

PAPER

Views of bereaved relatives about quality of survival after radiotherapy for malignant cerebral glioma

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Objective: To explore the views of bereaved relatives about quality of survival after radiotherapy for malignant cerebral glioma.

Design: Semistructured interviews with the bereaved relatives of 56 previously studied patients with glioma.

Setting: Patients treated at six London hospitals from 1990 to 1992 surviving between one and 46 months (median, eight).

Subjects: Fifty six relatives (44 spouses, 12 others) seen four to six months after bereavement and 20 again at 13 months.

Main outcome measures: Views about quality of life and satisfaction with radiotherapy.

Results: Relatives described quality of life as "good or acceptable" when patients carried on some normal activities or enjoyed social relationships. They described restricted and dependent states, constant deterioration, or loss of social interaction as giving "poor or unacceptable" quality of life. Length of time lived in such states also appeared important. Relatives' views of good or acceptable quality of life were independently related to low initial cognitive or personality change or low distress in the patient after diagnosis, and to their subsequent survival free from physical disability for at least one month. Satisfaction with radiotherapy was related to low initial distress, some degree of surgical resection, and overall length of survival longer than six months.

Conclusions: Carefully exploring the views of bereaved relatives can bring a useful perspective to difficult treatment decisions. Their values support including disability and distress in quality of life measures, but cast doubt on the QALY-type approach of using full years of survival or time free from disability to judge whether treatments are worthwhile.

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Radiotherapy for malignant cerebral glioma provides one example of a potential trade off between quality and length of life. Two randomised controlled trials show that radiotherapy prolongs median survival after surgery from three months to around 10.^{1,2} However, radiotherapy takes six weeks and may cause adverse effects including hair loss, tiredness and somnolence,^{3,4} deterioration,^{3,5} and irreversible cognitive problems.^{6,7} Because many patients present with some disability and most die within one year,^{1–3} published estimates of the cost for each Quality Adjusted Life Year (QALY) have generally been high.^{8,9} However, some clinicians find suggestions of withholding treatment to be nihilistic, whereas others question the value of life assumed in cost effectiveness evaluations.

We previously described a study of 92 patients and their close relatives or carers where we attempted to explore their views about this trade off.^{5,10} We had been surprised to find that only one quarter of the 75 patients whom we interviewed as they began radiotherapy appeared to be fully aware of their poor prognosis, compared with three times the number of relatives. However, most aware patients seemed willing to undergo treatment for the chance of longer survival. We did not find evidence that most of them regretted treatment, despite experiencing only brief remissions or adverse effects. We suggested that patients gained hope from treatment, from the protection relatives and doctors provided, and from their own psychological defences. We argued that this powerful response to life threatening illness makes any question of a rational trade off less relevant than well individuals might predict.¹⁰ In our current study, we explore the views of bereaved relatives about the quality of patients' survival and compare these with some assump-

tions made by the QALY-type approach to judging brief periods of survival as worthwhile.

SUBJECTS AND METHODS

Recruitment and follow up of relatives for the study

Our previous study comprised 92 patients receiving radiotherapy between 1990 and 1992 at six London hospitals and 85 relatives.⁵ Eighty relatives saw us again after the initial interviews, and 73 became bereaved between 1990 and 1993. We obtained local ethical approval from each hospital to interview bereaved relatives. We first sent a letter of condolence, and four to six months after the death we wrote again to ask to interview them concerning further thoughts about the illness or treatment. We emphasised that this was entirely voluntary and telephoned two weeks later to hear their decision. By late 1994, when the project ended, 69 relatives had been bereaved for at least four months and could be contacted. Fifty eight agreed, although four delayed the visit for up to 12 months and four preferred to talk on the telephone. To see whether their views changed we approached relatives again 13 months after bereavement. By late 1994, 32 relatives had reached this point, but we found that a higher proportion (12 of 32) declined interview here, mostly saying that they felt they had no more to tell us or did not wish to go over painful memories again. However, 20 did agree to a second interview, one by telephone. In all but one instance the same interviewer visited as before.

Abbreviations: CI, confidence interval; df, degrees of freedom; MRC, Medical Research Council; OR, odds ratio; QALY, Quality Adjusted Life Year

SEMISTRUCTURED INTERVIEW SCHEDULE

Introduction (spoken by interviewer)

There are two purposes to this interview. The first is to hear any reflections you have had about the management of the illness in general and what you feel about the care (name of patient) and you received in the last months and weeks. The second is to ask how you have been yourself and any problems that you have come up against in the past months. Perhaps you could tell me what happened after I last met you?

Instructions to the interviewer: let the person tell you the story in as much detail as they need.

Along the way, ask these questions if the answer does not become apparent in their own comments.

What did you think of the way in which you were told that he or she didn't have very long to live?

What sort of care did the hospital/hospice/general practitioner provide? Were they where you wanted them to be at the end?

Looking back on it do you think the radiotherapy achieved a reasonable quality of life?

What do you think most affected the quality of their life?

Knowing what you do now do you think you would have opted to have the radiotherapy again?

Or the chemotherapy?

Is there anything else that you would have wanted to do differently?

What advice would you give other families looking after someone with a brain tumour?

Would you have found it useful to have met with other families?

Figure 1 The semistructured interview schedule.

Data collection

We had previously collected data on the clinical state of each patient after the diagnosis, such as their initial disability,¹¹ score on the Medical Research Council (MRC) Prognostic Index,¹² and the treatment they received.⁵ We also had information on the course of the illness, including the patient's initial distress,¹⁰ severe cognitive or personality problems reported by the relative^{10,13} at first or second interview, and patient and relative reports of improvement at "best follow up interview".¹⁰ At bereavement interviews we confirmed how long the patient had lived free from disability,¹⁴ the date of their death, and details of care in the last months or weeks.^{5,10} We used a similar semistructured interview approach to explore bereaved relatives' views about overall quality of life and the value of radiotherapy (fig 1). We expected to find negative views about a treatment that had not cured the patient and, not wishing to raise doubt or distress,¹⁵ we probed carefully after spontaneous comments, asking directly only if their views appeared unclear. For example, "Looking back on it now, do you think (s)he had a good enough quality of life?" and "Do you think radiotherapy helped?". We did not ask relatives to make decisions about future health policy on treatment or make a standard assessment of their grief.

Analysis

Our method followed the tradition established by research into life events and illness.^{10,16} This has provided a model for attempting to move from initial qualitative descriptions of events to simple categorisations that can then be compared with independent clinical factors. This approach relies on: (1) a careful reading of the comments to identify common themes within examples, (2) devising explicit rules by which examples may be categorised depending on the themes within them, and (3) checking the inter-rater reliability when two or more interviewers use the rules to make independent ratings on the same examples. For this exploratory analysis, we extracted all qualitative comments about quality of life and radiotherapy from the first 21 transcribed interviews. These had mostly been conducted by one of us (ED), who identified by content analysis some themes for descriptions of quality of life from them (fig 2). It initially seemed that the examples might fall into a simple dichotomy—overall, whether relatives felt the patient's quality of life had been

"good or acceptable" or whether they thought it had been "poor or unacceptable" (fig 2).

A similar dichotomy did not seem possible for views about radiotherapy because these appeared to fall into three responses: "satisfied", "uncertain", or "dissatisfied" (fig 3). The 21 examples were organised into these simple categories for quality of life and satisfaction with radiotherapy and discussed within the research team. Another interviewer then independently used them as a guide to extract comments and rate examples from the next 40 interview transcripts, most of which she had conducted herself. When ED independently rated this second set of examples, inter-rater reliability between the two interviewers was good (κ values: 0.73 for quality of life and 0.87 for radiotherapy). Given this high level of reliability it did not seem necessary to undertake a more detailed qualitative analysis to identify further themes to guide the ratings. We settled differences by discussion and ED rated comments from the remaining 18 interviews that had mostly been conducted by a third interviewer. These ratings could not be made blind to any knowledge about the trajectory of each patient's illness because each case had been discussed within the team previously as the project progressed. However, the ratings were made several years before this and analyses already published.¹⁰ Social class was rated directly into the then current Registrar General's classification using information on the relative's occupation. It is not possible to update this to a more recent classification because the supporting details were not retained.

For the current analysis, we compared relatives' views to previous ratings and observations on the course of the illness using the two tailed Pearson's χ^2 test or χ^2 test for trend. We then explored, using a backwards conditional logistic regression analysis, which aspects of the initial illness and its course were most independently associated with the relatives' later views.

RESULTS

Characteristics of relatives and deceased patients

In two cases we did not collect enough information to rate individual views and we therefore report the results for 56 relatives four to six months after bereavement and 20 relatives at 13 months. At the first interview there were 35 widows, nine widowers, four parents, and eight other relatives (median age, 52; range, 24–75 years; table 1).

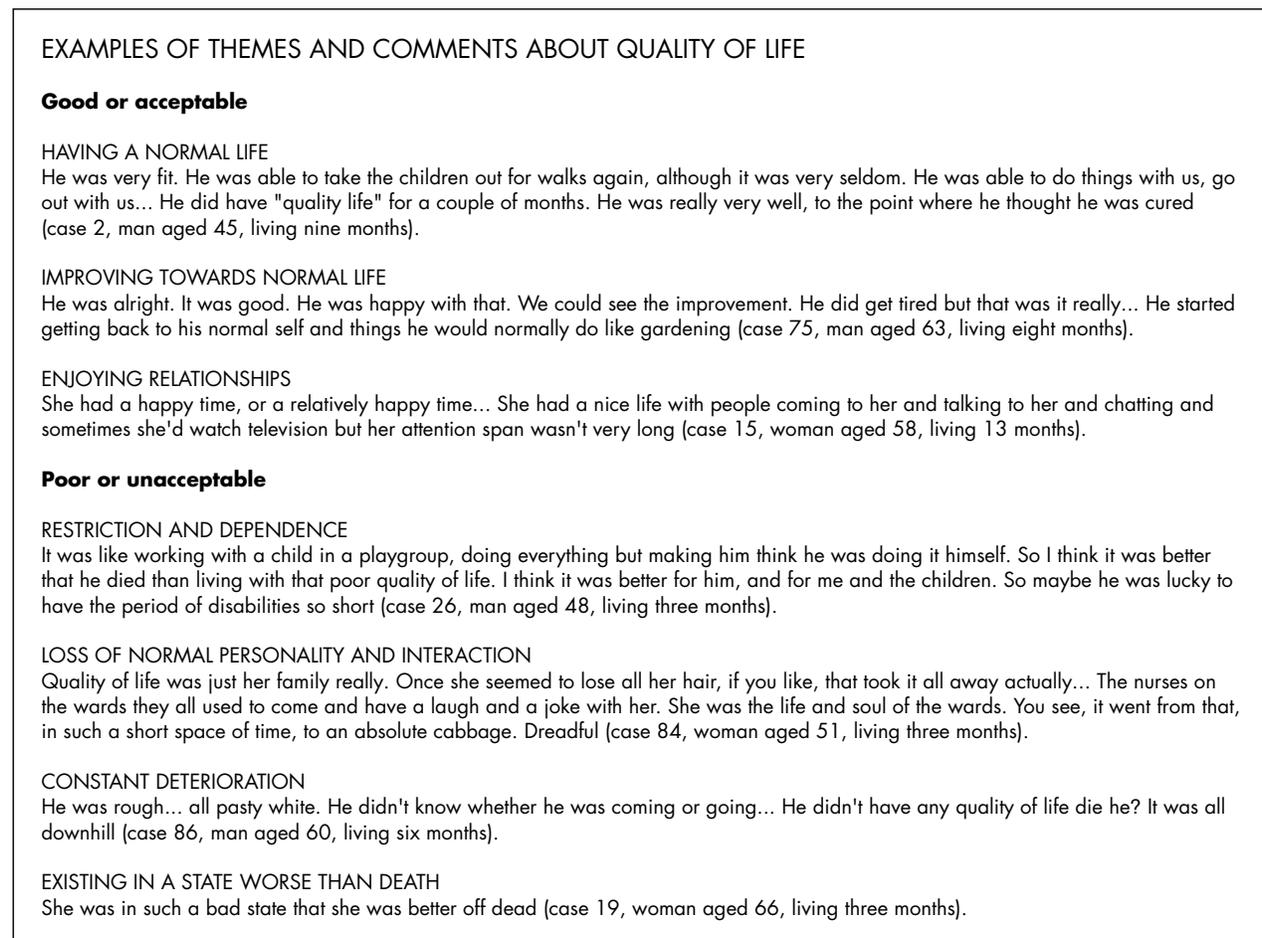


Figure 2 Some examples of the themes and comments made by the relatives about the patients' quality of life after radiotherapy.

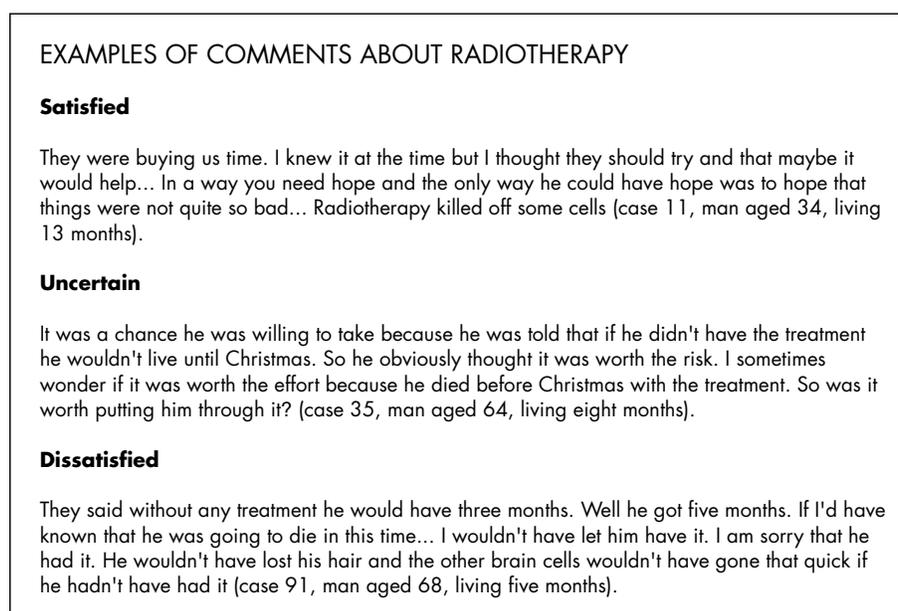


Figure 3 Some examples of comments made by relatives about their satisfaction with radiotherapy.

Table 1 Demographic characteristics of the 56 bereaved relatives

| Characteristic | Relatives |
|--|-----------|
| Age (years) | |
| 21–44 | 16 (29) |
| 45–59 | 22 (39) |
| 60–82 | 17 (32) |
| Sex | |
| Men | 12 (21) |
| Women | 44 (79) |
| Racial origin | |
| Afro-Caribbean | 1 (2) |
| Asian | 4 (7) |
| White | 51 (91) |
| Age leaving full time education (years)* | |
| <16 | 22 (41) |
| 18 | 23 (42) |
| >21 | 9 (17) |
| Social class† | |
| I | 8 (15) |
| II | 23 (42) |
| III NM | 15 (27) |
| III M | 5 (9) |
| IV | 4 (7) |
| V | 0 (0) |
| Relationship to patient | |
| Widow | 35 (63) |
| Widower | 9 (16) |
| Parent | 4 (7) |
| Daughter | 5 (9) |
| Other relative | 3 (5) |

Figures are numbers (percentages of subjects).

*Data missing in two cases; †data missing in one case.

The 56 relatives seen for the first bereavement interview did not differ from those seen during the illness. However, of the 32 approached again 13 months after bereavement, those who had already described the quality of the patient's life as poor or unacceptable more often refused the second interview than those describing a good or acceptable quality of life (10 of 17 v two of 15; $\chi^2 = 5.23$; degrees of freedom (df), 1; $p < 0.05$). The 56 patients described by relatives at their first interview had survived between one and 46 months (median, eight) and were broadly similar to the original cohort (table 2). We had data on the course of the illness for all 56 patients, and their own views about improved problems

and radiotherapy for 34 who had been well enough for two interviews during the illness.

How do bereaved relatives describe quality of life?

The first 21 comments from relatives suggested three themes contributing to the perception of good or acceptable quality of life. These were being “fit” and having “a normal life”—for example, working, carrying on interests, or looking after their family, improving some way towards “normal life”, and being able to do some things and enjoying close relationships or friendships despite some disability (fig 2). Using the simple scale based on these we rated two fifths (22 of 56) of relatives as feeling that the quality of life had been good or acceptable. In contrast, themes for poor or unacceptable quality of life for the remainder (34 of 56) were severe disability restricting activities leading to dependence or distress, loss of normal personality and interactions, constant deterioration, and existing in a state worse than death. Figure 2 shows examples of comments around these themes. These may appear stark but their context was often a long, detailed description of both the illness and their grief. In this sample, relatives' views were unrelated to their own age, education, social class, or relationship to the patient. However, men were more likely than women to describe the quality of life of the patient as good or acceptable (eight of 12 v 14 of 44; $\chi^2 = 4.80$; df, 1; $p < 0.03$).

How do relatives view radiotherapy?

Just below one half of the relatives (26 of 56) were rated as satisfied with radiotherapy, judging that the patient had improved, remained able to do things they enjoyed, or that their deterioration had been slowed. Others placed value on the time the patient gained with their family and the hope that radiotherapy had brought (fig 3). Nearly one fifth (10 of 52) were less certain, feeling that the patient had not improved or survived as long as they had expected. They observed that the patient had been willing to try treatment and that this may have been the correct decision for them, but looking back they would be sceptical of accepting such treatment themselves. The remainder—just over a third (20 of 56)—were dissatisfied, feeling that radiotherapy had made no difference, kept the patient alive in a damaged state, detracted from the quality of life, or simply wasted precious time. Satisfaction with radiotherapy and views about quality

Table 2 Patients described by 56 bereaved relatives compared with those in the original cohort

| Characteristic | Original cohort (N=92) | Patients described by bereaved relatives (N=56) |
|---|------------------------|---|
| Sex | | |
| Male | 63 (68) | 42 (75) |
| Female | 29 (32) | 14 (25) |
| Age (years) | | |
| 21–44 | 24 (26) | 13 (23) |
| 45–59 | 34 (37) | 18 (32) |
| 60–75 | 34 (37) | 25 (45) |
| Surgery | | |
| Biopsy | 47 (51) | 29 (52) |
| Partial or complete resection | 45 (49) | 27 (48) |
| Initial disability* | | |
| 0–1 | 23 (25) | 13 (23) |
| 2 | 38 (41) | 24 (43) |
| 3–4 | 31 (34) | 19 (34) |
| Time lived free from physical disability† | | |
| 6 months or more | 37 (40) | 17 (30) |
| 1–5 months | 23 (25) | 18 (32) |
| 0 months | 32 (35) | 21 (38) |
| Overall survival | | |
| More than 12 months | 35 (38) | 16 (29) |
| 6–12 months | 32 (35) | 21 (38) |
| Less than 6 months | 25 (27) | 19 (34) |

*Assessed using the World Health Organisation Clinical Performance Status¹¹; †time the patient survived before the Barthel score¹⁴ dropped below 20.

of life were closely related. Only one relative who thought quality of life had been good or acceptable (one of 22) felt dissatisfied with radiotherapy compared with just over one half (19 of 34) of those who perceived quality of life to have been poor or unacceptable ($\chi^2 = 23.86$; df, 2; $p < 0.001$). Of the remaining 15, eight were uncertain about the value of radiotherapy. Too few patients (seven of 34) had been dissatisfied to relate this to relatives' views. However, relatives' views were not related to demographic characteristics, and only two of the 20 seen again expressed different views at the second bereavement interview.

Do these views relate to the course of the illness?

Table 3 shows how relatives' views about quality of life were related to the patient's age and score on the MRC prognostic index, a range of initial aspects of the illness (extent of surgery, initial distress, and disability), its course (time lived free from disability and overall survival), and to patients' and relatives' reports of improvement after treatment (in the 34 cases where we had these data). There were similar associations with satisfaction with radiotherapy. At least one half of the relatives expressed satisfaction with radiotherapy even when patients had lived for only one to five months free from disability (10 of 18) and survived six to 12 months overall (12 of 21).

To determine which factors were independently associated with bereavement views, we entered those factors that

seemed related, and for which we had near complete data, into a backwards conditional logistic regression analysis. (This analysis concerned 53 cases because data on distress were missing for three patients who had been too confused for us to make this initial rating confidently.) The factors that emerged as associated with good or acceptable quality of life were initial cognitive or personality change in the patient (partial odds ratio (OR), 4.39; confidence interval (CI), 1.40 to 13.79), the time they lived free from physical disability (partial OR, 2.5; CI, 1.00 to 6.29), and the degree of the patient's initial distress (partial OR, 2.56; CI, 0.98 to 6.73). (We include the last factor because it is very close to a two tailed level of significance: $p < 0.055$.) Figure 4 shows that when these initial aspects of the illness and its course are considered together a fairly straightforward picture emerges. Where there was initially either high psychological change or distress, very few relatives considered that the quality of life had been good or acceptable, irrespective of the time the patient lived free from severe physical disability. However, without these initial profound problems, there is a clear gradient in terms of the acceptability of the patient's life according to the length of time they lived free from physical disability: over four fifths felt that quality of life had been acceptable when the patient achieved six or more months free from physical disability ($\chi^2 = 4.88$; df, 2; $p < 0.03$).

Following the same procedure, extent of surgery (partial OR, 6.40; CI, 1.61 to 25.40), overall length of survival (partial

Table 3 Aspects of the course of the patient's illness and the views of 56 bereaved relatives about quality of life and the value of radiotherapy

| | Good or acceptable quality of life | | Satisfaction with radiotherapy | |
|---|------------------------------------|----------|--------------------------------|----------|
| | N (%) | p Value* | N (%) | p Value* |
| Age (years) | | | | |
| 21-44 | 5/13 (38) | | 7/13 (54) | |
| 45-59 | 9/18 (50) | | 9/18 (50) | |
| 60-75 | 8/25 (32) | 0.50 | 9/25 (32) | 0.50 |
| MRC Prognostic Index Score | | | | |
| 0-15 | 3/7 (43) | | 4/7 (57) | |
| 16-25 | 11/23 (48) | | 14/24 (58) | |
| 26-38 | 8/26 (31) | 0.50 | 8/25 (32) | 0.20 |
| Surgery | | | | |
| Biopsy | 8/29 (28) | | 7/29 (24) | |
| Partial or complete resection | 14/27 (52) | 0.06 | 19/27 (70) | 0.01 |
| Initial distress† | | | | |
| Nil | 10/16 (63) | | 11/16 (69) | |
| Some | 10/23 (43) | | 12/23 (52) | |
| Marked or moderate | 2/14 (14) | 0.01 | 3/14 (21) | 0.02 |
| Cognitive or personality change‡ | | | | |
| Nil/some | 16/30 (53) | | 16/30 (53) | |
| Marked or moderate | 6/26 (23) | 0.02 | 10/26 (39) | 0.50 |
| Initial disability§ | | | | |
| 0 or 1 | 9/13 (69) | | 8/13 (62) | |
| 2 | 10/24 (42) | | 14/24 (58) | |
| 3 or 4 | 3/19 (16) | 0.01 | 4/19 (21) | 0.02 |
| Time lived free from physical disability¶ | | | | |
| 6 months or more | 11/17 (65) | | 12/17 (71) | |
| 1 to 5 months | 8/18 (44) | | 10/18 (56) | |
| 0 months | 3/21 (14) | 0.01 | 4/21 (19) | 0.01 |
| Length of survival | | | | |
| 12 months or more | 9/16 (56) | | 11/16 (69) | |
| 6 to 12 months | 9/21 (43) | | 12/21 (57) | |
| Less than 6 months | 4/19 (21) | 0.05 | 3/19 (16) | 0.01 |
| Patient report of problems** | | | | |
| Remained well/improved | 13/17 (76) | | 13/17 (76) | |
| Continuing/worsening | 5/17 (29) | 0.02 | 9/17 (53) | 0.30 |
| Relative report of problems†† | | | | |
| Remained well/improved | 12/14 (86) | | 12/14 (86) | |
| Continuing/worsening | 8/24 (33) | 0.01 | 12/24 (50) | 0.06 |

Figures are numbers (percentages) of relatives.

*Pearson's χ^2 test for difference (two tailed) rounded to two points or χ^2 test for trend. †data missing in three cases because the patient was too confused; ‡from ratings of relatives' reports made in the initial part of the illness at interview 1 or 2; §assessed by the World Health Organisation Clinical Performance status¹¹ after the diagnosis; ¶time lived before the Barthel score¹⁴ dropped below 20; **data from "best follow up interview"¹⁰ for 34 patients who were well enough for interviews; ††data for 38 relatives seen at follow up during the illness.

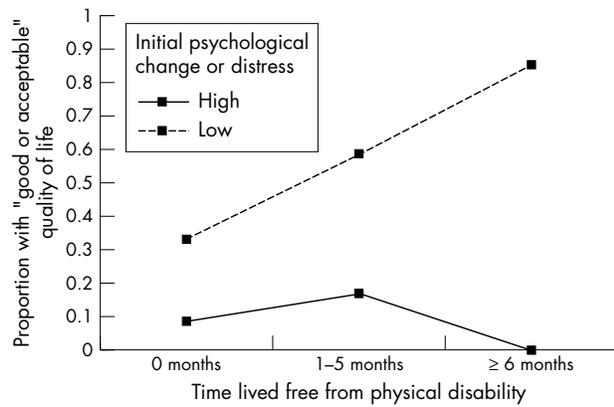


Figure 4 Patients’ initial psychological change or distress, time lived free from physical disability, and relatives’ views about quality of life.

OR, 3.15; CI, 1.22 to 8.16), and initial distress (partial OR, 2.59; CI, 0.99 to 6.82) emerged as associated with later satisfaction with radiotherapy. (Again, we include the last factor with a p value of 0.053.) Figure 5 shows that there was a high rate of satisfaction among relatives of patients who had either partial or complete resection, irrespective of the length of time the patient survived. The slight drop for those with less than six months of survival is well short of significance. However, for relatives of patients who had only a biopsy, there is a marked correlation between satisfaction with radiotherapy and the length of time the patient survived ($\chi^2 = 5.38$; df, 1; $p < 0.02$). If initial distress is taken into account the same picture emerges (data available on request).

DISCUSSION

In our study, we interviewed bereaved relatives of adults with malignant cerebral glioma to explore their views on the quality of survival of 56 patients we had previously studied.^{3, 10} We found that relatives expressed a wide range of views about quality of life, describing this as good or acceptable when they saw that patients carried on some normal activities or enjoyed social relationships, and as poor or unacceptable when they saw restricted and dependent states, constant deterioration, or loss of social interaction. Their descriptions of good or acceptable quality of life could be related to previously recorded aspects of the course of the illness and to the patients’ and relatives’ own reports of

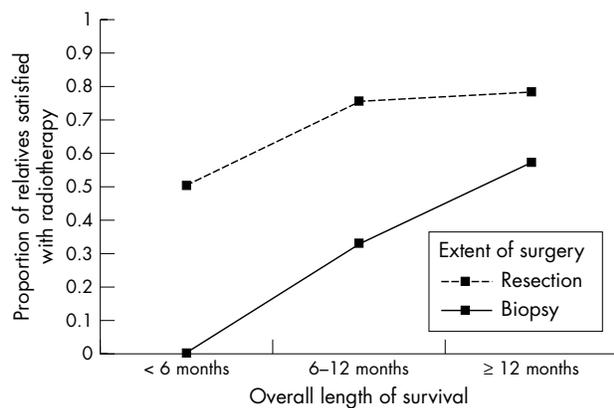


Figure 5 Extent of surgery, overall length of survival, and relatives’ satisfaction with radiotherapy.

improvement after treatment. Three aspects—the patient’s initial distress, cognitive or personality change shortly after the diagnosis, and the time they lived free from disability—emerged as independently associated with relatives’ later views. Where the patient did not suffer initial profound psychological change or distress, relatives saw increased time lived free from physical disability as providing good or acceptable quality of life. For satisfaction with radiotherapy the extent of surgery, initial distress, and overall length of survival were most important. Relatives of patients undergoing some form of resection were satisfied with radiotherapy, irrespective of overall length of survival, but the relatives of patients undergoing only biopsy were less likely to be satisfied with radiotherapy unless the patient survived longer than 12 months.

Limitations of our study

This is an exploratory study comprising a small number of relatives, most of whom were white women from higher social classes describing similar men. We used standard measures to assess disability and attempted to develop other ratings for quality of life and satisfaction with radiotherapy based on the views and emotions expressed independently by patients and relatives at separate interviews. We achieved high reliability for our ratings but we did not include a detailed formal assessment of the patients’ cognitive ability or of the relatives’ grief. The relation between the relatives’ views after bereavement and those obtained during the illness could possibly represent some measurement bias in interviews. Although our study elicited relatives’ views about quality of life that described mostly its health related aspects, these were not entirely explained by objective aspects of the illness that we were able to measure. Undoubtedly, there are other relevant meanings for quality of life including cultural, spiritual, and personal aspects that we could have explored further. However, the strength of relatives’ views surprised us, and as far as we could determine these did not change radically in the first year after bereavement.

Comparison with other studies

One other study of adults with malignant cerebral glioma has combined data from 28 patients and their bereaved relatives to define the “time of everyday life” where life resembled that before the illness in at least a couple of areas such as work, family, and social life.¹⁷ Salander and colleagues found a median of six months and distinguished this from “time of disease”—where life was disrupted and centred around the illness and its treatment (median, 5.4 months). They argued that patients could experience “time of everyday life” despite objective disability or disease progression, and suggested that hope is not simply about cure, but may be created by the patient’s ability to adapt and re-experience everyday life.¹⁷ No study has asked bereaved relatives about radiotherapy. Our earlier study showed the difficulty in asking patients directly about any trade off from treatment, but suggested that they were willing to undergo this for the chance of improvement or longer survival.¹⁰ The emphasis that bereaved relatives place on relatively brief periods of improvement and survival is consistent with this impression.

Implications for clinical practice

Although our sample seems similar to patients in treatment trials,^{1, 2} critics disputed that it was typical of those receiving modern focused radiotherapy within specialised centres.¹⁸ If, as we suggested, some patients experienced adverse effects from treatment,¹⁹ there might be higher satisfaction after more effective palliation.²⁰ Our finding that relatives’ satisfaction with radiotherapy was higher in patients who had undergone some surgical resection might be explained by

the fact that removing part of the tumour made patients better able to tolerate any subsequent oedema or tissue damage as a result of radiotherapy. We believe our results support the clinical view that radiotherapy can provide short periods of survival that are highly valued, but should be offered hesitantly to patients already disabled after diagnosis.^{18–20} The views of bereaved relatives are not a proxy for patient choice, because with time relatives may reinterpret events and overestimate specific symptoms.^{21–23} Therefore, our results provide useful information for clinicians counselling patients,²⁴ but not an easy answer for treatment decisions.

Implications for health policy

In recent years, health economists have been interested in developing models to compare the cost of different treatments in terms of each QALY gained. This has generally involved asking well individuals to predict the value or “utility” they place on varied future states of disability and distress, combining and weighting their scores, and applying them to different clinical trajectories. Where outcome or survival is poor, data from several patients may need to be combined to achieve one QALY. Early calculations based on estimated trajectories suggested a cost of over £100 000 for treating malignant cerebral glioma,^{8–9} although retrospective and prospective studies of real patients now find lower costs.^{25–26} Our finding that relatives’ views about quality of life are related to initial distress and time spent without disability supports including these factors within such indices as they were originally developed.²⁷ However, the value relatives place on brief periods of survival questions the later notion of assessing treatments as worthwhile by full years free from disability and distress, and of summing individual trajectories across one diagnosis of varying prognoses.

Malignant cerebral glioma is an extreme disease that gradually steals physical, cognitive, and social ability, and therefore tests our conception of quality of life. Our study and others suggest that, despite the severity of the situation, patients can cope with and find hope within their situation.^{10–17, 24} With first hand knowledge of an individual trajectory, their relatives did not always reinterpret this earlier hope as “false”, or necessarily regret radiotherapy. These outcomes may seem modest but the issue seems one of perspective. If doctors see things differently from the patients they treat, and relatives in turn have different views from the patients they care for, there seems little chance of well individuals accurately predicting their own response. We suggest that to be meaningful, QALY-type approaches need to be more grounded in the situations they purport to represent, rather than in the statistical manipulation of values expressed in the abstract.

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