

Carers of patients with a primary malignant brain tumour: Are their information needs being met?

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Patients suffering from a primary malignant brain tumour can experience physical, cognitive and behavioural alterations that can make significant demands on family life. It is not unusual for carers to feel fatigued, have poor sleep patterns and receive insufficient support. Carers need access to good quality information, timely, sensitive and accurate assessment of needs and access to both good professional support and peer support. People diagnosed with PMBT have a very poor prognosis but survival is increasing for some groups of patients (Mirimanoff et al, 2006) and quality of life following treatment is a great concern for patients and carers.

Background

Many patients with PMBT experience memory problems and personality changes. Problems with short-term memory loss, fatigue and feelings of apathy may lead to difficulties with initiating activity, decision-making, adhering to treatment, self-care activities and performing tasks in the home (Fox et al, 2006). Furthermore, cognitive impairment may be subtle and only detected by close family members (Weitzner and Meyers, 1997; Davies et al, 2003). Many carers in the context of cancer and other chronic illnesses report feeling invisible to health professionals, leading them to feel alone and overwhelmed (Thomas et al, 2002; Stoltz et al, 2006).

Carers also report difficulties in asking for help and want to give as much care as they can themselves. However, this can lead to exhaustion and physical and emotional problems for the carer (Greenberger and Litwin, 2003). In a study of home-based palliative care, carers identified a lack of attention to their needs by specialist staff (Hudson, 2004). Additionally, carers' needs do not seem to be routinely documented in case notes (Arber et al, 2010). There is evidence from a small interview study that hospice nurses, therapy radiographers and GPs felt that they lacked knowledge in managing patients with a brain tumour and this contributed to a lack of awareness of the relevance of rehabilitation services (McCartney, 2010).

In one interview study of 39 patients with terminal cancer and 35 relatives, information-giving was one of the most important areas identified, and, in particular, the issue of prognosis and hope (Kirk et al, 2004). However, many people reported distress at how the

ABSTRACT

Providing care in the home is very demanding, particularly where people with a primary malignant brain tumour (PMBT) are concerned, as there are physical, cognitive and behavioural alterations that can make significant demands on family caregivers.

Aim: The aim of this article is to consider carers' access to information following diagnosis of a PMBT and information on managing the caring role.

Method: A grounded theory approach was used, with 22 open-ended interviews carried out with active carers at the time of the interview.

Findings: Carers identified a lack of attention to their need for information particularly regarding medication, caring and working, and becoming a carer. They develop strategies such as using the Internet to search for information and support and using friends to filter information so they are not overwhelmed with depressing information. Using these strategies, carers reduce uncertainty, alleviate stress and find a way to continue to hope.

Conclusions: Carers lack guidance on how to access information at different stages of the caring journey. However, they are resourceful in finding support and information and expect health services to include and signpost them to the most appropriate sources of information.

Key Words Caregivers, primary malignant brain tumour, information

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information was provided, such as bad news being given too soon or when it had not been asked for. The second important issue was the need for a hopeful message such as the possibility of cure, or continued care and 'not giving up'.

Aim

There are specific difficulties and unique challenges that complicate the PMBT caring role. These include the often rapid recurrence and/or progression of the tumour following treatment (McConigley et al, 2010) and a poor prognosis with many associated symptoms (Lidstone et al, 2003). There is a great need for infor-

mation on the part of carers to try and understand the diagnosis and treatment and then to understand how to manage the patient in the longer-term at home (Janda et al, 2006; Schubart et al, 2008). Additionally, the need for information may not always be known by the carer at the time of the outpatient appointments. In this study, the researchers wanted to assess carers' access to information and how helpful they found it. In particular, they wanted to assess the information and support carers receive at diagnosis and in the early stages of the disease, and how the information is accessed.

Method

In-depth qualitative interviews were undertaken using a grounded theory approach, with 22 family carers who were actively caring for a PMBT patient at the time of the interview (Charmaz, 2006). The study was approved by the NHS Research Ethics Committee. Written information was provided to participants and written informed consent gained for each interview. A single researcher carried out all the interviews and two researchers analysed the data.

Research participants

The sample of carers was purposive, from one specialist hospital in the South of England covering a large geographical area. Participants included twelve female partners, five male partners, two daughters, one son, one mother and one father who were caring for family members with a PMBT. The majority of carers in the sample were under 60 years of age—five carers were in their 60s, six were in their 50s, four were in their 40s, six were in their 30s and one was in her 20s. Of the 22 carers, eight had been caring for over 2 years.

Data collection and analysis

Interviews lasted between 60 minutes and 2 hours. The interviews were audio-recorded. Interviews were open-ended and started with an open question: 'Can you tell me about your caring role?' Most of the interviews were conducted in the carers' homes apart from three which were conducted in another location of the carer's choice. The data was audio-recorded and transcribed verbatim. The two researchers involved in analysing the data read all of the transcripts independently and separately coded the data using line-by-line analysis. Inter-coder reliability was checked. Constant comparative analysis was used to interpret the data to generate categories and then themes. A search was also conducted for deviant cases. Data saturation was reached as no new data categories were generated.

Findings

A key theme that emerged from the data was that of the carer's very challenging journey. This journey was negotiated with significant difficulty alongside the person with a PMBT and there were gaps in information provision along the way that caused anger, fear and

upset to carers. Carers reported a mixed picture regarding information provision and support. Areas that carers found difficult and where they reported a lack of information were:

- Combining employment and caring
- Managing finances and benefits
- Locating support groups
- What to expect following neurosurgery
- Managing medications.

Information at discharge

Many carers felt taken for granted and were critical of the lack of information they received from hospital services following surgery. For those who were followed-up in district general hospitals, gathering information was extremely problematic. One carer described how she felt she was given no useful information:

We weren't given any information, nothing. We weren't given any help until last year when I kicked up a fuss big time. (Wife 15)

After eventual referral to a specialist, the level of information the carer received was described as significantly improved. She was particularly concerned about information in relation to benefits and respite care as she not only cared for her husband but also had to care for a disabled child. Three carers remarked on how good the specialist hospital was in providing explanations and written information, in contrast to other centres. In the specialist hospital there was a designated neuro-oncology clinical nurse specialist whose role involved providing information and support and this made a significant difference to the perception of the quality of information this participant had received.

A further carer describes how she felt unsure about whether information was available or not, although she was aware that she may have been given information verbally and could not remember it:

In the beginning I had no advice on what happens to people with brain tumours. The health professionals didn't guide me where to go. I think it was all there but I didn't take it, I don't know. (Wife 1)

This carer felt she lacked information on what happens following diagnosis and treatment of a brain tumour and would have liked someone to guide her. When carers experience high levels of anxiety and worry it is very difficult for them to retain information. This carer experienced high levels of distress and anxiety as her husband was declining and reaching the end of his life. Although she had good support from Marie Curie nurses and district nurses she did not have regular visits from community palliative care nurses.

Another carer mentioned the lack of information from the neurosurgical unit when his son was discharged following surgery:

The day they finally said he could leave he scrambled in the car, he just wanted to go, but you're feeling very insecure if anything goes wrong. You've not got a checklist, I wasn't given anything. Just all the Sister said, it was a Sunday night, she said 'Well give us a ring if you've got any problems.' But I said: 'Have you ever tried to ring this hospital? I have and you don't get through.' 'Oh,' [she said] 'I think you will.' I said: 'No, you're telling me what you want me to hear, not what happens ...' If this had been his first operation I would have been terrified because you get him home, you don't know. Then his wound got infected. I've seen infection, I said 'This is infected, we've got to do something', but our local hospital doesn't want to know and he won't go to them anymore because he's had such a bad experience. (Father 5)

This father reported his insecurity and worry about caring for his son post-surgery. He felt that having a checklist of what to look for following surgery would have helped him understand his son's needs. This father and son had a very negative experience at their local hospital and are now reluctant to seek further advice there. A recurrent theme in the data is the lack of trust in non-specialist hospitals which patients perceived as ill-equipped to care for them—patients and carers reported being 'in limbo' between the surgical unit and the district general hospital and felt a lack of information from health services. In one instance a carer described how she was given inaccurate information at her local district general hospital:

I did have a call from one lady, a physiotherapist from the district general hospital, who actually, I don't think lived on the same planet as the rest of us. She basically said to me 'We're going to be discharging your husband', and I said: 'Oh okay, so what are you going to put in place to help us?' because I work and I was working full time at that stage. She said: 'Well, can't you give up your work?' And I said: 'I'm sorry but no, I can't give up work', and she said: 'Well if you give up work they'll pay your mortgage for you.' I said: 'I don't think it works like that' and she gave me all this wrong information that I knew was a load of old rubbish, and in the end she said: 'Well there's nothing much we can offer you.' And I thought, well great, you know. (Wife 18)

This carer was angry when she told this story about inaccurate and insensitive information received from a health professional and the lack of consideration and understanding of her need to continue working and balancing her caring role with work.

Managing medications

The short-term memory loss associated with PMBT means that carers have more responsibility in managing medications. One area that carers felt they needed help with was the management of corticosteroids and oral chemotherapy. One carer explained:

Well he's recovering from being taken off the [cortico] steroids too quickly. I knew it was happening, we'd already been [given an] authorized dose. I didn't quite understand the working of them. I guess I need to know a bit more. (Wife 12)

Another carer referred to the problems related to corticosteroids and insomnia:

I could have done with a two day seminar on [cortico] steroids and the effects of [cortico]steroids. Nobody tells you ... He didn't sleep on steroids. They don't tell you that. (Wife 1)

The side effects of corticosteroids are also reported as considerable problems for patients and for carers in an Australian study of those with a malignant brain tumour (Halkett et al, 2010). This was evident in the recollections of a carer who described how his son would return from the hospital with no recollection of what he had been told by staff about his chemotherapy:

So I would take him to the hospital and he'd go in and I'd say: 'Do you want me to come in' –'no' – 'ok alright,' I had to respect that. And then he'd come out and we'd come back and would be querying straight away. 'What do I do with these tablets? What do I do?' I would phone up and they would say: 'Oh no, we're not allowed to discuss this with you because you are not put down as a person.' So I think once you have established there is a carer, whoever they are—whether they are a parent or a wife—that aspect has got to be sorted. Because you know you are up there usually all day going from one clinic to another and if you're not given the information, the patient in many cases is not capable of relaying it to you. I came back here the first time with his drugs for the chemo and you had to make it up. I think the dose was something like ... There were three tubs to open, take the right amount out and calculate the dosage. In his worse state he couldn't remember what he'd had for his lunch when he got it. I am sure I'm not the only one to come across that. But this time I've gone in and I've seen people like the clinical nurse specialist who've got it clear. (Father 5)

In this instance, staff were unwilling to share information with this father until the clinical nurse specialist intervened. The clinical nurse specialist was a key person to sort out the difficulties in clinic for this father, and the importance of this role is a key feature in the accounts of the carers.

Accessing information

Virtually all carers reported using the Internet to search for information and that this helped to maintain hope. However, feelings were mixed about the benefits of information on the Internet. Carers said that one of the main limitations of searching for online information was that it could be depressing,

inflicting more bad news on already worried and anxious carers. However, some websites recommended by health professionals were found to be very clear and useful. Two carers reported that the Macmillan Cancer Support site was helpful. Another carer found an organization on the Internet that offered some hope and optimism:

There is a really good website. It's called the International Brain Tumour Alliance. Because his condition is so devastating and everything [and] the prognosis is really bad, it is good to find some websites that give you, actually, hope. And there is some hope [that] there are people who can survive. (Wife 17)

The Internet was also found to be useful in searching for information about new treatments:

We've got to go back at the end of March and they will review it again. There's a new drug out that I looked at on the Internet that's supposed to be quite effective with radiotherapy and I don't know whether it would be possible for him to have that if he does have to have another course at some stage but we'll wait and see. (Son 16)

A carer also reported finding an in-person support group on the Internet:

He was being treated at the [district general hospital centre], and it was only through searching the Internet that I found out about the support group at the specialist hospital. (Wife 19)

It is interesting that this carer was getting support from other carers in a similar position via the Internet and this form of support has been found to be helpful in other site-specific cancer communities, for example breast and prostate cancer online support groups (Broom, 2005). Another found the website of UK-based Hammer Out, a brain tumour charity in South Gloucestershire, which allows users to upload and share their stories:

I found it very useful. You could write your story, just a few lines, and then I've emailed [it] and you know in fact I printed all my emails to one particular lady the other day. I don't know what I'm going to do with this but I'll do something with it all one day. But you can see the shock, my shock, her resignation because she was a month ahead of me, and then you could see my hopeful bit, like at Christmas, the scan was good. (Wife 1)

Others avoided the Internet as they were anxious about what they might read and one carer (Husband 21) was warned of the dangers of using the Internet by a doctor who told him that it could offer false hope and ineffective therapies, 'phoney treatments' and that it could 'break your bank'. Another carer expressed her

concern that there was too much information available on the Internet, although she found that:

Cancer Research UK's been quite good but again they have warnings up that you might not want to read what's coming. (Female partner 8)

One carer (Mother 11) had a strategy of filtering information by asking a friend who was a GP to search the Internet and to pass on anything which she thought might be useful. There is evidence that people use the Internet when they feel dissatisfied with information provided by health professionals and to help make sense of the illness (Rosmovits and Ziebland, 2004; Broom, 2005). Carers recognized that information on the Internet could be overly negative and inaccurate. Therefore, they were cautious about which sites they used.

Discussion

This study identifies the problems that this group of carers have in accessing information and support from the health services. Nearly all of the carers in this study report negative feelings about the information they received at different points of the caring trajectory. Carers feel particularly fearful and insecure about what to expect following brain surgery. These feelings of uncertainty are compounded by the responsibility they feel for managing changes in cognition, behaviour and personality, which affect the whole family.

The role of specialists

Access to information at this time is difficult as staff in district general hospitals may not have expertise in this area. Therefore, if carers do not have access to neuro-oncology specialist nurses or therapists throughout their journey, they may not receive the good quality information and support that preserves hope (Davies and Higginson, 2003; Hackman, 2007). The National Institute for Health and Clinical Excellence (NICE) (2006) recommended that clinical nurse specialists should be core members of the central nervous system tumours multidisciplinary team and take on the role of key worker during the early stages of the patient's clinical care. However, it is unclear who should take on the role of key worker later on in the patient's care and the point at which specialist palliative care professionals become involved (Arber et al, 2010).

One of the problems faced by health professionals, patients and carers is the rapid changes taking place in the patient, particularly after diagnosis and surgery (McConigley et al, 2010). Following diagnosis, carers reported that they lacked practical information about what to expect and were not given time to ask questions of medical staff. Provision of information at the early stage of the disease appears fragmented and uncoordinated, and not all centres provide access to specialist nurses and physiotherapists (Davies and

Higginson, 2003; Hackman, 2007). There is an urgent need to firstly examine and improve practices regarding the giving of information following surgical intervention, and secondly to help with adapting to caring in the early stages of the disease and to balance working and caring. Written information is essential and other techniques such as use of check lists, online sources of information and audio/video recording consultations could be used.

Preparing carers for the role

Many carers in this study felt unprepared for the role that they were compelled to take on, and would have valued a mentor or guide experienced in caring in order to prepare them for their new 'job'. One carer mentioned that there is no manual or job specification explaining how to be a good carer. Finding information and becoming an 'educated' carer was dependent on trial and error. Furthermore, the unique challenges of the brain tumour journey meant that the changes in their dependent's health, personality and memory capabilities presented constantly shifting and substantial hurdles. Two carers expressed the desire to meet another experienced carer who could prepare them for their new role. Having a 'buddy' or mentor is a strategy worth considering and could be part of a carer support intervention. Many organizations such as Brain Tumour UK now use 'Phone Pals' where patients and carers can take part in a conference call managed by a trained facilitator. Patients and carers could be prompted to ask medical and nursing staff if there are other patients and carers in the same situation who might be willing to talk to them.

Managing medications

Carers reported that they have needs related to information about managing medications such as corticosteroid therapy. In McNamara and Rosenwax's (2010) study, 84% of carers of people with advanced disease reported helping patients with medications. Problems with short-term memory loss meant that carers had a great deal of responsibility in monitoring side effects of therapy and calculating drug doses. A number of carers in the present study reported insufficient knowledge of the side effects of corticosteroid therapy, particularly problems with sleeping. Patients with malignant glioma are reported to have worries about weight gain with corticosteroids and feel concern for their carers' ability to cope with this weight gain (Halkett et al, 2010). The issue of corticosteroid therapy and associated side effects is therefore shared both by carers and patients. Information provision about corticosteroids could be shared by specialist neuro-oncology nurses and/or pharmacists, and written information could be provided in the patient information leaflet.

Monitoring oral chemotherapy regimens was also challenging and needed to be taken into account, particularly where patients had short-term memory loss.

The carer should be invited into the consultation when this information is provided. Audio-recorded consultations, with copies given to the patient/carer, is now practised in some specialist centres. Furthermore, the information journey should include what will happen at each stage of the pathway and when and where each event will occur, with attention to helping patients and family members understand medical terminology (NICE, 2006).

Appropriate information giving

In a systematic review of communication, information and support for those with PMBT, it was reported that patients and carers receive information that lacks coherence, and the ability to retain information is not fully considered (Davies and Higginson, 2003). The demands of the caring role and the changing nature of disease progression results in new needs for information. Guidance proposes that because of cognitive impairment, information should be provided in a variety of formats and made available both to the patient and to family members (NICE, 2006).

As well as being a medical crisis, brain tumours can pose significant financial challenges to families and this may not be fully recognized. There are few rehabilitation programmes that help brain tumour patients and survivors improve their quality of life and return to their previous occupation. Carers' working lives may suffer due to the demands of caring when they have to work part-time or give up work altogether, particularly if there are other dependents in the household. If specialist information on benefits and finances are not available within the hospital setting, patients and carers need to be guided to sources of information such as Macmillan Cancer Support. The benefit system is very complex especially when families have many financial problems. Younger families in particular may experience more financial problems and medical services may be slow to address this (Osse et al, 2006). Claiming benefits and filling in forms can be complicated, demoralizing, and stressful as the benefit system is complex and difficult to understand.

As most carers use the Internet, it is important that they are guided to websites that offer good quality information and support. In a US study, all caregivers ($n=25$) of patients with a brain tumour also used the Internet either themselves or with the help of family members or friends (Schubart et al, 2008). It is recognized that there is high quality information available on the Internet, including charitable foundation web pages. Eurocancercoms is a new European project which aims to improve communications within the cancer community by providing a super-portal to reliable, accurate and innovative information for professionals, patients and the public. In the present study there were some concerns about the negative impact of Internet use. However, using a trusted person who could filter information was a recommended strategy.

KEY POINTS

- Patients with a primary malignant brain tumour experience physical and cognitive alterations that make significant demands on family life
- Carers' access to information at initial diagnosis and on managing the caring role was assessed
- Carers identified a lack of attention to their need for information regarding medication, caring and working, and financial issues
- Direct contact with a specialist neuro-oncology nurse or therapist was experienced as very helpful

Clinicians need to be conversant with good quality resources and to take every opportunity to educate patients and carers about the existence of websites and other resources such as patient groups and charities. Using the Internet to search for information and to find support was found to be a source of empowerment, allowing patients with prostate cancer to feel more in control (Broom, 2005). As in this study, Caiata-Zufferey et al (2010) found that Internet use helped to reduce uncertainty and can be a source of encouragement for carers.

Conclusions

Carers' access to information and the quality of information received differed significantly between participants. Direct contact with a specialist neuro-oncology nurse or therapist was experienced as very helpful. There are times when the need for information is high but timely information is hard to access. Carers' experience is fraught and fragmented and they often feel inadequate for the task of being a carer. This is particularly so in the early stage of the disease following diagnosis and brain surgery when carers feel in limbo and find it hard to identify a key worker who can provide practical information. Carers are nevertheless resourceful and find ways to cope with the caring role such as online support, use of websites to access information and making links with patient and carer support groups. Carers used a number of sensible strategies to access good quality information but were not adequately signposted to these services. There are limitations to the general application of this study. Carers were recruited from one centre in the UK covering a large geographical area in the South East of England. There were more female carers than male carers and the views of male carers may therefore be under-represented.

The needs of carers looking after patients with PMBT specifically related to accessing high-quality practical information are high and emergent and cover physical, social and emotional aspects of the caring role. This study identifies a gap in the provision of consistent advice and support for carers of those with a malignant brain tumour at key points during the caring journey.

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