left......what I am having done now basically, I am hoping that is going to cure me....maybe they won't get rid of it but maybe I can go on living for a good life.

81. A: ..and the reason that I'm having the therapy is to help the confusion and make sure it has all gone.
Q: And has it been helping with your confusion?
A: I should imagine so.I haven't been confused much lately.

Some Dissatisfaction

57. I mean if it wasn't for the radium affecting my mouth and ears I mean I'd be fine, so I can't grumble really.... As I say I'm still waiting really for the radium to wear off to see if these things do clear up. My mouth was so bad I couldn't eat.... I went up to Hospital X a fortnight ago and they don't seem interested.

Marked Dissatisfaction

63. I mean some people have the radiotherapy and it works for them, not everyone is the same. (For me) obviously it didn't do what it was supposed to do, otherwise I don't think the tumour would have come back. I don't regret having it but it wasn't a very nice experience. ... because you are literally bolted down to that table, you can't move... but, no I wasn't sort of angry that I'd been put through thirty days...
Q: So it was worth going through?
A: It was a waste of time... with other people it probably worked..

74. I was horrified when they told me (hair loss). My hair was right down my back, it was all very curly and high-lighted. But as soon as I knew that I made my sister-in-law come and cut all my hair off because I was dreading it falling out in great big lumps. (Doctors) say things in bits and pieces and that's another thing that quite annoys me. I wish that before they started the radiotherapy that somebody would have perhaps sat down for half an hour and explained what I could expect because after the first and second lot of therapy I didn't feel well and it frightened me and I was walking down the road and I was everywhere, all dizzy...
24. Negative comments about radiotherapy

Subjects may make a range of negative or critical comments about the radiotherapy treatment. It is not uncommon to find the view that while the radiotherapy was considered satisfactory and worthwhile in an overall sense it was a difficult and unpleasant experience to go through. At the high end of this scale would be those patients who felt that the negative effects outweighed any medical usefulness of the treatment and these patients would often be left with a sense of regret, dismay or disappointment.

Include;

a) Claustrophobia over mask making, lying still for rays etc.
b) Unpleasant side-effects or anxiety over possible ones.
c) Time consuming or conveyor belt feeling.
d) Uncertainty, perhaps in retrospect, of its usefulness.

Rating

1. Marked Subject has 2 or more negative things to say about it, and is very distressed about it.

2. Moderate Subject has several negative things to say but does not appear to be extremely distressed, or has one thing they are very distressed about.

3. Some Subject does not really see the benefit or has one negative thing to say and shows some distress.

4. Nil No negative things to say or is matter of fact about the treatment.
24. Examples of negative comments about radiotherapy

Marked

6. Had I known that the radiotherapy wasn’t going to work I don’t think I would have bothered to have it.

116. I found the radiotherapy quite unpleasant. I almost wish they’d operated rather than have to go through the radiotherapy... The radiotherapy department is a rather depressing place. I mean I can still smell the smell - a horrible acrid smell, and it seemed to linger afterwards... I’d touch my hair and literally a whole handful... and I’d put it in the bag for rubbish and I’d feel “Oh God” you know “What are people going to think in the morning?” I knew it was going to happen but it was still a shock.

11. I felt really angry toward the radiotherapy when the tumour recurred. I felt awful you know and I saw all these people going down to have it from the ward, and I felt like saying to them not to bother.

21. That was frightening. That was really the first time anyone has been playing around with my head and I was very nervy about that. It was a bit scary but they were very nice but of course these things are routine and to a stranger it’s awfully alarming. Of course, it brings it back and you think “My God you’re getting better”. Now I feel “Why can’t they leave me alone?” I feel so much better now and I feel I’m being pulled back, reminded.... I mean it is alarming that hateful machine.

89. ... my hand improves very slowly during the week, it improves rapidly at the weekend when I am not receiving the radiation dose, and am, then slows down again during the week. I know what they are doing and it is quite horrendous. It is quite a horrendous dose, you know, ...which is something like ah, 10 1/2 times what we work to, 11 times what we work to in Administrative Health as the yearly dose. The first Wednesday of the radiation treatment, I had a focal fit... I proceeded with the first treatment and I had another one when I tried to turn over for the radiation from the other side.... I had another one, so they abandoned the treatment.

25. I’m getting some very strong side-effects from this radiotherapy. First of all, when I get tired in the evenings I get splitting headaches. I didn’t realise they were giving my brain double units. Every treatment they gave me was a double treatment so it was as intense as they thought my brain could take. Since then I’ve got certain side-effects. My head itches like crazy. I can’t stop scratching.... and I’ve got this thrush which is affecting my throat and it has also come out through my backside and between my legs. It itches like a cow. It drives me crazy.

81
Examples of negative comments about radiotherapy

Moderate

2. I felt very cross when the radiotherapy hadn’t worked, but still would advise other people to have it.

95. The first three, four was a little bit, not discomfort in the way of pain or anything; it just sort of... uncomfortable in the way of having it stuck round you. I had a lot of visual trouble, the first weeks, I mean I just couldn’t see so whether the treatment had anything to do with it? I don’t know if it’s improving or not.

19. I don’t like the hotness of the treatment...I began thinking about that eventually I might die after a few days when the treatment wasn’t bringing back the sensation and wasn’t making me better.

73. But that is radiotherapy because my libido was intact although not particularly forceful....but since the radiotherapy, I have had no libido whatsoever. I have slight hand shake...both sides.....but I have been told, that that again is the radiotherapy and the shock to the system of the operation. I can’t remember where I put things but, that again is part of the insult, part of the radiotherapy.

63. It was choking me (the mask) I think the only that....it hasn’t got me down...is that my hair is falling out now. I feel that it is dropping everywhere, dropping in the food.I don’t want to eat it. The skin is sore.

95. The first time I had it, from the very first day, I think I got a slight headache....it was heavy, it wasn’t like an ordinary headache.......but it was just a funny type. I took Paracetamol and it went and that was it.....I am gutted that I might lose it (hair).
24. **Examples of negative comments about radiotherapy**

Some

45. If I come in from downstairs from the treatment I feel sleepy, you know, tired........this therapy () and coming out very tired.

30. And somebody else said I would never have proper hair again, that I would only have wispy hair or patchy hair and that it would never grow again, ever again. It is probably best to assume that I won't go back before September (work). I should imagine that is how it will work out - what with the hair loss and... Well not especially happy but doesn't worry me terribly.

55. Radiotherapy itself is not a problem really. I haven't any symptoms....except I feel tired.....a little bit. She's (wife) not gone back to that yet (work), she's taking me up there so that's a bit of an inconvenience going there.

Nil

54. I don't think I have had any effects from the radiotherapy at all. .. I didn't have any tiredness, I didn't have any sickness. I'm not smug about it, I'm not bragging about it, but it just so happens that I was lucky and I didn't have any of it.

58. The treatment is not distressing. They are very nice.

61. It never worried me. No problems there.

70. Well, it started soon after I was ill so I don't really know what I was like immediately after that period but, oh yes, I think it gradually got helpful as it went along.

125. I came up here for the second lot of radium treatment and there was no improvement on my walking, and if anything I was slightly worse. But I never said anything, you know. I took full responsibility. I wouldn't, no way, ever think of blaming anyone in the hospital.... they're all diamonds.... they've done their best and, unfortunately, their best wasn't good enough.
25. **Overall satisfaction with chemotherapy**

Chemotherapy is generally offered as part of the MRC trial or as a last resort on recurrence of the tumour. The regime involves up to 12 doses starting with an injection of Vincristine, a BCNU tablet and a 10-day course of Procarbazine. The injection is usually given in clinic, but if the person has had a prior reaction they may sometimes be admitted for a day or so. The course is repeated at six week intervals. Although individuals are often initially wary about the reputation of chemotherapy, the regime does not usually have the same side-effects as the much stronger drugs that are used to cure lymphoma or leukaemia. It is therefore often a better experience than the patients expected and this may be seen as a positive feature. Hair is not lost again nor is prolonged nausea a feature. Similarly they may be pleased that there is still hope, pleased at how simple the regime seems to be, and sometimes also pleased with an improvement. Since the effects on physical state seem to be less pronounced, or because chemotherapy is often given once disability has set in it is less common for patients to be as positive about the chemotherapy as they are about the radiotherapy.

**Rating**

1. **Marked Satisfaction**
   S has several positive things to say about the chemotherapy and is very pleased indeed.

2. **Some Satisfaction**
   S has several positive things to say, or one point that they feel strongly about but is not wholly impressed by the chemotherapy.

3. **Neutral**
   S is either matter of fact, does not have strong views on the matter or is ambivalent about chemotherapy.

4. **Some Dissatisfaction**
   S has some definite negative views about chemotherapy but still retains some positive feelings about the treatment.

5. **Marked Dissatisfaction**
   S has nothing favourable to say about the chemotherapy treatment and in fact is highly critical of it.
25. **Examples of overall satisfaction with chemotherapy**

**Marked Satisfaction**

37. I'm on chemotherapy now. I went up there and they give me a brain scan and he says, well, he showed me all the pictures. He said, "You have still got a little bit there," and he says, "(We will) start to put you on chemotherapy." I said, "What's this chemotherapy? I haven't heard good reports about it." "Well, you can be ill," he says, but, touch wood I haven't had no trouble with it.

63. I mean he was very nice, he shook my hand... and he felt sure I would take this treatment well. I'm happy that they're doing further treatment and I feel sure that if they thought I was going to die overnight they wouldn't waste their money or time.

121. I said, "What treatment is there?" He said, "Well, there's chemotherapy." And I said, "Well, I've seen loads of people having chemotherapy and I don't think it is very dignified at all." It is a job to say, "Yes I'll have it!" So I said, "What's the alternative?" and he said, "Nothing" so I said, "Oh, we'll go along with that then, we'll have some of that." And from when we started chemotherapy ...... within a couple of days I was out of the wheelchair and walking and now I can walk 6 or 7 miles, and last week I managed to get on my bike and go round the block. But you know, that's the way I am, I won't admit defeat.

**Some Satisfaction**

15. Well they thought I ought to try the chemotherapy because they thought I wasn't feeling well enough soon enough. It was all taking too long, and I'm amazed to find that chemotherapy now is just a little injection and a tablet - seems amazing.....the sickness passed over that night really. I was lucky, I haven't felt sick at all since. I was fairly happy about it because Dr T had mentioned it before I left hospital.....and it seemed from the result of the last scan that the radiation hadn't shrivelled up the tumour and he seemed to think chemotherapy was the next good thing to try. So if that's what the experts say it's fine by me....I said about this feeling not very well generally most of the time (and) he seemed very surprised and disappointed, so presumably the chemotherapy is to try and improve on that. I don't think they made me any more tired than I was but it did seem to sort of keep up, that feeling of general malaise, as it were, and tiredness too, but perhaps a bit better generally in myself. It's hard to sort of remember from one day to the next when you're just generally not feeling very well.
25. Examples of Overall satisfaction with chemotherapy

Some satisfaction

38. Q: You said last time that you had some difficulty in the beginning, with the first couple of treatments?
   A: Yes.. when I told them how I was I got this other medication to stop the anti-sickness. That worked very well but I could guarantee that on the clock I always had to rush to the toilet at the same time. It was about three times within half an hour. Once I had the third one I knew that was it and I was able to go back to bed. Q: Anything else that you noticed with the chemotherapy? Any other sort of kind of side-effects you noticed?
   A: No.

Neutral

13. It doesn't give me any trouble at all.

17. I'm being sick with the treatment but it only lasts for that weekend. You know, you feel like nothing on earth but it only lasts for a couple of days. I can handle that. The treatment, it doesn't really affect me.

80. I am concerned as to whether I should continue with chemotherapy or not because I feel that I don't want to spend a long time on the chemotherapy and it will take me at least a year to get rid of all the side-effects.

Some Dissatisfaction

11. I don't feel bad (now) when I take it.I was very very disappointed... by the radiotherapy especially...let down by the radiotherapy, by the treatment..So Dr X said..."We'll try another system - chemotherapy". So after they give me chemotherapy...I very much want to know...It's just common sense. It's working from the inside and it's working against the bad cells so it's just common sense that it's making to see that it couldn't be anything worse than it is now. Obviously it must be for the better and I am accepting it. The second course I am prepared for but the first course took me by surprise.

57. A: I thought it'd all (hair) come out again, having this chemo, but it hasn't, not yet. Dr E. just said he thought I should have it...so I said, "Alright" and started it.
   Q: Did he say what he hoped it would do or what it was for?
   A: Mainly he hoped that it would take the swelling down. I mean I know they're giving me treatment. I mean they must think it might help, otherwise they wouldn't do it would they?
25 Examples of overall satisfaction with chemotherapy

70. Well, things seem to be alright. Can't really comment. Just hope it's... does something now. You don't really feel with it, you see, that's the trouble, you feel drugged up. It's as though... you don't feel in control. Mainly my head, I can't concentrate, I feel very tired... I'd like to know what's going to happen in the end, if I get some more drugs or something. But they're quite strong, these drugs. I find myself, I go off to sleep and I don't know if I'm supposed to or not. Maybe that's what helps you get better, if you get a lot of sleep. Might be a good thing. I wish someone would tell me.

Marked Dissatisfaction

2. I can't see the point of giving a treatment which doesn't have any chance of cure. It seems to me just a waste of time. The chemotherapy, I'm told will not cure it, that, I really didn't need to hear, one would like to think the treatment one is getting - there's a possibility of it working!

56. Well, he give me this chemo in my hand and told me I got to take these other tablets and we come home and we done what we was told. So we went to bed that night, my wife went to sleep, and that's ... I just sat out in the toilet with my head down the toilet all night long. I've never been... all my body was aching and I thought I was going to split in two.. Oh, my God, next day I just lay on the bed feeling sick and that night I was up again. It looked like the lining of my stomach was coming up. After six weeks I went back there and I saw another registrar and she said, "I can't give you chemo because your blood count is too low." So I said to her, "Well, thank Christ for that because I haven't eaten anything." This is now nine weeks and all I've been getting down me is biscuits, I couldn't eat anything. My stomach was just turning me upside down sometimes, it would make me ill. Most of the time I tried to sleep. I couldn't get off the bed, stayed on the bed for nine weeks! (The registrar) said, "Look, you don't have to have this, you had the option" and I said, "We didn't have an option." She said, "Yeah, you are on a clinical test, this is a clinical test, you don't have to have this chemo." And she explained it all to us and she said, "It's been explained to you" and I said "It hasn't, nobody's explained anything about this clinical test or anything else." And she said "Well it should have all been explained to you." I said, "I can assure you it wasn't."
26. **Negative comments about chemotherapy**

Some patients do find the chemotherapy regime demoralising in that it continues for such a long time, does not produce any noticeable improvement, or causes them anxiety each time the course is due.

Include;
- a) Dislike of the idea of having chemotherapy.
- b) Regrets and distaste over side-effects or administration.
- c) Dissatisfaction with explanations about the chemotherapy.

**Rating**

1. **Marked** S has two or more negative things to say about the chemotherapy and is very distressed by it.

2. **Moderate** S mentions several negative things but does not appear extremely distressed. Or there is one matter which has caused them a good deal of distress.

3. **Some** S does not really see the benefit of the chemotherapy or has only one negative thing to say. They do not appear distressed by this.

4. **Nil** S has no negative things to say or is matter of fact about the chemotherapy.
26. Examples of negative comments about chemotherapy

Marked

11. Q: How was it?
   A: It was very painful....It not because of the headache. I think the effect of the drug. I don't know what it is...The drug really shook me.....they give me some injections and they were taking my blood almost every day - needles. Plus I was not mentally prepared for it. Chemotherapy it was just too much for me. ....I would have preferred to wait a while. Or just give me chemotherapy without opening me up.

89. ....this is my fourth session that my haemoglobin was too low and they got me a bed in X hospital and I was transfused four pints of blood. ..... my balance was great at the beginning but now that I'm at the end of it my balance has gone again and my hands are not quite as warm as they were..... I feel fairly normal when I wake up in the morning but sometimes I have a headache, which is most unusual for me, so as far as I can tell it’s associated with the chemotherapy. ..... I don't want to be depressed but... it’s caused by the chemotherapy. It affects one's day to day living.... and that's what makes me depressed.

95. That really screwed me up last time. I've only had one but that screwed me up. I was bad for about two days, sort of feeling sick. The first day I was sick quite a lot, the second day I was sick a couple of times, after that I was sort of.... well I just call it dreamland, you know I didn’t know too much of what was going on. I call it down in the dumps, for about 10 days.... I'm keeping my fingers crossed I might not be so bad next time.

Moderate

57. A: I'm having chemo now. I think it's that you know. Makes me sick for about two days.
   Q: Does it - after you've had your shot?...How many have you had?
   A: I've only had two. Had one last thursday and one six weeks before that.
   Q: Yes. So it made you sick the first time did it?
   A: Mmm.
   Q: For two days? That's a long time.
   A: More or less, yes, on and off.
   Q: Did they tell you it might make you feel sick?
   A: Yes Yes.
   Q: Any other side effects?
   A: Yes, me hand's gone again. All pins and needles and if I hold anything I drop it.
26 Examples of negative comments about chemotherapy

Moderate

99. Well, I was dizzy, and just generally wobbling around a lot and felt more headachy than usual. And the chemotherapy gave me a lot of sickness. And just kind of made a bit of a messy week really.

60. When I woke up I thought I was going to die. I couldn’t breathe properly and they brought me to hospital and it was something wrong with my lung. A lung infection. Because apparently through the chemotherapy my resistance to catching colds and things like that was somewhat lowered because of the chemo. That took three weeks to get over. I was bedridden for 2 or 3 weeks. I went to get up and I couldn’t move. I had a blood clot in my leg. So, I got rid of the lung infection and I feel fine, and I can’t bloody walk!

Some

38. When I first went up there they were able to tell ..through the first scan that there were abnormalities there and I’m thinking, "Well if they can tell me that, why can’t they tell what’s happening now after all this radio and chemo?"
But when he explained it to me I suppose I can understand that it’ll only show what they know. They can’t see whether they’re active or they’re going to be active again. They can’t put a time and a date, let’s put it like that. Having said no (side-effects), I found that I was more emotional a day or two after having the treatment. And that would only be a day or two and then it sort of like my body...I’d settle.

15. I suppose the initial sickness was about 10 minutes or so. It was very embarrassing because we were going to a play and it was in the bar afterwards suddenly. Yes I felt very embarrassed about it. I mean they were wonderful the ones who knew about it they crowded round me so that other people couldn’t see. And then once when I got home I was sick again in bed unfortunately but not too badly....So in a way it was successful and in a way I could have done without it - a nuisance and a blessing I don’t know which but I haven’t been sick since then I don’t think.

Nil

63. Maybe I’ll get vomiting with it like I did before. But I’m just hoping and praying that this medicine helps poison it a bit.

6. Oh, I expected it to be a lot worse. I expected it to be really awful but it wasn’t. It wasn’t so bad.
COPING STYLES
Psychological Reactions to the condition

These ratings cover a range of attitudes and behaviours that the subject may take towards their illness. Following in the tradition of Greer and his colleagues, it seems essential to consider the stance that a person takes towards their cancer and its prognosis in order to understand much of their experience. Interviews and assessments for this have, however mostly been developed for women with breast cancer and it is not at all clear that all these aspects will be relevant to patients with brain tumours.

In the first place it is often observed that 'denial' is common among patients with brain tumours and that this may well be a physical consequence of the disease. We did not feel that a reliance on available measures such as the 'Mental attitudes towards Cancer' questionnaire would deal sufficiently well with all the possible determinants of denial in these patients. This questionnaire, for example, includes agreement with items such as 'I firmly believe I am going to get better' under the 'fighting spirit' category rather than under 'denial'. Clearly if the patient has been told that it is unlikely that the radiotherapy will cure their disease and still answers this question in the affirmative, this is a different situation from someone who says that they understand that they are in a very serious situation but they feel they may be able to increase their life expectancy by taking a positive attitude.

Rather than using the former categories, we felt that we wanted to dissect out different components of coping. We felt, for example, that "fighting spirit" probably contained a small amount of protective denial but included aspects of "control", and often a need to "seek meaning" about possible causes of the disease. It was also possible that because of cognitive deficits, these patients might maintain contradictions between what they believed and how they acted. We therefore chose to base our ratings on those that were being developed in relation to 'life events' in general (Bilfuco et al, 1992). Their use is also presently being investigated in relation to women with breast cancer (Pinder et al, 1992). We feel that this scheme allows some unpacking of the different elements of a coping response that might be more relevant in these patients.

In this study the interviewer is also ideally placed to corroborate from the closest relative what information the subject has been told and distinguish between patients who have clearly been told that there is little chance of cure, but fail to recall this, persisting in believing in cure, and those who appreciate this but still feel that they could keep going for longer by using other methods.
RATER'S JUDGEMENT OF THE SUBJECT'S PSYCHOLOGICAL COPING STYLE

27. [ ] Resentment/anger

28. [ ] Rater's judgement of subject's ability to retain information since the diagnosis or last interview

29. [ ] Peak despair/shock/devastation

30. [ ] Acceptance
   a) of brain tumour
   b) malignant potential
   c) of possible shortened life expectancy

31. [ ] Cognitive Avoidance of:
   a) Prognosis
   b) The implications of any disability on their present lifestyle

32. [ ] Seeking meaning about:
   a) Diagnosis or Prognosis
   b) Possible causes of the disease

92
33. Seeking control over:
   a) Prognosis
   b) The implications of any disability on their present lifestyle
   c) Their emotional reaction to each of the above

34. Positive appraisal/down-playing
   a) Spiritual/Philosophical
   b) Family and friends
   c) Others are worse off

35. Belief or hope in the possibility of cure
   Any belief that the subject has about cure, despite a previous rational assessment of the situation.

36. Belief in possibility of death
   Any thought that the subject has had about the possibility of death.

37. Getting life ‘in order’ behaviour

38. Present Uncertainty
   a) Diagnosis, Prognosis and medical management
   b) Present and future activity

39. Rater’s judgment of apparent lack of expected emotional response to the situation

40. Subject’s awareness of emotional tactics or apparent lack of emotional response to the situation
27. Resentment / Anger

This rating is made on the basis of the subject's response spontaneously, or on direct questioning about feeling angry over the diagnosis or the change in their lives. Surprisingly this type of response does not seem particularly strong or common and it should therefore be a rating made on the basis of all available information, including behaviour as well as thoughts.

Ratings

1. Marked  S feels a good deal of anger and is behaving in a way that suggests that anger is being displaced on to those around them. They could convey anger in their voice during the interview.

2. Moderate  S feels angry and is able to admit to this but there is no evidence that this is manifest in their actions.

3. Some  The S has some feelings of resentment but they are not very intense.

4. Nil  S feels no anger at the situation and there is no evidence that this is the case.
27. Examples of Anger and Resentment

Marked

11. At times when she's saying, "Rest, rest, rest," that gets me. At times the phone will ring and no-one will answer it and she will say she's too busy and complain that I'm not answering the phone. Say in the evenings I might say I'll just pop into work. It's only 2 stops on the tube and she will say, "What are you doing? This is supposed to be your rest." This is driving me mad. Nobody need take me. I can go by bus. To tell a man like this, an active person, to tell him to stop at once, it will do more harm than good.

43. I was getting niggly. Bits of arguments that you never actually see in yourself before. Plus you would take it out at home as well... (Some) people who talk to you they talk double-dutch to you because you just can't understand what they're talking about. You know, they've got their own words... A lot of them don't seem to realise a lot of people would like to know what's the matter with them. No, none of them (doctors) was helpful really, none of them, to be quite honest they haven't done me any good.

I just lost my temper. I said "If you don't get it off (mask) I'll rip it off" I said, "I have been telling you weeks ago (that it is too tight) but nobody seem to take any notice."

Yeah, because even thought it's a year gone you're still angry over it. I'll be angry for a long time on that actual part - why I had to lose everything like that.

80. I'm living at my mum's (at the moment). So like I say little things there annoy me. You know, I find myself getting quite boiled up. I actually get boiled up about it inside, get really steamed.... before I was really laid back, you know, really laid back.

Moderate

5. What has annoyed me is that I never took drugs in sport and I could easily have got them. All the blokes I lifted against took drugs and then I'm.... That really annoys me. I could have gone out the pubs drinking. I could have smoked and I could have been the strongest man that's ever walked this earth.

Q: Does your anger come out?
A: No I've got to keep quiet.

2. Sometimes I snap at the kids. That actually hurts me. I do that more than I would in the past I get more angry with myself when I act like that and I feel I should be able to express it in a different way. I'm also aware of suppressed feelings of anger and this shouldn't happen at all.
27. Examples of Anger and Resentment

Moderate (cont)

22. Yes, I think if I sat down and said to myself "My God, how do I deserve this? What the hell have I done? I must be really evil I shouldn’t really be here." That would be the easy way, to lay down rather than carry on.

6. I get frustrated with the children when they won’t do things because I know I could. Now I have to get J to do things like clean out the rabbits, and I get she doesn’t like doing it, and I think "Oh this damn tumour" I could be out there raking out the rabbits and not have to shout at her and things like that you know, it gets on your nerves…. very sad and cross more than anything, you know that it’s me. Well we’ve done all of this to get here from when we got married, not having children to get the place and bought a new car last year. We thought we had everything……

8. You just think to yourself you’re too young to die. You’re obviously angry. You look at pictures in the magazines and think, "Why not them? Why me?"

I know people who smoke like troops, alcoholics and they’re perfectly alright. I used to smoke until two and a half years ago. I’m a social drinker. I’m no hardened (?). I’ve got a job, got a car. You think everything’s going so smoothly. Life is going ticky-boo and you can’t put a foot wrong. Then all of a sudden - BANG!

21. Of course there is always the frustration and the anger you know, "why me?", because I don’t smoke, I don’t drink, I walk to work and I eat sensibly and I do yoga every day. I used to do ballet, and I think "My God I am very fit." But I can’t understand why it happened to me and I feel very angry because I do all the right things and I thought it through a long time ago - decided that it was probably bad for me so I don’t drink coffee.

Some

25. I didn’t really believe it. I didn’t see the point.I was walking through the hospital thinking, "Well J you’ve got all this energy and all your bloody ideas and 3 to 5 months." - it’s ridiculous.

9. I thought a tumour doesn’t happen to me. It happens to other people.

26. Yes, sadness and anger. Of course you can say "Why me?" but in exactly the same way "Why not me?" But yes I do feel moments when I feel that the whole thing’s been pulled out from underneath and cross that that has happened.
27. Examples of Anger and Resentment

Some (cont)

82. Oh yes, of course you do. But then it's got to be someone hasn't it? I mean I'm not the only one like this and literally over the country there must be thousands I would have thought. But obviously you do think "Why me?"

81. I just get pissed off with being in hospital...because I've been in so long and I want to be home and out of here. Not just this hospital, any hospital. I've had enough of it. It's been a long time.

13. You can't expect good things all the time but there are others in worse situations. I thought it's something not very nice to happen. Not being able to do things myself. I miss the independence....I feel like a bag of shopping that's been left ...you know to be picked up after.

Nil

24. Not really. I was puzzled about it but not sort of victimised by it.

10. The one thing that has been very important is that I'm a Christian, and I don't sort of think,"Oh why is all this happening to me?" Perhaps somebody who doesn't feel that way would feel angry.

19. I just couldn't believe it.

30. I haven't felt anger, no, because I still feel in a dream really. I've just thought - oh it's bad luck that this has happened to me. But maybe it'll come later I don't know. No, I haven't felt anger at all, no really, no.

28. I mean, I'm not angry or anything, don't get me wrong. I've just accepted it. There's just one or two little things I'd like to know.

23. No not really.

7. I haven't felt anger. It's just a random thing that happened. I don't feel it's like being at a fairground with someone taking pot shots at you. I think it's permitted. It's OK. It's allowed.
28. Rater's judgement of subject's ability to retain information

There is a considerable range in the cognitive abilities of patients shortly after diagnosis. Some may seem relatively unaffected by their tumour with little evidence of perceptual loss, whilst others may be completely confused. If however, confusion is intermittent or defects fairly circumscribed, the subject may have difficulty retaining information and consequently maintain that they have been told nothing about their illness. It is possible that there can be some psychological element of avoidance in addition to such deficits. This scale aims to crudely assess the overall ability of the subject to retain information at the last point at which they saw a doctor. This should take into account reported episodes of shock or confusion, the coherence of the subject's account and their attention and concentration throughout the interview. It can also be supplemented by information from interviews with the carer. Although this is a rating of the subject's potential as demonstrated by their ability, it is somewhat complicated when information is being withheld by relatives. In these situations, the subject's abilities are not being tested out, and the rating has to be made on the basis of other information the subject has retained, and their general performance with other cognitive tasks. Rate the subject from the time at which the diagnosis was established ie. about a week after surgery, and discount any confusion before this time if it resolved on steroids and with surgery. In later interviews rate in relation to the time since the last interview, but with particular relevance to any contacts with doctors where prognostic information has been conveyed.

Rating

1. Marked There is no evidence that S was or is now sufficiently mentally impaired to affect taking in basic information.

2. Moderate There has been some failure to take in information and it seems most likely that this is psychologically mediated for example by avoidance or denial. Not all avoiders are rated here, only those whose tactics are most extreme.

3. Some There is evidence that S is intermittently confused or else impaired in a number of areas that would make comprehension difficult but not impossible if the situation were to be carefully explained.

4. Nil There is evidence of sufficient distractibility, vacancy or disorientation to make it unlikely that much can be retained.
28. Examples of rater's judgement of subject's ability to retain information

Marked

2.  S is able to recall the prognosis, and also demonstrates his competency by going back to work.

121.  S shows complete awareness of the diagnosis and the prognosis. Every time that he sees a doctor he asks what the outlook is likely to be.

Moderate

7.  I'm afraid that part is all a bit of a haze you'll have to ask my wife that.

8.  I just went into a bit of a panic and couldn't really take much in. My husband took over then.

21.  I didn't have any sense of panic, just a sense of relief in a way. It was strange feeling because when I go to hospital and visit my friends I faint. I mean I can't stand it, you know...I felt that they knew what it was and it was going to be alright. I wasn't actually worried at all...I didn't realise. I asked nothing, no details.

82.  Q: Did the surgeon explain to you what was going to happen?
A:  No. He wanted to I must admit, but I didn't want to know - just let him do his job. So long as he does his job all right, that's all I bothered about.

60.  Now it is 8 weeks on, since it all happened, and I'm knowing a lot more about what's happening. At first it was like I was in another world, what the hell is going on, what's happening to me? My whole ... it wasn't me, it wasn't my life, I was totally out of it.
28 Examples of rater's judgement of subject's ability to retain information

Some

81. S is distractible during the interview changing the subject to irrelevant matters and watching other people although her attention can be drawn back.

49. S fiddles with the microphone several times despite explanation. He responds on questioning, but has difficulty collecting his thoughts.

15. S seems pretty alert but says she has to concentrate a good deal in case she should miss something. She also recalls that a good friend came to see her, and she was so embarrassed because she could not remember her name. She remembers the interviewer and talks coherently in great detail about her diagnosis. She says she has not been told whether her tumour is malignant yet checking with the doctor it turns out that she has been told.

13. S forgets where he has met the interviewer previously and for how long his problems have lasted in total. His wife reports good long-term memory but some problems with short-term memory - forgetting appointments and when people are visiting as well as disorientation in time. Despite this he appears coherent in the interview and clear about what he seems to want to know.

Nil

4. S does not remember the interviewer from hour to hour, does not know the ages of their own children, name of the hospital etc.

27. S is incoherent believing he is in the dining room rather than the hospital.
29. (Peak) Helplessness and Despair

This rating records the peak sense of despair that the subject can report feeling. In the early stages the response on hearing the diagnosis, or to becoming seriously ill may be described and later it may relate to learning of recurrence. To a certain extent it records how the subject managed to block off their feelings and also the extent to which they can do this in recalling that experience. The rating should record the peak of distress that the subject has experienced since the previous meeting.

Rating

1. Marked  S reports a peak of several days in a trough of despair.

2. Moderate S reports unpredictable episodes which did not last more than a day or several hours in which they feel they lose control but from which there is some reprieve.

3. Some  S describes moments in which they may be overcome but from which they quickly recover.

4. Nil  S describes feeling extremely calm throughout the period.
Examples of Peak Helplessness and Despair

Marked

5. When I first knew I had a tumour I couldn't bear it. I wanted to kill myself because I couldn't bear not being fit and strong.

19. I feel sad all the time now about whether I might die (cries). I started thinking about it when the sensation didn't come back in the last 3 days when the treatment hasn't improved it. I just don't want to be a burden.

26. My first response was not a courageous one, but in a way was "I've had a good life, I'm 48. I'm going to die." I'm surprised at how I went into a trough at that point... I felt it would be much easier just to disappear at this point.

54. I think initially they may have said there is a slight swelling of the right hand side but they were talking about a lesion as well. That was really all. At that moment the roof sort of fell in if you like and I had two weeks bad... I mean I think the first week I just about kept sane. I don't actually know why I went like that but I did...... I was sitting there one night, not so much frightened about anything but just totally devastated because here I have been living a totally full life in every way, thinking nothing of jumping into the car and driving down the motorway and just wandering around the place doing anything I wanted to do and I was laying in a sort of corner of a hospital ward with the curtains around me, totally isolated from the ward and everything I knew, and I did have a very bad time and I think I became a little schizophrenic.

43. I've been through depression where you want to actually even top yourself at times. When I heard that they were giving you the time limit of living you know you felt like saying to yourself "What's the point? You're going to die anyway, I'm going to take the tablets." I asked if I could see a psychiatrist because I thought I was cracking up completely.

80. The other day I did have a really bad couple of days and I really felt suicidal. I was starting to think suicide was.... see it as some big romantic thing, you know, like going down to the beach and taking sleeping tablets, and then I thought, "Oh God, you're getting weird here."
29. Examples of Peak Helplessness and Despair

Moderate

21. Well I never felt that it (writing skills) wouldn’t come back strangely enough.... I just felt, well, blame the drugs....you know, and as I got more....the better I felt then the shock hit me a bit and then I suppose I started thinking about things. And I suppose my husband thought, "Should I tell her what they had originally said about the tumour being inoperable?", and he decided to tell me. I took it very lightly... the next day I was quite horrified. But you know I have my weepy moments and minor rages.

30. I cry only in the night I do get odd moments I can’t sleep very well. I get a low patch in the night and I do get a bit tearful.

82. That’s after they’d done the scan. Yes that was like a bomb. Terribly frightening. I wanted to come home and talk to my family first and have a chat with them. I wanted to be able to talk to my wife on my own, have a cry on my own. That’s what I did. It’s just a terrible blow when you’ve found out you’ve got it.

99. I do still wake up on days thinking, Oh my God, this is the end of the world, I feel really terrible today, why don’t I go and shoot myself or something, on a bad day...... But then there’s nothing to be feared about death because it is inevitable.

Some

24. Not too bad but it certainly clouds things a bit. I get a bit depressed about it at times and it sort of comes and goes... At times I can think that future prospects don’t seem too bright... the problems of finding a job in my condition.... If there’s a scale for measuring this where 0 is nothing and 10 is suicidal I’d say I was about 2 or 3, but obviously I’m something.

23. The first thought I had was, "Would I be alive by Easter?" and then I thought that’s stupid.

13. A bit traumatic of course...As I said I wasn’t frightened. I get the odd moments, but nothing I can’t cope with.

Nil

25. I’ve never felt like releasing tears or anything like that. I’ve never felt, "You poor bastard."

3. I was upset during the day when they told me but I was all right by the evening.
30. Acceptance

It is common to hear patients described as "accepting their illness" but the concept requires considerable unpacking in reality. Subjects may accept the diagnosis but not the prognosis, accept their present disability but not that they will never work again. They may accept the change in their work life but not that in their home life. In short, acceptance can be rather patchy, and here it is used only in relation to the prognosis. It therefore measures the degree to which the subject has come to terms with a limited life span.

Rating

1. Marked  S accepts they have a prognosis of less than a year.

2. Moderate S accepts that the tumour could lead to death and that they could die.

3. Some S accepts that they have a tumour or cancer but the prognosis may be perceived only vaguely.

4. Nil S does not accept they have a brain tumour.
30. Examples of Acceptance

Marked

7. We talk about it openly and honestly that I will die in 6 months or after Christmas, whenever.

125. We've been looking into hospices and I'm trying to take a positive attitude to it. The reason I've been able to accept this is because of my wife - you'll see when you meet her.

43. There's nothing more you can really do, nothing more you can really do. I mean what can anybody say to you... they've just got to accept it. You know, what they say can't bring anything back. We know it's going to happen, so that's that. That's the way I look upon it - there's nothing they can really do. I tell them "Come on, don't get upset about it, open a bottle of wine, we'll have a glass of wine."

Moderate

35. He said my life may last a while but he could not say how long. I must enjoy every moment.

26. We found five years in a book ... I'm persisting in the belief that everybody's an individual and you can probably push these things a bit by using other techniques.

73. I live in the full realisation that I have had maximum surgery. There is no more in my brain they can remove. There is no more RT they can offer me when this course is finished. The only help they can give me after that is help to die. I can handle it. I have no fear. Ex-soldier you see, it is different. The long box I have seen before. Death doesn't frighten me. Faced it before, I have seen it in all its forms. Violent death, peaceful death, the death of children, the death of old people, the death of fellow servicemen, the death of relatives. And for me at the end it is peaceful. I am not a church-going man but I do believe there is a power greater than us, that someone or something cares, and at the end I will be free of pain. I will be given peace and I won't be allowed to suffer.
30. Examples of Acceptance

Some

8. After a while you accept it (that you've got a tumour).

22. I've had to adapt to it.

10. It happened. You know I can accept that life goes on.

25. I accept that I'm only going to get about 10 years more life. I don't see myself living to old age.

2. I think what I was told at the beginning was right for the time that the disease could be fatal, but I've since been told that there is a 30% cure rate and I've decided that I'm going to be one of those. It's a change in perspective and death doesn't come into it now as a possibility.

17. I've just accepted what has happened, and I'm waiting for the treatment to be finished so that I can get back to driving and get better again.

13. ... and the doctor said to me "We've taken it out," or "We've taken quite a lot of it out, but it will come back again." I think ... they told me it would, it might respond to treatment. I just said, "Well, if it comes, it comes, you know, It's got to happen to us at some time."
No, I've accepted what has happened ... I think that you accept things as they come. You know, you don't worry about them. Well, I'll just ask to see whether there's any fresh development. Whether it's for the good or what. Perhaps he can tell what I can look forward to in the next few years. I think it's fair if they can give you some idea.

Nil

11. I am using my imagination to establish what might be the cause of the lump ... I was applying this hot rub so there would be a blood clot with the strain of the neck. I was sweating and that would have melted the clot so it travelled to my head and forms a lump in my head.

28. A: It was a nasty thing or something.
Q: Did you ask what they meant by that?
A: Probably not, no.
31. Cognitive Avoidance

As discussed previously, this strategy is different from denial in that the person often has a clear idea about what it is they are trying to avoid and can state what it is, ie. fear of dying, getting worse, not being able to get back to work. Their strategy however is to avoid those thoughts by avoiding thinking about the subject, by putting it to the back of their mind to keep busy etc. If asked, they can discuss their fears even obliquely with their interviewer they may not be particularly worked out. Someone who is rated on cognitive avoidance cannot therefore be thought of as simultaneously denying in the same area, although they may change between interviews to a different coping strategy.

Ratings

1. **Marked**  
   S only admits to a few fears. They find it very difficult and will not elaborate. The interviewer receives very clear messages not to stay on the subject for too long and may automatically find themselves veering off.

2. **Moderate**  
   Has some thoughts of worst outcome which may be of recurrence rather than death and they can elaborate on these fears to some extent.

3. **Some**  
   Attempting avoidance but as yet not that successful or uncertain if wants to know the truth. Or, aware of the truth, happy to discuss openly, but not to think about all the time.

4. **Nil**  
   Has very little obstruction to thoughts or discussion about their fears.
31. Examples of Cognitive Avoidance

Marked

22. No there's been no prognosis as to the expectancy as to whether I will die, and that's something I don't wish to ask actually... I don't want to know if it's 60 to 1... As for how successful they are I'm not sure. I haven't asked and they haven't told me. Presumably there's still hope or they wouldn't do it... I haven't asked what's the betting? because quite honestly I wouldn't be interested. I might be entirely wrong, I don't know. I haven't actually adjusted to this yet, but I don't want anyone to see me being weak. At the moment that's how I tackle it... I just have to be strong and hope. I've dealt with it very well possibly too strongly for some people's taste but that's how I want to deal with it.

89. I am a trained scientist. It is a distributed tumour in the left half of the brain concentrated in the hand and arm motor area.... it was not removable, it wasn't operable. So the only treatment is radiation treatment.... Now, each is an individual and that your personal reaction with your tumour is not going to be the same as anybody else. It may work for me and it may not. (What) I'm saying is, a lot of people are under great misapprehensions in this area.

Moderate

5. It's worse if you haven't got your mind occupied and start thinking about the worse... so I try and keep occupied, so I watch TV in the morning... all you can do is put yourself in the hospital's hands...(and)...well laugh as much as you can. But it's hard to keep laughing especially when you feel a bit dodgy, it's hard to laugh then.... If you get too emotional it can take over... I never get too emotional.

Q: What thought goes through your mind?
A: Dying young...

23. He did say there was a 50:50 chance of full recovery so I'm an optimist and hoping that'll be the way things are going... It comes with sales training. You've got to present an optimistic picture if you hope to win anything.

Q: What sort of techniques do you use?
A: I switch off from negative thoughts. The first thought was would I be alive after Easter and then I thought that's stupid, maybe it's not, but I remain optimistic on the advice of my mate who's had a brain tumour.

Q: Do you find that an effort, blocking out the negative thoughts?
A: No not really. I've got to anyway because it's part of the job. I do occasionally think about these things and wonder whether I will get better or not.
31. Examples of Cognitive Avoidance

Moderate (cont)

8. You’ve got to keep bright and perky. I’ve only been upset twice. Once when I was told, and once suddenly without warning.

6. Because you never think you’re going to die do you? You think you’re going to live forever, still do. So you’ve just got to think positive. I should think a lot of people probably would they’d be worried about it. No it’s at the back of my mind. I think it started to come forward then I would ask her (MacMillan Nurse).

21. I love my work and I love it passionately. I think if they said I couldn’t work any more that would be a blow...that is just my major fear. And then my other fear is that I’ve been told there is a tendency for tumours to come back. And of course I think to myself "Oh God, will I have to go through all this again?"...I suppose that will be a worry and I don’t suppose I will ever get over it.

I suppose my mind wanders but not...it doesn’t wander...I keep thinking about the operation or about the treatment, about happening now. It’s going on for such a long time. There is no way you can get out of it. You can put it to one side.

Some

30. (The nurse) said you seem to be the sort of person who is fairly sensible and maybe wants to know more. I do in a way as long as it’s good. I do really but it’s a bit frightening if it starts telling you life expectancy and those kind of things - I’m not too keen on knowing that at the moment.

19. I started thinking about it (dying) 3 days ago when the sensation didn’t come back with the treatment. I don’t talk to them about it. I would talk to my daughter but when I try to they get cross with me.

32. I didn’t have time to be disappointed, I think I was getting iller a bit faster and I haven’t really begun to think about that at the moment.
31. Examples of Cognitive Avoidance

Nil

7. They are all aware that I'm going to die within a year of after Christmas or whenever... we talk about it all the time. We talk openly and completely frankly.

73. I have always wanted to know what the bottom line is, I want to know the score. Death doesn't frighten me. Faced it before. I have seen it in all its forms. There is no more radiotherapy they can offer me when this course is finished. The only help they can give me after that is help to die. I was told that yesterday. I asked the question, I wanted the direct approach and he gave it to me.

38. I thought, hang on a minute, I'm not stupid.... so I went absolutely berserk. I told her (sister) straight, I said, "Now what's happening, I want to know?".... I said, "I'm telling you I'm not having it, I am not having people know, I don't care if it's family, friends, family." I said, "I am not having people know things that I don't know, and I don't like sympathy. I'd rather know what's happening, because," I said, "I'll tell you something, it will upset me more not to know than to know."
32. Seeking Meaning

The rates the degree to which the subject seeks out information about the disease and places importance on finding why it should have occurred. The reason for measuring this that being able to place the tumour into some kind of category or framework seems to increase an individual’s sense of control over their illness. It is a process however which cognitive avoidance may sometimes inhibit since the individual cannot allow themselves to contemplate the tumour for too long. Denial can however sometimes be associated with a great deal of searching for a cause in the past, with little equivalent thought about implications for the future. Obviously this scale might also tap passivity which is the result, not of a psychological coping style but of brain disease.

Ratings

1. Marked S has developed a coherent model to explain why the disease occurred, has sought information on it, either from alternative or mainstream sources. One gains an idea of the patient as being active in this process, not merely as a passive recipient of misfortune.

2. Moderate S has made some attempt to find an explanation or information about the disease but it is not highly salient for them to do this.

3. Some S shows some interest when questioned about their ideas but has made little effort to ask their doctors or seek information themselves.

4. Nil S has no interest or need for any information.
It's strange really because in many ways when these things happen they send you a very strong signal. I'm sure my life was not really heading in a sensible direction. I was working too hard, trying to do too much, getting over stressed, travelling too much and I think I needed to slow down. Maybe this gives me an opportunity to re-appraise my life and perhaps do something quite different.

I'm sure I'm ill as a result of 37 years of holding down emotion. I've no doubt about it. I think it's an extraordinarily stressful thing to do. My mother died when I was 8 years old and I was told that big boys don't cry. So I didn't. I never did for 35 years until I started to train as a psychotherapist... it was a total release, a total ability to deal with one's emotions. Holding things back is very stressful and uncomfortable, very stressful. And another aspect is accepting things as they are and not trying to change them... I'm sure that after my meditation you would find a difference in my immune system.

What might have sparked off my problem might have been that clump on the head on me bike, and then there's that girl I was going with. I think when you've got something stressful like that you don't really want. And it says that stress can start off things. It might have been just small laying about there.

I do think there is something controlling things around here. I mean some sort of purpose for these things. One of my last thoughts at night is, "Well, if I'm going to go in six months or whatever, I'm going to go. Whoever is up there wants that then fair enough, you know, I'm sort of accepting it." I wrote in my diary, got to a fairly peaceful point, I thought something makes things happen in the world and if I'm going to die when I'm thirty-one or thirty-two or whatever then that's my card that I've been dealt - that's the way it has been dealt to me.

But, can I tell you my philosophy on life itself? If it has got your name on it, you are going to get it. I am a firm believer that if it is not your time, all the doctors in the world won't kill you, but if it is your time, no doctor in the world will save you. I have been writing about all this. You will find it published if you look for it. The title will be 'Learn to Reach Out'.

This is what I think, my own theory. I think that somehow it was my destiny. How can I put it without sounding weird? I think that someone's put a spell on me... I think my father is the one, he's the main suspect.
32. Examples of seeking meaning

Moderate

30. One of the nurses said I'll have a look in my books to see if I can find anything on it for you in fairly simple terms and I'll bring it to show you. I thought that was good I've been reading this on radiotherapy. I did look up what I've got but I couldn't find it so I've abandoned that... We talked about whether we thought it would be a good idea to know a lot about it... I do really but it still is a bit frightening if it starts telling you life expectancy and those kind of things - I'm not to keen on knowing those at the moment. (S also been to a bookshop to find information)

25. Of course I've been exposed to all sorts of CFC's and chemicals in the jobs I've done. I don't think the stress of the company closing caused this, I think this has been growing for years - that's what Dr G said when I asked him.

10. There was a lot of stress. It was a stressful relationship and I feel perhaps 'this' (tumour) was all working up during that time... But I can't look back and say "Oh maybe if I hadn't got involved I wouldn't be sitting here with arthritis and a tumour." I don't blame him or feel cross or anything. I feel in a way it's made me into a better person. I feel that God suffered for me and now I'm suffering for him.

63. I don't know (what brought it on) stress, worry. I mean I've got a good marriage, I've got lovely children, I've got a nice home, but I'm a worrier. I just worry. I can't think of any other reason..... I mean I sat here thinking did I bang my head hard .... or did I bring it on through smoking? I mean, at first, I felt like I'd been to hell and back...."Why me?"  "What have I done?" "I've never done any harm to anybody, I haven't done anything wicked - "Why have you chosen me?" I did feel like that but not any more.

Some

6. I've been a vegetarian since I was 4 and then I thought bugger me I better start eating meat now! Obviously it's not doing me any good... But alternative..? I've always been an alternative person anyway so it can't be very good can it?

8. I know people who smoke like troops, alcoholics and they're alright. I used to smoke until 2 and a half years ago I'm a social drinker. I'm no hardened core.
32. Examples of Seeking Meaning

Some (cont)

22. I think I must have been pretty evil to get this, in one of my previous lives. I’ve no idea at all, no idea at all, I haven’t been able to do any reading on it as such as I’ve been reading the papers. But these things happen now and again don’t they. I’ve not played around too much. I’ve played rugby for 21 years and I don’t suppose that’s caused the problem.

81. I’m wondering if it could be the death of my dad starting it off. I’ve started to wonder, but otherwise I’ve no idea at all.

21. I think the whole think is bizarre but I don’t think that had anything to do with it - about ten years ago, maybe a bit longer I got a wire caught in my throat. It was from a chicken bone....I don’t think that had anything to do with it though. I can’t imagine. I just asked how big it was. For some reason I thought that if it were small it wouldn’t be so serious, and if it were big then it was very serious. I asked how long it had been growing and they said they didn’t know, maybe six months or a year. Yes everybody has difficult lives and problems and it doesn’t happen to everybody so I don’t feel that ....but obviously I would like to know why it happened.

Nil

13 I’ve accepted what’s happened because, you know, you can’t expect good things all the time. My faith helps me to be content with that I’ve got. Others are worse off.

24. I’ve no idea what might have caused it. The only suggestion is some kind of radiation off a computer screen I don’t dwell on how and why it happened. My main concern is that it’s a wretched nuisance losing the vision and I would welcome some advice on ways of going about it.

23. No, I just accept it as a normal part of life. I’m told that tumours might be caused by radioactivity so I thought it might be the Chernobyl disaster re-surfacing again.

Q: Do you feel a need to explain why this happened?
A: No not really.

82. He wanted to (explain) I must admit, but I didn’t want to know - just let him do his job. So long as he does his job alright I’m not bothered about it..if it’s going to make me better. That’s all I’m interested in. The rest of it I don’t want to know. The technical terms I’m not really worried about.

Q: Have you any idea what might have caused it?
A: Not off hand, no. I wouldn’t have a clue.
33. Seeking control

This rating is of the degree to which the subject seems to try to exert some degree of control over the situation. There are several different domains in which an individual might exercise control. They may fight specifically against the disease, or they may aim to minimise the consequences or they may be preoccupied with keeping their emotions in check so that they can keep a calm front in the situation.

There has been considerable interest in the phenomenon of 'fighting spirit' as a prognostic factor in cancer, and in classifying patients with cancer into this and several other coping styles such as 'denial' or 'acceptance'. We will not make an all or nothing decision about the subject’s response so that we may distinguish the 'deniers' who fight from those who ignore, or even at times accept that there is limited prognosis. In this way we can capture the richness of different forms of coping, changes in the components of coping styles over time as well as apparent contradictions in approach that the subject maintains. If a patient seeks control over their disease it is often implied that they are using "will power" directed specifically against the disease. This assumption in the rating of control might, however, introduce a class bias towards those who have access to fashionable ideas and alternative medicine, rather than capture the sense of control that another patient may get from following to the letter each word of their doctor's advice. This latter approach is not as passive as it may initially appear since it can clearly identify goals to be achieved by certain behaviours. Seeking control should therefore describe a sort of dogged determination to keep going, and to control aspects of life affected by the disease. Although it is possible that control could be rated in several domains including the degree to which the patient can gain a voice in their own care, or the degree to which they can control their home environment, we will limit its measurement to three areas:-

1) Willpower directed against the tumour or the symptoms it has produced.
2) Control over the impact of the illness on valued activities.
3) Determination to get the best out of life.
   and finally to a lesser extent
4) Determination to control either the emotions that could be let lose by the disease or those of the relative. The subject may be determined to put a brave face on it, to be strong themselves or to keep their family from collapsing under the strain.
33. Seeking Control

Rating

1. Marked  S feels they can exert control over the disease or its physical consequences by being determined, by thinking the tumour away, or by making the very best of the situation. There should be firm evidence of the kinds of tactics they have employed and that they have been used concertedly.

2. Moderate  S has used some techniques, perhaps experimenting but has not kept them up. There is however evidence that they have tried to follow some kind of regime for example pacing themselves, taking a definite strategy against their emotions, or making decisions in their treatment.

3. Some  S has an interest in controlling the disease but there is no sense that this has been pursued with great vigour. They may, for example, be sceptical that there is much they can do.

4. Nil  To all intents and purposes S seems to have taken a passive approach. There seems little get up and go in them, and they have allowed most things to be organised by others.
Examples of seeking control

I have two choices. I can either snuff it or I can enjoy what time there is, and there's no way I'm going to get depressed over anything....One of the main problems in people's lives is their attitudes. Now there's so many that get depressed and think,"Oh dear, what am I going to do?" I think to myself that's a waste of time. I am going to enjoy my life. My sole desire is to enjoy myself.

When I'm under the radiotherapy I concentrate my thoughts on destroying those...little cells. When I go to sleep - again killing the little bastards.

I began to fight it, just began to start the battle. I am now..I won't say consciously fighting but what I am doing ... is thinking of next year, a strategy if you like, in that I've got to get planned what I think I can do....I'm judging myself. ..The main thing is to plan, you see.. I haven't yet quite reconciled to that I'm not quite in as much control as I would like.

He removed a tumour. A question he had never been asked before was, "What colour is it?" It was grey with white streaks and it had a yellow axis on the side. Now what does that say to me? General Paratroop Alpine uniform. It's the uniform of the enemy. I regard this tumour as an enemy. So we have had the heavies in, the bombers and the heavy artillery and we have taken his command centre out. I have no fear. Death doesn't frighten me. Faced it before. Seen it all before. Ex-soldier you see. Yes, I have short-term memory loss. I put a book down or a piece of paper and can't remember where I put it. But now, if I particularly want to find out maybe quickly, I write where I have put it on a piece of paper and put it in my pocket. It's not clever, it is just self-preservation.

I had a few cigarettes and I thought, well, I'm not going to let it grow back. And I really feel positive that it won't. And if it does, they'll do more treatment and it will go. I mean, as a child at 14 I had TB, but I fought that. I'm not the type of person that if I've got flu to put myself to bed. I think if you put yourself to bed you're telling yourself you're ill .... actually, I've got a sheet... about imaginary pain and self-healing. You imagine that you've got little men in your head that are digging out trenches and washing the walls down or, when I had my radium treatment I think of Luke Walker from Star Wars and he's fighting the Jedi. And I find deep breathing helps you relax. When I do my exercises of a morning with Lizzie on the television, I feel quite emotional and when I'm doing it I think to myself, well, you're washing your brain out, giving it a wash... it does help.
33. Examples of seeking control

Marked (cont)

99. I have a lot of visualisation. I see in my mind the scan of my brain with the tumour in it and I have a thing where I say "I'm free from my tumour, I'm free from my cancer, I'm fit and healthy and I'm well." And when I say "I'm free from my tumour" I have a huge scrubbing thing that wipes out ... I can see the egg shape shadow in the brain and it's wiped clear off that. And I kind of scrub out the little remaining cancer cells in there with my little scrubber and I see myself going on a very long run in Sri Lanka, like I used to, across the fields really puffing and straining and feeling very very fit. So, I have that morning and night and, you know, that makes me feel good.

Moderate

22. As far as I'm concerned it's getting 100% support and beating it even if it's 10 to 1 against...I just have to be strong and hope. If I sat down and said to myself "My God how do I deserve this? What the hell have I done? I must be really evil. I shouldn't really be here." That would be the easy way to lay down and say...rather than carry on.

5. A: When I do something I really go for it. When I was having the treatment I was being steady. I was getting out on the bus, doing a little bit of shopping, playing a bit of pool, coming home, having something to eat. But all you can do is put yourself in the hospital's hands.
   Q: Do you think that there's anything you can do?
   A: Me? Well laugh as much as you can. But it's hard to keep laughing when you feel a bit dodgy. It's hard to laugh then.

21. When I was at home, just getting on...after the second day I got out of bed and got dressed and that was it. I was determined that once I was home....And once you are at home in your own surroundings I think you do get better quicker. I feel I ought to be doing more, like going for walks or doing something more active, because my working life is so frantic.

   I cry but not hysterical sobs. I have weeps for 30 seconds or something and then I think "Pull yourself together...."
33. Examples of Seeking Control

Moderate (cont)

82. Because as I say, they do their job. The surgeons done his and now it’s down to me to do mine. I think I could quite easily say I’m stopping or not easily because I wouldn’t do it. I could quite easily say I’m stopping, I’m not coming any more and they’ll have to send the police round here to take me, but you know, that won’t happen.

You just let it go over your shoulders or over your head. It’s no good being miserable, not really. I mean you’re not well, you’re not well. You’ve got to get better or try to get better. Keep worrying and crying over it or whatever is not really going to help you I don’t think. You have got to try and look on the positive side. You have got to try to get to grips with it. Or to me you’ve got to come to grips with it. You’ve got to turn round and say "Well I’m going to be the one that does beat it", and prove them all wrong hopefully. For my family, not so much for myself. Well for myself as well, yes, but for the family more than anything.

Some

30. I think the visualising helps a bit. In fact I used it a bit when I was under the scanner for imagining I was somewhere else. My friend did suggest that in radiotherapy you didn’t think of it as harmful ray that was killing you, but you looked on it as a healing ray - a healing light which I thought sounded quite positive really.

49. I thought perhaps if I think positively the bloody thing will go away, says he, you know in inverted commas! I’m living day by day really in the hope quite honestly, if I were honest with you, that it might all go away. On the other hand I realise it may, it’ll probably persist and I don’t know what the outcome will be. Sometimes when I look on the bright side I think it could go well. Sometimes when I’m looking on the depressive side it could go badly. But on the other hand I seem to have responded to treatment.

Nil

85. It is nothing to do with me. I am just the patient. And if they are explaining to the students, I mean you can’t just chime in and say, "What is wrong with me? Leave the students!" can you? I mean you have got to hold your peace and everything is just "Do as you’re told!" You are only a patient being looked after, aren’t you?

17. It’s just the way I am. I don’t know. I think me and my brother are that way, don’t push things to get things done or ask lots of questions. It’s always left to my mum or dad to ask...
34. Positive Appraisal or Down-playing

This is the degree to which S is able to find or make something positive out of the situation and so rationalise or normalise away the worse aspects. This may involve comparing themselves to other patients whom they meet in the course of their radiotherapy or hospital treatment, of looking only on the bright side, appreciating family and friends more or developing a completely new philosophy of life.

Ratings

1. Marked S sees a good deal of positive coming out of the situation, to the extent that they have developed a new perspective on life, or discoveries about themselves or their family.

2. Moderate S sees some positive aspects and has made some discoveries, for example, is more aware of support of family and friends but it has not reached philosophical proportions.

3. Some S can name a few positive features when asked. They may, for example, see themselves as better off than others in a similar situation.

4. Nil S cannot see anything positive arising out of the situation and tends to dwell on the negative.
34. Examples of Positive Appraisal or Down-playing

Marked

26. The thing is there have been some very good moments. I’ve noticed the spring for example for perhaps the first time for years and I’ve seen people and done a few things. I’m learning to cook and these things are very helpful... positive..... reaffirming you know. I find everyday I do something and I bring back another skill. I learn to appreciate what it is to be alive. Maybe this gives me the opportunity to re-appraise my life, and perhaps do something quite different. I think in many ways I feel there are a lot of pathways opening out, so not hopeless at all. It’s quite exciting because you don’t know in which direction it’s going to go. So I try to see it in that light.

2. I find everyday something extraordinary happens. It’s quite extraordinary. It may be my perception of seeing things in a different way. It’s a certain spiritual awareness that comes on. I guess if you’ve almost died it has to...it gives you something to think about. Everyday something happens, a cheque arrives from work, somebody calls to find out how I am.

It’s also a change in the perception of awareness of time. Time is more important. People are more important, and the relationship between people. I feel as if I’ve seen how wide human experience can be. I have an analogy to playing the piano. It’s as if the potential for living is the whole keyboard, and it’s as if we’ve only been playing a bit of it. I feel I’m more aware of psychological boundaries, they’re not flowing out all the time. I’m aware of dropping all those boundaries and being aware of what goes on and letting it all happen, as a positive decision.

12. It is an amazing thing what my illness has done for the community. People are coming to me and thanking me for the things I have done for the ministry here but really I haven’t even begun formally. There was a bit in the local paper about me, the bishop came to thank me for moving people. I’m finding that God is showing me what he can do through other people. Instead of me showing people how they should act they are doing it to me. I feel it has deepened my ministry and I think it will take my ministry in new directions. We shall be forming a new healing group. I feel that God is using me for his own purposes in some way.

99. You want to make things special because you think this is the first day of the rest of my life. One thing I learnt from my illness was just to cut off the past, snip it off and discard it... think about tomorrow and build from there... make it precious, make it special.
34. Examples of Positive Appraisal or Down-playing

Marked (cont)

60. I must say that after the operation I felt a completely different man. In the way that I’m using my brain now. Maybe for years I have been, because of that pressure from the tumour, it made me very moody. I used to panic sometimes and now my whole attitude has changed. I’ve always been a fairly moody person and now it’s like water off a duck’s back. I am much calmer, much more laid back. I don’t seem to worry about anything. I have been positive about it all, a healthy attitude towards it, and as I say, since the operation life seems to have been better. Better in the way I am thinking, the way I am doing things, the way I am treating people. So many things have changed. I feel my whole attitude, my whole being has changed. In a way it’s the best thing that could have happened to me.

... before I used to be frightened of dying, I don’t feel I’m frightened of dying now, so not a worry any more, if you like.

My whole being has changed. It is as if I am the person I was born. This has restored my faith in human nature. I feel this is more me than I’ve ever been. This is John D, not someone else. I find I am enjoying life a whole lot more, I feel a lot more satisfaction. Being happier with the things that I do and being happier with the people around me. Yes, I recommend it. I am completely different.

Moderate

35. But I’ve got two chances. I can either snuff it or I can enjoy what time there is. And there’s no way I’m going to be depressed over anything. I’ve made my mind up about that. I’m going to enjoy life..... Now there’s so many get depressed and they think “Oh dear what am I going to do.” I think to myself that’s a waste of time. I am going to enjoy my life. If physically I am not in a position to walk about and things like that it doesn’t mean to say I can’t go in a trolley (wheelchair).

5. In fact there was a bloke in the hospital who had a benign tumour and he got into a lot of trouble because he couldn’t string a sentence together. In fact it says in the Backup book that some people have to have speech lessons. I haven’t had the same so some people must be hit harder than me. So all you got to do is look at the little kids. I mean why do little kids deserve cancers? I mean they don’t. And when you start getting the treatment and you read a bit about people that have had it; loads of people have had cancer. I in 3 isn’t it? Then you think blimey! Then you think it’s not always a killer.
34. Examples of Positive Appraisal or Down-playing

Moderate (cont)

25. It makes you think because when you’re running around trying to make money you don’t have time to think. It’s the first time in my life I’ve actually had time to do nothing, just sit back and relax. Well, you’ve got the time to do it. The thing is I’ve had such terrific support. People I never knew would care, and they’re all waiting for me to go back. I never knew I was so well-liked. I thought well I’m a rich man with, you know, yachting buddies. One of the things I couldn’t believe is that everybody’s asking "How is he? How he’s doing? Come on!" They’ll be a reception and that support has bolstered my determination to keep going.

30. I’m sure something to the head brings out something in people. They are just so caring of you and want to give you things. Our house is like a greenhouse. It is full of flowers and cards, and I’ve had relations ringing me who I haven’t spoken to for years.

I think it changes you, the whole experience of being ill like this changes you. I do feel different. I feel a different person. I have more time to stop and think about things, and I do feel different....I think this is an experience really, in a way one of the biggest experience in my life. I can’t explain how different I feel but I am totally different to the way I used to race around. And being in hospital...how people will talk to you about their illness, about how they feel about it, about their approach to it. You are instantly closer to people than you would get maybe in years to someone outside of the hospital. That must alter you in some way.

7. Oh yes there are marvellous aspects to all this. I have to say that, although it is a little ironic...We talk and learn things from one another, our relationship is richer, stronger. It’s open and quite full.

10. I try to look at the good points. I don’t sit around feeling sorry for myself....I just feel very much that God suffered for me and now I’m sharing in a bit of that suffering. I think that makes me a better person.
34. Examples of Positive Appraisal or Down-playing

Some

23. I've got people who work at Wormwood Scrubs praying, people popping up all the time. A friend of ours who's a vicar who we haven't seen for some time. Across the road they're Catholic. I suppose you could say that I'm having to see what God can do and leave it at that - God doing things through other people. It gives me a sense of caring.

11. One nice thing has been the children I've spent more time with them and they were sad for me to go back to work.

6. But I suppose we're more fortunate than most. If the worse came to the worse, could sell up and live in a small house.

21. But I have been lucky you know. I mean my family, they have been so sensible and lots of friends. I have been fortunate.

82. They've (family) been brilliant really. The whole lot of them.

91. (After the operation) I made them all laugh. I said, "I'm the only one with a cat-flap." Yes, I've got good healing skin, very good healing skin.

Nil

22. At the moment I'm the man of the moment. I'm everybody's popular choice. But, no, I don't enjoy it. I'd rather be making a fuss of somebody else. I have to accept it as part of the illness.

1. No I can't think of anything positive at all.

80. Something that was really getting on my nerves was everybody's attitude, well, a lot of people's attitudes. I felt like I was really weird because everyone was saying, "Well, we've got to beat this thing, bla bla bla." And I felt a bit of an outsider because I didn't feel like that, I felt really bloody angry, do you know what I mean? And I thought it's like they don't want to hear you saying, "Well, look, I'm really miserable and fed-up."... So I did feel a bit of an outsider whereas all these people were, sort of, really optimistic and everything and I didn't feel optimistic at all.
35. Belief in the possibility of a cure

This rating is made on the basis of what the subject seems to think will happen. It is quite possible for someone to talk about the possibility of dying, or to be realistic that it is a risk, whilst at the same time holding out cure as a long-term possibility. We decided to rate each of these thoughts separately so that we could show how inconsistent their views might be, and so that a comparison of this scale and the next, which considers thoughts about the possibility of death, might show the extent to which the individual has 'accepted' the situation.

Rating

1. Marked  S believes cure is the almost inevitable outcome.
2. Moderate  S believes that cure is reasonably possible and if this is not the case then further deterioration does not seem likely.
3. Some  S believes that there is some chance of cure which must be worth pursuing.
4. Nil  S believes that there is little chance of cure but more of delaying recurrence of the disease.
35. Examples of belief in possibility of cure

Marked

30. They did explain that they'd taken as much of the brain tumour as was safe to do, and that I needed radiotherapy to remove any...to get rid of any that was left, to kill off the cells that were there.

2. Death doesn't come into it now as a possibility. It doesn't occur to me now that that's going to happen...it's rather cliched, it's to accept the diagnosis, don't accept the prognosis -a hope and belief that you're going to be an exceptional case.

11. He said the chances of it coming back are always very small in fact nil after the radiotherapy which made me feel very reassured.

24. I didn't specifically ask him. He spoke as if it were pretty certain. I can see that some people who had a biopsy and that most of their treatment would be the radiotherapy because they have growths in awkward places, that there would be a question mark over how complete my treatment was going to be. But in my case because it seemed to be something that was on the surface...then you should be able to wipe it out completely because the thing has taken a good deal of pacing anyway.

21. I should be more concerned as to if it's going to come back, you know - what to do to avoid it coming back. I am 50 now, and I think "My God! If it comes back in 20 years I will be 70. How am I going to cope with it?" I mean I'm still strong enough to get over it now. So I suppose yes, that will be a worry and I don't think I will ever get rid of that.

25. He did say something about the chances but I thought that wasn't relevant to me because I was going to make it.

28. An earlier team did say that it was some sort of pressure that was removed - a nasty thing or something. Then they said that the treatment was to sterilise the area.

11. He reassured me that it would cure me. It would reassure it plus stop the chance of it coming back again. According to him the lump is no longer there.

60. He told me exactly what they were going to do. They would make a hole in the skull, remove the tumour and, unfortunately it's cancerous, but he's pretty confident that with therapy and everything else it will be clear. I'm sure they can clear what is left of the tumour and in a couple of years time, give me a clear bill of health.
35. Examples of belief in the possibility of cure

Moderate

9. I've had what they call at the hospital a miraculous recovery. They were quite thrilled. ....but there was no guarantee that it wouldn't come back.

They said it was a slow-growing one that it had taken 9 years to get to it present size...I'm hoping the radiotherapy will work.

23. He said there was a 50:50 chance of full recovery, so I'm an optimist and hoping that'll be the way things are going.

5. I worry whether they can treat it again. I've heard they can. In fact in the paper yesterday a woman had radiotherapy 6 weeks, chemotherapy 7 weeks - something to do with cancer of the stomach. So if it did happen again it could still get treated at a later date.

19. I worry whether they'll be able to shrink it or not. Even if I get 40% back I'll be happy. I don't mind if I lose my hair as long as I'm cured.

82. Q: Did he give you any idea of the chance that it would work at all?
A: No, but I'm not bothered if it's going to make me better. Because I've got it at the back of my mind it's going to make me better and that's all I'm interested in. The rest I don't really want to know. The technical terms I'm not really worried about. They're (family) are still frightened that something may happen. Do you know what I mean? Because you read it in the papers everyday don't you - this trouble? Cancer - person dies from brain tumour. So I suppose it's at the back of your mind as well. It's at the back of everybody's mind I would have thought.
35. Examples of belief in the possibility of cure

Some

8. You’re told in one breath (that you have a serious tumour), but you’re told in another that there is still a chance.

22. As for how successful they are I’m not sure. I haven’t asked and they haven’t told me. Presumably there’s still hope or they wouldn’t do it.

35. Well, the alternatives of cancer growing in you, what do you do? Do you say "Oh well, I’ll keep that for 6 months and then snuff it", or do you say to the bloke "It’s all yours mate, have a go."

26. We found 5 years in a book somewhere...but again I’m very conscious of the fact that that’s a statistical norm and everybody’s individual and therefore it’s very hard to make these statements. I’m persisting in the belief that everybody’s an individual and you can probably push these things a bit by using other techniques

13. He said "We’ve taken it out, or we’ve taken quite a lot of it out, but it will come back again, I think". They told me it would, it might, respond to treatment.

32. Yes, well, I suppose I’d have to say that I’m hoping, well, I am still hoping about success.

Nil

7. Fundamentally it just delays the process, it doesn’t stop it, wish to God it did but it doesn’t.

2. Well basically I’ve got a few more weeks or months if I’m lucky....I think at the start of the chemotherapy, understanding that it almost definitely would not work might have been helpful.

95. I feel more concerned about other people having worries about me, if you can understand what I mean. There are certain things I try to hide, if I can, but I do tend to worry about my family, .. what happens if something should happen to me because once anything happens to me I’m not around to have worries, on a personal basis, you know.

80. It wasn’t until we were in the cafe and I was sort of having a laugh and a joke and my mum suddenly looked at me and said, "You do realise it’s incurable?" And I was sort of flabbergasted. I didn’t realise that was what he had said at all. Do you know what I mean?

30. It’s not good news, there’s no more treatment. There’s nothing else so I just have to accept that really. It was supposed to have cured it, no, I don’t think it has.
36. Thoughts about the possibility of death

This rating records the degree to which the subject is able to contemplate the possibility of death.

Rating

1. **Marked**  S is able to discuss philosophy of death and the fact that it is likely to happen at some point.

2. **Moderate**  S can mention that it is a possibility and elaborate on this even if not quite accepting that it could happen earlier rather than later.

3. **Some**  S mentions it but does not allow it as a realistic possibility. May be able to talk about it.

4. **Nil**  S is not aware or unable/not willing to mention it.
36. Examples of thoughts about the possibility of death

Marked

7. I mean my whole job has been spent dealing with people who are going to die and on the focus of death. It's having hope in the face of death. There's a carving on the church door, "Bonne est mort et dolce vitae est" - Death is good and life is sweet, and I think there's some truth in that. In a sense I'm looking forward to it, but not in the sense that it will leave my wife a widow. That is very painful.

80. I mean mine is a specific type, do you know what I mean, mine's incurable. And I want to know how come mine's incurable when they don't always have to be incurable. I don't understand that.

Personally, I think that he's (father) put something on me (a spell). Things weren't normal because it would never be normal with my dad because he's not like a dad, do you know what I mean, because there's been so many years that I haven't spoken to him. So last year my mum rang him up before I was going to have the operation and he told her "What are you telling me for? She's going to die and I hope she does die. It's in the plan that she will die." And then two weeks after I had the operation they told me I've got two years to live, sort of thing! So I just connect it all with him basically. I believe in those sort of powers.

99. I talked to my mum the other day and she said something like she couldn't imagine life without me being around. And I said something like "Well, don't believe it 'til you see it" which is perhaps a stupid thing to say but I have a real divide in my mind. On the one hand, obviously the doctors have told me something which is, you know, their knowledge, is, if you like, the truth, that this thing will kill me before very long. But on the other hand, when you feel good and when you feel positive you do have a thing in the back of your mind that somehow, somewhere, you just never never know what might happen to it. I mean, it sounds ..... it is a complete contradiction of ideas. I can't really explain it. It is just that on the one hand you say, "Right, fair enough, the doctor said you are dead meat" and on the other there is something inside that just says, "You never know, not yet, not yet, we're going to get through it somehow."
36. Examples of thoughts about the possibility of death

Moderate

22. He's not said you're going to live. I haven't asked him and I wouldn't expect him to.... he's not over the top like "You're going to die in 2 weeks".... perhaps he thinks I don't need to know. Probably if he told me I was going to die in 6 weeks it would be a different story.

5. I worry about dying young.... I just don't want to die. I've always thought I could possibly reach well over the eighties. Now I ain't so sure. ...If you're having the treatment and you don't know how it stands... but I don't want to look on that side of it.

19. I think about eventually I might die... I started thinking about it when the sensation didn't come back. My children don't like it you see but I want to make a will. I don't mind if I lose my hair if I'm cured.

2. It's very stressful thinking about death and spiritual things. There has to be something after death, some sort of God. Then there are the financial aspects and the lack of close friends and what she would do with the sons. We've been together since she was 16, and when we think of that it's a very sad situation. Death is not frightening, what is frightening is the feeling of not having achieved one's potential.

32. I haven't got round to asking Dr G in that sense, this timing thing is perhaps what we are talking about. Are we talking there's a 50 / 50 chance of a ten year life or are we talking of two year life? You know, that's the sort of numbers that doctors tend not to want to talk about and yet, you know, I would just like to be a bit more efficient in organising, I mean if someone's going to tell me "Look, there isn't a chance of more than a year" well, I need to know it. It is as simple as that!

26. My first thought was "Oh well I'm 48 I've had a good life -I'm going to die..." I almost had a death wish I think but I managed to pull out of that one with the help of some friends. The anxiety is mostly concerned about the future, coping financially, and I suppose being uncertain about how long one's got to live. Being able to see the boys through - that's very important.
36. Examples of thoughts about the possibility of death.

Some

24. My first thought was that I wouldn’t be alive by Easter but then I thought that’s ridiculous.

82. They’re (family) are still frightened that something may happen. Do you know what I mean? Because you read it in the papers everyday don’t you - this trouble? Cancer - person dies from brain tumour. So I suppose it’s at the back of your mind as well. It’s at the back of everybody’s mind I would have thought.

21. I was told about two weeks ago that they said at first that it was inoperable, and that I had two or three months to live which no one told me. They told my husband and my sister and she was very dogged and said "Inoperable, nonsense! We'll get another opinion".

I suppose my husband thought, "Should I tell her about it not being operable? And he decided to tell me and I took it very lightly, and then the next day I was quite horrified.

Nil

84. I think we have another 10 years business working, God willing, am, and then we will retire, we hope and have a nice retirement, so but I mean, if it means we have to retire a bit early, well we do... My husband and I are both only children and my parents have got their own property and so we haven’t got those sort of worries, no, and as I say we have got good pensions, we have always had big private pensions, so we should be alright.

25. For the first time in my life I’ve had time to dream up all sorts of nice little projects for the future. I’m very confident, very hopeful and I have the best care that I could possibly expect.

11. He reassured me it would cure me.....I’m a station foreman... I have to wait and see what my doctor says. the treatment will take four weeks and the social worker is going to talk to them. I should call back and see them after my treatment and they can assess my case then. I’m hoping to go back.
37. 'Getting life in order' activity

The degree to which the subject acts on information they have received. The aim of recording this separately is to see if there may be some discontinuity between knowledge and behaviour. Areas to cover include wills, finances, future plans for the spouse or sorting out personal papers or belongings. Use all available information including what the spouse says they have done if the subject does not volunteer information themselves.

Ratings

1. Marked  S takes an interest is how and where spouse will live alone whether they should re-marry, and there is fairly prolonged discussions about this.

2. Moderate  S makes plans for spouse’s financial security. Must involve some action of re-organisation and discussion with another person such as a financial adviser or the spouse. They may have mentioned the possibility of re-marriage.

3. Some  May do something minor such as change bank accounts to joint names, tell wife once where the will is or mention re-marriage once.

4. Nil  No evidence for any of the above.
37. Examples of 'Getting life in order' activity

Marked

7. We talk about it all the time. We talk about it openly and frankly. I'm going to die and she knows it and she'll be living alone in a house by herself, not this one, that's all arranged. She'll be living there alone... I don't think she'll remarry.
(S has also made contact with a lot of old friends, made tapes and decided on his funeral service).

43. I said to J (partner), "I'm going to a walk down the market, are you going to come with me?" I says, "I'm going to go to the funeral parlour." He said, "What for?" I says, "Well, got to start somewhere, I'm going to make arrangements." I said "We've got time to do it" that is why I wanted to start it now. And I went in and J came down with me and they were surprised. She was actually surprised that somebody was actually out to sort out their own funeral.

2. S has discussed with C where she will live and does not want her to move from England. He has consulted a financial advisor about the total assets he possesses and how much income she would have based on his life insurance etc. He has had several meetings with company for this (only two weeks after discharge) and has not yet signed anything.

Moderate

35. We've changed our wills together.

26. Concerning our financial future there's a lot we've got to get sorted out what the position is and what the options are. It's critical to be sure that she is thoroughly advised about everything.

74. I feel guilty that I know I'm going to leave Dean. (And) every time someone mentions Amy I always try to change the subject and I think they think sometimes that I don't care but... I write her letters and then I tear them up half way through. Like letters to keep about different things and I get half-way through and I can't write anymore. I've kept one. It took me about twelve hours to write and it is only a little letter.

54. I am having quite a long discussion with my accountant over various problems, a few things we are trying to sort out and get the best things for the future. I decided it needs to be done, we get ourselves sorted out so we don't suddenly find ourselves up against something we didn't realise was coming.
37. Examples of 'Getting life in order' activity

Some

19. I tell my children that I want to make a will. (S in hospital bed bound unable to visit any practitioner herself).

22. I’ve been tidying up one or two personal affairs... I felt the need to do that (S has not discussed this with C).

2. I’ve procrastinated about it - got lazy, I’ve basically still got to get signatures on a few things and that’s just another one of the things I should be doing. I managed to consolidate on the house, work out what would happen, how much I’d be worth if I dropped dead. I need some more advice. They’ll be quite well off, they’ll have enough to take care of themselves.

30. ....looking after yourself and doing as much as you can really. Going to retire, try and get early retirement and just live as nice a life as I can. I shan’t go back to work. I shall have to get the retirement things sorted out, my pension and that’s what we’ve been doing last week.

Nil

5. I wouldn’t need to do anything as everything I have would go to my family anyway. It’s already sorted out.
38. Uncertainty

It is often stated that uncertainty is more difficult to bear than the truth and it is hoped that this final concerning coping scale might shed some light on the phenomenon.

This rating attempts to take an overall assessment of the sense of certainty that the subject feels at each point in time. It specifically relates to uncertainty about three areas. In the first place the subject may be thrown into uncertainty by their diagnosis - they may be unable to find any rhyme or reason for it. On the other hand they may be uncertain about the future either directly concerning the prognosis and the possibility of death or about the kind of life they can expect in the future. They may also be uncertain about aspects of the treatment or its organisation.

All these areas therefore need to be considered before deciding on the overall rating.

Rating

1. Marked S feels extremely uncertain. They are uncertain in at least one of the areas of diagnosis, prognosis, treatment and activity or their anxiety over one area is intense.

2. Moderate S senses considerable uncertainty or anxiety but feels some control in at least one area.

3. Some S acknowledges some uncertainty or anxiety but it does not become a preoccupation.

4. Nil S is very clear about their situation and they have no worries.
38. Present Uncertainty

Marked

32. I think there's a bit of anxiety and I'm actually going to go and talk to the doctor on Monday morning..... I'm saying I'm clearly better in one sense, I'm worse in another sense... what I've got to say is I don't think anyone really seems to know. I've tried to talk to Dr A. Dr G has rather sort of advised that it's, you know, just going to get better and nothing you can do about it. I'm looking for someone who will explain to me how I am, how my health is, and above all would explain a little bit about this problem (with reading). I want to know if it's (chemo) going to give a chance, what is the normal proportion? If it's 1 in 1000 are bound to get better from it but nobody else within a year, well, I'd like to know please. I want to know whether I should stay doing a job but they won't tell me. Dr G won't tell me, no one else will tell me, why do they not look at it? Why aren't they answering to that one?

54. It may have been a little helpful if something of a little bit more could have been told at the very beginning. I've never really been put into a full picture I suppose. I think I look at it now that I have cancer of the brain. Let's be quite blunt. No point in beating around the bush. I'm a great one for believing in getting to the point and if that's right, now I have got to learn to live with it. Now nobody, just nobody, can tell me what is going to happen in the future, I realise that, well, nobody knows. ..... because you can't say what it (treatment) will do, I appreciate that, but presumably you're not doing it just for the sake of doing it!

Moderate

49. I'm living day by day really in the hope quite honestly if I were honest with you, that it might all go away. On the other hand I realise it may...it'll probably persist and I don't know what the outcome will be. I don't know whether I'll be, what sort of support I will need. I don't know what I can expect. I honestly don't know. I think it's very difficult to think of these things. One thinks particularly of one's family you know. I mean you're bound to think of one's family and how it will affect them. You know, looking sometimes on the bright side I think it could go well. Sometimes when I'm looking on the depressive side it could be badly. But on the other hand I seem to have responded to treatment, you know. I mean, do you think I'm...do you think.... This is a terrible question for you to answer, do you think I'm over-doing the business of cure?
38. Present Uncertainty

Moderate (cont)

21. I can’t understand why it happened to me and I feel very angry because I do all the right things. And I thought it through a long time ago...and when the doctor asked me questions, you know - "Do you drink? Do you smoke?", all these are the right answers as far as I know, so why me?

But obviously I would like to know why, why it happened.

My major fear (is being made redundant) and my other is that I have been told there is a tendency for tumours to come back, and of course I think to myself "Oh God I will have go through all this again. I can’t go through this again."

99. It is a hugely uncertain thing. There’s a huge uncertainty of why it’s there, or how it came about, or even the uncertainty of how it will be treated, how successfully, and the matter of uncertainty of how long I’ve got and if I’ve got a certain amount of time how well will I be in that time to do what I want to do? And if I’m well enough, what do I want to do in that time, what can I achieve? It’s just massively full of gaps..... there are so many things you can’t fill in for certain.

Some

82. So long as he does his job all right that’s all I bothered about, you know? No, but I’m not bothered if it’s going to make me better and that’s all I’m interested in. The rest of it I don’t really want to know. The technical terms I’m not really worried about. Because as I say, they do their job. The surgeon’s done his and now it’s down to me to do mine. No, as I say, I’m not one to worry about the operation. It’s done it’s over, finished. What they give me is good enough, does me.

I don’t know how long this treatment is going to last yet, at the moment. I think they said it’s going to be about 12 months, 4 weeks to 12 months - that’s what I’ve been told so I don’t know whether I will have to put my holiday off or not. I can only wait and see.

Something might happen, do you know what I mean? Because you read it in the papers everyday, don’t you, this trouble. 'Cancer - Person Dies.' So I suppose that’s at the back of your mind as well. It’s at the back of everybody’s mind I would have thought.
38. Present Uncertainty

Some (cont)

13. I’ve had no details about prognosis. I don’t know how long this is going on for or what to expect.
   Q: Have you asked anybody about that?
   A: (pause) Yes and no ... but they told me it might respond to treatment. It sort of started off "Well, let’s hope it’s done the trick and if it doesn’t, well, we’ll take it from there." I said "Well, if it comes, it comes, you know, it’s got to happen to us all sometime."
   Q: Is that something that worries you? Do you find yourself worrying and thinking over what might happen?
   A: Nope ....

   No, I’ve accepted what has happened because, you know, you can’t expect good things all the time. I think you accept things as they come. You know, you don’t worry about them ... Of course, I get odd moments when I get a bit depressed, but nothing I can’t cope with.

Nil

7. I don’t know how much it is in the top of their (sons) consciousness that I’m going to die within a year, say, or after Christmas or something and ... but my eldest son, who I think is the most afraid of death, actually ... tends to say "How’s the treatment going? Is it going all right?", you know, as if "Is it doing it?" and presses the question a bit. But my wife and the others absolutely, I’m sure, openly acknowledge the fact that, you know, one has a limited span, as I think I do. Indeed, in a sense, I’m looking forward to it. But I’m not looking forward to it in so far as it will leave my wife a widow. That is very painful.

30. It can’t get much worse really, I think it’s as bad as it can be. No, I shan’t go back to work, I couldn’t possibly go back to work. There’s nothing else so I just have to accept that really.

94. Well, I don’t think I’ve stopped to think about it but I have heard all my friends and relatives saying that the doctors said I made one of the best recoveries in the hospital. I was out within five days and home and practically back to living a normal life again. As I say, the next week I was down moving house and so I wanted back to normality.
39. Rater’s judgement of lack of the expected emotional response to the situation by the subject.

In an attempt to refine rather more our thoughts on mechanisms of denial we thought it might be useful to separate out what the subject appeared to be doing from what they were aware of doing with their emotions. This rating and the subsequent one therefore deal solely with the emotional tone of the material described by the subject, and with the number of nonverbal emotional clues that the subject gives during the interview. The subject may recount a distressing episode in a rather deadpan manner but at the same time be aware that they do not seem to be feeling the intensity of distress that they would have expected. On the other hand they may recall a good deal of distress and be particularly introspective in their analysis of their coping. Sometimes emotional responses can seem quite bizarre to the interviewer, and their own feeling of the “normalness” of the response ie; whether euphoria or continued joking is to be expected should be fed into this rating.

Rating

1. Marked  S appears completely flat showing no response, or else shows an extremely bizarre response such as euphoria with no tearful episodes specifically about the situation.

2. Moderate  S shows quite a flat response or else a rather unusual response but the interviewer gets a glimmer of some emotion hiding behind this response eg; inordinate joking masking tense off-hand comments or momentary losses of facial composure.

3. Some  S shows or alludes to the depth of their feeling but it seems that this has in part been suppressed by avoidance strategies or else denial is fairly brittle.

4. Nil  S talks about or shows a reasonable amount or good deal of emotion. Include here those who cry at the smallest thing to do with their illness even if this is thought to be a drug effect.
39. Examples of rater's judgement of lack of expected emotional response to the situation by the subject.

Marked

28. S remembers only waking up in the hospital with a bandaged head. He has been told that he has had a "nasty thing" removed but he does admit to any more than mild surprise at this. There is no shock, dismay, fear or indeed any sort of response.

77. S is at home six months after the diagnosis but was admitted to hospital shortly after her treatment with a deterioration due to radiotherapy. She is markedly reduced in her previous ability and has someone present in the house most of the time. She denies any distress at all and is verbose, talking in a high excited and childlike manner. At the mention of a pet which had died shortly before her illness she bursts into uncontrollable sobbing. Despite exploration of this issue it is not possible for the subject to link this death with her own situation.

In each of these examples there appears a curious incoherence to the story the subject is expecting us to believe and these leave the interviewer completely baffled.

Moderate

115. S is very weak and nearly chairbound at home 2 years from diagnosis. He jokes about thinking that his first fit was an attack of coca-cola poisoning, that they could have got the wrong bloke for the operation, that it was a good job they didn't use an electric saw for the biopsy, that he might be heading for a heart attack next, that he one of these days he's going to leap onto his exercise bike and miss and fall on the floor, that there were not very many survivors from the titanic, that he might as well have stuck a couple of sticks of gelignite in each ear. He notes since the illness he has become clairvoyant or is having deja vu phenomenon but then comments that he keeps dreaming that he's winning the football pools and the interviewer can imagine that he gets very disappointed. There is also a great deal of sexual humour. This all occurs in the contexts of fears of becoming worse, and of feeling socially isolated.

The underlying coping style is inferred as disinhibition which has been captured and put to use as an avoidance strategy.
39. Examples of rater's judgement of lack of the expected emotional response to the situation by the subject.

Moderate (cont)

122. S is 2 years from the diagnosis and can recall very little distress over the diagnosis. All he can say is that he felt he just had to get over it. His wife can recall only a few moments of upset and describes him as invincible and superhuman.

The underlying coping mechanism is inferred to be denial where the implications of the situation do not appear to have been grasped.

17. S is 33 years old and 2 years from the diagnosis of his tumour. He feels handicapped both in his work life and in his independence and conveys some dissatisfaction. There seems no great depth to this and it is difficult to obtain much description of the subject's inner state. He talks in a calm matter-of-fact way about the diagnosis, concentrating on the technical aspects without mentioning any fear or shock about the potential seriousness of the situation.

The underlying coping mechanism is assumed to be denial in which the subject does not appear to have worked out the seriousness of the situation.

Some

114. S is a man of 33 who is extremely avoidant and finds it difficult to talk. Initially he avoids eye contact and gets his words muddled up but as he becomes relaxed he admits to feeling depressed and isolated as well as anger about the situation he is in. During the interview he becomes uncomfortable but manages to control himself so that he does not show any distress. The interviewer is aware however that a great deal is there.

113. S is a young man who knows that he has had all possible treatment. His descriptions are vague and he repeats "You know what I mean", and "It's as simple as that" several times. He denies feeling depressed although he mentions that he could "Throw himself over a wall".

The coping style is inferred as denial of the emotions that the situation might elicit although he is acting cognitively on the knowledge that he has about his situation to sort out his papers.
39. Rater's judgement of lack of the expected emotional response to the situation by the subject

Nil

121. S describes tremendous upset on being told the diagnosis, bursting into tears with his wife on many occasions. He clearly describes the depths of despair that he has plummeted on his since then on recurrence. He shows signs of becoming upset during the interview but can control this.

125. S talks freely about the situation and the fact that he is now trying to look positively at hospice care. He becomes upset talking about the support that his wife has given him and feels at that point that he will have to finish the interview.
40. Subject’s awareness of emotional tactics or apparent lack of emotional response to the situation

The previous rating is solely the judgement of the interviewer but this last coping rating takes into account the degree to which the subject is able to assess and take stock of their own response. To some extent it is a measure of introspection but this might be seen as the degree to which emotional material can be perceived at a conscious rational level.

Rating

1. Marked  S can give a detailed and precise description of the way in which they feel they are coping with the situation.

2. Moderate  S has some awareness of their response but is not so caught up in assessing it. They may, for example, be aware of the fact that they are not as upset as they might have been, but is happy to take this at face value.

3. Some  S may make an attempt to explain their response but since this has little salience to them they may use platitudes or flounder around after a few sentences to explain their technique.

4. Nil  S appears to have no awareness of how they are coping, of any strategies they are using, or of any incoherence in their response.
40. Examples of rater's judgement of subject's awareness of the use of emotional tactics
or of the lack of an expected emotional response to the situation

Marked

121. S is aware that he has had periods of extreme upset when he has cried about dying and leaving his family. On the other hand he can describe how he deliberately keeps himself as busy as possible and pushes himself to the limit in order to fight the disease. He says he is certain that the disease is not going to get him, and that he can sometimes go for several days without thinking about it. He even describes making rather morbid jokes about his tumour which he clearly describes as a front he puts on.

5. S is very well and several years from his last problems but he is well aware that he needs to wait at least five years before he can really be considered free of cancer. He wonders whether he is going to survive an elderly relative and live long enough to emigrate as he had previously planned. He describes very clearly the fear that he had at the time and the way that he tried to get himself to think positive. He feels it is important to keep himself busy.

Moderate

115. S says that he keeps going by thinking the tumour away and telling himself that it will not get him. He says he does this is by laughing and by thinking positive thoughts. It did however seem that he was not consciously aware of this since much of the humour seemed to be inappropriate ie; sexual innuendo with every female member of staff which considerably embarrassed his father. His lack of awareness of the actual quality of his humour rated him as moderate.

125. S could describe that he had taken a positive approach to his illness initially always wanting to know the bottom line. He described feeling depressed and the need now to look at his terminal phase in a positive light. He was not however either interested or able to elaborate on this.

63. S is aware that she felt distressed and anxious when she was told that she had a brain tumour and immediately asked how long she had to live. As the answer was deferred until the following day she thought about this whilst having a smoke on the balcony of the ward. She describes suddenly realising that she felt calm going to bed and sleeping soundly. When she woke up she was aware that she felt completely different. She did not feel frightened at all and was so certain that she was going to be alright that she did not wish to ask for any further prognostic information. She was aware that a great part of her distress had disappeared while at the same time she does not particularly question this phenomenon too closely since she is much happier with this state of affairs.
40. Examples of subject's awareness of emotional tactics or of the absence of the expected emotional response to the situation

Some

123. S describes the initial diagnosis as frightening and puts his recovery down to the sheer amount of support that he has received from his family, his religious faith and from friends. When asked if he himself used any specific techniques he says that he was not consciously aware of having done so. He says that at the time he felt no pain, had after all only had a small problem before the operation, and had felt very well afterwards. He makes a few jokes throughout the interview.

122. S describes feeling initially stunned but then getting used to the situation. He says that nothing really bothered him about being in hospital although a lot of other people were terrified. He says that his family all thought he was mad because the whole thing didn’t bother him, and in fact that when he returned from theatre he was sitting up in bed and cracking jokes. He said he thought to himself that he might have a rather cavalier approach to life but he had thought there was not really much to it. He said that other people in his ward were worried about not coming around from their operation but he had thought if that was the case one would never do anything. He doesn’t think that the experience has changed his life and that he doesn’t really worry more than the average person. He seems mildly impressed by his coping rather than perplexed as to how he should have managed this.

Nil

11. S thinks that he does not have a tumour but is suffering from a blood clot caused by muscle rub that he had been using prior to becoming ill. He says that everyone is making a fuss and there is nothing wrong with him. In fact he is stronger than ever. He is not at all reflective about his coping and seems to have no insight into the real situation.

28. S thinks that he had a "nasty thing or something" removed from his head. He has not asked what it was but feels that some of his friends have been unhelpful in suggesting their ideas about what it might have been. The interviewer can find no evidence of any emotional response and much less of insight into the protective strategy that he is using.

81. S is amicable but fairly unresponsive and seems not to have been told or shown any initiative in finding out what is wrong with her. She talks about her husband being worried but her own concerns extend only to the length of time she has been in hospital. She is generally very blank giving only short answers and at times is monosyllabic.
FAMILY RELATIONSHIPS
EFFECT ON FAMILY RELATIONSHIPS

41. Felt interference in relationship with carer

42. Subject’s satisfaction with support from carer

43. Rater’s judgement of subject’s family support

44. Subject’s satisfaction with family support

45. Subject’s perception of child’s difficulty coping

SOCIAL SUPPORT RECEIVED FROM NON-FAMILY MEMBERS

46. Perceived support from religious/spiritual belief or religious community

47. Rater’s judgement of subject’s social networks

48. Subject’s satisfaction with social support
41. Felt interference in relationship with carer

Illness often brings about changes in the relationship with the main carer. These changes are not however necessarily for the worse. The change in routines and tasks that the illness may necessarily force is covered in the handicap section, but here we consider problems in the emotional aspects of the relationship. Very often patients volunteered that their relationship had in fact become stronger, and that this could be an extremely positive aspect of the illness. At other times they had talked about feeling a burden on their partner of increased tension, or the fact that they disliked the fact that the carer now fussed or had more control over them.

Severe illness can cause a re-working of priorities and there may be a sense of regret over past quarrels and the amount of time spent working away from home. S and C may now spend more time together, talk more, approach problems jointly and set into action the processes of anticipatory grief. In other relationships this process may not occur, and although the carer may provide physical and practical support unstintingly, the couple’s relationship does not develop. In these cases they may well be implicitly awaiting the subject’s recovery and assumption of independence so that they are then able return to previous roles.

The scale is rated in the same manner as the those later in the handicap section:-

**Rating**

1. Marked Subject feels that there are serious problems in the relationship as a result of the illness or disability. They see no way out of these or may have considered seeking some sort of help from an outside agency.

2. Moderate Subject feels the relationship has suffered some strain or there has had to be some re-working of the normal interactions or balance of power. They have or think that they may be able to settle this between themselves.

3. Some Subject feels there has been little or no change in the relationship.

4. Nil Subject feels that the relationship has probably improved.
41. Examples of felt interference in relationship with carer

Marked

25. We're getting very uptight, a) because I'm so bloody independent - I like to do things on my own and b) she's telling me too much what to do. I'm getting very uptight about it. And I've got into the hospital routine - six o'clock get up, have drugs, seven o'clock wash and shave, eight o'clock wash, breakfast. And it's very hard to get out of my system. And she says, "But darling you've got to sleep", that if I don't sleep I'm worthless, which is fair enough but it's not....I've fallen over a couple of times. This morning she found me on the floor because I went to slip off my bed to have a pee. She put a little plastic sheet underneath where I go to the bottle so I won't dribble on the carpet. She's very fussy like that. She's a very hygienic person - everything has to be sort of sterilised, homogenised and pasteurised! Well, if I make one dribble in my underpants it's got to be washed that day.

We're having a problem which I'm trying to solve but I find we're both getting on each other's nerves terribly. I know we've got to adjust somehow but I find this flat a death trap.

73. A: It has strained my relationship with my wife and sons. She had cancer three years ago, of the cervix, and it changed her, changed her dramatically. She never had counselling. She refused help from anywhere. She works for social services and the worst thing that could happen did happen: she went on a counselling course. And now she believes she has the answers to everybody's problems, but she can't see the ones right under her nose. (She says) that because she didn't have counselling I don't need counselling. But I go to counselling regardless. This is one of the victim traps (she says). "Why can't you be more like me? Why aren't you more like other people?" She sees everybody as having an ideal marriage. Now she can see no further than a vastly expensive holiday in the boiling sun at the end of my treatment.

Q: Are you going to?
A: Am I hell! No I don't feel like boiling sun with hair like mine. That's all I need - a long aeroplane flight, that's something else I need! And a vastly expensive holiday when my business is running at half is something else I need! I ain't going.

61. Her behaviour towards me is not very nice because I'm not a well man. Why doesn't she come and see me here? I'm very depressed in here, I want to get out of here, I'm the loneliest man in the world. You couldn't rely on her, she's a strange woman. She's not well, she never said nothing (about his illness), she doesn't want to talk about it. It makes her sad.
41. Examples of felt interference in relationship with carer

**Moderate**

41. Oh yes she was upset, she was a mad.....I was crying and praying to God but for her it was worse because she was running back and forwards, all the worry and everything. In fact she’s just now managed to recover but she’s still watching me now. She’s worried in case I’m falling down and bang my head; she’s always behind me and that is that.

38. I think I told you last time I spoke to you we’ve never been close. She’s(sister)never been here with me, she’s never been around. Been on my own for ten years, I’ve had to get on with it. And when I was ill, to see her sort of, you know, doing what she was doing, it was too much. She’s very over-powering and she’ll overtake the situation and obviously I’m not used to it because I’ve never had it and I don’t like it. I’m very independent, and for ten years I’ve coped. Well, we haven’t spoken for about six weeks.

57. No, don’t say nothing (to husband). I don’t feel as if he’s interested - I don’t know how else to put it. I don’t think he realises at times how I do feel, you know what I mean?

74. People say I’ve been brave. When I have off days people tend to get a bit annoyed with me, even my husband, he can’t really .... I don’t think he can handle it..... He tries to dismiss most of it. I think that he thinks that I can’t be cured which annoys me, but I think that he doesn’t think that I’m going to die, you know what I mean? He tends to treat me like everything is the same as normal but I’m a little bit not well and I think that sometimes he doesn’t realise that I don’t feel well.

**Some**

11. From what she has showed me I now realise her concern for me. I’m very flattered that she cared that much about somebody. I’m not surprised, in that sense, I would have expected it anyway, but not to this degree. She is concerned just with me. It has confirmed what I thought were her feelings for me. But I do get angry with her and the others telling me to calm down, sit down, rest, rest, rest.

13. I think she goes out of her way to keep me happy and that must be a strain....and she’s never really moaned about it...She’s had lots and lots thrown upon her which you wouldn’t normally get. I think it’s harder for her.

62. I’ve been married to J for thirty-one years.... whatever happens I’ve had a good life. I don’t really like to talk to her about it. I’m a funny bloke, I know it sounds silly but I’ve not gone on about it. That’s it full stop. You know. I’m going to live, I’m going to live. I’m going to die, I’m going to die. That’s all. I know what state she is going to get in, it don’t seem fair to her does it?
41. Examples of felt interference in relationship with carer

Nil

7. She's at home and loving it because she's with me and we're together. There are marvellous aspects to all this, I have to say that although it seems a little ironic...we talk and learn things from each other and have fun. Our relationship is better, richer...it's open and quite full. The greatest feeling of remorse actually is that I would come home and I would see my wife with starry eyes watching the television or reading a book and I'd just not been there...the remorse is for having neglected her and so many men do it. Work is first you know and I really think I was very tired. I'm fortunate that she loves me. I am blessed.

25. It's allowed me to realise how to love.

2. I like to try and take care of her. We're much closer now than we were....the only person I need for support is her. She's my ally. We got re-married again. The first one had been quite quick in a registry office in the East. We couldn't get re-married exactly, the bishop wouldn't have allowed it but we had a service of blessing.

8. It's just knowing that you've got someone like that who cares. I don't know how anyone could cope who didn't have someone like my husband I really don't..... (cries). I've realised now how strong he is, or at least that's the side I'm seeing. I can't tell how much he's acting.

10. I think we are close. I used to feel rather left out because she was very close to my sister, but I think since my sister has left we have become a lot closer. I definitely feel that. I think that we support each other. I used to think "Oh I shouldn't be at home" but it's just how things have turned out. My illness has rather kept me at home.

60. We have a good relationship which helps very much.

63. You know, he said, "I don't care what you look like, whether you lose one side of your body, as long as you're there. That's the most important part". We're very close. I found that whilst I was in hospital I had his dressing gown with me the whole time and that helped me get through. It helped me sleep. And they called us the "courting couple", like we just got engaged.

88. I think it brought us closer together and we appreciate each other more, you know, it makes you stop and think. When we had our anniversary I gave him a toast for being so patient this past year with me and for being so good about staying by my side, and he was saying, "Oh hush," you know, "You don't need to do that." But I feel that, I am thankful.
42. Subject’s satisfaction with support from carer

Felt support is recorded separated from felt increased interference with relationship although they may often go together. This is because the subject may equate ‘support’ with practical coping and may not wish for or feel they are not receiving emotional support from the carer. Thus support can be the time and attention C has devoted to S’s hospital stay or needs at home.

Rating

1. Marked  
S is extremely positive about the care that the carer has provided, and feels they cannot be faulted.

2. Moderate  
S is positive about the carer, but not effusively so.

3. Some  
S feels that there are some areas where the carer is letting them down, but is not extremely critical.

4. Nil  
S has very little positive to say about the carer, and is in fact very critical.
41. Examples of subject's satisfaction with support from carer

Marked

26. She's been absolutely fantastic. She's been such a sort of pillar of strength. Really when it first happened it was so much extra work for he and still is a lot of the time. She's been so fantastic I must say. It's just as well I've got her strength.

7. She's an immense support to me. I would say she's coping on a scale of 1 to 10, about 9. We've decided to walk in the garden everyday. Although it doesn't take a lot of energy the energy comes from her. She's a good motivator.

25. I don't need anyone else but her. I want to carry on with the physio at home. She has a particular way of doing things that is so right. I feel confident with her. She has a way of doing things which allows me to concentrate on the movement rather than talking to me at the same time. She's doing wonderfully. She says I'm the best patient she's ever had!

10. My mother has aged. There has been a lot of worry on her shoulders as she's been around she's had to sort of well...she hasn't had to do it because she says she wants to, and if I were in the reverse role of course I would do it for her. But she's visited me everyday. I told her I want her to carry on whatever she had on but she's always been there and I took comfort from her.

2. I think she has changed. She has become more self-reliant and firm. I was amazed by all she had to cope with, her organisation and the way she found out as much as possible from the doctors.

5. My aunt has been marvellous. She just listens and is wise. I can talk to her about anything.

88. We talk about everything. He has got to almost everything he can with me. He has been to almost every treatment with me, he has come to the hospitals when I have gone to have the scans. He is always there. When I have the fits too, you know, so it is shared. He got his hair cut because I had to do mine and we raised money together because it was a sympathy cut to raise money for charity..... I have got a wonderful husband.
42. **Examples of subject’s satisfaction with support from carer**

**Moderate**

23. She’s done very well....I delegate to her.

24. She got very tired, but coped quite well really. Her mother came down, otherwise she wouldn’t have been able to come up and see me.

8. He came up to see me and we went to the day room and I started shaking and twitching. My immediate thought was that I was going to have a fit and I said to him that I couldn’t stay there. He said "It’s alright it’s just the feeling coming back." So I calmed down, just walked back and I was OK. That’s what I said, you see, he keeps me going.

82. The best person I can talk to is my wife. I can let my feelings go and tell her how I feel and she can do the same.

41. She’s watching me now, when I wake up she’s watching me. She’s worried in case I fall down. She’s behind me and that is that.

**Some**

22. It’s been quite difficult for me to get her to deal with it in a positive manner. She knew about it before me and fortunately she was able to have the strength to tell some friends.

89. My wife is very fed up with being confined to the house and all the rest of it. I think she’s coped very well but it stressed her terribly. Yes... we’ve had to deal with not only my retirement but also to deal with this illness which is very difficult. So really, you know, I think a lot more of the problems have appeared in her direction as you know she doesn’t like driving.

95. Now I stop and try and think deeper than I used to, whereas before it was everybody else’s problem and not mine. We don’t have rows as much now. There’s a couple of times where I’ve felt she could have perhaps had a bit more information or help towards me but then ten minutes later I think, "Well, why? She didn’t know I was in that frame of mind."
42. Examples of subject's satisfaction with support from carer.

Nil

11. At times when she's saying "Rest rest rest" that gets to me. At times the phone will ring and no-one will answer it and she will say she is too busy. So she'll say "Why didn't you answer the phone?" I'll say "You're now complaining that I'm not answering the phone when you say that I can't do it. That's wrong." Say in the evenings I might say I'll just pop into work, it's only two stops down the tube. And she'll say "What are you doing? This is supposed to be your rest." This is driving me mad. Nobody need take me, I can go by bus and I can stand. I don't need to climb the stairs. To say this to an active sort of man to tell him to stop at once, it will do him more harm than good.

38. I felt she (sister/carer) was taking over my mind. You know, I mean to the point I think when I said, "Look I've had a brain tumour, they removed that, but they did leave my brain!" I mean I just had to say this. I mean I appreciate all that (her help) but, you know she began to overtake too much. So it was inevitable that it was going to crack. She told me I was selfish and, I laugh at this now, materialistic. So I thought, "Right" and I said to her, "Look you are overpowering, dominant, bossy and patronising." So there were a few things said and she went. And I never heard from her for six weeks.

74. I said to him the other day, "I wonder how I will know when I'm getting right to the end and there's not much time left." He was furious. I tell you he was absolutely.... well, I just can't say anything like that to him. But, I mean there is nobody I can talk to and that really upsets me.... I do feel that I'm on my own.

76. Q: What will you do when they let you out of hospital?
   A: I won't be capable...
   Q: What do you think you won't be capable of?
   A: I don't know, I don't know....
   Q: It is a bit difficult if you can't walk very well?
   A: What do I do if I don't?
   Q: I don't know. Is there anybody who could look after you?
   A: I have no one, no one who, you know.
   Q: Not your wife?
   A: I told () don't want to (wife wants a divorce and keeps leaving him)
   Q: No, I know, you don't want that. What about your children?
   A: What can they do for you?
   Q: I don't know, take you into their house?
   A: They haven't got any houses, staying in a room, what can I do?
43. Rater’s judgement of subject’s family support

Most often subject’s talk about support in terms of the family and in particular from the
carer. As the carer has already been considered above, this rating deals with the kind of
support that the subject is receiving from grown-up children, parents or from their own
siblings. All these people may rally around the subject or, because they live some way away,
have many other commitments or find the subject’s illness difficult to cope with, do not in
fact see them very much. This rating is the rater’s own judgement of the kind of support that
the subject is receiving and should not be influenced by any views that the subject expresses
about it. In-laws, although they can sometimes be of great support, are not included here and
this rating is confined to the subject’s blood relatives.

Rating

1. Marked  S has received emotional and practical support from most family
members who have generally been helpful and supportive.

2. Moderate  S has received some support from family members who have been
visiting but there appears to have been either little intense discussion,
or lots of discussion but few offers of practical support.

3. Some  The support of the family may be mixed - some people are helpful,
some are not. This rating would be made for families who have little
contact with each other, for example, those who keep in touch by
phone.

4. Nil  There appears to be little family support for the subject and there may
even be lack of support and avoidance.
43. **Rater's judgement of subject's family support.**

**Marked**

38. S has an elder daughter (age 19) who has been a great support both emotionally and practically. S able to rely on her for whatever help she needs. S also has an aunt living close by who is constantly on hand should she be needed to take S to the hospital or help in other ways.

95. S has a sister in Norwich and a brother in Suffolk who phone regularly and are looking after his welfare, helping where they can. All four grown-up children help in practical ways and are emotionally supportive. Plenty of family support.

71. S has a highly attentive close-knit extended family. His sister, in particular, act like a mother to him, which he appreciates greatly. He says, "They treat me like an angel."

91. S has very large, very supportive family. Son and grand-daughter have been especially helpful to S and to his wife. Members of the family have stayed over at his house to help out.

**Moderate**

74. S has lots of practical help from family members around her but little emotional support or chance to talk about her experiences in an open and honest way. Thus she feels alone with her illness even though there are many people about her.

26. S feels he can talk to his family and share his feelings. He has a sister who is helpful and available. His children express some difficulty adjusting to his changed behaviour and physical capabilities but he understands how hard it is for them and feels they are generally supportive.

37. S has a son in this country and a daughter in South Africa. The son helps with practical assistance and keeps in contact with the hospital to make sure that he is properly informed but he does not talk to his father about the implications of the illness or about his feelings. The daughter came over to stay with her father for many months while he was ill.

100. S has three daughters who all show care and concern to their mother. Two visit regularly and one lives at home and helps with S's exercises. They talk to their mother a lot about the illness and keep her occupied by bringing the grandchildren around.
43. Rater's judgement of subject's family support.

Some

63. S sees her mother once a week but doesn’t say this is helpful. S is in contact with her brother and sister occasionally but S cannot cope with her sister’s small children and consequently would rather not see her. Her own children are young teenagers and S has to support them rather than being able to receive support from them.

30. S's only daughter came to see her initially in hospital but after a while her visits tailed off. S says that she cannot talk to her daughter and doesn’t want to let her see that she has been upset. S says that she knows her daughter is very busy with work but she really would like more support from her.

45. S lives with daughter and son-in-law but neither of them are at home very much and she gets lonely. S says she loves her children and that they are good but seems to have a rather distant relationship with them.

Nil

80. S receives little or no support from immediate family. S has a brother who refuses to talk to S about her condition even to the extent of leaving the room if the subject comes up. S has a sister who "gets too over-emotional" and a mother who she hasn’t seen for ages because her mother has a new boyfriend and is "living a dream-life at the moment".

5. S has two sons, neither of whom offer him any support, and in fact, annoy him. The youngest one of them has just started a prison sentence after years of getting in to trouble as a young offender. The oldest one is unemployed and sometimes violent with his father. S is so displeased with his sons that he has made his aunt the beneficiary of his will and if she dies before him all his money will be left to medical science! He has not told his sons about this.

43. S has no family of his own. Has lived with partner for 20 years. Partner’s family have not come to visit him. Partner and S got angry at this unsupportive attitude and when partner's mother did visit partner "threw her out". S says "the whole family is such a split up family."
44. Subject's satisfaction with family support

Rate here how satisfied the subject appears with the support they have received, regardless of what seems reasonable considering what might have been omitted or offered. This is not the rater's own judgement of the adequacy of the support since some people may be satisfied with very small amounts of help.

Rating

1. Marked
   S is extremely positive about support from family members and feels they cannot be faulted.

2. Moderate
   S is positive but not effusively so. There is no major criticism but they make general remarks suggesting that support has been quite good.

3. Some
   S feels that some aspects of support from family members has been insufficient, could have been a bit better or has been unthinking. They may feel let down by some family members.

4. Nil
   S has very little positive to say about their family and feels that they could have had much more support or contact.
44. Subject’s satisfaction with family support.

Marked

38. Thank God I had relatives, two of them with cars between them. Sort of took me alternate sort of days and it worked out vey well.

My cousin went to the pharmacy while I was having this treatment and came back with my drugs. My cousin wrote down the times on the box for me when I take them.

M, my eldest one, stayed with me and every time I vomitted she was there rubbing my back and sort of.. you know. And I was getting sort of really paranoid about bringing up these drugs so I phoned up my aunt and she said to me, "I’ll phone up the emergency doctor and explain."

46. I’ve got my nephews and nieces. Two nieces came down last week to see me. One came all the way from Northumberland. I’ve got one sister in America, I’ve spoken to her on the phone.

15. The family are very good about rallying around, you see, my daughter’s here today and my sister and friend who share a house they have been coming most of the time.... They have been smashing, they really have. I am particularly impressed with my son... he is super, and my daughter is great too, she’s doing so much, she’s a good girl.

Moderate

60. My sister, she’s been a brick, an absolute brick. She works in London so she was able to get to the hospital most days which was great for me. My parents live down in Basingstoke. My mother has been very ill, she has been in hospital for the last two months. So my father has his work cut out visiting her... it’s been an uphill struggle for him because he’s still working, then this has happened to me. He’s been phoning up obviously, he came up a couple of times. There has been a lot going on in my family. My sister, unfortunately, is going through a rough patch in her marriage. So one thing and another this year has been an absolute terrible year for us lot.

81. My mother-in-law lives on the floor below us and she was up in our flat sitting with him (worried husband) until two o’clock in the morning forcing him to eat. He couldn’t eat, he couldn’t drink, he was praying all night long. We’re a very close family, all of us. My mother knows all about it (her illness). She comes here to see me. I think it has helped her that I spoke to her about it because daddy didn’t (S recently lost her father from cancer).
44. Subject’s satisfaction with family support.

Some

76. Q: Do your children come and visit you?
   A: Oh well, they do come on and off maybe, sometimes everyday.

74. If mum comes round she’ll say, "You look tired. Do you want me to take her (daughter) out?" I say, "No, I’m fine" and I wish that I could just sit down and moan to her…. I think I come across a lot harder than I am but I think I do that for everybody else, my mum especially. I don’t know, I don’t think she has had a very nice life and I almost feel guilty, not because I’ve ever done anything to her, because I’ve always been really good, but I feel guilty that I am going to die and this keeps sticking in my mind that I’m the only one and I feel really selfish that I’m going to leave her. And I’ve never been able to say it to her, do you know what I mean?

25. My son hasn’t been, but then he’s the same. He’s got a full-time job. He’s got to make a living. He just can’t take time off when it’s convenient. My daughter can’t just take off. My other daughter has been taking her final exams. My youngest daughter is coming this weekend which should be very helpful.

94. We’ve three adopted. One in Sussex and she was very upset but she, her husband and their baby came up to the hospital and visited me there and I’ve seen quite a bit of her since. The youngest is, I’m afraid, a disappointment. She’s been loved, adored, lavished, being the youngest. We spent far more money on her than anybody else. We sent her to a Rudolph Steiner school, to Swiss finishing school, to New Zealand to visit her sister. And everything has just been wasted. When she heard I was ill she dashed in "Oh mummy, I love you, I love you, I love you and I’ll be there to help you, I’ll come every Monday and Tuesday to help you" and I haven’t seen her since. She hasn’t crossed the doorstep.

Nil

80. I mean, I think it’s too heavy for him (ex-boyfriend) myself. Because if he comes round and I take off my hat he’ll say "oh put your hat back on" and "when is your hair going to grow?" He’s always on about it. Obviously it sort of gets to him. But I mean the way I’m feeling it’s his loss not mine, do you know what I mean. There’s a lot of men like that. My brother’s like that. If we were ever talking about it he’ll just sort of go out of the room, you know, he won’t say anything. My sister’s fine, she just gets too over emotional. I haven’t seen (my mum) for ages. She’s got this new boyfriend so she’s living dream life at the moment (laugh).

5. I don’t get any help from E (son), none. He’s unemployed now. I told him "go and get a job." The youngest one’s just got a prison sentence. Six months, finally got caught!
   Q: So how are you getting on with them?
   A: Not too bad now I’ve hit him a couple of times, Eddie, when he’s been sort of going to punch me and all that. You know I stopped all that. It was giving me headaches.
45. Subject's perception of child's difficulty coping

This scale assesses how disturbed the subject feels their children have been by the illness and is relevant to children of any age, living with the parent or away from home. Although a low rating does not necessarily mean the children are not having problems, the subject may notice acting out, unwillingness to stay with the parent because of fears of an epileptic seizure, or nervous complaints that need the school or the family doctor's attention.

Rating

1. Marked  S feels that a child is having serious problems or behaving in a manner that might require outside intervention or help.

2. Moderate  S feels that the child is having significant problems that require deliberate strategies on their part but feels that they can deal with them.

3. Some  S feels that a child is having no greater problems that one would have expected in the circumstances.

4. Nil  S feels child or children are unaffected by their illness.
45. Examples of subject’s perception of child’s difficulty coping

Marked

7. My eldest son is the one who is most afraid of death. He sort of tends to ask things like, "how is the treatment going dad?" as if that were the most important thing happening.

19. My son doesn’t really understand. When I try to talk to him he gets cross with me.

Moderate

3. My daughter has been acting rather silly she laughs at my head and won’t kiss me goodnight. I’m rather disappointed that she’s acting in such a spoilt way really.

26. The youngest has probably found most difficulty. He said to the elder that he found it odd that I was incompetent in some ways and competent in others. It’s difficult for him when his father starts behaving in slightly strange ways.

38. I do worry how emotionally M (daughter) is coping with this because I know at the beginning not very well. And my friend said that she needed counselling, she said, "She’s a growing adult, she’s twenty, no one has spoke to her." So I worry about her more than the younger one. I think that the fear "What would it be like if mum wasn’t there?" is all too overwhelming for her.

46. It was a terrible shock to her. I’m afraid she wouldn’t talk about it to anybody. She went off on holiday and she came back looking marvellous. I only hope that the shock has come out of her system.

81. I’m just not there for him. One minute I’m there all the time, taking him to school, doing everything for him at home. Then I just went and I’m not there anymore. I try to give him as much love and affection here as I can but he doesn’t seem to want to come near me. It must be very upsetting for him. I think he feels I’ve deserted him. I’ve told him I’ve had an operation, I’ve had my head cut open by the doctor..... I don’t want to frighten him, he’s only four. I think I was 40 or 41 when I had him.
45. Examples of subject’s perception of child’s difficulty coping

Some

24. She doesn’t understand. She thinks that if I’m here when she comes home from school I’m here for her benefit. It doesn’t happen that when I’m doing things with her I have to go and lie down.

22. My youngest son is more of a problem. He’s more like his mother but he’s been very strong. I dare say there have been a lot of tears but not in front of me, not in front of me.

2. They found it a bit funny to begin with. The youngest one since he’s been back, he’s been incredibly noisy, unnecessarily so. It took them some time to get used to my beard. When I kissed them good night they complained about the tickling.

89. I think they were very upset to start with but they have put a brave face on it to me. And because I know such a lot about science management and research and all the rest of it I have been able to help my daughter in doing her PhD and I think she appreciates that.

74. She’s getting naughty but.... I mean I don’t complain much and some days I used to just sit there and stare at her and think, "I love you so much but I just want you to go away for the whole day." And I used to think that it’s because I’m not well that she’s not good, and I wish now that I had asked for help more. I feel guilty that she spends a lot of time with my mum now, and D’s mum and dad, I mean I feel terrible about that.

Nil

11. They enjoyed me being at home. I used to go out with them a lot and they were disappointed when I got out my uniform to go back to work so that was nice.

8. She does things as a woman that a son wouldn’t do. She does things without being asked.

26. I don’t notice him being awkward. It must be hard for them and I try to have little times with them to talk about it and how they are feeling. It must be hard for them.

30. Yes she has been very supportive as well. She’s been amazing too. She says things like "You’ve got to hurry up and get well." I don’t know how she feels about it.

15. Q: How do you think that your son and daughter are coping with you?
   A: Extremely well, they have been smashing, they really have.
46. Perceived support from religious/spiritual belief or religious community

It is particularly noticeable how important religious belief can be in compensating to some extent for illness. Religious belief brings with it a system of meaning for understanding misfortune, as well as a language and structure for talking about death. Up to one half of the subjects mention their religious belief as a source of solace, and in addition many non-believers can be touched by the concern and care that a local group praying for them can convey. It is therefore important to ask about this area, as it may well correlate with decreased levels of overall distress and increased acceptance of the situation.

Rating

1. Marked S is very positive about religious beliefs and the extent to which they have helped.

2. Moderate S has found elements of their belief useful but they are not extremely positive about this.

3. Some S has felt some support but it is not particularly important. Include here non-believers who are touched but not converted, and believers whose faith has been shaken by the severity of their illness.

4. Nil S feels that religious ideas are of no use at all.
46. Examples of perceived support from religious/spiritual belief or religious community

Marked

23. My ideas have not changed as got deeper because of the numbers of people praying for me... I suppose you could say that I'm having to see what God can do and to leave it at that.

10. The one thing that has been very important is that I'm a Christian and I don't sort of think "Oh why is all this happening to me?" Perhaps somebody who didn't feel that way would feel more angry. I feel very much that God suffered for me and now I'm sharing in a bit of that suffering...well you know I can feel quite calm about it. It happened you know, I accept that, and life goes on. I feel now he's looking after me. I don't feel alone.

26. I've been to one or two healings which have been very good, have been very helpful and calming. It's wonderful, I shall keep going to that. And also a definite move towards quakerism, having been Church Of England all my life. That was coming before but has to some extent been re-enforced. I like the quiet. I like their sort of openness you know...it gives this feeling of peace and calm which I think I crave more than anything actually.

7. I have no despair in the sense that I've got to die. I believe there is life after the grave. I have every reason to believe that.

41. I have been praying at night. I am a strong catholic and all the way at night before I go to bed I say my little prayer. That's the routine. If I stopped praying I would have a bad dream. I do believe in God but I have never believed 100%. Sometimes I have done wrong things, and the way I receive this gift, I believe it's a miracle. I have never respected God properly, so the way he look after me I think it's a miracle... the minute I went in (to have the operation) I remember this .... I was with God all the time, praying, crying. I think I have a miracle.

60. Yes my whole being has changed. It's as if I am the person I was born, if you understand what I mean. Maybe something happened on the operating table or something. I had a visit from God. I was brought up catholic and still am catholic. I think I believe in God. Over the years I have sat down and talked to him sometimes. Lately I have an awful lot.It has restored my faith in human nature. It has restored a certain faith in me very much so.

46. You know, I've got faith in the Lord. He's helping me. I feel him very close to me on several occassions.... Prayer moves mountains doesn't it?
Examines of felt support from spiritual/religious belief or community

Moderate

2. I do find silent prayer, just sitting and talking to God, quite useful.

24. The vicar who we know quite well, he is at pains to keep in touch. I’ve been reassured by people from the church.

13. Q: Are you a churchgoer as well?
   A: No, I go to please her, but not you know...
   Q: Do you have a faith yourself?
   A: Oh yes...Yes, we do in our own quiet way.
   Q: People often find that it’s very helpful. Would you say that?
   A: Yes
   Q: In what way?
   A: It’s ...it helps to become more content with what we’ve got and what we’re doing.

32. Well, I was really very offended that God had struck me down! My father was a priest, an Anglican priest, so perhaps I come from that religious background. A bit of a sinner now.

43. I asked to see the chaplain. I was away in therapy when he came. I’m not a churchgoer because I was working all the time, well I used to be, and I wanted to see if he’ll bless my rosary beads. I don’t know if he’ll do it. I’ve been praying. A lot of people are looking upon miracles for me. They’ve given me all the different holy pictures, you know.
46. Examples of perceived support from religious/spiritual belief or religious community

Some

30. I'm not a religious but the number of people that are praying for me it does mean a great deal - well it does really that they're thinking of me. So many people have said we're praying for you in our church ....that makes you stop and think. I'm not a religious person I don't think, but it has quite touched me to think that people are using it, that does make you think about it a bit.

93. Well, I would say yes (that my faith had changed). Yes, you tend to look at something different, something more than every day situations. You look to something different, to be... to give you (pause) what shall I say, to give you some backing. I don't think everybody can do it on their own, you've got to have some form of backing. A couple of times in the hospital they (chaplain) came round and read from the book and they talk to you and, yes, I did feel more contented.

5. I've never been really told to go anywhere, church and all that. I've only been in a church a few times in my life. I don't think you have to go to church to have faith in things. I've only prayed once (since having the tumour), inwardly.

Nil

28. I'm not a religious person no.

35. To be perfectly honest we haven't been to church since we were married....because a lot of people make that mistake to my opinion. If a person dies there is no way they are going to start off and live somewhere else.... All you're going to do is that once you've snuffed it, forget about it. You have got to enjoy life up to that point. Now there is no one who has been able to come back and tell you that something else in going on. It is a load of rubbish.

95. I'm not anti-religious and at the same time I'm not a strong religious type person. I suppose in truth I've not really changed at all in that.

89. No, I am not religious. I have no faith.

76. A: It's sickening.
Q: Is it? Is that how you feel?
A: Most of the time. It's a hard life.
Q: Yes, life can be hard. Have you talked to anybody about what you're feeling and what you're thinking?
A: Who would you talk to?
Q: Well, for example, the priest that comes round, or the chaplain?
A: Well, he wouldn't do a lot of good for you, would he. What can they do? I am continually worse, what's the point in talking about it?

94. I don't have much religious faith. I didn't get involved.
**47. Rater's judgement of subject's social networks**

Whilst "support" is obviously important, it is rarely possible to obtain very detailed information about what has been offered or the intensity of this help within the time available in the interview. Very often subjects offer broad statements about the support they have received from non-family members, so that it seems that the majority of support comes from immediate family.

The non-family support to which subjects most often refer is a general rallying round of friends after the diagnosis, rather than to close friends who can give emotional support in the long term. It is difficult to know whether we should concentrate on the more intimate or general cheerful kinds of support. The latter may be just as helpful, if not more so than a friend who encourages one to talk about one's worse fears. In fact a friend who appears too upset themselves or pessimistic about the future might be of little help to the subject. In other cases, an individual who has no close friends but suddenly experiences acquaintances showing increased concern and care for them may find this particularly affirming.

The ultimate aim of a support rating must be to show that it can have some influence on the emotional well-being of the subject and so keep up morale. To do this the subject must be "attached" to the person so that their interest can produce self-worth in the subject. They need to be able to affirm the person's value in some way. Disappointment will follow if people thought of as close do not seem to respond, or actually appear to avoid seeing them.

The aim is to decide whether the person possesses 'a very close other' or to a lesser extent, a close group of friends.

**Rating**

1. **Marked** S has received emotional support or a good deal of practical support from a specified close friend. They may in addition have had general good wishes or help from many other people.

2. **Moderate** S appears to have some good friends but they may not be offering exactly the right kind of support that S wants. As well as this however they have had a good deal of general well-wishing from many other people.

3. **Some** S has had some sporadic contact with specific people which has been of some use. It has however not been sustained or there have been shortcomings in this which must be obvious to the interviewer. Also rate here those for whom there appears only to have been a general rallying around of acquaintances.

4. **Nil** There appears to have been little reaction in any individual or the subject appears effectively isolated.
Examples of rater's judgement of subject's social networks.

Marked

7. S is a vicar who regularly sees a colleague with whom he talks a great deal about his illness and about the issue of dying. In addition he has numerous friends and parishioners who come in all the time and who help in many practical ways.

26. S has a counsellor whom he sees every week with whom he talks about his emotional reaction to the situation and explores some of his concerns about dying. In addition there have been many visitors and offers of support. Friends have in fact raised enough money for he and his wife to go away together.

8. S's former boss at work has been very supportive, coming round to see her, bringing things without being asked, and organising flowers from people at work. There has been an almost constant telephone calls so much so that she jokes her mother has become her secretary.

25. S's boss has provided a good deal of practical support, paying for travel costs (which were great), arranging for a wheelchair to be delivered, giving him advances and phoning regularly to see how S is.

Moderate

23. S has a number of friends who he is on reasonably good terms with a, one of whom who has himself had a brain tumour and who has given him some advice. In general there has been a flood or well-wishers from the church community. Flowers and cards keep on arriving for months.

30. S has a number of friends but she does not discuss too much with them. One friend who has had cancer gives her some advice on visualisation. She generally has a lot of visitors and receives very many flowers and messages of support.

11. S had very many visitors in hospital and in particular people who travelled to their church to see him. He does not appear to have any particular close friends.

22. S has an extraordinary number of visitors who come to see him in hospital and a great many more who show concern. These are generally cheery encounters and he does not seem to have a particular relationship with any one in particular.

74. S still sees good friends and work colleagues regularly and she is pleased about this. However, most of her friends avoid talking to her about the terminal nature of her illness and thus she finds it difficult to talk to them honestly about what she is going through and especially about her thoughts on death. S has people around her but she actually feels alone with her illness. She would like to be put in touch with a brain tumour support group.
47. Examples of rater's judgement of subject's social networks.

Some

2. S has two close friends whom he does not see but speaks with on the telephone. Many people in his circle show concern.

19. S has a number of friends who have not yet been able to visit her in hospital despite the fact that she has been ill for several months.

5. S has a wide circle of acquaintances rather than friends. The person whom he spoke to most died suddenly a few weeks ago. Several mates have been good but a few have been embarrassed and tried to avoid him.

71. S has never had many friends. One old friend did visit with his brother-in-law.

Nil

10. S appears to have no close friends apart from one whom she rings from time to time.

61. S is utterly isolated. No friends or relatives except his common-law wife who cannot cope with his illness. She is under the care of the local psychiatric services for her own problems.

95. S has strong family connections but few friends, neighbours or acquaintances.
48. Subject’s satisfaction with social support.

Again the subject’s satisfaction with social support is rated separately from the assessment of what kind or the level of support they actually seem to be receiving. Include here comments about close friends and colleagues, more distant friends and members of local community. Do not include family members.

Rating

1. Marked  S is extremely positive about the support they have received, and feels this cannot be faulted.

2. Moderate  S is positive about social support but not effusively so.

3. Some  S feels there are some areas in which they have been let down by friends and colleagues etc but is not extremely critical.

4. Nil  S has very little positive to say about the social support they have received.
**Marked**

7. I have a fellow priest who comes every week and talks about God and death and that sort of thing with me. I find him very useful and very supportive.

8. She’s turned up trumps she really has (supervisor). Up until now when I was ill she was just a workmate, but we’d always get on well together. She’s done things without having to ask. She bought in some puzzles and knitting. I get no end of flowers and cards from work that she’s organised and that must have cost a fortune.

25. The thing is I’ve had terrific support. People I never knew would care, and they’ll all waiting for me to go back. I never knew I was so well-liked. I thought well I’m a rich man with you know yachting buddies. That’s one of the things I couldn’t believe is that everybody’s saying "How is he? Is he going? Come On!" They’ll be a reception, and that support has bolstered the determination to keep on going.

11. I do feel happy because of the care and love that people have shown me while I was in hospital. And I didn’t know how many people would care.. I went to this club of our people and they had a meeting yesterday...... and many people had come purposefully because they knew I was coming.

60. I’ve been amazed at people’s response to me on this. A couple of people in particular have really shone through as true friends. I didn’t realise I had so many friends. It has been an eye-opener, it really has. Everyone has been so kind.

**Moderate**

30. I’ve got a few friends who have had cancer and they have been helpful to me. One particular one has lent me quite a few books on radiotherapy. I have also got a friend who has been doing alternative methods, which are quite interesting and she bought me loads of vitamins. She has told me about visualising but I don’t need any of that, not now. She is more of a mystical person and that is how she is coping with it. I think the visualising helps a bit. In fact I used it a bit when I was under the scanner for imagining you’re somewhere else rather than there. And she did suggest in radiotherapy that you didn’t think of it as a harmful ray that was killing, you looked on it as a healing ray. The support from friends has stunned me.... So many people have said we’re praying for you.

2. I didn’t tell my best friend in the end (that I was going to die within the year) which is just as well. I have an old friend who called me twice, extraordinary because he could say exactly what he thought.

19. I’ve got quite a few friends and they all want to come to see me in hospital. I even have some in Canada and when they heard they wanted to come.

24. I was quite amazed at all the people who want to know how I’m doing and knew all about the state I was in. It does help but you’re still tired and it doesn’t change that.
48. Examples of subject’s satisfaction with social support

Some

22. The only person I’ve been open with has been yourself, because I’ve got a lot of friends and it’s important for them that I’m being strong... At the moment I’m the man of the moment. I’m everybody’s popular choice. But I don’t enjoy it. I’d rather be making a fuss of somebody else but I have to accept it as part of the illness. I’ve seen a lot of my friends. I had 23 visits one day. They had to get me out of the hospital! The rest of the days I was averaging 15-18.

5. Most have been good, but some of me mates...in fact I met a bloke only the other day. He was out in Australia...and he’s back here and I met him the other day down the pub. And he was too embarrassed to phone me up. He said he felt too embarrassed to phone because he didn’t like to see me ill. No one likes to see anyone ill, but your mates should still phone.

95. Well, this is the second week now and I’ve not had so much in the way of friends. As far as friends go I don’t know if they’re sort of worried about coming round, I don’t know, but we still get phone calls. A few neighbours have popped in but that’s about it. .... they seem to... they tend to... they don’t want to know too much.

Nil

10. I don’t really have any close friends. I have a friend from college who I ring from time to time.

61. I’m the lonliest man in the world. No one comes to visit me. All my family are in Ireland. I’m on my own.

37. Friends were very helpful in the beginning. They was coming up all the while, but as I got on they never used to come up, and I thought well, they have got their own lives to lead and I didn’t want them really.

74. Sometimes I think that nobody understands. People lately have started treating me like nothing’s happened. At first everybody was ever so shocked and upset and treated me with a lot of care and everything. People now seem to be treating me like they’ve always treated me and I think I’d rather they’d do it the other way round. Like people that rang every day when I first came out of hospital I haven’t heard from them for four weeks. Even if I’ve rung them and they have said they would ring me back and they haven’t. Like people at work - they just don’t ring me anymore. I feel like people are really avoiding me now, or they have lost interest or they can’t be bothered. I really feel that people have forgotten me and I feel really selfish about having felt like that.
FELT HANDICAP AND DISTRESS
SUBJECT'S FELT HANDICAP

This set of ratings covers the subject’s perception of the extent to which their tumour has interfered with a variety of activities in their life ranging from work to home life and cognitive ability in general. We try to rate here both the degree to which the subject assesses that they do in fact have problems as well as the amount of upset that the subject is able to admit about an area. This is not a rating of how handicapped we feel the subject actually is, but a rating of how handicapped we feel that the subject feels they are. Some of these ratings will be compared with what the carer feels about the same area and it is hoped that in this way we can highlight areas in which there tend to be disagreement about ability, as well as those in which the disagreement arises out of the patient’s inability (due to brain damage) to recognise the severity of their own problems.

49. | | Distress over hair loss

50. | | Frustration and interference from fatigue

51. | | Anxiety and impediment due to epilepsy

52. | | Present work status

53. | | Felt handicap in work

54. | | Dissatisfaction over change of work

55. | | Felt handicap in housekeeping/chores/odd jobs

56. | | Felt handicap in child care

57. | | Felt handicap in hobbies
58. Felt handicap in social life
59. Felt handicap in self-care
60. Felt handicap in sex-life
61. Felt loss of independence

SUBJECT'S FELT COGNITIVE HANDICAP

62. Subject's felt cognitive handicap
63. Subject's felt handicap in communication
49. Distress over hair loss

The degree of negative affect that the subject feels about losing their hair is rated here. Take into account expressions of dismay, feelings of change in self image and descriptions of how it has affected their life, for example, in preventing them doing certain activities. Repeat at each interview to show whether any adaptation occurs.

Rating

1. **Marked** S feels that the hair loss is very difficult to cope with. They feel self-conscious and limited because of it.

2. **Moderate** S feels that they can cope with the hair loss but not to the point at which they can become totally blase about it. It is still a significant area and they experience some sense of loss of sense of self because of it.

3. **Some** S notices a few minor points or inconveniences due to the loss but experiences minor self-consciousness.

4. **Nil** S is not at all worried by the loss.
49. Examples of distress over hair loss

Marked

8. I was thinking "Oh nobody like me - you look horrible". When my hair fell out it just hit me. I couldn't cope. I found it very upsetting. I got onto the nurses and had the whole lot shaved off. It really got to me - the horror of the situation.

6. That is hard to cope with, I think because it goes so quickly. Men know perhaps they are going to be bald one day... if they could get round that some way it would be nice. It stops me doing everything because people look at you. I've tried. I've gone into M & S with my scarf on but get people looking at you. Occasionally I do but not often.

10. I'd touch my hair and literally a whole handful ...and I'd put it in the bag for rubbish and I'd feel "Oh God" you know "What are people going to think in the morning when they see the difference?" I knew it was going to happen but it was still a shock. Wearing a wig I felt people were all noticing... I wouldn't go out without my mother saying "Yes it looks alright". I needed that. Even though it was a nice wig, I still felt people were looking at me.

30. I didn't know at the time that it (radiotherapy) wasn't going to work, I was in their hands really, I presume that was the best thing. No, I don't (regret having it). I regret losing my hair, but that's all really. I've still got some on the back and I'm hanging on to that but that is the worst thing really. I just hate it. It's the worst thing really, I suppose.

Moderate

17. I mean on this side it's grown pretty well. In fact I'm pretty happy with this. But this side it grows in tufts and that sort of thing. You get people looking at you and thinking, "What does he look like, what's happened to him? He looks a funny man". It's normally children.

80. My ex-boyfriend can't handle my hair loss. I was upset about it at the beginning but it's not really worth it. I prefer to wear a scarf (to the wig). I sort of think "Oh the wig might fall off". But it's not really that important anyway.

63. I think the only thing that....it hasn't got me down...is that my hair is falling out now and I'm a hairdresser. I mean I have a wig but I hurried into buying this wig .... and it was too small, it's rising up. And I hate it and my head itches like mad. I'd like to have the whole lot shaved off, well, it was shaved right off but what's happening now is that the very short hairs are falling out just like cats' hairs. I feel it is dropping everywhere, dropping in the food, and I don't want to eat it.
49. Examples of distress over hair loss.

Some

2. There's a bit of hair that the radiotherapy didn't touch, I looked like a Hare Krishna, it looked ridiculous, but no, the baldness didn't bother me at all. I have it all shaved off.

21. You know it's remarkable what you get used to. I just don't think about it. I go to bed and take my wig off and put it on in the morning. It's just like cleaning my teeth. I do worry a bit that it hasn't started growing back though.

60. At first I didn't really feel like going out because I was a bit conscious of my hair. I used to have long hair.

47. Just the hair loss. A new style (laugh). The first three weeks it was fine, then, suddenly it just fell out overnight in a sort of band.

Nil

19. I don't mind if I lose my hair as long as I'm cured.

14. The hair loss didn't worry me because I was warned it would happen. (This woman has been told the scan is clear).

5. No it doesn't worry me at all. In fact I can see that when I'm an old man I won't look too bad!

95. Not bothered me, you know, had a few jokes and laughs out of it. I was under the impression that when I started this chemo I'd lose a lot, body hair and everything. But I don't seem to be doing any of that. It seems to be growing real crazy again like.
50. Frustration and interference from fatigue

Fatigue seems a prominent symptom both during and after radiotherapy. Even a year or so after the diagnosis, and in the absence of any physical signs, subjects often complain on being unable to engage in strenuous activity. For some this is a particularly frustrating feature of the illness and they may spend a considerable amount of time trying to explain and understand this.

Rating

1. Marked S feels greatly incapacitated by fatigue and feels it interferes with particularly important activities.

2. Moderate S feels there is noticeable fatigue but they can vary activity to cope with this although they may be dissatisfied that they should have to.

3. Some S notices this as a minor frustration.

4. Nil S does not notice it as a problem.
50. Examples of frustration and felt interference from fatigue

Marked

57. If I've been lying down and I get up I'm ever so wobbly. I think it's because I'm tired. I mean yesterday when I got home I was in bed by about quarter to four and I didn't get up until this morning and then I was still tired. I could go to bed and sleep all day and all night.

5. It must have been the treatment. I wasn't that bad through the treatment....It might be the after effects of the treatment. I mean some people do go down don't they? I think what I've got to do is rest. I tried a lot of resting while I was having the treatment. I was coming back and resting, well trying to kip for a couple of hours. Then after the treatment I should have carried on, but I thought after the treatment you could sort of go out. So I was going out and playing pool, and I got involved with my mate who was playing chess, and I think it was a bit too much. I lay in bed most days til 2pm. I feel weak in my arms and legs.

64. A: Well, I don't get up until about eleven. And then by the time he makes lunch, goes shopping and that's that...
Q: You have lunch and then what do you do?
A: Then I come in here and lie down. And then I get up ... then he makes the dinner.
Q: Do you read at all?
A: No, I can't read now, I just look at pictures. I just a bit tired.

Moderate

24. I seem to be more tired and I don't know to what extent it's caused by the radiotherapy or to what extent I was conscious of improving and convalescing and now the radiotherapy is a complicating factor. I don't know whether it's maybe pushing me back in order to make me better later, and indeed I don't really know. They'll say no doubt it was the treatment once the radiotherapy is finished. They'll tell me how long it will take to get over the effects of radiotherapy because they say it goes on having an effect afterwards.

23. When I came home to begin with I was out quite a lot in the park but that's come to a stop now.

2. I didn't expect to feel so tired. I'm sure I was told but I didn't take it in.

95. I mean I walk out to the toilet and things like that, but about 10 minutes, quarter of an hour, I've got to sit down. I've got no sort of long day energy or anything like that. I have to keep stopping to rest my back and it is dragging me down a little tiny bit.
50. Examples of frustration and interference from fatigue

Some

25. Sometimes I feel I like to have a sleep in the afternoon.

26. I do get tired and I find a nap in the afternoon helps.

12. They tell me this is the effect of the treatment and I’ve found going to rest with my walkman helps for an hour or so very much as a routine.

63. Yes, I might not get as much done. It just gets to a point maybe around 8 or 9 o’clock, although I don’t want to go to bed, I don’t want to do anymore work. I just want to sit and relax.

80. Last week I was getting really tired. This week I’ve been OK. Last week was the first week in a long time that I was getting really tired and I just thought "Oh, I can’t be bothered". Just laziness.

Nil

11. I don’t like all this "Rest, rest, rest". I have no problems but may family seem to feel I can’t do anything.

41. ....So it’s nothing one worries about (sleeping on the settee during the daytime).

73. Q: Do you feel you get tired at all?
    A: No. I walked 5 and a half miles the other day.
51. Anxiety and impediment due to epilepsy

Although the majority of patients with cerebral glioma are spared fits, the unpredictability, stigma and loss of control that epilepsy brings with it can be extremely distressing for those who are affected. Some subjects may be more worried about the epilepsy itself than they are by the tumour. In fact it can be something of a relief for the subject to discover that it is a tumour that is causing the epilepsy rather than the fact that they are suffering from idiopathic epilepsy.

Ratings

1. Marked  S is highly anxious about the possibility of epilepsy or extremely distressed when it occurs to the extent that they will not leave the house or is unwilling to be left on their own.

2. Moderate S is concerned or anxious but this worry is not interfering too much with their life ie they will go out or try to pursue some normal activities.

3. Some S expresses epilepsy as a worry but it is not a severe preoccupation. It does not interfere too much with their life.

4. Nil  S is not at all worried or is not aware of the possibility of epilepsy.
51. Examples of anxiety or felt impediment due to epilepsy

Marked

88. Q: For you what do you think is the most difficult part of the whole thing?
   A: Having the seizures definitely. That is because at first they were alright and I have had some bad ones but it is just the fact that they are starting to upset me...and there was nothing that I could do to stop them...And actually being conscious of what is going on in your body, but not being able to control or do anything about it is really upsetting, horrible. Now when I see someone else who can you know, I know how they feel. That is just the worse thing, being trapped inside your own body and not being able to express yourself or make yourself stop shaking or move yourself or feel things. It is just really really upsetting.

6. A: My daughter is still frightened (about the fits) because she won’t stay with me on her own. Either I have to go out with my husband and her, or I have to have my mum down and she’ll stay if my mum’s here. It’s really made an impression on her.
   Q: It has. She’ll be in the same room with you on your own or will she not?
   A: She won’t stay in the house with me on her own. If my husband goes out she’s got to go as well.
   Q: That must be quite upsetting for you?
   A: I understand it. No I’m not upset by it but I do understand it because it must have been a terrible thing for her to have seen me.
   Q: I think the fits are a frightening thing to see but do you think it interferes with the normal being a mother?
   A: What the fits?
   Q: Well the whole problem really?
   A: Oh yes. I’m terrified of having another fit.
   Q: What when she’s here?
   A: Anywhere you know, regardless of who is here, on my own, with my mother or my husband. No it’s horrible...They just hit me apart from the last couple - they were just localised to the hand. And it’s a dreadful feeling thinking "Oh no, here we go again".

184
51. Examples of felt impediment or anxiety due to epilepsy

Moderate

15. Well, I suppose on the whole they’ve tailed off a bit. It’s funny they seem to go in fits and starts because I can go several days without any attacks and then I had four over the weekend... My poor husband always seems to get the brunt of them I think, perhaps because I feel more relaxed and secure with him. So if I feel an attack coming on, I don’t mind clutching him and saying "Help"! I’m aware of them...I don’t lose consciousness at all and I don’t sort of go thrashing around or anything like that luckily. It’s just that they feel unpleasant and really sort of quite frightening but otherwise they’re really not too bad.

Some

89. I have minor fits involving my hand, fingers and my lower arm, but they are minor and sometimes they have extended to perhaps 80 or 90 cycles. Am, you know they are minor and I found that if I rest enough they don’t normally happen.

90. I haven’t gone dizzy or anything like that, but also with the pills or I could get another attack (stops him going to work).

80. Sometimes I only take them (Phenytoin) three times a week and I find when I don’t take them I can feel, I don’t know if I’m getting paranoid or what, I can feel twinges in my head, this side of my head, and I wonder what that is. I always think to myself that there’s a possibility that I will have a fit. But then they say to me "Oh well, you haven’t had one now so you’re not likely to have one." Then I think, well why should I keep taking these tablets?

99. It was quite a big step having my first fit on my own. I was worried about it before but by the time I actually had it I was not too worried. Both my flat mates were out. I was on my own cooking and suddenly I felt that I was going to go. So I just turned the gas off and got to the carpet and lay down. And you know, 5 minutes flapped around, had the fit, lay on the floor, got a cushion and slept it off. And that was like a major step .... then there’s nothing to worry about having a fit on my own somewhere.

Nil

38. There is a possibility I could have a fit.

57. I don’t get them now - just a twitching in the face and then it’s gone.

185
52. Present work status.

This is a simple rating of the occupational status of the subject. If the subject is working note whether this is in a full or altered capacity, or in fact a less skilled job altogether.

Ratings

1. **Full or near normal capacity**
   Working in more or less pre-operation capacity in the same job. Include here those whose workload is not quite as high as previously, but certainly more than a part-time commitment.

2. **Altered responsibility**
   Performing some kind of work - either an adaptation of their previous job or else in a different and less skilled position. This may include those working part-time.

3. **On-hold**
   Subject considers him or herself "on hold" and is awaiting either the outcome of the treatment or a doctor’s pronouncement before deciding what to do about work.

4. **Maintaining contact**
   Subject has definitely given up working but keeps up a good deal of contact with the workplace.

5. **Given up**
   Subject has given up working altogether.

6. Not relevant as previously a housewife.

8. Not relevant as previously retired.
52. Examples of subject's work status

1. Full or near normal capacity

2. S works as a management developer in a city bank. Whilst having radiotherapy he teaches a course with a colleague and commences full-time employment after that. He travels to work alone.

3. S is a carpenter and during radiotherapy continues working on outside sites. He is given a supervisory role rather than doing too much manual work.

5. S has a small roofing business and he employs a few casual labourers and works himself. He is still running the jobs but more as a supervisor to the men than engaging in any heavy work himself.

10. S is a part-time appointments clerk in a hospital. After surgery she returns to this job in her previous capacity.

2. Altered responsibility

63. S is still going to work at her hairdressing salon but doing less than usual. Attending to 2 or 3 customers instead of 6 or 7. Working at about half capacity.

17. S is an assistant manager in an Insurance company. He does not feel he can take the responsibility of this post and starts working part-time on a food stall owned by his parents.

11. S is a railway station manager who because of epilepsy /brain damage is removed from his responsible job and given a job in the head office. This involves him in doing odd clerical jobs for other people with no fixed responsibility.

3. On-hold

24. S was made redundant from his work in computer programming coincidentally during radiotherapy. He is waiting to see how he recovers from the fatigue of the treatment and when he declared "off the sick list" before beginning to look for further work.

22. S is a sales manager whose post has been temporarily filled. He does not want to think about keeping in touch with work but instead to concentrate on his treatment and in getting better before going back in a full capacity.
52. Examples of subject’s work status

4. Maintaining contact

6. S runs a clothing and carpet business with her husband. After radiotherapy she employs a friend to take over the selling, supervises from home to a certain extent, visiting factories and choosing stock, but finds this tiring, and the accounts, which she would normally do very difficult.

7. S is a vicar who although replaced by a temporary vicar, continues to receive parishioners and local clergy and is able to contribute to a youth weekend on the topic of the cycle of life.

5. Given up

30. S is a primary school teacher who has a mild hemiparesis and attention defects, and decides to give up work after her radiotherapy.

8. S is a clerk in the roads department of the local council. Her place is held open for her but she talks in the past tense about her employment and does not see herself returning.

6. Not relevant as previously a housewife

8. Not relevant as previously retired
53. Negative feelings about not being able to work

Although the subject may feel extremely handicapped as far as work is concerned, they may be quite pleased to have given up or coped with it well. The amount of displeasure or otherwise that S feels about any change that has occurred should therefore be recorded.

Rating

1. Marked  S is extremely upset and dissatisfied about not being able to work.

2. Moderate  S is generally dissatisfied but may be able to find some compensating aspects.

3. Some  S expresses some dissatisfaction or would like to be back at work but this has not yet become a great preoccupation.

4. Nil  S expresses no regrets or dissatisfaction over not working, or is in fact very pleased to have time off and to be at home.
53. Examples of negative feelings about not being able to work

Marked

25. That is what the problem is because I'm completely frustrated being so active before, and then being pushed out into the cool or into the coolest place and left to think about things.

16. It's being at home all day with nothing to do, that really is the most difficult thing.

6. It leaves us very short of money because you're only ticking over and with someone else doing it you've got to pay their wages.

11. I get bored being at home all day - in the house all day. I just feel so disabled which is difficult at my age.

41. Financially it is a problem now....We make ice cream for selling and it's very bad. That's why we are waiting for the insurance to give us something.

89. ...because it is you know my life (shaky voice and tears in eyes).

95. I would give up everything to be able to get back to work tomorrow and do the job I was doing.

Moderate

60. Initially it is nice to have a break. Yes I do miss it although it's nice not going to work but I do like the job. I like the idea of the whole business, and I do like the people. There is only so much you can do at home.

21. ...it has made me make decisions and look ahead and plan and all kinds of thing. But I am always looking to see what time it is. Is it time to go home now? Have I done too much time at the office?.. Yes, I am doing a little, nothing major. Any concentrated burst .... of concentration, if you like, does leave me a bit tired.
53. Examples of negative feelings about not being able to work

Some

8. Yes I liked my work, I expect I shall miss it.

2. Here they've been accommodating. I don't always want to work in the morning. I call and say I'm not coming in. I'm not feeling very well (tone of voice dissatisfaction).

Nil

7. It's lovely being at home with my wife. There really are some positive features.

30. It's quite a relief really. It was all beginning to get so difficult with all the changes in education. It had become so much of a struggle really.

22. I don't even want to think about that until I've finished that treatment. I want to divert all my energies towards getting well, not in trying to read through things they might send me.

63. This week I went in yesterday after I did my treatment and I did two or three customers. So I only did a couple of hours work (hairdressing). But it's not like working for somebody else because it's my husband's shop. And I feel it is good therapy. It really is. To cut someone's hair, to feel that you've created a style and feel that you've achieved something.
54. Felt handicap in work

This rating is the degree to which S feels able to function in their workplace. It is deliberately an assessment from their point of view of how the illness interferes with what they would normally want to do.

**Rating**

1. **Marked**
   
   S feels they are not able to do anything.

2. **Moderate**
   
   S feels that the work needs some definite modification.

3. **Some**
   
   S feels that there are some problems but that these can be overcome.

4. **Nil**
   
   S feels they are working normally or would be able to work normally if they were allowed back to work.
54. Examples of felt handicap in work

Marked

18. I don’t really think I’d have a hope as a lift engineer .... I definitely think I’ve had it. I definitely don’t think I’ll go back, not out of choice but because of safety reasons. I wouldn’t like to put anyone in danger .... I would have thought if the hospital say I can do it, my firm will say I can’t.

16. My speech just came out funny on a few occasions. I just said things that nobody could understand and I couldn’t serve the customers because I couldn’t see anything on my left hand side so I completely missed people who were waiting.

6. Oh dreadful ...I couldn’t. I had two columns for the VAT, and in my head... I couldn’t not at all. It (ability for addition) was completely gone.

26. The problem is I don’t think I could hold down a job because first of all the sight, and secondly the short term memory. You can’t sort of say something to somebody and then say "Well yes, what were we talking about?" I would look ridiculous.

Moderate

25. I’m terribly excited - I couldn’t sleep thinking about setting up this radio. Ideally it would suit me down to the ground and I could even do it now. I’ve got my facilities at home in an office. It’s something I can do sitting down rather than running around.

17. At the moment I don’t feel that I could do that kind of job that’s got stress built in with it. But the outside catering is just sort of .... I don’t know if you’d classify it as remedial. It’s meeting customers, figure work, making up rolls, trying to keep my brain alive with the figures.

63. So I only did a couple of hours. I’m not saying I could go into a full, not how I used to work. I didn’t get to the shop until 11.30 and we left again at quarter to three.
54. Examples of felt handicap in work

Some

2. I arranged for a colleague to back me up, but as it turned out I managed alright (with giving a lecture), so I was pleased with that. I tend to get tired and I've noticed that's not so much in the mornings so I've arranged to go in then. I don't have a full day. That suits me nicely. I don't feel I'm out of touch with what's going on.

21. S feels that she would like to return to work on a full-time basis although she is presently too tired and lacking in concentration to do this. The rate at which she has already improved suggests to her that she will be able to do this even though work have offered her the possibility of part-time employment.

73. I have been travelling around to see if the work has been done. (S's children have taken over his business whilst he was in hospital and although he is not yet working he sees little impediment to continuing after a while).

Nil

3. No I feel I'm managing fine really. They seem to think so. They seem quite pleased with me.

10. I feel so well really I feel guilty that I should be back at work.

11. I felt strong enough to do my job, carry on my job, but it was the red tape. It really annoyed me.
55. Felt handicap in housekeeping/chores/odd jobs

This scale measures all activities involved in the general maintenance of the home rather than of simple housekeeping per se. Thus for man this can include accompanying the wife on weekly shopping trips, or any domestic tasks they would normally have undertaken.

Rating

1. Marked  S feels they are unable to do anything they would normally do around the house.

2. Moderate S feels they are unable to do very much at all but can do some tasks. Rate S here if they feel that C prevents them from doing things.

3. Some    S feels they are only limited in one or two things. Rate here those men who admit to only previously doing a few things but have now given up as well as those who previously did a lot but now feel slightly limited.

4. Nil     S feels that they are managing fairly well or normally.
55. Examples of felt handicap in housekeeping/chores/odd jobs

Marked

6. I am a bit grotty because I can’t do the things that I used to do. I always felt that I did everything around here and now it’s changed and I don’t like it. It’s very strange to me.... (I appreciate) what they’re doing for me, still they don’t do it as I did it.... my control’s all gone.

7. The frustration while we were away on holiday was that I couldn’t help my wife, bring the coal in that sort of thing, and I couldn’t fix the window with a screwdriver. I went to put the fireguard in front of the fire last night and it fell down .. all those minor domestic things .... if I do the washing up I’m just as likely to break things as to help so I tend to steer clear of that....I can swipe things onto the floor. If my left hand were to go, the chances are I would drop it.

13. My wife will take me out. When you say shopping, she does the shopping and deposits me on a bench somewhere whilst she goes off and does something. You know, I sometimes think that’s all very nice, going out, but I feel like a, you know, just a bag of shopping that’s been settled down somewhere and left, you know, be picked up later.

Moderate

16. Since I have been home I have been trying to do a bit more. So I have been making coffee and tea and helping prepare meals, but I haven’t sort of done a whole meal myself. I think a lot of the trouble is I can’t get... it seems I can’t get my brain working together with my hands. My brain sort of goes so far and then it sort of shuts off.

13. Q: Or making a cup of tea?
   A: I can make a cup of tea (all that S can do)
   Q: Would you normally be somebody who would normally be tidying up or cleaning or doing odd jobs around the house?
   A: Yes I think so, helping out anyway.

89. The garden is a chaos.....It took me a long time (to plug a toaster) - I am not safe to wire things up.

95. Oh, I go and make tea and I actually look forward to trying to do it. But it’s very, very limited to what I used to do. You know, even when I came home from hospital, I found I could do more, I could go and wash up or do odd jobs. But since I’ve done my back I do find it awkward to help the wife. I just keep my fingers crossed it will come back and I can do some of these jobs again.
55. Examples of felt handicap in housekeeping/chores/odd jobs

Some

38. I am unable to do my shopping. It’s too heavy, too much for me to do. A friend of mine does it once a month. So that’s done monthly. It’s not difficult... I could do it with help for the simple fact that if you’re doing it in bulk say.. Even if you’re doing it weekly you have nine carrier bags, and you’ve got to get those from downstairs into the lift along the balcony.

95. I’ll go and perhaps wash a couple of bits up or dust something you know....it’s just to do something.
I do all things, clean out the kitchen for a while you know, washing it down...I want to do the decorating but I don’t feel I’ve got the energy for that at the moment.

63. I might not get quite as much done. I may hoover all the downstairs and dust and maybe I didn’t get around to doing the upstairs.

Nil

2. She would normally do everything anyway but I look after the garden and I got that done on my first weekend home. I was also up in the loft sorting things out.

26. She used to do all the cooking and now I am learning to do some of that which I enjoy.
56. Felt handicap in child care

The extent to which the subject perceives that the illness or its consequences have interfered with their ability to be a parent.

Rating

1. Marked  S feels they are unable to have much interaction at all whether this be in a role as an authority figure or in playing even simple games with them.

2. Moderate S feels unable to do much strenuous activity with the children but can play a bit with them, be with them and exercise some control over them.

3. Some  S feels slightly limited in some practical tasks such as washing, lifting or playing sports.

4. Nil  S feels they have no problems at all with their children.
56. Examples of felt handicap in child care

Marked

47. It feels so frustrating sometimes, like the children, I can’t help with the children, like "can you do my coat up dad?" and I can’t and I am really frustrated that I can’t do it. They take advantage of me as well. If they are naughty I can’t chastise them. They need to be chastised. And it is a big strain on C because she has to do it all.

Moderate

2. They have more energy than I do... it’s annoying because 4 hours just disappears out of the window .... If I could I would arrange my day so that I was out at that time (when the children come home from school).... sometimes I’m happy to just let them do what they want to do. Sometimes I get very cross.

Some

6. She won’t want to stay in the house with me. If my husband goes out, she’s got to go out as well. She wouldn’t want to do anything with me. She’s really frightened of whatever I do.

(S has another child with whom she has no problem).

Nil

11. I don’t think it interferes at all.
57. Felt handicap in hobbies/interests

Hobbies generally mean interests that are carried out on a regular basis. Some people simply do not have such pastimes and may volunteer this fact when they realise that they need to fill large amounts of time at home. In this cases, this section is not relevant. Examples of interests of hobbies include:

**Sports** - tennis, rugby, weightlifting, hill walking, bowls, yoga.

**Evening classes** - French, photography or counselling

**Group activities** - amateur dramatics, bell ringing, visiting historic sites

**Home activities** - painting (pictures), woodwork, computer programming, crosswords (if the person does one these religiously)

Gardening is included here if it is particularly "creative" rather than seen as a chore, similarly DIY/home decoration if it is a means in itself.

Darts or cribbage are hobbies but "going down the pub" we have decided to include under social life.

Many men miss driving and this should be rated in relation to the activity it interferes in as well as under independence if this seems to be the issue. It may, for example, be important for work, interests (driving around to stately homes and gardens) or interests and social life (getting to the pub).

**Rating**

1. **Marked**  
   S feels they are unable to do any of the things previously valued.

2. **Moderate**  
   S feels they are able to do some small part or take on slightly new ones which are not so complex or rewarding.

3. **Some**  
   S finds some difficulties in doing some aspects of interests, but is able to do something or the most part.

4. **Nil**  
   Able to pursue interests in more or less pre-illness manner.
57. Examples of felt handicap in hobbies/interests

Marked

7. I was writing a hymn and the creative urge has left me you know - to get the music right it's very demanding. That makes me feel sad that I was on the threshold of writing a number of things. I was also going to write a little bit of local history. The major frustration is not being able to read and find the things I had planned to do. There are a whole lot of things I don't see on the left. In reading I have to go back to the beginning of the line. The first word is generally missing so I can't read the newspaper without enormous concentration. I do watch television, but sometimes I can't see it at all and I can't read the subtitles.

20. There is so much I had wanted to do in my shed. I could do anything. You could have given me anything and I could make it - but I can't do that now.

25. I can't live strapped to a chair. I can't even get up to reach for an ash tray. I have to ask her to turn on the television.

13. ... not being able to play bowls... I used to do it in the summer 3 or 4 times a week. And I can't do that now. For one thing I can't keep my balance and that's the thing that has kept me going, the fact that they may be able to get my balance back and I can just walk out unattended and if I wanted to I could just walk up to the shops. I can't do that. And I have an allotment. I've been working on that, and I'd be reading. That's one thing I can't, haven't been able to do, read. You know, I haven't been able to put my mind to picking up a book. I miss the independence of it.

6. The gardening? Yes and I would get tired if I went out doing the gardening so that's the main sort of thing I did. I haven't really tried much else. I wouldn't attempt to try things you know. I certainly wouldn't cycle on my bike because of the weakness in my arms and legs. I'm not going to evening classes. I used to do photography - well I'm not going to be able to hold the camera still ... Photography I am going to miss because we were just getting good at doing the evening photography. I couldn't hold the.... I couldn't get there anyway and I couldn't hold the tripod.

47. I can't play football, I can't take the kids to the park, I can't do anything I used to do really.
Examples of felt handicap in hobbies/interests

Moderate

17. Well if I was reading ... if it were longer than this article here I probably wouldn’t get to the end of it. I don’t know I just get disinterested in things like that I don’t know why. I just feel like doing other things as well but I don’t get round to them, like playing golf.

(Unable to concentrate on tennis). Well I’ve always been in the team right up until the operation and was always playing then. But since then I haven’t got a look in I’m afraid.

95. Since I’ve been in hospital I haven’t been back at it but over the next week I’m happy to try again you know (at the computer)

Some

54. There’s so much I can do. I used to play the piano years ago. I haven’t played for 20 years now. They (family) got me a keyboard in , so I’m starting to do that. that’s a new hobby. I can’t go out bowling at the moment. You see I haven’t given up the idea. I might be bale to once I get a bit more co-ordination. I reckon I can go out and ring a bell (bell ringing) Physically there’s nothing wrong with me as far as I know.

21. I can’t read for as long as I did before. I mean, I could read a whole book, now it’s in smaller chunks.

Nil
58. Felt handicap in social life

Include here obvious social activities such as visiting or receiving friends, going out in general, or going to the pub if this is the only activity.

Rating

1. Marked  S feels they have no social life to speak of.

2. Moderate  S feels they have a modified social life with some positive features, but this is markedly reduced.

3. Some  S recognises some problems but feels that their social life is reasonable.

4. Nil  S feels social life is as good or even better than previously.
58. Examples of felt handicap in social life

Marked

13. The only thing it's really affected to any great degree is my social life. There was bowls and friends. Of course it's meant I couldn't have overseas holidays. We booked two. We had to cancel them.

18. We went out for a meal the first time around, but we haven't been anywhere since. We used to go out nearly every Friday for a meal, have drinks and go out for a meal. We would see my son every other weekend to see the grandchildren. It's the driving that upsets me more than anything else.

Moderate

17. There is a bar which isn't far away. I can walk up there and if it's raining my dad can give me a lift. But to get anywhere else I would most probably feel a bit restricted, you know, asking your father or your sister to give you a lift. If I could drive things could be a lot better. If I was driving then I'd obviously be going out a lot more. People say "You don't want to drive - things have got a lot worse in town" and that sort of thing. But they're all things I used to do. So it's a bit frustrating in that way.

41. Q: Can you go out by yourself?  
A: No, I daren't in case I fall over.

7. I suppose it has disrupted the even tenure of life... we were going to stay with my sister who will now come here next month. We are going to drive round the countryside taking the dog and sitting out.

Some

25. We had some friends over last night and were invited out to dinner. She said we're not accepting that. She said I can't take the kids because I get terribly tired - "He gets tired and he can't balance". But that was a decision made for me. It's not my decision. I said it doesn't matter if I get a little tired one night, it doesn't matter if I can't balance. I can go to bed and sleep.

32. I mean, I slowed down quite a lot in the number of going out.

Nil

60. I can do most things, it just takes a little more time sometimes. I can walk up the shops, yes, I can go down to the local pub.
59. Felt handicap in self-care

This is an overall assessment of the items covered in the Barthel score, but is the subject’s perception of their problems.

Ratings

1. Marked  
   S feels they are unable to do anything for themselves.

2. Moderate  
   S feels they are now unable to do many things but can still manage some things themselves.

3. Some  
   S recognises some problems but feels they can do most things.

4. Nil  
   S feels they have no problems.
59. Examples of felt handicap in self-care

Marked

19. As long as I got 40% of my function back I'd be pleased. I just don't want to be a burden to my family.

13. I miss the independence of it.... not being able to do things myself. Going up and down stairs. I mean I use the frame most of the time going from one room to another and that sort of thing.
   Q: What about dressing yourself?
   A: No. Once again it's choice, I don't choose what I wear.

47. My arm is completely useless. It's the pain really. It is frustrating. I can walk with a stick they gave me at Hospital X. It holds the foot straight so I can get to the toilet and I can sit on a board in the bath with my wife's help. Not without her help. And eating is alright, anything sort of big she will cut it for me. I cannot cut my food. I have got a wheelchair.

Moderate

7. I can't really get in and out of the bath. I slip and slide and bang and crash all over the place.

30. I can't get up out of a chair because of this arm. It's got no power... when I first came home I could go into the kitchen and make a cup of tea quite happily, but now I can't. Probably frightened of falling over. We've had two rails by the back door to get out there, those are excellent. We've got a wheelchair, we've got a commode.
59. Examples of felt handicap in self-care

Some

25. I can transfer and do all my ablutions. I'm washing myself and shaving myself and cleaning myself. I'm washing myself... there are little things I can't do like cleaning my plate and cutting my nails. Getting dressed I can do a lot of it. It's my left hand that's not fully operative and I can't hold the plate. Suddenly it just slides across the table and knocks everything aside so my wife has to scoop up the last bit.

18. I can shave and I can get in and out of the bath although that's getting a bit harder. My arms are getting weaker. I can manage most things and give a shout if I need any help.

15. I daren't have a bath on my own, so I wait until one of the family is free to help me. It's a shame because we have a new bathroom, only finished this year and of course not knowing all this was going to happen, didn't think of putting a hand rail by the shower. Luckily we've got one each side of the bath so I can just about pull myself up afterwards, but we could do with an extra rail or two.

Q: What about getting dressed, can you cope with that all yourself?
A: Yes, that is no problem.

60. I don't trust myself. When I eat I use an adapted knife. I made it thicker so that I can grip it and cut my food. It was a bit difficult. I had to get someone to cut my food but now I can do it myself. I can dress myself now. I can go to the toilet alright. I can do my teeth with my left hand. Yes apart from my right side not functioning properly, the feeling I have is a lot better in myself, I feel a lot happier.

Nil

63. I do my exercises of a morning with Lizzie (on the television). It's basically stretching exercises, lifting the leg out, going over to one side. Well, I just think if I do those each day it does help.
60. Felt handicap in sex life

It is important if possible to obtain some picture of whether the subject's sexuality has been affected by their illness. A lot of problems seem to be of an emotional nature and it is noticeable how this occurs in patients who seem very fit. It is not necessarily something that is volunteered although it may be an additional source of anxiety. If there is a problem enquire about how salient the subject feels this is. They may notice a decrease but not be at all bothered.

Rating

1. Marked  S feels they have lost all sexual interest or function and that this is a severe problem.

2. Moderate  S feels that their sexual interest is markedly decreased and it is of some concern to them but that they can cope or it is not interfering in their relationship.

3. Some  S notices some problems, but feels they are to enjoy sex in some way or that it is not a problem.

4. Nil  S feels sex has not been affected or if it has is not at all bothered by the change.
60. Examples of felt handicap in sex life

Marked

22. It worries me a lot. I shall probably ask them next time next week. You know it might be in my head anyway, you know. I'm feeling tired and I'm not feeling up to getting on to it.

I love my wife dearly but it's entirely gone. I haven't had the urge. I just haven't had the will to do it.

Moderate

18. I suppose it is just the feeling - I haven't been interested. I am interested but I haven't had the feelings for it.... It is annoying... I don't think it will affect the marriage or anything like that.

2. We laugh about it but sex is just not there. My motivation's not there.

6. Not with thrush. (S feels relationship has deepened).

21. We are very affectionate but that's all. I feel I just have to.... we haven't been together....no, but there is great affection.

Q: Have you noticed that it is a problem, or is it something that you have thought "oh..."

A: I have thought about it, but then again I suppose it's me, not wanting to do anything like that until I'm better....We haven't talked about it, maybe he would like it to be another way but we haven't discussed it, but there has been a great closeness.

Some

15. Not really. We don't have much sex.... but I think since all this happened that has seemed so unimportant in a way that hasn't bothered me. I thought it's just a good idea, and not in the least interested in sexual activity, but I wouldn't think it's very good thing.... no, everything is sort of fairly placid at the moment.

Nil

11. No in fact I would say it has increased. I feel much stronger.
61. Felt loss of independence

Some statements about the disability that the subject feels do not seem to entirely fit within the categories above, and relate instead to a general notion of the self as independent of other people. These feelings and statements are therefore rated here as well as in relation to other activities since they are represent one other aspect of the loss of the sense of self.

Rating

1. Marked S clearly states that they feel they have lost all sense of choice and independence and finds this distressing.

2. Moderate S feels they have a markedly reduced independence although there are some areas in which they feel they have some control.

3. Some S notices some loss of independence but for the most part feels they maintain some freedom to do as they wish.

4. Nil S feels that they are independent or is not bothered by any loss they do notice.
61. Examples of felt loss of independence

Marked

13. I miss the independence of it... not being able to do things myself. Going up and down stairs. I mean I use the frame most of the time going from one room to another and that sort of thing. I miss the car, I miss driving but I think that’s what I miss most of all, that’s being independent.

43. The job is out, the job is definitely out. Driving - there’s no way I’ll drive again. I was told that straight out at the beginning. I’ve just got to wait and see what I can really try... it does affect you, you know, when you know you can’t go anywhere you could go. That was all taken away in a year, know what I mean. It is unbelievable that your whole life can just be cut off like that in a year!

47. My arm is completely useless. It is the pain really. It is frustrating. I can walk now with a stick and this thing they gave me at X (hospital). It holds the foot straight. So I can get to the toilet and get around the house .... with my wife’s help, not without her. And eating is alright... anything big she will cut it for me. I can’t go outside at all by myself. I have got a wheelchair. And it is a big strain on C because she has to do it all. I feel angry that I can’t do it. Frustration is the worst of it.

30. I want to do everything but I can’t. I can’t walk very well now because it’s affected this leg. I’ve fallen down stairs twice. I still can’t use my arm, that’s exactly the same so I still can’t do much. Even though you’re probably a thorough nuisance it is much nicer to be back in my own home.... I’ve lost a lot of balance. I really have to concentrate to get around.

Moderate

41. She’s worrying in case I am falling down, in case I fall down and bang my head somewhere. She’s always behind me and that is that.... Yes I can walk with a stick, or they hold my arm....I might go on my own but I daren’t in case. I am afraid I might fall over.

60. I want to get back to normal. I’ve made a big step by going back to work. I’m a bit fed up with doing things differently as to how I did them before, alright I may have to live with it... I get so frustrated with myself because I want to do it how I did it. There are one or two things that I can do but it takes me a lot longer.
61. Examples of felt loss of independence

Some

17. S goes out to work (in a reduced capacity), plays sport and meets friends. He is unable to drive because of epilepsy and although he feels he is doing well in most areas regrets that he has to rely on his parents to chauffeur him around.

2. S is working, seeing friends and looking after his children. However he notices that he has to rely on his wife to find things around the house for him and feels he is not yet self-sufficient.

Nil

5. S is working at doing up his two flats. He has continued with strenous sports as well as an active social life. He sees himself as physically fit and although he is no longer working full-time he sees this as a blessing.

121. S takes great pride in the fact that shortly after his diagnosis he was able to complete a major re-building of his house. He also points out that he has re-planted the garden and regularly overhauls his car engine himself. He sees himself as being as good as the next man.
62. Subject’s felt cognitive handicap

These is a simple self report of the problems that S feels they have in recalling and organising their thoughts. Minor problems that are often first noticed are names of acquaintances, doctors or odd appointments. This may or may not progress through forgetting their tablets or to losing their own possessions, and even looking in completely absurd places. Finally they may not be able to remember things from hour to hour, forgetting even the most basic facts about themselves.

This scale aims to pick up on the subject’s awareness of problems of getting going with things and managing to do slightly complicated tasks that require some application. They may comment on this in relation to all sorts of activities. It is therefore a feeling that the subject is not functioning sufficiently well in their life that is important rather than any specific cognitive function or task-related activity.

Rating

1. Marked  S feels they are unable to organise anything other than most basic care.

2. Moderate S feels has marked problems but able to do some things.

3. Some  S experiences some problems but feels they are able to cope with most things.

4. Nil  S feels they have experienced no problems.
62. Examples of felt cognitive handicap

Marked

I don't know whether I'll be of any use because my mind is just .. oh I don't know
I just don't seem to grasp ... I do hope that you'll see me in better state when you
come next time.

35. I found that when I went out of the house with the idea of walking somewhere I
didn't know where I was going to walk and I didn't know which places to go to. I
lost my memory when it started. I forgot a lot of things - all the flowers I grew,
everything I used to work on. I have known the names for so long it is unbelievable
and now I haven't got a clue. I can't put a name to them now and I find that difficult.

4. Q: You said that your memory was a bit of a problem.
A: It is.
Q: What sort of things do you notice with that?
A: Oh, lots of things. I hate it.
Q: What's the worst thing you hate? Do you remember things like what day it is
today?
A: Wednesday.
Q: Yes that's right. What time is it about do you think?
A: (Long pause) Oh, I hate this.

Moderate

26. My memory isn't as sharp as it used to be. On the other hand it's not desperate you
know. I consult her a lot about dates and times - what I'm supposed to be doing, what
pills I'm supposed to be taking. I'm dependant on her enormously. I find difficulty
on the word processor. It's generally things I've forgotten how to do which I find
frustrating. I'm forever hunting in my brief case and not finding things. I have
difficulty with finding the name of a street and then finding it on the map. My time
sense is not brilliant.

23. It's like engage brain first and do things afterwards. I get things in the wrong order
and I think to myself that I could do better than that. It takes me a while formulating
what I want to do. I find I can't find things around the house.

25. I leave the drugs to my wife because I can never remember. I think I'm on.... no I
wouldn't like to say because I could be completely wrong. If my wife says to me
"these people are coming round at 7pm tonight", half an hour later I will say to her
"what time are they coming round?" I don't think I could hold down a job.

32. I lose words occasionally. I couldn't put words together. I mean, I think I've held my
argument together but the language is in a different way and it is very odd, I mean, one
awful moment I couldn't remember Professor T. I forget names. I can't read quickly and I
can't think very deeply.
62. Examples of felt cognitive handicap

Some

2. I find I’ve forgotten things like names. It’s just as well my appearance has changed because I see people and I can’t quite put a name. I haven’t quite got it. I know almost exactly but it’s not quite there. It doesn’t happen often. It’s seldom but when it does it’s a little disconcerting. She sorts out my pills. She keeps a check on the pills and stuff like that. Very clearly there are difficulties, either on taking in too much or else in getting bogged down in the nitty gritty of the same thing. My wife is very good with that. I’ve got bits and pieces to be done and I’ve not yet got stuck into it. She’s very good at saying what needs to be done. Talking about it that’s fine and battling away that’s fine, but buckling down that’s difficult.

6. For instance you know the name of the taxi driver than won mastermind? I couldn’t think of the name. It drove me mad and I went upstairs and tried to think of the name. Anyway half an hour later I shouted down 'Fred Houskowl’ (also forgets name of hospital during interview).

22. I forget people’s names and I forget where I put things.

19. I do need help to get organised with things. I find I want to know where things are all the time. I find I’ve lost all sense of date, time and days.

5. When things are complicated or when there’s pressure I don’t like it. I’d rather sleep for six months, people are such a pain. I don’t like people trying to make me make a decision when I’ve already made it, putting pressure on you to do something you don’t want to.

Nil

9. My memory is better now than it was before the operation (denies problem).

24. I find I have a few lapses for silly little things.

60. No, no problem at all (with adding up). No, I’m still the same. Rather than forgetting things or not remembering I feel better about remembering.
63. Subject’s felt handicap in communication

The degree to which S feels hampered in everyday conversation. there can be concerns with using, incorrect words, not making sense or becoming over-emotional.

Rating

1. Marked  S feels unable to hold a coherent conversation or communicate for whatever reason.

2. Moderate  S feels they have severe difficulty speaking or being understood: can include memory loss, confusion of words, physical impediments or drowsiness.

3. Some  S feels they have some problem difficulties with conversation but is able to communicate.

4. Nil  S feels communication is as usual.
63. Examples of subject's perception of handicap in communication

Marked

1. It is .... so difficult.... it's so simple what I want to say.

Moderate

23. I find sometimes when I'm speaking on the telephone I might get all emotional and can't speak, and then I have to hand over to my wife.

50. A: Still having problems with the dialogue, you know... conversations. Sometimes I get a bit of a run but no real sense if you know what I mean. Not real sense. Like I can say "a, b, c, d, e, f, g, h, i. I can....And sometimes I can't make any sense at all.
Q: Do you feel that you're fishing around for the right word or are you just a complete blank?
A: No I try to get the right words...that desperate...I can't get....conversation.

Some

8. You must excuse me because sometimes I say the most ridiculous things and I don't realise I'm saying them. I can go on for a while saying them before I realise.

5. Did you notice sometimes I don't say things correctly. I miss the end of the words. It irritates me doing that and it's worse because I speak fast.

32. My speaking is still quite good, my reading and writing is totally gone...seems to get worse and worse.

84. I expect you notice that my speech is a bit muddly sometimes. I say funny words, all of a sudden I say a funny word or something.

Nil
64. Overall Distress

Ratings

Marked

S is totally overwhelmed by the situation and seems unable to gain enjoyment from anything else. Include here;

1. Frank depression
   ie. depressed mood with
   loss of interest, loss of self respect and tearfulness

2. Anxiety states

3. Confusion with pockets of lucidity during which S is aware of their confusion.

4. Anger

Moderate

S admits to feeling upset or anxious a good deal of the time but feels able to control this and to gain pleasure from other activities. This really represents what would seem a reasonable or normal response to the situation.

Some

S admits to the occasional feeling of depression, anxiety, dismay or disappointment but remains generally cheerful. They may seem less upset than one would expect in the situation.

Nil

S feels very well. They have no worries for the future or is confident of a cure.
63. Examples of Overall Distress

Marked

19. I feel sad all the time now. I think about whether I might die...I don't want to be a burden to my children...It's not a very nice thing is it? I thought it was upsetting because nobody seemed interested you see.

80. I just can't be bothered to do anything. I don't know why, I'm not usually like that. I just leave things .. I think "Well, what's the point?" Pathetic, really. I cry about certain things, sometimes I have a snivel. I must admit I do feel anxious quite a lot... If I could relax, be less anxious, not be so paranoid... I don't feel I've got much quality of life at the moment.

114. S is depressed and feels he cannot talk to anyone about his position. He is angry that he might die and frustrated at his loss of independence due to not being allowed to drive. He is critical of the medical care. He cannot do much at home and his memory has deteriorated. He feels that his illness has had a detrimental effect on his family life.

Moderate

22. I think I must have been pretty evil in one of my previous lives to get this one....I can't be sure of the success, for God's sake don't tell my wife this.

S cries in the interview, and has cried on his own, is sleeping poorly and in fact later became depressed but at this time was going out and enjoying watching sports.

2. S feels anxious about dying and has fears of being buried alive. He has angry and violent outbursts with his wife and youngest son. He has paranoid thoughts. He seems to accept that he has only a short time to live and continues to take his chemotherapy despite feeling that any treatment which has no chance of cure is pointless. He complains of not sleeping well, poor organising skills and slight nausea. Nevertheless, he is planning holidays and work projects and trying to sort out his relationship with his son.
Some

26. S feels that the illness has reaffirmed his religious calling and given him a purpose in his community. He does feel sad when he thinks that it might be the end of his earthly life and mean parting from his family. He is tearful but says this is due to the steroids and in fact he feels great joy.

7. We are all dying and it's having hope in the face of death, I suppose - it's my job all reversed onto me, so I had to be the one who received care and attention. Indeed, in a sense I'm quite looking forward to it. But I'm not looking forward to it in that it will leave my wife a widow. That is very painful.

99. I was in a very sort of grim stage for quite a time about the whole business of dying possibly, how shall I say, yes, I don't know, just I was dying very young or something, that sort of thing. I was scared of the actual disease. I suppose I'm not at all scared of it in a way these days. I'm just more at one with it.

Nil

25. S feels they have made good progress in regaining some walking function and feels he will be able to beat his disease.

11. S feels very well and denies the significance of the tumour.

1. S has dismissed his problem and concentrates on taking his tablets and thinking of the day when he will be able to drive again. Even though he has some difficulty with reading and remembering things he does not admit to any distress.

46. My mind is quite clear you know. Quite clear about things. I don't have any anxiety whatsoever. Prayer moves mountains, doesn't it? If I've got a problem I get down and pray about it, ask the Lord for guidance and I'm sure he does guide you.
References


Mahoney FI, Barthel DW. Functional evaluation: the Barthel index. MD Medical Journal 1965;14:61-5.