

## ORIGINAL ARTICLE

# Caring for patients with brain tumor: The patient and care giver perspectives

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## Abstract

**Background:** Patients with brain tumors form a heterogeneous group in terms of clinical presentation and pathology. However, the impact of the disease on patients' families is often more homogenous and frequently quite profound. A considerable body of literature is available on the management of brain tumors and recently, the National Institute for Clinical Excellence has developed guidelines on the care of brain tumor patients that should improve the overall outcome for the patient from both the disease and psychological aspects.

**Objectives:** An increasing number of studies have attempted to address the impact of the disease on the care givers and relatives of these patients, but few have considered the problem simultaneously from both the patient's and care giver's perspective. In this study, we analyzed the psychosocial and general health of brain tumor patients and related this to the care givers.

**Materials and Methods:** This is a questionnaire-based postal survey of 168 patients and their relatives. We examined how the health and psychological well-being of the caregiver may affect the quality of care.

**Results:** There is significant physical, social, and psychosocial morbidity associated with caring for brain tumor patients. Patients worry about their care givers and this constitutes additional stress for the patient.

**Conclusions:** No constructive and lasting improvement can be made to the quality of life of patients with brain tumor until the health and welfare of their care givers are factored into the care package. With better service to the patient, it is hoped that the burden of care will lighten for the care givers.

**Key words:** Brain tumor, care burden, patient perspective

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## Introduction

The diagnosis of brain tumor, irrespective of histological grading, represents a life-changing process for patients and their families. In addition to the recognized problems associated with a diagnosis of cancer, patients with brain tumor often develop physical, cognitive, and behavioral changes. The threat to life apart, patients and their care givers are subjected to physical and psychosocial stresses that, if not properly addressed, profoundly alter the individual's view of existence for the rest of their natural life.<sup>[1-4]</sup>

The burden of care for patients with cancer in general is receiving increasing attention.<sup>[5,6]</sup> Depression and anxiety are well-established psychological consequences of cancer

and its treatment.<sup>[7-10]</sup> In a recent study of patients with advanced cancer with life expectancy of <2 years who were not receiving formal palliative care, Rainbird *et al.*<sup>[11]</sup> identified a high level of unmet psychological and medical communication/information needs. Most patients with malignant brain tumors fall into this group.

It has been shown that physical and psychological stresses affect both the patients and their care givers.<sup>[12]</sup> This care burden often remains with the care giver and may be intensified after bereavement.<sup>[13]</sup> Ingleton *et al.* showed

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that one of the most common reasons for unplanned admissions in the late stages of chronic illness management is the inability of the care giver to cope with the continuing demands of care.<sup>[14]</sup> The degree of clinically significant detriment to quality of life by a brain tumor is similar for the patient and their care giver.<sup>[15]</sup>

Patients with brain tumor achieve comparable functional outcomes and rates of discharge as acute stroke patients.<sup>[16]</sup> It has also been shown that in patients with subarachnoid hemorrhage, the burden of care often increases later in the disease process<sup>[17]</sup> and this may be from both care fatigue and patient deterioration. This phenomenon is also recognized for cancer patients.<sup>[5]</sup> The level of psychosocial stress in care givers of patients with subarachnoid hemorrhage (SAH) is directly related to the perceived change in the patient<sup>[17]</sup> and it is important to clarify this relationship in brain tumor care.

In this study, we aimed to define the relationship between the physical and psychological welfare of the brain tumor patient and the quality of care they receive in the community. We also analyzed the psychosocial and general health burden for the primary care givers and how these are impacted by the quality of life of the patient.

## Materials and Methods

This study was carried out using a postal survey. In the period between March 2000 and end 2004, 203 patients operated on for brain tumors in the Hull Royal Infirmary were selected based on the completeness of available records; 168 were alive in February 2005 and formed the focus of the study. The total follow-up period was between one year and 3 years. These patients and their principal care givers were contacted by letter and asked to complete a set of self-administered questionnaires. The patient had to give permission for the care giver to be approached and was requested to pass on a further set of questions to their principal care giver.

Ethical approval for the study was obtained from the local ethics committee.

The questionnaires to the patient included Functional Living Index (FLI), General Health Questionnaire (GHQ), and the SF-12 questionnaire. The questionnaires to the care giver included demographics (age, sex, occupation, relationship to patient), the SF-12, and the GHQ. In addition, the care givers also received the Caregiver Coping Questionnaire (CCQ) and the Neurosurgery Impact Questionnaire (NIQ).

The FLI is a 21-item inventory requiring a response on seven-point Likert scale. Some of the items are reverse scored and taking this into account, the score on the FLI is obtained by summing all item scores. The internal

consistency of this index for the patients was calculated in the present study to be Cronbach's alpha = 0.93 (n = 51). A high score indicates better functional living. The SF-12 is a commercially available validated instrument for measuring health-related quality of life which provides two scores: one on physical impact and one on mental impact. It is scored using an online scoring system and a high score indicates better quality of life.<sup>[18]</sup> The GHQ is also a commercially available validated instrument for measuring psychological morbidity.<sup>[19]</sup> It is scored by summing all items and a high score indicates greater psychological morbidity.

The CCQ is a 12-item questionnaire which assesses care givers' problems with daily living, such as sleep disturbance, etc.<sup>[20]</sup> It is scored by summing the number of problems identified by the care giver. The NIQ is a 29-item inventory with semantic differentials regarding the patient<sup>[17]</sup> (such as 'when I compare the patient with how he/she was before surgery I consider him/her to be "Talkative" or "Quiet" with "Same" as the neutral response and 'A lot more' at either end of the differential and 'A little more' as an intermediate response). Some of the items are reverse scored and treating the response as Likert type responses, the score on the NIQ is obtained by summing the item scores. The response is summed as a Likert response. The internal consistency of this index was calculated in the present study to be Cronbach's alpha = 0.90 (n = 36). A high score indicates a greater impact of the patient's condition on the care giver. The SF12 and GHQ-12 for the care giver were analyzed in a similar manner with the patients'.

Data were entered on an SPSS database and statistical analysis was carried out for internal consistency of FLI and NIQ using Cronbach's alpha; correlation between dependent variables (e.g. quality of life, psychological morbidity, and care giver coping) using Pearson's correlation (r); and listwise deletion of missing cases was used. Care givers' burden was also analyzed against the patients' tumor type and grade. Because of multiple modality of treatment for many of the patients, it was difficult to analyze against treatment.

## Results

A total of 66 questionnaires were returned, representing a low return rate of 39.3%. This was due to deaths and serious illness within the study population during the period of the study. Although the patient's age ranged from 21 to 82 years, the care giver's age ranged from 23 to 85 years. The male/female ratio for patients is 1 : 1.4 and for care givers is 1 : 0.9. Of the 66 respondents, 18 were operated on for glioma, 27 for meningiomas, and 21 for other tumors; 14 patients were self-caring and two were under professional care. The demographics of the 50 nonprofessional care givers are presented in Table 1 and patients in Table 2.

Eleven care givers either took early retirement or worked only part time.

All patients had surgery; 15 had additional radiotherapy and six more were aware that they need radiotherapy. The extent of resection was not determined for this study.

Table 3 shows the correlation matrix for all independent variables. The patient's FLI correlates significantly with their

**Table 1: Care giver demographics**

Sex	M	26
	F	24
Age	<30	2
	30-65	30
	66-80	17
	>80	4
Occupation	Working (part/full)	23
	Retired	15
	None	11
Relation to patient	Spouse/partner	45
	Offspring	3
	Other (friend/parent)	3

**Table 2: Patient demographics**

Sex	M	27
	F	39
Age	<30	6
	30-65	43
	66-80	31
	>80	1
Tumor type	Glial	18 (27.3%)
	Meningeal	27 (40.9%)
	Other	21 (31.8%)

**Table 3: Correlation matrix for independent variables (n shown in brackets) Negative correlations are not shown**

	FLI	SF12PP	SF12PM	GHQP	CCQ	NIQ	SF12CP	SF12CM	GHQC
FLI	1	0.667* (44)	0.715* (44)	0.819* (49)	0.512* (51)	0.602* (31)	0.069 (31)	0.288 (31)	0.346 (32)
SF12PP		1	0.211 (52)	0.485* (50)	0.343+ (52)	0.350+ (32)	0.186 (30)	0.037 (30)	0.319 (32)
SF12PM			1	0.782* (50)	0.465* (52)	0.404* (32)	0.105 (30)	0.331 (30)	0.120 (32)
GHQP				1	0.570* (60)	0.585* (35)	0.140 (36)	0.435* (36)	0.331+ (37)
CCQ					1	0.634* (36)	0.173 (37)	0.606* (37)	0.638* (39)
NIQ						1	0.210 (29)	0.310 (29)	0.350 (30)
SF12CP							1	0.126 (37)	0.107 (36)
SF12CM								1	0.799* (36)
GHQC									1

FLI Functional Living Index (patient), SF12PP: Physical quality of Life (patient), SF12PM: Mental quality of Life (patient), GHQP: Psychological morbidity (patient), CCQ: Care coping (care giver), NIQ: Treatment Impact (care giver), SF12CP: Physical quality of life (care giver), SF12CM: Mental quality of life (care giver), GHQC: Psychological morbidity (care giver), \*P<0.05, \*P<0.01

physical and mental quality of life (SF12) and with their psychological morbidity (GHQ). The FLI also correlates significantly with the care giver's ability to cope (CCQ) and the degree of impact of the disease and treatment on the care giver (NIQ), but not with quality of life or psychological morbidity in care givers (GHQ, SF12C). The ability of the care giver to cope (CCQ) correlates significantly with impact of the disease on the care giver (NIQ), with care giver's mental quality of life (SF12CM), and with care giver's psychological morbidity (GHQC). The impact of the disease on the care giver (NIQ) does not relate significantly to the quality of the care giver's life (SF12C) or their psychological morbidity (GHQC). It does however correlate well with the patient's functional living, physical and mental quality, and psychological morbidity.

No differences in the scores on quality of life or psychological morbidity were found between those designated as working/retired and spouse/other relation. Both physical (P<0.001) and mental (P<0.001) aspects of quality of life were better for patient's children (n = 2) who were care givers than for spouses (n = 32) who were care givers.

### Discussion

This study examines the long-term burden of brain tumor diagnosis and treatment on both the patient and their care givers and how the care givers' burden is affected by the severity of the patients' illness. Despite a lot of effort being made to ease the burden of care for patients with chronic illnesses, this has often been poorly targeted.<sup>[15]</sup> Increasing number of studies<sup>[21-23]</sup> have addressed the problem of care for brain tumors and the recent National Institute for Clinical Excellence guidelines<sup>[1]</sup> have streamlined the

process of management for this difficult disease. However, these studies only capture either the patient's or the care giver's perspective. Only few<sup>[4,10,15]</sup> have simultaneously looked at the interplay between the patient and the care giver in any detail.

The FLI of the patient and the impact of the illness on the care giver (NIQ) both have Cronbach's alpha of 0.93 and 0.90, respectively, indicating good reliability of these scales. The positive correlation between the FLI and the impact of the disease and intervention on the care giver (NIQ) suggests that the patient's view of their illness is congruent with the care giver's view. The patient's living index also correlates with the patient's psychological morbidity, indicating that the patient's quality of life is affected by their psychological adjustment to the diagnosis and treatment. The significant correlation between the FLI and both the patient's psychological morbidity and the degree of impact of the disease on the care giver may suggest that the patient's quality of life is affected by their perception of the impact of the illness on their care giver and vice versa.

The patient's general and psychological health also directly and significantly affects the care giver's ability to cope with care ( $P < 0.001$ ). Since the ability to cope by the care giver is directly affected by the impact of the disease on the care giver ( $P < 0.001$ ), the quality of care reduces with any deterioration in the patient's quality of life. This in turn increases the stress on the patient. The better the patients' living index, the better the care giver can cope.

The living index of the patient was found to be related to the tumor type and grade. It has been established that the better informed the patients are about their diagnosis and available support, the better their quality of life.<sup>[24]</sup> Irrespective of the tumor grade or type, initial communications and adequate support systems are essential for both the patient and their care givers. We did not however measure the living index against treatment modality because many patients had multiple modalities of treatment.

The mental and physical quality of life of the care giver (SF12C) as well as their psychological morbidity (GHQC) did not significantly correlate with the patient's functional living, although they correlate with each other. The care giver's psychological morbidity is also significantly related to the patients (0.331;  $P = 0.045$ ). Thus, the care giver's quality of life is profoundly affected by the patient's psychological and general health and this must be taken into account if we are to improve the care giver's health profile and the quality of care for these patients.

Although there is increasing awareness of the need to refer patient's early for support, the care of brain tumor patients in the community still remains a family burden.<sup>[25]</sup> We found that care givers who are spouses have a lower psychological

morbidity and a lower physical quality of life (SF12C both subscales) than those who are offspring of the patient. This suggests that the spouses are better motivated and accept the status of care better. However, since they are on the whole a generation older, care constitutes a significant physical burden. In general, there is an inverse relationship between care givers' age and the physical score on the SF-12. Nevertheless, although they generally scored better on physical well-being, social burden was more marked in younger cares.

The fact that the caregivers' ability to cope with the demands of care correlated strongly with the care givers' mental and psychological quality of life may also have been due to social deprivation rather than an index of extent of care required. Indeed, 38% of care givers were concerned that the burden of care had deprived them of their own social interaction.

Thirty-six care givers were either retired or not working. Of those who were retired, the majority (80%) were females. All males and 50% of the females who retired did so reluctantly. Those who were not working were either past the age, were housewives, or had never worked. There was no correlation between the patients' tumor type and grade with the care giver's return to work, perhaps because patients who are very ill die early.

We conclude that there is significant physical, social, and psychological morbidity associated with caring for brain tumor patients and that like patients with SAH,<sup>[17]</sup> this is directly related to the care giver's perception of the patient's outcome. Our study also showed that patients with brain tumor worry about the effect of their illness on their care givers and this may constitute considerable stress for the patient. We believe that care processes for brain tumor patients must take into account the welfare of their primary care givers. Considerable work needs to be done among care givers of patients with severe neurosurgical illnesses. Patient's and care givers need structured support at least to the standard for other neurological diseases such as Alzheimer's.

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