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Shortman, R., Beringer, A., Penn, A., Malson, H., Lewis, S. and Sharples, P. (2012) The experience of mothers caring for a child with a brain tumour. To be published in *Child: Care, Health and Development*. ISSN 0305-1862 [In Press]

We recommend you cite the published version.  
The publisher's URL is <http://dx.doi.org/10.1111/cch.12005>

Refereed: No

Article first published online: 13th September, 2012

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# THE EXPERIENCE OF MOTHERS CARING FOR A CHILD WITH A BRAIN TUMOUR

## ABSTRACT

**Background:** Brain tumours are the second most common form of childhood cancer, accounting for over 20% of all cases in European children. Understanding the impact of diagnosis and treatment of a brain tumour on the family is an essential pre-requisite to identifying ways to provide effective support.

**Aims:** (1) To explore the impact of having a child with a brain tumour on the main caregiver in the family; (2) to describe mothers' experiences of coping with their child's illness, including personal barriers and strengths; (3) to identify causes of stress and sources of support to inform improvements in care delivery.

**Method:** Participants were drawn from a group of caregivers enrolled in a longitudinal study of outcome following diagnosis of a childhood brain tumour. Six caregivers took part, two from each of the high, medium and low impact groups based on their Impact on Families Scale scores.

Semi-structured interviews were used, with questions covering; (1) impact of the diagnosis on main caregiver and family; (2) personal barriers and strengths; (3) causes of stress and sources of support. Interviews were transcribed verbatim and coded manually into five themes which comprised 19 sub-themes.

**Findings:** Coping methods and provision of help and support were major preoccupations for main caregivers from all impact groups. Caregivers in the high impact group reported less conflict. High and medium impact group caregivers had experienced less "hindrance and heartache", than those with low impact scores, suggesting that the stress associated with diagnosis and treatment of the tumour may have increased cohesion and acceptance within these families.

**Conclusion:** Families of children diagnosed with a brain tumour experience considerable negative impact and may perceive themselves as struggling to cope. Provision of help and support, within and outside the extended family, including from health, education and other services, is perceived as helpful. (300 words)

## BACKGROUND

Brain tumours are the second commonest form of childhood cancer (Steliarova-Foucher et al., 2004). Prognosis has improved over 20-30 years, approximately 65% of patients achieving long-term survival (Peris-Bonet et al., 2006). However, treatment, recovery and rehabilitation may be lengthy.

Caring for a child with a brain tumour can negatively impact on family functioning (Spinetta, Murphy, Vik, Day, & Mott, 1989). Parents may experience stress and marital conflict (Manne et al., 1995). Psychological symptoms, such as anxiety and depression (Hoekstra-Weebers, Jaspers, Kamps, & Klip, 1998), may be exacerbated by work problems, financial difficulties and poor social support (Allen, Newman, & Souhami, 1997). Parents have to assimilate a large amount of information about the child's illness (McCubbin, Balling, Possin, Frierdich, & Bryne, 2004) and will be fearful about long-term survival (Brett & Davies, 1988).

Parental difficulties have important implications for the child. Familial conflict and maternal depression can lead to maladaptive behaviour (Carlson-Green, Morris, &

Krawiecki, 1995) (Dumas & Serketich, 1994), an effect which may be amplified in children with a chronic illness(Eiser, 2004).

Despite evidence that families of brain tumour children experience significant negative impact, few experiential data are available. Understanding the impact of diagnosis and treatment on families is an essential pre-requisite to providing effective support.

This qualitative study aims; 1) to explore the impact of having a child with a brain tumour on the main caregiver, (2) to describe their experiences of coping with the child's illness; (3) to identify causes of stress and sources of support.

## **METHOD**

### **Participants**

Ethical approval was obtained from the LREC.

Participants were drawn from caregivers enrolled in a longitudinal study of outcome following diagnosis of childhood brain tumour (Penn A et al., 2008). Six participants were invited to participate, including two each from families reporting high, medium and low impact, assessed by Impact on Families Scale (IFS)(Stein & Riessman, 1980). Exclusion criteria were child's death after enrollment and failure to obtain informed consent.

### **Data collection**

Participants took part in a one-to-one semi-structured interview guided by a schedule of specifically designed questions (Appendix A). Participants were encouraged to raise any issues they considered important. Interviews were conducted at home, lasting 60-120 minutes. Before commencement, the interviewer reiterated the purpose of the qualitative investigation, the voluntary nature of participation and the confidentiality of information.

### **Data analysis**

Audio-taped interviews were transcribed verbatim. In the text, names are replaced by pseudonyms; abbreviations LI, MI and HI indicate low, medium or high IFS scores. Each transcript was assigned a colour for ease of recognition and analysed using the following iterative process. Transcripts were read and re-read by research team members and prominent features, topics, themes and issues recorded. Responses across the whole data set were grouped into themes, which were divided into sub-categories.

## **RESULTS**

All participating main caregivers were mothers. All were married. One had separated from the child's father prior to diagnosis. Four had one other child, one had three other children. Four children were boys, two girls. Median age was 10.5 years (range 8–13).

Median time from diagnosis to interview was 27 months (range 17–35). Treatment included surgery (six), radiotherapy (five), and chemotherapy (four). Details are summarised in Table 1.

### **Impact**

Caregivers described being surprised and shocked by the diagnosis, closely followed by fear for their child's future, e.g.

*'Well, it made us feel devastated really and then after that you start to worry about the future – about whether you will have her in the future and especially with Daisy losing some of her eye sight – how she will cope with that? Her memory is obviously not too good so we were worried about that, just really what kind of life she will have for the future?' (Lisa-LI).*

In coding the 'impact' theme we included expressions of guilt, insecurity, and depression, e.g.

*'I felt at that time it was a sort of a death, you know like a grieving being at that time, it was horrible...I just felt very insecure, very... well I just went to pieces really.'* (Mary-MI)

*'You feel you should have done something to stop it. Guilt, a lot of guilt'. (Sue-MI)*

### **Coping**

Asked how they coped, mothers' responses revealed the strengths they drew on. They felt that their coping ability derived from feelings toward their children, and the responsibility of being a mother. Maintaining a positive outlook in adversity seemed to be regarded as part of this responsibility, e.g.

*'My kids are my number one in life, full stop, and I will do anything and everything for those children.'* (Bea-LI).

*'You don't want to show him how you are feeling. Tell him everything's going to be all right but inside you are absolutely devastated really'* (Sally-HI)

Several mothers related their ability to cope to particular aspects of their personality, e.g.

*'I suppose really a sense of humour helped because we have got a wicked sense of humour in this house so although when things were really low we managed to maintain that sense of humour as best we could'. (Sue-MI)*

Asked how their husbands coped, mothers felt their attitudes differed. They felt fathers were less able to acknowledge the impact of the disease and tended to use avoidance coping strategies. This sometimes led to conflict, e.g.

*'...we just got on with it and you can tell what my husband is like, he is not one of these that dwells on things and he did move on with it and I hated him for it at the time, that is a strong word but I did and I though how dare you dismiss this as something that is just over. As I said he went back to work after two weeks and that did cause us a lot of heartache really probably for the first year on and off but not constantly but I couldn't believe he could just get on with his life like that and pretend it never happened, not that he was pretending but to me that was how I felt'. (Sue-MI).*

## **Help and support**

### *Familial support*

Although they adapted, mothers reported needing increased levels of support. Sources of help they found particularly useful included the extended family. Members assisted with child-care, transport, and financial support.

*'...It was too much and luckily I had a good Mum and a good Mother-in-law who worked together because if I didn't have them I don't know what I would have done with childcare'. (Mary-MI).*

Emotional support was obtained from extended family members and the child's siblings.

*'... The arm round your shoulder - we'll be alright Mummy, we'll be alright won't we. It'll be fine. An eleven year old child [sibling] doing that. You can't get that much more comfort than that really from someone. He was the star because he was taking it more than anyone in a way ...' (Bea-LI).*

Few comments were made about receiving emotional or practical support from husbands. Mothers appeared to perceive support mainly being provided by maternal relatives.

### *Support and information from health care, rehabilitation and education services*

Mothers reported satisfaction with health care provision and rehabilitation services, reflecting that this was a source of relief.

*'...so much happened in that short period of time that you think, well you know it was all from having her first scan to getting the results .... was like literally, hours, so it was all put together really well and all the treatment, and if you talk to the doctors and the nurses and you ask questions and you say - you know even if it is a stupidest of things you know you don't know you just want answers don't you and everyone was first class with the treatment we had.. .' (Lisa-LI)*

Participants reported being able to ask professionals questions about the condition to be extremely beneficial, although, early post-diagnosis, they sometimes found it hard to assimilate information.

*'well what I tried to do was ask lots of questions all the time and sometimes it was really hard to listen to people when they were explaining something' .. 'if I didn't get it I would ask again' (Lydia-HI)*

Some commented on the value of being provided with written information.

*"But just by talking to experts and people you know – definitely talking to the nurses at [name of hospital] they went through and explained about everything you know especially when he had her shunt put in as well. We didn't really know anything, we had never even heard of one before so you know, they sat down and got different leaflets and booklets for different websites that we go into to have a look and that was more helpful because that makes you feel more positive than just talk to other people.'" (Lisa-LI)*

The value of telephone access to support and advice was also mentioned.

No mother reported wanting, or seeking, counselling. One child was offered counselling, but was reluctant to participate.

Time away from school was a major concern. Mothers feared their child might be 'left behind' academically, and expressed gratitude when education services provided schoolwork and/or extra tuition and support.

*'[The school said]... don't worry just keep sending him in, it's normal and from that respect, [the school] were brilliant. They kept Sam in - he couldn't write his name, he was running out of class, he was having fits all the time and they just let him go in and the children were brilliant in his class, the teachers were brilliant, the classroom assistants were brilliant.'* (Bea-LI)

## **Conflict**

### *Familial*

Despite gratitude for family support, mothers' reported that familial interactions were not always positive. Conflicts arose, often relating to differences in coping styles e.g.

*'I had come back from the hospital very tired, distressed and upset and I came through the house and she [mother in law] said she couldn't hug me or she would cry. Now who gives a damn about that because I needed to hug somebody that night and she didn't hug me because she didn't want to make me worse and then cry herself...I can't forgive her for that.'* (Sue-MI)

Mothers reported siblings feeling jealous, because they were getting less attention than the patient. In some cases they felt the sick child became manipulative, 'playing off' parents against each other, e.g.

*'I suppose like I say, everything revolved around Josh [affected child] and Josh's well-being, so for Andy [sibling] he was starting to get a bit cheesed off with it. Josh's very good, this sounds terrible but Josh's very good at playing Derek*

[partner] and I off against each other but that has probably got nothing to do with the brain tumour, he would do that anyway so I don't know.' (Sue-MI).

### *Health Care Services*

Mothers' experience of health care services was not always positive. Other studies have suggested that parents can feel helpless and disempowered during their child's treatment (Enskär, Carlsson, Golsäter, Hamrin, & Kreuger, 1997). Such feelings may lead to frustration and conflict with professionals, e.g.

*'..one doctor on the rounds started to do all medical things and sort of talking over your head and sort of like I was thinking – could you say that in English please, this is my son and I did want to know...' '...they all had different ideas and they were all different and I thought – what is going on?' (Mary-MI)*

Feeling disempowered and/or neglected by professionals may add to parental distress, resulting in relatively minor additional stressors producing conflict (Nezu et al., 1999), e.g.

*'But the social worker, she was only part time and we always had to go to the hospital to see her, and several times she just didn't even turn up when it was a pre-arranged date and time, '...she never ever came here to see us which you know was difficult getting to the Hospital when Daisy wasn't walking because it needed two people to drop her off outside. I did have words with her about it though.'* (Lisa-LI)

### **Hindrance and heartache**

Some difficulties seemed to constitute more of an irritation ("hindrance") than a major source of stress ("heartache"). One example related to difficulties obtaining a wheelchair for a disabled child.

*'the only let down we had really and it was a strange thing was with getting her own wheelchair...It didn't come for some months and it seemed to stay in a store cupboard and was forgotten so that is perhaps one thing, instead she had a new wheelchair she has never used because by that time she didn't need it. Also by that time I was getting calls from the hospital saying they wanted their wheelchair back so that was a bit of a breakdown somewhere...' (Lydia-HI)*

## **DISCUSSION**

This study offers an insight, in their own words, into the experiences of main carers of children diagnosed with brain tumours and their families. High levels of anxiety and stress were associated with diagnosis and treatment, in keeping with other quantitative (Penn et al., 2009) and qualitative studies (Young, Dixon-Woods, Findlay, & Heney, 2002). Our results illustrate how extended family support systems play a major role in helping mothers cope.

Immediately following diagnosis, mothers reported fears for their child regarding death and concerns about physical or cognitive deficits, or personality changes, which might impact on academic performance. A recent Australian study of parental perceptions of the hospital experience, also found that the diagnosis of a brain tumour is characterised by marked shock, accompanied by a high level of dependence on medical professionals (Jackson et al., 2007).

Coping strategies that mothers reported adopting to cope included emotion (“trying to stay positive”) and problem-based (“getting on with it”) approaches. It has been noted that to promote adjustment of the child to their illness, parents attempt to adopt emotionally positive responses (Young et al., 2002).

Our mothers welcomed support and practical help from extended family and professional services. This emphasises the importance of ensuring that appropriate ongoing support is provided, particularly to those who have little familial or other non-professional support. In a previous study, parents expressed dissatisfaction with interactions with the health care team six months post-diagnosis, possibly reflecting a reduction in attention once families had settled into the treatment routine and the crisis of diagnosis had passed (Young et al., 2002).

Our mothers appeared to place higher value on practical, rather than psychological, support. Mothers may feel inhibited from seeking psychological support from professionals, feeling that this conflicts with their need to stay positive and in control, yet might benefit from such support if it were provided routinely. Since spouses and siblings also had problems coping with the diagnosis and its implications, it might be helpful to extend such support to other family members.

An alternative to providing formal psychological support might be ensuring that families are supported by more informal schemes such as “friends for parents”. Different approaches are not mutually exclusive, and carers and families might benefit from being offered a range of support systems, enabling them to pick one most compatible with their coping style (Freeman, O’Dell, & Meola, 2003).

Mothers’ responses clearly indicated the importance of receiving appropriate practical support from health, education and other services in a timely manner. Provision of Information was also clearly important, although our mothers appeared to place less emphasis on this than parents in an earlier study (Young et al., 2002).

Our mothers’ comments highlight the value to families of reducing potentially remediable sources of conflict and “hindrance and heartache”. Waiting for a wheelchair, for example, is not uncommon (“Teenager stranded by chair delay,” 2006). Action by health, education and other community services, to identify and resolve such practical difficulties, could have considerable benefits in terms of reducing unnecessary familial stress.

Overall, mothers were positive about the care provided to their sick children. Interestingly, comments relating to “conflict” and “hindrance and heartache” were made less frequently by mothers of families with high IFS scores than those whose IFS scores suggested a lower impact. The two families with the highest overall IFS scores had children with significant neurological sequelae. It is possible that families of disabled



children develop increased cohesion and resilience. They may also develop greater insight into, and therefore patience with, the workings of NHS, education and social services.

The study was designed to capture the experiences of care givers with low, medium and high IFS scores. However, in many respects the families were relatively homogenous; parents were married and living together in 5/6 cases and all but one family were relatively small. Larger and/or less cohesive families may be at greater risk from stress associated with brain tumour diagnosis and treatment, and perhaps have greater need of professional support.

Understanding the experiences of carers and families is essential, if professionals are to provide the support necessary to facilitate the successful adaptation of child and family to the illness and its consequences. Positive adaptation by carers, including mastery, may increase the likelihood of positive emotional, behavioural and cognitive outcomes, thereby improving quality of life (Penn et al., 2009). We suggest future studies should explore what additional forms of professional support mothers would regard as useful and acceptable.

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**Appendix A – Questions used in the semi-structured interview with main caregivers of children with brain tumours**

1. What has been the impact of the diagnosis of a brain tumour in your child on you as main caregiver? *How did it make you feel? What were your greatest fears?*
2. What did you do / how did you think / what did you tell yourself to manage these feelings?
3. Do you think the way you dealt with things affected your child's well being?
4. How do you think that your child's illness affected your spouse,
5. and other children?
6. How do you think that your ability to cope affected your child and family?
7. What were the main practical problems you experienced during treatment for the tumour?
8. How did you manage these problems?
9. Who or what did you find most helpful during this time?
10. Do you think more could have been done by the medical team, social workers, or educational services or other people to help you?
11. If you think more could have been done, what sort of help would you have liked?
12. Were there any problems / barriers that you had that may have to prevent you from dealing with your child's illness in the way you would have liked?
13. In caring for your child during their illness did you overcome this problem?
14. How has the way you've approached your child's illness made you feel about yourself?
15. What are the things about you do you think helped you and your family get through this stressful situation?
16. Is there anything that you would like to have approached differently?
17. What piece of advice would you give to other caregivers in the situation?
18. Is there anything you would like to add?