


# The 'radiation vacation': Parents' experiences of travelling to have their children's brain tumours treated with proton beam therapy

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## Abstract

Proton beam therapy is a new form of radiotherapy. Little is known about patients' experiences of proton beam therapy and less about parents' experiences of children receiving treatment. Semi-structured interviews explored 10 parents' experiences of travelling from the United Kingdom to the United States to have their children's brain tumours treated with proton beam therapy. Thematic analysis uncovered themes of 'adjusting to the PBT routine', 'finding benefit in the situation' and 'readjusting upon returning home'. Parents' initial worries were elevated by travel, but they found benefit in their experiences, describing them positively. The periods before and after treatment were most difficult, illustrating a cycle from upset to calm, back to upset upon their return home.

## Keywords

cancer, children, experience, family, parent, proton beam therapy, qualitative methods, radiotherapy, travel, treatment

Proton beam therapy (PBT) is an advanced cancer radiation treatment. It is more precise than other forms of radiotherapy and can limit damage to healthy tissue, meaning fewer side effects, making it particularly useful for treating certain types of paediatric brain tumour (Armstrong, 2012; Gridley et al., 2010; Semenova, 2009). Such patients in the United Kingdom must travel if they are to receive treatment with PBT as there are no facilities currently available in the United Kingdom. Very few studies have explored psychological aspects of PBT and those that have largely focused on quality of life, usually for the patient.

There is some evidence to suggest that quality of life can be better for patients treated with more advanced radiotherapy techniques than with less advanced ones (Huang et al., 2010), although research has not included PBT. One study did find that there were no adverse effects of PBT on patients' quality of life during treatment when compared with pre-treatment measures (Srivastava et al., 2013). However, this study was only conducted on a small sample and it is unclear whether this would generalise. Although these findings provide emerging evidence to suggest that PBT may be a favourable treatment, they relate to adults and do not divulge anything about the experiences of children.

Laffond et al. (2012) measured quality of life in children who had received PBT, and patients did not score themselves significantly lower on overall health-related quality of life measures following treatment; however, their parents consistently did. This could indicate a greater impact for parents than the child patient. Half the patients had mild-to-moderate depressive symptoms following treatment (Laffond et al., 2012), which likely would have implications for their parents, but this was not examined.

A study that explored the family impact of PBT found various negative psychological implications resulting from a child receiving the treatment, including a reduced number of family activities and parents experiencing instability in their daily life and changes in their social identity (Houtrow et al., 2012). The study participants were US families receiving treatment in the United States, and therefore, it is

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not clear whether this would generalise to UK families and whether issues would be similar, particularly as PBT is currently not available in the United Kingdom and patients must be referred abroad to receive it.

The wider cancer literature shows that the child's treatment is a particularly difficult time for parents. Research suggests that compared to after treatment, parents' experiences during treatment are worse; perceptions of the illness are more negative, care-giving burden is higher, parents' quality of life is lower and general psychological distress is higher (Hutchinson et al., 2009; Salvador et al., 2011). During this time, in particular, social support from friends and extended family has been linked to positive outcomes for parents whose children have cancer, helping them to cope, be optimistic and find benefits (Bayat et al., 2008; Brody and Simmons, 2007; Cassidy, 2013; Hoekstra-Weebers et al., 2001; McCubbin et al., 2002; McGrath, 2001; Schweitzer et al., 2012). For parents travelling to obtain PBT for their child, there is potentially added pressure from the burden of travelling and the associated upheaval as well as being away from this usual support network. Therefore, being away could potentially jeopardise their well-being, although research does suggest that health professionals and other parents whose children have cancer can also provide support, so it is not clear whether their presence would compensate for the lack of family and friends in the immediate vicinity to assist with practicalities and provide support in person (Brody and Simmons, 2007; McCubbin et al., 2002; McGrath, 2001). To date, no research has explored how parents experience this and what the psychological impact is.

Few studies have investigated the experiences of patients and those close to them who need to travel to receive cancer treatment. An early review found only 11 studies that had included adult patients travelling for cancer treatment and surmised that no firm conclusions could be drawn about the psychological impact due to methodological problems with the studies (Payne et al., 2000). Subsequent research with adult patients indicates that there are added pressures associated with the need to travel for treatment, both financial and practical (McGrath et al., 1999). This study did not, however, include patients who had to travel to a different country and the added complications this may bring. A further study with adult patients included those from Canada, some of whom needed to travel to the United States to receive their cancer radiotherapy treatment (Fitch et al., 2003). The conclusion was that travelling away from home caused concern, but overall the experience was not as bad as anticipated and some were even able to find benefits. Whether this would follow for parents whose children were being treated is, however, unclear.

A study involving caregivers from various nations who travelled to the United States to obtain treatment for seriously ill children would suggest that difficulties arose as a direct result of travelling to a different country for the

child's treatment. Margolis et al. (2013) found the main issues raised were language barriers and concerns for responsibilities such as other children left at home. However, the caregivers in this study were not necessarily parents of the children being treated, and therefore, concerns may differ as may the relationship with the child in comparison with the parent-child relationship.

Another study that found similar issues included South American mothers. Crom (1995) studied mothers travelling to the United States for their children's treatment and found additional pressure for mothers resulted from cultural differences and financial hardship. The mothers did, however, seem to cope well and adapt to their situation. Crom (1995) did not specifically include only parents of children with cancer but limited participation to those with seriously ill children. Although experiences may be similar across life-threatening conditions, it is unclear from this whether there is something specific to cancer that influences individuals' experiences. Even within cancer types, differences in experiences have been shown, with, for example, paediatric patients' parents experiencing more fear if their child had a brain tumour than if they had leukaemia (Anclair et al., 2009). In addition, parents from the United Kingdom have not yet been studied in this context. For UK parents travelling to the United States, language should not pose a problem, so it is unclear whether other concerns would prevail in this case; the physical distance from home is greater, so perhaps this may lead to elevated distress. Investigation of the experiences of parents travelling from the United Kingdom to the United States for their child to receive PBT is therefore necessary to understand the additional burden and psychological impact this has.

Currently, little is known about the experiences of patients being treated with PBT. No research has explored the experiences of UK patients travelling abroad as a result of a referral to receive PBT. Children with brain tumours are among those being sent for PBT, often to the United States. This potentially causes extra upheaval and pressure for parents during an already stressful time.

This study therefore aimed to gain insight into the experiences of parents whose children have had brain tumours treated with PBT following a referral from the United Kingdom to the United States and to understand the issues faced and the additional burden experienced as a result of travelling for the treatment.

## Method

### Design

Qualitative methods were used to gain in-depth data relating to participants' experiences. Interviews were conducted due to the sensitive nature of the topic and were semi-structured in order to elicit detail about experiences but not be so rigid as to exclude avenues that participants may wish to

explore themselves. This research has been evaluated using Yardley's (2000) criteria for qualitative research. In particular, sensitivity to context: the literature review plus the participant details to follow; rigour: recruiting until data saturation was achieved; transparency will be shown in the procedure presented below; coherence should be evident throughout, as should the impact and importance of the study (Yardley, 2000).

### Sample

The participants were 10 parents (seven mothers, three fathers) aged between 34 and 61 years at interview; 9 were White British and 1 White European, with a range of occupations; 7 were married, not necessarily to the other parent of the patient, 2 divorced and 1 separated. Participants' children all received PBT treatment at the University of Florida Proton Therapy Institute, Jacksonville ( $n=8$ ), or ProCure Proton Therapy Centre, Oklahoma ( $n=2$ ), for a range of brain tumour types between August 2011 and April 2014. A child was classified as under 18 at the time of treatment; ages ranged from 2 years, 5 months to 15 years. Further information is included in Table 1.

### Interview schedule

The interview schedule was developed by the lead author supported by the co-author. It was semi-structured and encouraged participants to talk openly about their experience, expanding where they felt comfortable. The schedule followed a logical order of events relating to participants' experiences, from diagnosis and initial treatments to experiences before, during and after PBT treatment. In addition, content was influenced by an informal conversation with a parent who had experienced PBT. Key questions regarding the time before treatment included 'What led to the referral for PBT?' and 'Can you tell me a bit about how you prepared for PBT?' and regarding the time during treatment included 'And what was it like during the treatment itself?' Additional prompts were added to the 'during treatment' section following the first two interviews as it was felt this would elicit more detail. The key question about the time after treatment was 'could you tell me about what it was like when you came home?'

### Procedure

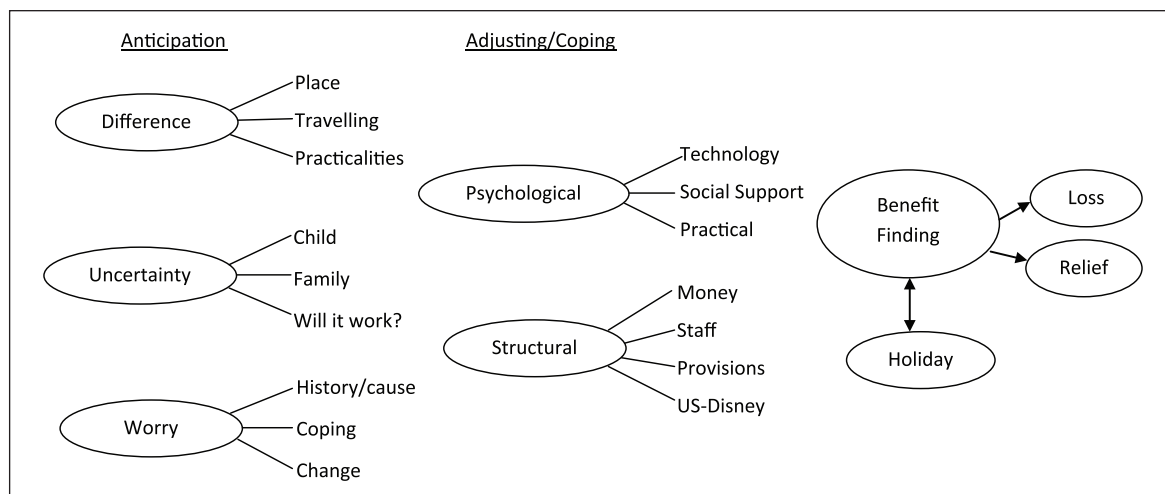
Ethical approval was gained from the University Ethics Committee. An advertisement was placed on the Facebook page 'Proton Therapy Support Group for All Proton Families' with permission from the administrator, which invited parents to e-mail to volunteer. An information sheet with further details was sent in response to e-mails. For volunteers, e-mail consent and background information were obtained and a convenient time arranged to conduct the

**Table 1.** Participant background information.

Participant <sup>a</sup>	Gender	Age	Ethnic background	Occupation	Marital status	Child's age	Tumour type	PBT location	PBT date
Fiona	Female	44	White British	Last Occ. IT Manager	Married	10 years	Subependymal giant cell astrocytoma (SEGA)	Jacksonville	August 2013
Tom	Male	38	White British	Cancer Support Specialist	Separated	4 years	Anaplastic ependymoma	Jacksonville	November 2012–January 2013
Olivia	Female	42	White British	Teaching Assistant	Divorced	8 years	Ependymoma grade 3	Oklahoma	May–July 2012
Laura	Female	48	White British	Project Officer	Married	13 years, 1 month	Grade 1 benign ganglioglioma	Jacksonville	September 2012
Natalie	Female	38	White European	Lawyer	Married	3 years, 10 months	Craniopharyngioma	Jacksonville	December 2012
Stephen	Male	52	White British	Retired Police Officer	Divorced	15 years	Irritativ astrocytoma	Oklahoma	July 2013
Maria	Female	41	White British	Film Production Co-ordinator	Married	8 years, 7 months	Astrocytoma optic chiasm	Jacksonville	October 2012
Helen	Female	38	White British	Secondary Teacher	Married	7 years, 8 months	Optic glioma	Jacksonville	August 2011
Eve	Female	34	White British	GP	Married	2 years, 5 months	Rhabdomyosarcoma	Jacksonville	February–April 2014
John	Male	61	White British	Medical Practitioner	Married	12 years, 11 months	Cerebral Grade 2 Ependymoma	Jacksonville	April 2013

PBT: proton beam therapy; IT: information technology; GP: general practitioner.

<sup>a</sup>Names are pseudonyms.



**Figure 1.** Initial themes and subthemes.

interview, over the telephone due to diverse geographical locations. All interviews were conducted by the same interviewer to enhance consistency. The interviewer contacted the participant, reiterated the purpose of the study and rights to withdraw and checked it was permissible to audio record the interview. The interview schedule was followed, and then participants were thanked and debriefed. Interviews lasted 21:29–48:47 minutes and were conducted May–June 2014.

### Data analysis

Thematic analysis was selected due to the flexibility this allows to ground analyses in the data (Braun and Clarke, 2006). Interviews were transcribed verbatim and anonymised using pseudonyms. Transcripts were coded. Four were then selected as the focus and used to generate an initial proposal, suggesting some themes and subthemes (see Figure 1). This was achieved through discussions between the two authors, following individual reviews of the data. One author has much experience using thematic analysis and in a range of health psychology-related research. The coded transcripts were then revisited to elicit passages that fell under the suggested themes, as a means of checking the suitability of the initial themes and subthemes. Analysis was then widened to the remaining interviews whereupon it was discovered that alterations were necessary to the first proposed themes. Adjustments were made accordingly and this led to the final themes and subthemes presented below and summarised in Table 2.

### Findings and discussion

From the beginning of their experience, parents were unsurprisingly in a state of worry. This worry began with their child's symptoms and diagnosis, with most having had

**Table 2.** Themes and subthemes.

Theme	Subthemes
1. Adjusting to the PBT routine	(a) Actively engaging with resources, support and distractions (b) Structural and contextual factors of being in America for treatment
2. Finding benefit in the situation	(a) Treatment process (b) Upheaval of being away from home
3. Readjusting upon returning home	(a) Loss (b) Relief (c) New normal

PBT: proton beam therapy.

lengthy investigations prior to diagnosis. It then continued through treatments received prior to PBT, which were often carried out over a relatively long period of time with limited success. PBT created further uncertainty and worry as parents had to wait for a decision from a referral board as to whether their child could receive PBT and when approved were then unsure what to expect about the treatment, its efficacy and the side effects, and the experience of travelling to America for treatment. A further source of worry for participants was the anticipated and experienced differences between the United Kingdom and the United States, evident from the preparatory stages to beginning treatment. This was mainly in relation to practicalities, such as driving and money, but also to the fact that participants were in a different place, needing to orient themselves.

In line with previous research, participants experienced worry and this was elevated by the need to travel.

The way participants described experiences of having a child with a brain tumour treated with PBT can be presented in relation to three themes: 'adjusting to the PBT routine', 'finding benefit in the situation' and 'readjusting

upon returning home'. These themes will now be detailed and divided into subthemes, as per Table 2, including quotations to illustrate.

### *Theme 1: adjusting to the PBT routine*

Parents went through a process of adjustment, particularly when they were in America and their child was being treated. This process was aided by behaviours that parents actively engaged in and undertook in order to better cope with the situation. It was also a result of the structural and contextual factors resulting from being in America for treatment and the associated provisions and resources available, as explained below in more detail.

*Actively engaging with resources, support and distractions.* Among the things that participants actively engaged in was the use of technology – to find information and support in preparation to go and to make contact with home and help reduce homesickness:

I would do a weekly blog with pictures and so everybody could see what was going on and reply back and we did a lot of ... Skype-ing and FaceTime and phone calling our friends and family just to ... keep in touch. (Fiona)

Participants also actively engaged in seeking social support – from taking family members with them to making friends when they were in America, both with people experiencing PBT and the wider community. Before travelling, participants who chose to contact other parents who had been for PBT found comfort in the help that resulted.

Choosing to engage with others who were being treated at a similar time or staying near to them was a way for families to gain support from people in a similar situation: 'there was the camaraderie ... with the other families ... which helped enormously 'cause we were all in the same boat we were all away from home all very scared parents not knowing what the future held' (Olivia).

Where participants chose to accept support from local people, this greatly assisted adjustment: 'the residents round the pool were brilliant absolutely brilliant with David and made me feel ... quite at home' (Laura).

However, in some circumstances, participants actively sought their own space and found comfort in being able to spend time alone with family: 'Although we could see the advantages to ... spending time with others we also wanted to kind of keep the family unit together and have some privacy' (Tom). Furthermore, having their own space helped to create a home-like environment in which participants could create a routine and make things feel more normal, appreciated by many participants, helping them adjust: 'we could just be a family and have things ... run a bit more like normal' (Natalie); 'we wanted to build a home ... and be settled' (Helen).

There were various practical activities and cognitions that parents engaged in to help adjustment. These included turning their attention to the practicalities of organisation, focusing on the task at hand and becoming very matter-of-fact, demonstrated by Helen: 'that's what you're there for so you just get on with it'.

Other activities were sought and carried out often as a form of distraction and to reduce the otherwise potentially mundane nature of the treatment routine. This occurred both during and outside of treatment times: 'we did try and make sure that we were busy and we weren't ... just going back and forth to the hospital 'cause ... otherwise it can be a long day and long weeks' (Fiona).

These activities were numerous, including going 'to the pool in the hotel', 'shopping', 'to the pictures', 'down town' (Stephen), 'to the beach', '[to] a museum', '[to] a zoo' (Natalie).

*Structural and contextual factors of being in America for treatment.* Structural and contextual factors of being in America for treatment helped participants to adjust, things they did not actively seek but which were provided as a result of their situation. One factor was good organisation from proton centres; this was clearly appreciated by participants and helped adjustment and coping, relieving some of the pressure and worry. Initially, this was mentioned in terms of arriving in America: 'got a car straight to a hotel it was just like clockwork it was so well organised it was incredible really' (Helen). Then, it was also mentioned in terms of the treatment process:

we were given a schedule every day they're extremely organised which was very helpful. (Natalie)

they had on the website the timing so that ... you knew if they were running on time or running late and that was quite useful ... sometimes some of them were running quite late ... but because everybody was informed ... people accepted it. (John)

Further to this, clear instructions were given to participants and they appreciated knowing the details of upcoming events: 'it was extremely well explained, very clear, very precise, you got the impression that ... it was very, very professional' (Maria). This value of preparation for treatment is particularly seen in John's description of the tour received prior to commencement of treatment, something also mentioned by others: 'one of the radiotherapy technicians ... takes you round and shows people the treatment areas so that it's not a great myth, it's not a great shock when you go in' (John).

Another important factor was the treatment environment itself and the physical characteristics of centres, with participants describing proton centres as 'more like a hotel' (Olivia), 'very plush' (John) and 'very relaxing ... because everything's very calm, everything's very quiet' (Helen).

This was complemented by the care shown by staff: ‘the nurses were very kind and ... very good to Ben and we really felt like he was in safe hands’ (Natalie). A father, Tom, explained how he was greeted after an awful journey: ‘they ... could see that we’d been through a really stressful and distressing situation ... and did everything from that point on to kind of make us feel welcome’.

Laura travelled with her son David and was there for a number of weeks before her husband arrived. She explained how availability of staff made the time less isolating for her: ‘I knew if anything went wrong straight away I had somebody that I could link into so ... it felt like I was on my own with David but not’.

The level of individual attention received and the personal experience given by staff appeared to add to this:

they cared ... that Nick wasn’t getting as much done as everyone else they realised that his reaction to the therapy wasn’t the same as others ... that concern and empathy ... you could feel it, it was nice, it was reassuring. (Stephen)

Altogether this created an atmosphere that was highly regarded by participants and clearly helped them to adjust: ‘the whole place was a very – we describe it as a special environment’ (John).

Additionally, centres provided activities to serve as a distraction while waiting or in their time away from the centre at little or no expense. Some of these activities could have encouraged and created opportunities for the social relationships participants chose to engage in: ‘they had ... social events every couple of weeks where the children and families could come together to meet each other’ (Tom); ‘they organised things for us to do after treatment and certain days they’d have a get together and show you part of Oklahoma’ (Stephen).

Participants often spoke of personalised experiences centres organised and funded for children. For example, Laura’s son David went to see a live show by the television programme ‘Myth Busters’: ‘he just mentioned it in passing that he likes the Myth Busters and they went ahead and sorted that out for him’ (Laura).

In addition, some people participants met also arranged attention-diverting activities that seemed to foster feelings of being cared for, such as in the case of a trip to an evangelical church organised by locals for Stephen’s family:

they all had their choir going like you see in the films and it was just lovely, they were beautiful – and we’re not particularly religious or anything it was just we were accepted and treated so well ... it was fantastic. (Stephen)

The value of this distraction was particularly apparent in Fiona’s description of a time during the treatment when doing anything else was impossible due to her daughter suffering side effects: ‘going from your apartment to the

hospital and back again it becomes quite hard ... a bit more claustrophobic and it’s not so easy’ (Fiona).

These factors, along with those things in which the participants actively engaged, fostered feelings of being in a ‘bubble’ (Olivia; Eve) or a ‘cocoon’ (John) while in America.

*Summary.* Participants adjusted well. Being practical assisted this, as previous research has also shown in parents of cancer patients (Papaikononou and Nieuwoudt, 2004). This is therefore not unique to this study, but the volume of practical tasks to be undertaken is much greater when travelling – therefore as is the potential to utilise this coping strategy.

Desires to try and recreate the comforts of home, normality and routine appear to be an attempt to provide comfort and help participants adjust. This is not something that has been included in other research involving travelling for treatment but the concept of retaining as much normality as possible is something that is seen in other literature (Fletcher and Clarke, 2003). This could also be viewed as participants taking control of the things that they can control, in order to better cope with their situation – something that aligns with previous research (Fletcher and Clarke, 2003).

The issue of being away from usual sources of social support is one which could potentially have made it harder for participants to adjust, given previous findings regarding the importance of social support to parents’ psychological well-being when their child has cancer (Bayat et al., 2008; Brody and Simmons, 2007; Cassidy, 2013; Hoekstra-Weebers et al., 2001; McCubbin et al., 2002; McGrath, 2001; Schweitzer et al., 2012). It seems that participants created their own support network by seeking out people to socialise with, in addition to support from caring and attentive staff. Proton centres enhanced feelings of support through activities they provided. These activities also afforded opportunities to focus on something other than the treatment. It is well documented that distraction from symptoms can reduce their perceived severity (Chapman and Martin, 2011) but perhaps this uncovers an additional use for it in parents’ coping with their child’s illness.

The feelings of being in a ‘bubble’ or ‘cocoon’ show how well-supported participants felt, something which clearly helped them to adjust. This feeling has not been highlighted previously; the available evidence does not allow conclusions to be drawn about whether it is the effect of travelling for treatment or the PBT experience.

Previous research has shown that in similar contexts, the use of technology for information finding is becoming more common (Hardy and McGrath, 2008; Kilicarslan-Toruner and Akgun-Citak, 2013) but the diversity of technology use here is broader, perhaps because the recruitment was Facebook-based with a resultant familiarity with technology. Regardless, it appears to be assisting adjustment,

perhaps due to a reduced perceived distance from home, given the ease with which participants could make contact.

### *Theme 2: finding benefit in the situation*

By adjusting, participants were able to find benefits and turn an otherwise terrible ordeal into an experience providing enjoyment, recalled with some positivity. Benefits were found in the treatment process and the upheaval of being away from home, as detailed below.

**Treatment process.** While reflecting on the PBT decision process, participants used social comparisons to find benefits: ‘we were probably pretty lucky it was something that was suggested us ... they put it forward, she got approval and we went’ (Fiona). Such comparisons were also made when describing their child’s side effects:

although the treatment ... gave her headaches ... she never vomited or needed to go on a drip or need any antibiotics ... so we were lucky from that point of – I’m sure if we’d have had a sick child with us it would have been a lot more stressful. (John)

Participants enjoyed aspects of attending proton centres and so did their children, and expressed a great deal of gratitude that their child could receive PBT, sometimes explicitly:

We were extremely grateful to be sent for the treatment I think it’s a wonderful thing that the NHS does send families over ... it’s an awful thing to know that your child needs this kind of treatment but to be told that ... everything will be taken care of is extremely comforting. (Natalie)

**Upheaval of being away from home.** Participants were able to find benefits in the upheaval of going away from home. This started from the beginning of the journey by comparison, describing themselves as ‘fortunate’ (Maria) for having had previous experience that would help, like having travelled long-haul.

There was also implicit social comparison when participants talked about work and the ability to take time off, often on full pay. Even redundancy was looked upon favourably in one case: ‘although that was a ... blow it meant that we both went out without having to worry about our work’ (Fiona).

Participants also felt they were fortunate when another adult was able to be present, usually their spouse, and were obviously very grateful when they were not alone: ‘we were very lucky in that respect’ (Eve).

Participants talked generally about getting the best out of the situation: ‘we had some really good times and really did make the most of that situation’ (Tom); ‘we thought we’re going for 3 months in America it’s a chance of a lifetime we’re going for treatment but let’s enjoy it’ (Helen).

Simply being away from home and the daily practical worries were cited by some as positive: ‘in a way it was quite nice because it was family time without the pressures of being at home with ... the cupboard’s broken we’ve gotta fix it and all those kind of little niggly things’ (Eve).

The activities that participants did while in America were recalled as enjoyable, such as one mentioned by Laura, whose son David was 13 at the time: ‘my son could actually ... experience shooting ... a gun ... David hasn’t stopped talking about that’.

Undertaking such activities, being away from home and the atmosphere created by adaptation allowed participants to try and treat their experience as a holiday, termed jovially by Maria as ‘radiation vacation’. Most participants used the word holiday when describing at least one aspect of their time in America. For example, ‘I mean it wasn’t a holiday by any stretch of the imagination but it kind of felt like it in some respects’ (Olivia); ‘when we weren’t at hospital we were there on holiday’ (Helen).

Altogether, these things allowed participants to reflect upon the experience in a positive light, describing it as ‘unbelievable’ (Stephen), ‘extraordinary’ (John), ‘fabulous’ (Maria) and ‘amazing’ (John).

Participants also benefited from building lasting friendships with people they met. This was generally spoken of in the context of other parents and children who were being treated and sometimes other adults receiving PBT and their partners. These were friends who provided great support out there, enjoying activities with them and who continue to be valued: ‘to this day we’ve still got friends who live out there’ (Helen).

**Summary.** Participants showed an admirable capacity to find benefits, sometimes through downward social comparisons, something that research shows individuals utilise to make themselves feel more positive about their situation (Taylor and Lobel, 1989). The current research shows that even under such circumstances, downward social comparison is utilised to individuals’ advantage.

The research on benefit finding in general is vast and it has been shown that people can find benefits when faced with all sorts of adversity, including cancer (Dunn et al., 2011). This study is the first to show it to this extent in parents of children with cancer who have travelled for treatment. Whether this is a result of the particulars of PBT is unclear and warrants further investigation.

The current research extends findings that parents of children with cancer are resilient (Cassidy, 2013; McCubbin et al., 2002) and shows the real strength of such parents in their coping and adaptation in the context of travelling for PBT.

### *Theme 3: readjusting upon returning home*

Readjustment was necessary upon participants’ return home as they stepped out of the ‘bubble’ and back to home life.

Participants experienced mixed feelings of relief to be home and loss resulting from no longer being in America. There was a sense of getting back into a routine and establishing the post-PBT new normal, all of which is detailed below.

**Loss.** Participants seemed to miss at least one aspect of being in America, upon their return home experiencing feelings of loss. Initially, some felt ‘it was quite strange getting back after spending so long in the US’ (Tom). Loss arose from climactic and cultural differences, but in particular participants missed being around others in a similar situation, compounded for some by the fact that they were unable to regularly see friends they had made out there. They had valued others understanding without the need to explain everything in detail and found comfort in the fact that having an ill child was normal, as exemplified by Eve:

You’re surrounded by other families who’ve got normally their tumours ... with not great prognoses and that just becomes the norm and when you get back home and you have to kind of explain things again to your friends and you know not everybody speaks the same language, cancer language.

Participants missed the supportive environment created in America. The level of support received once home seemed to vary, so for some this loss was further inflated by a lack of support initially upon returning.

Having good contacts from prior to treatment appeared to help, such as in Tom’s case: ‘when Carly was officially diagnosed and undergoing the chemotherapy we got a lot of support from the hospital and the charities that work in and around the hospital and so we did kind of make use of those again’.

Medically speaking, loss was felt in terms of intensity of care. The American system is different and participants often reported feeling as though specialists in the United Kingdom were not doing enough because they had been used to the American specialists doing so much; they needed to readjust to their local health-care system:

Maybe it’s just perception but you really get the sense in the States that things are very organised and over here things happen perhaps when they should but ... it doesn’t give you the impression of being as organised ... so I think I felt the difference there. (Natalie)

There was also a loss of action. Some participants represented the time of treatment as being proactive and when they returned home being left to wait and see whether the treatment had worked – a situation which is exacerbated by the fact that it is not immediately possible to tell whether PBT has been effective:

When you’re waiting ... and you don’t know whether it’s been successful or not ... you just ... keep hoping and praying that everything did go well ... I suppose it felt a bit like ... after exams finish you just ... feel at a bit of a loose end. (Natalie)

**Relief.** While overall positive about their experiences in America, by the end of the treatment, many, although not all, were relieved to be returning home. This feeling continued when they reached home with some strong feelings, sometimes due to the amount of time spent away. This relief was evident in pleasure expressed at physically being in their own house. Fiona was particularly happy to be home:

It’s just nice ... to sleep in your own bed and do the things you’d normally do even though you still have a child who’s not well ... you’re able to potter around your own house and have those home comforts that you just don’t have when you’re somewhere else. (Fiona)

Cultural factors contributed to this, such as walking when desired rather than using the car and differences in food availability. In addition, participants expressed pleasure at being able to see those close to them who were unable to travel with them to America.

**New normal.** Upon returning, as part of readjusting participants talked of getting back into a routine, creating the new normal for them, post-treatment and with both the immediate and long-term future in mind.

The immediate focus was often on getting back to normal: ‘it was just a case of trying to find our feet and settle back into some sort of normality’ (Tom). In line with this, participants spoke of wanting to recreate a routine for themselves and their children. This was not always easy, perhaps because it was the new normal, the new routine, not stepping back into an old one: ‘it was very hard to get back into routine at home because at the end of the day life goes on and everybody else is just carrying on in their own everyday jobs’ (Helen).

Being able to complete hobbies or pre-arranged activities was a benchmark for returning to normal. For John’s daughter, this was positive:

Rachel went off on a school holiday ... that was one of the big landmarks of her coming home was that she would be well enough ... and independent enough to go to America with her school.

In some cases, being away was a bit of ‘escapism’ (Eve) and the return home to the new normal was back to reality and therefore a readjustment: ‘I think it all caught up with me ... actually realising what my son had been through, where we’d been and the fact that I’d done it’ (Laura).

Participants also talked of returning to hospitals, going for check-ups and scans as before with the added pressure of discovering whether PBT had been successful:

The cyst had grown to pretty much the size it was before he had the surgery which ... was a huge let down ... but we were told that it was probably just a reaction to the proton beam therapy, it could actually be a good indication that the treatment was working and that hopefully over time ... the cyst would go



down ... It was kind of still stressful but ... we were just very glad that we had done it and ... that he'd made it through it and then we just hoped for the best. (Natalie)

Furthermore, the extent to which the treatment had worked was something participants had to come to terms with, including the possibility that some of the side effects and symptoms their child was facing may not improve. Stephen spoke about how things were different than expected for his son Nick following treatment:

Bit naively thought you'd go to the States and after 3 months things would be almost mended ... but that's not the case ... it's a hell of a long journey. With Nick ... it's not growing anymore which is brilliant ... but I suppose we thought it'll be shrinking now if it's dead, dead things go away but that's not the case and he's still got a terrible tremor ... and weakness on his right hand side which still affects his guitar playing and ... he can't write with his right hand side and the fatigue has really got to him ... we didn't have a really full understanding of what to expect in the future.

Participants were aware that further side effects for their child may result from having PBT into the longer term, so this was perhaps something that was being incorporated into their plans.

The future is particularly uncertain for Maria, as her daughter's treatment was unsuccessful. She spoke of the prognosis for Zoe and the attitude she herself now holds:

We don't know what's ahead for her and unfortunately ... the more you read and as time goes on the more I guess you will find out ... the sort of secondary cancers that maybe become apparent but I guess ... dealing with this all ... it is very much you just have to take each day as it comes ... and ... all this teaches you that and teaches you to value each day a bit more.

More positively, the new normal included maintaining contact with people they had met as a result of their experience, such as in Stephen's case: 'we keep in touch with the families that were going through the same ordeal as us ... and that's great' (Stephen).

**Summary.** This study shows that parents of children who have undergone PBT treatment following a referral from the United Kingdom to the United States go through a process of readjustment upon their return home. This is in line with the wider cancer literature, which shows that parents of children with cancer must readjust following treatment cessation (Quin, 2005). However, the need for readjustment here is more marked than is evident elsewhere. There is a clear difference between life in the United States receiving PBT and in the United Kingdom once home. Parents must readjust to cultural differences, and cope with a change to the social support that is immediately available, from being surrounded, in America, by people who could show real empathy to largely in the United Kingdom being with those

who may only be able to show sympathy. In addition to this, they must readjust from an American environment with higher levels of overall support and with greater intensity of medical care than they may receive in the United Kingdom. At the same time, parents experienced feelings of relief at being back in familiar surroundings and seeing people they were unable to take with them. These mixed feelings of relief and loss at being home exacerbate any feeling of the need to adjust to a new normal.

This readjustment takes participants back to the beginning state of worry and its associated concerns. There was a sense when participants talked about being home that they had experienced or were experiencing a further process of adjustment in order to find benefits in their situation once more. In this way, the whole process could be seen as cyclical.

## Conclusion

The current research shows that UK parents taking their children for PBT treatment in the United States experience worry, followed by a process of adjustment, which allows benefits to be found in the situation. Returning home following treatment instigates a process of readjustment to create the post-PBT normal.

Some of the worry evident here does parallel the previous literature regarding having a child with cancer, such as concern about symptoms and diagnosis, but there is clearly an added burden of having to travel a long distance for treatment. The additional concerns do not appear to be unique to PBT, although some specifics may be, but this cannot be firmly concluded from this study as it was limited to only parents whose children had received PBT. However, taken with the existing literature on travelling for treatment, this study provides more support, in a different context, that travelling for treatment introduces a considerable extra burden.

Although they have these concerns, the current research shows that parents nonetheless adjust well to their circumstances when in America for their children's treatment. Structural and contextual factors play a central role in this; well-organised, modern PBT centres with a calm atmosphere, the care shown by staff and activities provided as a distraction, all serve to assist parents' adjustment.

Parents also choose to actively engage in various things which helps them to adjust, such as finding their own activities to distract themselves, using technology to find information and contact home to reduce homesickness and seeking social support. A significant source of support for parents whose children are receiving PBT so far from home are other parents who are in a similar position.

Generally, parents seem very motivated to seek out distractions and use them and the resources around them to their advantage. The social aspect of this is perhaps unsurprising given that recruitment was from a self-selected support group. A different picture may emerge if other

PBT parents had participated and so this highlights a limitation to the current findings. The aforementioned use of social comparison suggests that participants felt others may not have been having such positive experiences as themselves, which may suggest that there is something different about the particular sample, but it also may just be an outsider perspective and part of the need for parents to feel they are in a more fortunate position than some. Whether the wider population have similar experiences warrants further investigation.

Despite concerns, and as a result of this process of adjustment, the experience of being away from home for a child's PBT treatment is shown here to prompt very positive reflections. The current research could, however, be suffering from recall bias and perhaps parents may not have been quite so positive had they been asked at the time of treatment. Nonetheless, participants were so positive that it is difficult to imagine that the benefits found in the current research do not accurately reflect experiences.

This study shows that the benefits of PBT for parents fall under two broad categories. The first is about the treatment process: the fact that their child has even been referred for PBT and the speed of this referral, the limit of their child's side effects and having the opportunity to attend the proton centres themselves. The second is about the upheaval of being away from home. This includes being away from daily practical concerns, being able to make the most of being in America and, although there for their child's PBT, being able to treat the overall experience as a holiday. In many ways, participants found additional benefit in the fact that they were away from home and in such surroundings.

Upon parents' return home from America, they go through a process of readjustment. They feel a mixture of loss and relief at being home. The loss is mainly in terms of no longer having parents around them on a daily basis who are in a similar position and in terms of intensity of care. The American environment is very intensive compared to what they experience in the United Kingdom and so coming back home can be quite a difficult adjustment in this respect. Upon returning home, having more opportunity for direct contact with other PBT parents could serve to mediate some of this difficulty by reducing some of the feelings of loss.

There is a strong need for parents to get back into a routine following PBT, but a lot is different for them and they have new concerns, so this is about creating a new, post-PBT, normal rather than simply getting back to how things were before. The current research has highlighted in PBT and travelling for treatment that, as found in previous research, readjustment is necessary following treatment, but it is more marked here than elsewhere.

Parents' experiences as a whole demonstrate a worry-adjustment-benefit finding cycle. It begins with worry before PBT and is followed by a process of adjustment which allows benefits to be found during PBT. Returning home following PBT gives rise to new concerns, necessitating a

further adjustment process, which may then allow benefits to be found once more.

In this way, the time during PBT appears more positive than the periods before or after it, but as this research did not involve direct comparisons, limited conclusions can be drawn regarding this. Future research could better examine this, particularly as it is contrary to previous research, which has suggested that the time during cancer treatment is psychologically hardest for parents (Hutchinson et al., 2009; Salvador et al., 2011).

New PBT facilities are being built in the United Kingdom. The current research suggests that treatment at home will reduce the added burden placed on parents by travelling for treatment, although this will still be present to some degree as only two centres will exist nationwide. Of concern, however, is that there may be fewer resources available to assist parents in the readjustment process and fewer opportunities for benefit finding. This should be taken into account in the setup of UK centres and consideration given to what can be implemented. Although it is appreciated that it would be impossible to recreate the US experience entirely, certain aspects should be achievable, such as creating opportunities for interaction between parents of children being treated.

Parents' experiences of travelling to have their children's brain tumours treated with PBT following a referral from the United Kingdom to the United States show that it is very difficult but not beyond their capacity to cope. Travelling for treatment places extra pressure on parents, but although it may be predicted that this could result in negative experiences, parents reflect positively. The resources available in the United States are clearly helpful in facilitating adjustment and benefit finding. Therefore, although treatment in the United Kingdom may alleviate some travel-related concerns, it could also reduce the potential benefits to be found.

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