

A study of patients with a primary malignant brain tumour and their carers: symptoms and access to services

Anne Arber, Sara Faithfull, Marek Plaskota, Caroline Lucas, Kay de Vries

Abstract

Aim: To investigate the symptom experience, access to supportive care services and rehabilitation of patients with a primary malignant brain tumour (PMBT) and their carers. **Methods:** A case review of 70 patients with a diagnosis of PMBT who received palliative care in five specialist palliative care units between July 2005 and June 2006. The review examined patients' symptom experience, care issues, access to rehabilitation and access to supportive care services. **Results:** The two most significant issues experienced by patients and identified in the case review were hemiparesis (17%) and cognitive problems (16%). There were a number of care problems concerning safety related to mobility and falls (9%). Symptoms related to fatigue and tiredness were reported infrequently. There was an absence of information relating to the needs of informal carers; however, 18% of carers accessed bereavement counselling services following the death of the person they cared for. **Conclusion:** The needs of carers were not found to be routinely documented within the case notes. For some patients, referral to specialist palliative care services occur late in the illness trajectory, which means that patients and carers may not be able to access the full range of supportive care services available. Initial assessment of patients should identify the range of support services that both carers and patients are offered; and the uptake and response to services should be documented throughout the illness trajectory.

Key words: ● Primary malignant brain tumour ● Case notes review
● Carers ● Symptoms ● Rehabilitation

hope for the future in terms of treatment and survival, as some patients such as those of younger age, with glioblastoma multiforme and with a good performance status have an improved prognosis following combined treatment with chemotherapy and radiotherapy (Mirimanoff et al, 2006). Glioblastoma multiforme is a highly malignant astrocytic tumour primarily affecting people aged between 60–70 years of age, which occurs most often in the frontal and temporal lobes, and causes invasion and destruction of surrounding brain tissue (Guerrero, 1998).

Cognitive impairment, alterations in functional status and the presence of neuropsychiatric symptoms are the most common problems associated with PMBT (Sherwood et al, 2004). In one study cognitive dysfunction was evident in 50–80% of patients at the time of diagnosis (Tucha et al 2000). Cognitive changes result in short-term memory loss, reduced attention, personality changes and altered mood (Weitzner, 1999). In an interview study of 95 caregivers of people with a PMBT, Sherwood et al (2006) report many concerns such as worries about short-term memory problems, and patients' difficulties in making decisions. In another study the most commonly reported neuropsychiatric symptoms were depression, irritability, night time disturbances, apathy and hallucinations (Klein et al, 2001). Klein et al found a link between the care recipient's neuropsychiatric symptoms and higher levels of depression in the caregiver. Poor cognitive functioning has been linked to high levels of stress and anxiety in carers (Pinquart et al, 2003). Managing relationships, cognitive difficulties, personality changes and symptoms such as fatigue can be exhausting and anxiety provoking for carers (Janda et al, 2007, 2008). Despite the demands on carers it is reported that for some people, family relationships can become stronger and closer, despite behavioural and personality changes (Cook 2005; Arber et al 2007). As well as cognitive changes there are

Anne Arber is Pathway Leader Cancer Care, Faculty of Health and Medical Sciences, Sara Faithfull is Professor of Cancer Nursing Practice, Faculty of Health and Medical Sciences, University of Surrey, Guildford; Marek Plaskota is Research Nurse, Caroline Lucas is Deputy Medical Director, The Princess Alice Hospice, Esher, Surrey; Kay de Vries is Senior Lecturer, Dementia Studies, Institute of Health and Society, University of Worcester, United Kingdom

Correspondence to:
Anne Arber
a.arber@surrey.ac.uk

Primary malignant brain tumour (PMBT) is a comparatively rare but devastating cancer, which places many demands on carers as well as health professionals. PMBT accounts for 2% of all cancers. There are around 3000 new cases of PMBT in adults each year in England and Wales, and it is associated with a very poor prognosis with around 2500 deaths a year. The median overall survival for those with PMBT is about 12 months. In Europe the mean 5-year survival in adults is 18.7%, a similar pattern of survival to patients with lung and oesophageal cancer (Berrino et al 2007). The majority of PMBTs in adults are high-grade gliomas, which are most common in older people (Chakrabarti et al, 1999). There is some

also safety issues associated with hemiparesis, which affect carers' ability to leave the home. Without good health and social care, support carers may be tied to the home, leading to difficulties in going to work and accessing support outside of the home. In a study by Janda et al (2007) a correlation was found between carers' and patients' overall quality of life, with patients and carers in the same household reporting similar reductions in emotional and social wellbeing.

The aim of this study was to identify the range of support services used by patients and carers; the type of symptoms experienced; the timing of referral to specialist palliative care services; and access to rehabilitation services. An additional secondary aim was to identify the support needs of carers and how they are met.

Method

A retrospective review of the multidisciplinary case notes of 70 patients who received care in five specialist palliative care settings was conducted. The five specialist palliative care settings included four hospice units and their community teams, and one palliative day care unit and its attached community team. The review was carried out on the case notes of patients with PMBT receiving care between 1 July 2005 and 30 June 2006. A tool/proforma was developed from previous pilot work carried out in one hospice service, which is published elsewhere (Faithfull et al 2005). The proforma included demographic information, symptom experience, care issues, services used and place of death (Figure 1). One person, a research nurse, collected the audit data to enable consistency in data collection. Data were analysed using descriptive statistics and content analysis.

Findings

Patient demographics and diagnosis

The median age of the sample was 64 years, ranging from 21 years to 94 years, 56% men ($n=39$) and 44% women ($n=31$). The majority of patients had a diagnosis of high-grade glioblastoma (59%, $n=41$), with 21% ($n=15$) astrocytoma, and 6% ($n=4$) oligodendroglioma. A total of 10% of patients ($n=7$) had no confirmed diagnosis. Sixty-one per cent ($n=43$) of patients were married or co-habiting with a partner. The majority stated that the main carer was his or her partner. Thirty-four per cent ($n=14$) were divorced, separated, single or widowed. Other primary carers were named as children (7%, $n=5$), e.g. sibling, niece (5%, $n=4$), parents (4%, $n=3$) or nursing home staff (13%, $n=9$).

Symptoms experienced

The data from the case review highlight the complexity of patient symptoms, with 56% of patients having one or more symptoms, and a further 10% four or more (Table 1). The most common problem was hemiparesis (17%) followed by cognitive problems (16%). In addition a number of issues concerning safety were identified related to mobility and falls (9%). Symptoms such as fatigue and tiredness were rarely documented despite the fact that fatigue and tiredness are reported as significant problems for people with PMBT in other research studies (Osoba et al, 2000; Janda et al, 2008).

There were few emotional and psychosocial problems identified in the case notes that relate to quality of life issues for the patient and the carer. It was difficult to identify carers' needs and problems from the information documented in the case notes. However, carer distress was identified in seven case notes. This suggests that staff may only document information about carers when there is significant emotional upset. Carers' ability to cope with physical, cognitive and behavioural manifestations of this condition was not routinely documented.

Access to health services

A total of 28% of patients were found to be admitted to a hospice inpatient unit and 15% to other acute inpatient services. Information was not routinely documented in relation to the reasons for admission to acute services. Eleven per cent of patients attended outpatient appointments with oncologists, which is lower than the figure identified in the pilot study conducted by Faithfull et al (2005), suggesting that hospital outpatient visits have reduced in number.

Within the community 49% of patients accessed district nursing services (Table 2). Seven per cent accessed other voluntary-based services such as Marie Curie services. Twenty-four per cent attended day hospice. Thirty-six per cent were referred to social services and this probably reflects their need for help with activities of daily living such as washing and dressing. Patients also accessed physiotherapy (35%) and occupational therapy (31%). Thirty-four per cent of patients were reported to receive financial benefits. These benefits were documented as being mainly disability and attendance allowance. Complementary therapies, mainly massage and aromatherapy, were used by 24% of patients and carers.

There was little evidence that patients or their carers accessed support groups, as only two

• *Poor cognitive functioning has been linked to high levels of stress and anxiety in carers* •

Figure 1. Proforma/audit tool

Audit of case notes			
Patients with a primary malignant brain tumour			
Unit location:		Date of review (dd/mm/yy):	
Study number:	Patients age:	Sex:	
Type of tumour (if known):			
Date of diagnosis (dd/mm/yy):			
Type of Initial treatment:			
Marital status:			
Who does the patient live with?:			
Relationship to the patient:			
Date of referral to hospice (dd/mm/yy):			
Where was the patient referred from:			
Initial referral to: Community team <input type="checkbox"/> Inpatient unit <input type="checkbox"/> Day hospice <input type="checkbox"/>			
Total number of admissions to hospice:			
Details of each hospice admission		Admission to other units	
(Use key over page for admission reasons)			
1. Date of admission: Admitted from: Date admission ended: Reason for admission:		2. Date of admission: Admitted from: Date admission ended: Reason for admission:	
3. Date of admission: Admitted from: Date admission ended: Reason for admission:		4. Date of admission: Admitted from: Date admission ended: Reason for admission:	
5. Date of admission: Admitted from: Date admission ended: Reason for admission:		6. Date of admission: Admitted from: Date admission ended: Reason for admission:	
7. Date of admission: Admitted from: Date admission ended: Reason for admission:		8. Date of admission: Admitted from: Date admission ended: Reason for admission:	
9. Date of admission: Admitted from: Date admission ended: Reason for admission:		10. Date of admission: Admitted from: Date admission ended: Reason for admission:	
Reasons for admission (state letter/s for each admission)			
Symptoms		Care Issues	
Neurological weakness	A	Not sleeping	L
Incontinent	B	Difficulty swallowing	M
Bowel problems	C	Headache/ Pain	N
Cognitive state	D	Speech deficits	O
Nausea/ vomiting	E	Unable to take medication	P
Crying distress	F	Nutrition	Q
Epilepsy or seizures	G	Pump IV/ SC	R
Vision	H	Falls/ risk	S
Extra pyramidal signs	I	Catheterised	T
Agitation	J	Psychological	U
Sleepy/ Drowsy	K	Carer distress/social problems	V

Figure 1. Proforma/audit tool (continued)

Services accessed by patient since diagnosis: (Add detail to all that apply)
Community team:
Other community specialist palliative care team:
District nursing:
Other nursing service (e.g. Marie Curie/private/twilight services):
Day hospice:
Other day centre:
Support group:
Clinic:
Social worker :
Social services (e.g. meals on wheels/carers/ attendance or disability allowance):
Benefits agency:
Physiotherapy:
Occupational therapy (e.g. equipment):
Complementary therapy:
Chaplain/minister:
Dietician:
Speech therapy:
Psychiatrist/counsellor:
Voluntary service (at home):
Other:
Liverpool Care Pathway:
To be completed if patient has died:
Date of death:
Place of death:

people who used support groups were identified. Support groups for patients and carers exist on all the sites studied so it could be that these were not accessible to the patients or carers due to the many complex social and physical problems experienced. There needs to be further investigation of this finding. Twenty-five patients and carers (35%) used counselling services, which focused on bereavement support after the patient had died (18% $n=13$), or individual patient support (10% $n=7$); only 13% accessed chaplains or had ongoing support from their church. Carer distress was documented as a concern for only seven carers but this was not cited as a reason for the patient's admission to an in-patient unit and did not appear to be related to symptom profiles. Thirty-three per cent of patients had additional problems documented under 'other' such as terminal care, chest infections or facial swelling.

Place of death

Details of place of death were available for 79% ($n=55$) of patients; for the remaining patients there was no information about whether they were still alive, or if deceased, where they had died. Of the patients who were recorded as deceased 30% died at the hospice, 16% died at

home, 20% died in another hospital, 13% died in a nursing home, 21% had an unknown place of death. Those in the younger age group were more likely to have died in a hospice. The time scale between diagnosis and death was a median of 130 days (18 weeks) with an interquartile range (IQR) of 47–330 days. Of the 55 who had place and date of death documented, the time from diagnosis to referral to the palliative care team was a median of 80 days (11 weeks) with an IQR of 17–193 days. Of these, the time range between referral and death was a median of 62 days (8 weeks). There was local variation in the time between diagnosis and referral to palliative care services; with a median of 66 days from diagnosis to referral at one service and a median of 106 days for the same referral at another service. This may reflect local variation in clinical nurse specialist provision and referral pathways. Some patients are therefore accessing specialist palliative care support very late in the illness trajectory, which may have implications for supportive care.

Discussion

Patients are identified as having significant needs in relation to hemiparesis causing mobility and/or safety problems. Worries about safety and the

risks of falling owing to functional impairment was a serious concern of carers in Arber et al's (2007) study and resulted in carers being tied to the home. Cognitive dysfunction is also common (Table 1) and is the most serious outcome of a primary brain tumour. Cognitive difficulties are reported to be much more frequent than physical disability in the literature (Kier et al, 2008). However, in this study there is a slightly higher incidence of problems with hemiparesis and mobility and/or safety issues, and the reasons for this are not clear. Janda et al (2008) found that carers ranked their number one need as adjusting to the changes in the mental and thinking ability of the person with a brain tumour. Managing difficult aspects of behaviour was ranked second, and fourth was adjusting to changes in the personality of the person with a brain tumour. In another study of carers of people with cancer many unmet needs were identified including a lack of skills to manage cognitive impairment and a lack of support from health-care services (Hudson, 2004). It is possible that cognitive

problems were under-reported in this study because of the difficulties in assessing cognitive status, as many changes may be subtle and difficult to detect. Davies et al (2003) stated that the cognitive and behavioural changes found in patients with brain tumours may not always be evident to health-care staff, and patients may appear physically and cognitively 'normal' to those outside of the close family. Executive functions such as managing multiple priorities may be impaired subtly and difficult to detect without the use of assessment tools related to cognitive assessment (Wideheim et al, 2002).

Problems such as fatigue and tiredness were rarely documented, with only one patient having this symptom documented in the case notes. It is well known that radiotherapy treatment causes neurological toxicity, and fatigue is identified as present at diagnosis of PMBT, and is negatively correlated with maintaining a good quality of life (Lovely et al, 1999; Pelletier et al, 2002). The issues of fatigue in patients with PMBT and the link with quality of life has not been fully investigated. This is an urgent area for investigation in future research studies (Catt et al, 2008).

There appears to be little documented use of patient/carer support groups although these were available in the locations of this study. Furthermore only a small proportion of patients (24%) used day-care services. This may be associated with 'being tied to the home' owing to mobility and cognitive problems, resulting in difficulties with social interaction, which may mean that patients and carers are unable to access or benefit from these services.

About half of the patients used district nursing (DN) services. This is lower than the figure identified from an earlier study where 72% of patients were found to access the DN service (Faithfull et al, 2005). Changes in the provision of DN services may mean that access to this service is restricted. A range of services are accessed by patients, predominantly physiotherapy and occupational therapy, with a few patients accessing speech and language therapy. Surprisingly no patient had a social work referral and about a third of patients and/or carers have referrals to counselling services. One of the issues that needs further investigation is the different practices in relation to the timing of referral to specialist palliative care services; in one service referrals occurred on average 2 months after diagnosis but this was 4 months at another service.

Assessment of carer needs and their coping was not routinely documented in patients' case

Table 1. Symptoms and care problems

Symptoms		Care problems	
Hemiparesis	12 (17%)	Speech difficulties	8 (11%)
Cognitive state	11 (16%)	Poor mobility/ falls	6 (9%)
Dysphagia	5 (7%)	Carer distress	7 (5%)
Headaches	3 (4%)	Agitation	3 (4%)
Nausea and vomiting	3 (4%)	Unable to take medicines	2 (3%)
Incontinence	3 (4%)	Psychological issues	2 (3%)
Extra pyramidal symptoms	2 (3%)	Syringe Pump	1 (1%)
Seizures (epilepsy)	2 (3%)	Other	23 (33%)
Tiredness/ sleepy	1 (1%)		

Table 2. Services used by participants

Services	Number (%)
District nursing services	35 (49%)
Social services	25 (36%)
Physiotherapist	25 (36%)
Counselling services	25 (36%)
Occupational therapist	22 (31%)
Complementary therapy	17 (24%)
Day hospice care	17 (24%)
Chaplains	9 (13%)
Speech therapist	7 (10%)
Voluntary Services	5 (7%)
Dietitian	3 (4%)
Support groups	2 (3%)


notes by specialist palliative care staff. However, carers' needs were identified if there is significant carer distress. This may reflect a reactive approach to carer's needs rather than a proactive approach. The absence of a focus on the carer is disappointing as there is a great deal of research evidence documenting the difficulties and worries experienced by carers coping with people with a PMBT at home (Janda et al 2008). In a small study of 12 patients who were 2-year survivors of a malignant brain tumour, Davies et al (2003) found that seven patients had considerable difficulties related to anxiety, irritability, fatigue and depression. These patients reported more psychiatric symptoms and had a wider range of cognitive deficits on neurological testing. In one third of cases, patients and carers disagreed about the extent of problems, with relatives rating the patient more disabled than reports from the patient. In another study Janda et al (2008) 70 carers of people with a brain tumour reported emotional problems linked with the strain of living with an 'altered' person as well as the threat of losing them. Carers also reported feeling frustrated with the person with the brain tumour (Adelbratt et al, 2000). At the present time the needs of carers and other family members are not comprehensively assessed and routinely documented in the case notes; therefore, it is likely that carers may not be able to access and benefit from practical supportive care strategies to help them cope with a challenging situation involving physical and cognitive decline. Carers may not be aware of the social support groups available to them and if they are aware may not be able to attend them owing to caring responsibilities in the home.

There are a number of limitations to this study. The five palliative care services studied use different formats for their notes. The notes were hand written and the extent and depth of documentation differed across the sites. For example, there was some incompleteness in relation to data in the notes such as place of death, information related to the coping of carers and a paucity of information about the problem of fatigue. To enable consistency in data collection one person collected all the data from all the study sites. None of the services were using the Liverpool Care Pathway (LCP) at the time of the study as all the study sites were in one cancer network where the LCP had yet to be implemented. A repeat study with the LCP in place might reveal more specific information on patient's symptom experience as well as carer's experience. However, it is advisable that standards are developed in relation to

documenting the needs of carers and how they manage cognitive, behavioural and personality changes and gain support. The results of this study cannot be generalized beyond the locations and context of the study due to the small numbers involved.

Conclusions

The results of this study raise a number of concerns. Of particular note is the lack of information about carers' needs at the end of life, which is receiving a great deal of attention at the present time (DH, 2008). The lack of documentation of the needs and support offered to carers is worrying as funding and resource allocation follows the identification of needs. It is important that health professionals identify the range of support services that carers and patients have been offered as well as the uptake of services and any barriers to service use; reassessment of carers and patients in relation to supportive care services is essential, as needs change over time for both the patient and the carer.

There appears to be some discrepancy across services in the timing of specialist palliative care referral. As identified by DH (2008) the care pathway for this group of patients (as for all patients requiring end-of-life care) should identify the timing of referral to specialist palliative care services as this opens the door for not only the physical needs of patients but also a range of support services such as respite care, complementary therapies, and psychological services. The lack of assessment and documentation of the symptom of fatigue needs further investigation as well as any barriers to the use of day care services and patient and carer support groups. 

• Carers may not be aware of the social support groups available to them •

- Adelbratt S, Strang P (2000) Death anxiety in brain tumour patients and their spouse. *Palliative Medicine* 14(6): 499–507
- Arber A, Hutson N, Faithfull S (2007) *The Carers' Journey: Exploring the Experience of Informal Carers of Patients with a Primary Malignant Brain Tumour*. Faculty of Health and Medical Sciences, Duke of Kent Building, University of Surrey, Guildford, UK
- Berrino F, De Angelis R, Sant M et al (2007) Survival for eight major cancers and all cancers combined for European adults diagnosed in 1995–99: results of the EURO-CARE-4 study. *Lancet Oncol* 8(9): 773–83
- Catt S, Chalmers A, Fallowfield L (2008) Psychosocial and supportive-care needs in high-grade glioma. *Lancet Oncol* 9: 884–9
- Chakrabarti I, Cockburn M, Cozen W, Wang YP, Preston Martin S (1999) A population-based description of glioblastoma multiforme in Los Angeles County, 1974–1999. *Cancer* 104(9): 2798–806
- Cook KL (2005) The carers' experience: caregiving for primary malignant brain tumour patients with palliative

- care needs. Unpublished MSc dissertation, Faculty of Health and Medical Sciences, Duke of Kent Building, University of Surrey, Guilford, UK
- DH (2008) *End of Life Care Strategy Promoting High Quality Care for All Adults at the End of Life*. Department of Health, London
- Davies E, Hall S, Clarke C (2003) Two year survival after malignant cerebral glioma: patient and relative reports of handicap, psychiatric symptoms and rehabilitation. *Disability and Rehabilitation* 25(6): 259–66
- Faithfull S, Cook K, Lucas C (2005) Palliative care of patients with a primary malignant brain tumour: case review of service use and support provided. *Palliat Medicine* 19(7): 545–50
- Guerrero D (1998) *Neuro-Oncology for Nurses*. Whurr, London
- Hudson P (2004) Positive aspects and challenges associated with caring for a dying relative at home. *Int J Palliat Nurs* 10(2): 58–65
- Janda M, Steginga S, Dunn J, Langbecker D, Walker D, Eakin E (2008) Unmet supportive care needs and interest in services among patients with a brain tumour and their carers. *Patient Educ Couns* 71(2): 251–8
- Janda M, Steginga S, Langbecker D, Dunn J, Walker D, Eakin E (2007) Quality of life among patients with a brain tumor and their carers. *J Psychosom Res* 63(3): 617–23
- Keir ST, Calhoun-Egan RD, Swartz JJ, Friedman HS (2008) Screening for distress in patients with brain cancer using the NCCN's rapid screening measure. *Psychooncology* 17(6): 621–5
- Klein M, Taphoorn MJ, Heimans JJ, van der Ploeg HM, Vandertop WP, Smit EF (2001) Neurobehavioural status and health-related quality of life in newly diagnosed high-grade glioma patients. *J Clin Oncol* 19(20): 4037–47
- Lovely MP, Miaskowski C, Dodd M (1999) Relationship between fatigue and quality of life in patients with Glioblastoma Multiformae. *Oncol Nurs Forum* 26(5): 921–25
- Mirimanoff RO, Gorlia T, Mason W et al (2006) Radiotherapy and temozolomide for newly diagnosed glioblastoma: recursive partitioning analysis of the EORTC 26981/22981- n cic CE3 phase 111 randomized trial. *J Clin Oncol* 24(16): 2563–9
- Osoba D, Brada M, Prados M.D, Yung WKA (2000) Effect of disease burden on health-related quality of life in patients with malignant gliomas. *Neurooncology* 2(4): 221–8
- Pelletier G, Verhoef MJ, Khatri N, Hagen N (2002) Quality of life in brain tumor patients: the relative contributions of depression, fatigue, emotional distress, and existential issues. *J Neurooncol* 57(1): 41–9
- Pinquart M, Sorensen S (2003) Association of stressors and uplifts of caregiving with caregiver burden and depressive mood: A meta-analysis. *J Gerontol B Psychol Sci Soc Sci* 58(2): 112–28
- Sherwood PR, Given B, Given C, Schiffman R, Murman D, Lovely M (2004) Caregivers of persons with a brain tumor: a conceptual model. *Nursing Inquiry* 11(1): 43–53
- Sherwood PR, Given BA, Given CW, Schiffman RF, Murman DL, lovely M, et al (2006) Predictors of distress in caregivers of persons with a primary malignant brain tumor. *Res Nurs Health* 29(2): 105–20
- Tucha O, Smely C, Preier M, Lange KW, Klaus W (2000) Cognitive deficits before treatment among patients with brain tumours. *Neurosurg* 47(2): 324–34
- Weitzner MA (1999) Psychosocial and neuropsychiatric aspects of patients with primary brain tumors. *Cancer Invest* 17(4): 285–9
- Wideheim AK, Edvardsson T, Pahlson A, Ahlstrom G (2002) A family's perspective on living with a highly malignant brain tumour. *Cancer Nurs* 25(3): 236–44