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**Title:** ‘I don’t want to hear statistics, I want real life stories’: systematic review and thematic synthesis of patient and caregiver experiences of Proton Beam Therapy

**Head Runner:** Patient and caregivers experiences of PBT

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## Abstract

### Problem Identification

Proton Beam Therapy (PBT) is an advanced form of radiotherapy, yet little evidence exists on patient experience to inform decision making and improve future care. We thematically synthesised the qualitative evidence of patient and caregivers' perceptions and experiences of PBT.

### Literature Search

Five electronic databases were systematically searched, using Medical Subject Headings (MeSH) terms and keywords. Two reviewers independently screened search results for qualitative studies relating to patients' and caregivers' experiences of PBT. The search generated 4020 records, of which nine were eligible. Study quality (assessed by CASP checklist) varied.

### Data Synthesis

Qualitative results were analysed using thematic synthesis. Three main themes were generated: 'decision making and perceptions', 'living in the PBT 'bubble'' and 'coping with the cancer treatment journey'.

### Conclusions

PBT is not yet widely accessible worldwide, which uniquely influences the patient experience. Our review uncovers areas PBT providers could target to improve patient-centred care, however additional primary qualitative research is recommended.

## Key Words

Proton Beam Therapy, cancer, oncology, patient, caregivers, systematic review, qualitative synthesis

## Abbreviations

<i>MeSH</i>	<b>Medical Subject Headings (terms)</b>
<i>NHS</i>	<b>National Health Service</b>
<i>PBT</i>	<b>Proton Beam Therapy</b>
<i>PRISMA</i>	<b>Preferred Reporting Items for Systematic Reviews</b>
<i>PROSPERO</i>	<b>The International Prospective Register of Systematic Reviews</b>
<i>UK</i>	<b>United Kingdom</b>
<i>US</i>	<b>United States</b>

## Introduction

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Proton Beam Therapy (PBT) is an advanced form of radiotherapy, increasingly recognised as a viable treatment for certain cancers. (1, 2) There is a progressing body of evidence on the potential clinical advantages of PBT compared to traditional radiotherapy (3), however less is understood about patients' views and attitudes towards PBT. As this treatment becomes more widely accessible, it is vital to develop a rich evidence-base of patients' preferences, attitudes and experiences of PBT, to inform discussions with future patients, and guide them in making treatment decisions.

Traditional radiotherapy uses rays of 'photons' to direct radiation towards a neoplastic area, irradiating cell DNA, causing cell death. (4) While 'photons' are widely used in cancer radiotherapy, they release energy along their entire trajectory, exposing healthy tissue to radiation. This involvement of healthy tissue creates the potential for undesirable immediate and long-term side-effects, impacting on quality of life for the patient. (5) These include radiation dermatitis (6) and haematological toxicity (7) as short-term effects, and neurocognitive effects (8), fatigue (9) and fertility impairment (10), in the longer term. The advantage of proton radiotherapy lies in its reduced radiation dose to surrounding tissues, by delivering a precise burst of high energy 'protons' towards a tumour. (4, 5) For this reason, PBT has application in treating cancers in parts of the body that are particularly sensitive to the side-effects of radiation, such as the head, neck, spinal cord and pelvis. (11) Current evidence suggests that PBT is not explicitly favourable over traditional radiotherapy for cancers in less radiation sensitive areas; systematic reviews have found low-quality evidence, with limited randomised controlled trials to provide clear conclusions. (3, 12-14) However, a

reduced radiation dose and potentially reduced side-effect profile may make PBT an attractive option to patients (15).

Previously, only a small number of proton centres existed. This means that only a select number of patients would travel to receive proton therapy. The UK NHS 'Proton Overseas Programme' sends patients for treatment abroad, predominantly to the United States. (2) Following initial successes of proton therapy in the United States and Switzerland, there has been global investment to develop new centres, with 112 centres operational across 20 countries and around 37 others under construction, as of 2021. (16) With the introduction of new centres, there is a need for insight on the experiences and impact of PBT that can be used to accurately inform discussions with future patients, support decision-making, and allow centres to target service improvements (1, 17). Due to the implementation of proton therapy across adult and paediatric settings (18), the views of parents and carers looking after a child receiving PBT can be considered as important evidence, alongside patient views. Synthesis of qualitative evidence allows for a deeper understanding of the subjective experience of PBT than could be expressed through quantitative measures. Previous qualitative systematic reviews of cancer treatment have focussed primarily on symptoms and complications (19-21) or supportive aspects of care (22, 23), and patient experiences of travelling for cancer treatment (24). However, there is an evidence gap for the review of qualitative literature specific to PBT.

This study aimed to systematically review and thematically synthesise the qualitative literature exploring patient and family caregivers' perceptions and experiences of PBT. We focused on evidence of patient and caregiver understandings, decision-making and treatment experiences.

## Methods

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We undertook a systematic review of qualitative literature relevant to the research question *“What are the views, perceptions and attitudes of patients and their caregivers, undergoing or considering Proton Beam Therapy as an alternative to traditional radiotherapy for cancer treatment?”* and followed the Preferred Reporting Items for Systematic Review and Meta-Analyses (PRISMA) 2020 updated reporting guidance. (25) We then thematically synthesised relevant findings. The protocol for this review is registered with PROSPERO, review number CRD42021247808.

### Searches

Five electronic databases (Ovid EMBASE, Scopus, Ovid MEDLINE, APA PsycINFO and CENTRAL), selected for relevance to the subject, were comprehensively searched. The search was designed to identify all English language studies from 1st January 1996 onwards, centred around three concepts – ‘cancer’, ‘patient experiences’ and ‘proton beam therapy’. The cut-off (1996) coincides with the clinical introduction of PBT. The detailed search strategy comprised of both Medical Subject Headings (MeSH) and concept-related keywords. A validated qualitative search filter was applied to refine results to qualitative data. (26) The final search strategy is detailed in Appendix 1. On 1<sup>st</sup> February 2021, all search results were imported into EndNote X9 (27) and duplicates removed.

### Study Selection

The target study for inclusion in this review reported on qualitative data relating to patient and/or their family caregivers' opinions, views and attitudes towards PBT. Defined inclusion and exclusion criteria are given in Table 1. To reduce bias two reviewers (EF and SS/EH), with the input of a third reviewer to resolve disagreements (SS/EH), reviewed the titles, abstracts and full text papers against the inclusion/exclusion criteria via the EndNote X9 file (27). Reference lists of included articles, as well as similar systematic reviews, were checked for relevant studies. Included study authors were contacted where possible, to ask for any other relevant publications and their names searched for further material.

#### Data Extraction

A standard data extraction form was developed (Appendix 2), summarising the key study characteristics, findings and text quotes from their results. Due to heterogeneity in reporting styles between the studies, extractable data was any text under the 'results'/'findings' headings. It was made clear within the data extraction when text was quoted directly from study participants, distinguished from authors' own descriptions.

#### Quality Assessment

Quality assessment of the final texts was conducted using the Critical Appraisal Skills Programme (CASP) Checklist for Qualitative Studies, to assess for rigour, credibility and validity. (28) An appraisal form, based on the ten CASP questions, was developed for ease of comparison (Appendix 3). A limitation of CASP checklists is that they lack a scoring system,



so after appraisal, each study was informally scored out of 10, against checklist criteria.

Scoring was used as a comparison aid; study quality was otherwise considered within context. A study was considered 'high-quality' if nearly all (>7) CASP criteria were present, and missing criteria were thought not to impact overall credibility of results. One reviewer appraised all papers (EF), with a second reviewer checking completeness (SS/EH).

## Data Synthesis

Qualitative data from final texts were compared and thematically synthesised, in order to integrate themes from across qualitative studies. This method involved three stages: text coding, assigning descriptive themes and generating analytical themes. (29)

NVivo 12 software was used for text coding and Microsoft Excel was used to map and organise descriptive themes. (30) One reviewer (EF) read the results of each study, methodically assigning each sentence a short code representing its meaning. These were re-reviewed by the main author to create a coding framework, and descriptive themes were organised into analytical thematic hierarchies. These were reviewed and discussed by three researchers (EF, SS, EH) to ensure that the themes reflected study results.

## Results

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### Study Identification

Overall, 4020 records were identified by database searching, of which 36 were eligible for full-text review. Eight studies (nine papers) were selected for final inclusion in the review. (31-39) No further relevant qualitative studies were identified after the search date, from database alerts or hand-searching. The PRISMA 2020 flowchart for study selection is presented in Figure 1. (25)

### Study Characteristics and Methodological Quality

Study methodology, alongside assessment of quality, can be found in Table 2. Three studies obtained qualitative data through interviews (31, 33-35), four with focus-groups (32, 36, 38, 39), and one study is a first-hand account (37). Sixty-one participants in four studies had gone through the PBT process, either as a patient (n=24; (34, 35, 36)) or parent of a patient aged under 18 (n=37; (31, 33)), and 123 participants across four studies were patients and caregivers considering PBT as an alternative to traditional radiotherapy (32, 36, 38, 39) (Table 3). Five studies were UK based (31-33, 36, 38), one was based in Sweden (34, 35) and two in the US (37, 39).

The quality of included studies varied, ranging between two and nine of the ten CASP criteria checklist items met (Table 4). The areas of low quality were: lack of author reflexivity (32,

33, 36, 38, 39), lack of credibility (32, 36-38) , no statement of aims (32, 36, 37) and poor evidence of rigour (32, 36-38). Two studies were found to be of particularly low quality, with no quotations to support analysis (32, 38), yet were included due to relevance to the research question. When extracting data, evidence from these lower-quality studies was corroborated and not given in isolation.

## Themes

Three major themes and nine sub-themes were developed from the data synthesis: decision-making and perceptions; living in the PBT ‘bubble’; coping with the treatment journey.

(Figure 2).

### Theme 1 – Decision-Making and Perceptions

All eight studies considered decision-making and perceptions of PBT treatment (31-33, 35-39).

#### Understandings of PBT

PBT is a new treatment, which uniquely impacts how patients and caregivers approach information-seeking and decision-making. Descriptions of understandings of PBT were found in five studies (32, 33, 36-38). One study included a robust explanation of PBT given by a patient, (37) in the context of the patient being a medical professional themselves. However, lack of understanding was more frequently reported (31-33, 37, 39), with the media cited as a common source of participants’ information (32, 33, 36, 39). When asked by

researchers to explain proton therapy, participants described its perceived advantages, such as precise targeting of tumours and minimised side-effects (33, 37, 38).

Understandings of PBT were often juxtaposed against conventional radiotherapy (32, 33, 37, 39). Radiotherapy of any form was generally described as dangerous, (33, 36) however PBT was described as a better option over traditional radiotherapy (33, 37), in terms of reduction in damage to tissues:

*“So I know that basically conventional X-ray sort of goes into the body, but it comes out in all kind of directions, so it can hit healthy tissues, whereas the proton, basically is a beam that goes in and it can be controlled, it comes out without hitting so much of the healthy tissues.” (Female parent, (33))*

Five studies (31-33, 36, 37) demonstrate the perception of PBT as a superior modality of radiotherapy. None reported perceived inferiority of PBT amongst participants. Superiority was generally expressed with regards to a reduced side-effect profile, (33, 36, 37) and participants felt privileged or grateful when given the opportunity to receive this treatment (31, 37).

*“...we concluded that because the radiation problem seemed to be reduced, [PBT] was a better choice if I were fortunate enough to be accepted as a candidate for treatment at [American proton centre].” (Male patient, (37))*

Information-Seeking and Informed Decision-Making

Patients and caregivers described gathering information to make decisions and to prepare themselves for treatment. Five studies referred to participant methods and preferences of seeking-information (31, 33, 35, 37, 39). Health professionals were seen as a reliable source of expertise by participants in two studies (33, 39), and for some, instrumental in decision-making:

*“I would need more information likely speaking directly with a doctor to get his input about whether I should get the IMRT or the protons. And that would make a decision for me.” (Male patient, (39))*

However, this trust in medical advice was not universal across the studies; two studies (33, 37) described lack of confidence in doctors’ knowledge.

*“Time and again, we heard stories of patients whose doctors did not know about proton beam radiation therapy, or who said it is experimental, or that it is not effective...” (Male patient, (37))*

One study reported how nearly all parent participants relied on the internet as a major information source (33), to supplement information from their child’s doctor. The parents were aware of the reliability issues faced by internet research and described a cautionary approach:

*“Yes, we were not looking at sort of, websites, information on websites that weren't linked to the NHS or the brain tumour charity or anything like that, because, you*

*know, you're just scared of seeing sensationalist information that is not really backed up..." (Male parent, (33))*

Anecdotal advice from other patients was a preferred method of information-seeking in three studies, due to the rarity of some cancers and the small pool of patients with PBT experience (31, 33, 37). Support groups were utilised to compensate for lack of web-based information or professional advice (33, 37). Communication with other patients was used to manage uncertainties (33) and influence decision-making (37). A benefit of gathering information from patients who have experienced PBT is their insight on practical matters such as travelling for treatment (31), and what to expect from PBT itself (33).

*"...I don't want to hear statistics, I want real life stories because, you know, statistics is so far away from reality, you are dealing within your family and you want to hear life stories" (Female parent, (33))*

In decision-making, several participants describe a balance between reduced toxicity and efficacy (33, 36, 37, 39). This links to the previous theme of perceived superiority – avoidance of side effects was appealing to participants, especially those who had radiotherapy experience (36). It was accepted that there is not enough evidence to determine therapeutic superiority (33), but reduced toxicity was appealing to participants.

*"... there was no evidence that proton is better than photon in treating the cancer, and that is still the case, it's not better in treating cancer but it is the better in the side effects ..." (Female parent, (33))*

## Theme 2 – Living in the PBT ‘bubble’

PBT is not yet widely available worldwide, so some patients and caregivers temporarily live away from home to be nearer a treatment centre. The idea that time spent receiving PBT is like being in a ‘bubble’ (31) is evident in three studies (31, 35, 37).

### Sharing the Experience

‘Camaraderie’ (31) between those receiving PBT was a common finding, contributing to the idea of being in a ‘bubble’ (2). Three studies highlight how patients share the experience with others, forming friendships and providing mutual support (31, 35, 37). The uniqueness of proton therapy, being away from home and the need to feel supported in the experience were all key drivers for these formed alliances.

*“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.” (Female parent, 31)*

Proton centres encouraged these friendships by organising group activities and support groups (31, 35, 37). Some patients and families preferred spending time with family or alone (31, 35), however those who did connect with others were comforted by the extra support (31, 35).

*“It is like therapy to be there [...]. To have the opportunity to talk and discuss with people who really understand what it means (to receive PBT).” (Patient, (35))*

#### Positive Treatment Environments

A positive treatment environment was described by three studies (31, 35, 37). The centres were described as ‘extremely organised’ (31), keeping patients well-informed, so reducing stress levels. The caring attitude of healthcare staff made participants feel as though they were in safe hands (31, 37). Welcome gestures, such as being familiarised with the treatment rooms, helped to put patients at ease and make them feel at home (31, 37). Well-run centres greatly improved the patient experience:

*“The warm, caring and accessible staff, from the top down, cannot be praised enough [...] They believe attitude is a major part of the treatment, both theirs and the patients’.” (Male patient, (37))*

#### Leaving behind daily life

When living away from home, there was a theme of being detached from life outside of treatment in three studies (31, 35, 37). For some participants who had travelled far from home, this meant feeling as though they were on holiday:

*“it wasn’t a holiday by any stretch of the imagination, but it kind of felt like it.”  
(Female parent, (31))*



In two studies (31, 35), the opportunity to detach from daily responsibilities was viewed positively. Participants had an optimistic approach to being away and described making the most of treatment time.

*“When I am at home, I have more expectations on myself to be part of the family and to be working. At home it is not allowed to just sleep or rest. But here I can do that.”*  
(Patient, (35))

Adjusting back to life post-treatment

As a result of treatment being detached from daily life (31, 35-37), when treatment came to an end, four studies (31, 35-37) described how participants adjusted to life post-treatment. Some patients and families were relieved to return home (31, 35); however, generally, participants found the readjustment difficult. There was uncertainty over the success of PBT (31, 33, 37), feeling alone with illness again (31) and return to normality and routine (34).

*“Then it's not only to get back into the everyday routine. To get back when you have kids, take care of daycare and school and that is the home, which is a stress in itself.”*  
(Patient, (34))

PBT was viewed as a superior treatment which was a privilege to receive, and this belief was enhanced by the positivity and support of the treatment bubble. Upon return to reality post-treatment, some felt let down by the outcomes of receiving PBT (31, 33).

*“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 [our son] ... 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...” (Male parent, (31))*

### Theme 3 –Coping with the Cancer Treatment Journey

Cancer treatment was often described as being like a journey (31, 36, 37). All studies expressed ways in which participants faced difficulties and learned to cope with the journey of treatment (31-39).

#### Symptom management and lifestyle changes

Symptoms, and participants’ coping mechanisms, were addressed by three studies, across four papers (31, 34, 35, 37). Overall, PBT-related symptoms were not frequently discussed, however fatigue was mentioned by four studies (31, 34, 37, 38). Due to the different types of cancers within the studies, there was little crossover between symptoms reported. However the coping strategies were similar– accepting their limitations (34, 37), planning ahead to avoid surprises (34) and controlling symptoms with lifestyle modifications (34, 37).

*“...Furthermore, I know how to act to get more or less of the symptoms. Healthy living. Too little sleep, too little food, and too much work. Then the symptoms increase.” (Patient living with a brain cancer, 34))*

Difficulties of living away from home and the need for social support

Due to PBT treatment centres often being far from participants' homes, one of the biggest barriers to receiving PBT was how they both perceived, and experienced, the practical and emotional difficulties of being away from home (31, 32, 34-39). Participants considering PBT expressed that due to career or childcare commitments, they would prefer an adapted treatment schedule, or to commute back-and-forth to home (32, 36). Household duties, loss of income and childcare requirements were all described as barriers to receiving PBT (31, 32, 36, 38).

*“So if I was going to choose this facility, maybe offsetting some of [the transportation] costs or having a place to stay.” (Patient considering PBT, (39))*

Three studies describe participants' guilt for spending time away from home (31, 35, 36). The guilt was split between the emotional toll of leaving children behind (30) and neglecting home or work responsibilities (31, 36).

*“So, I get a bad conscience because of the children when I am not at home together with them. And even for my wife that I cannot be at home and help her.” (Male patient, (35))*

Participants also expressed a fear of being separated from family during treatment (32, 35, 38). The need for a close support network during treatment was described by five studies (31,

32, 35, 37, 38). Those who underwent treatment alone describe making efforts to virtually keep in touch with family (31, 35).

*“It is important to have social contact with others, to not be alone and it is not possible to be alone for 5 weeks, no it is not possible, you have to have someone to talk to.” (Patient, (35))*

Family members were an essential source of emotional support (31,32, 35, 37, 38). Family helped participants to cope, and parents expressed gratitude for the support received from other family members during their child’s treatment (31).

Dealing with the unknown

A major theme of the treatment journey is that of unfamiliarity and unknown, from the treatment itself, to the centres and locations where treatment takes place (31, 33, 35, 37-39). One of the biggest unknown factors was how PBT would impact patients after returning home (31, 33, 37).

*“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” (Female parent, (31))*

Despite this uncertainty, participants generally maintained a positive approach, (31, 34, 35, 37), commonly expressing hope for the future.

*“... 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.” (Female parent, (31))*

## Discussion

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This systematic review considers the qualitative evidence on patient and caregiver experiences, attitudes and perceptions towards receiving Proton Beam Therapy for cancer treatment. Despite the small number of eligible studies, there was consistency in findings throughout the studies, even when comparing evidence from both parent and patient sources. Three clear themes emerged from thematic synthesis - decision-making and perceptions, living in the PBT 'bubble' and coping with the cancer treatment journey. Several features of care were identified that can have a positive or negative influence on the overall treatment experience for patients and family caregivers, such as: treatment organisation and logistics (31, 32, 36, 38); camaraderie with others in the same situation (31, 35, 37) and a support network during treatment (31, 32, 35, 37, 38). These findings have important implications for the promotion of patient-centred care in the future.

PBT was commonly perceived as a superior new treatment, despite a lack of definitive evidence. Such perceptions were often based upon its' media portrayal (32, 33, 36, 39). Media promotion of new cancer treatments has been shown to hugely influence patients' opinions (40) and treatment decision-making can be influenced by the marketing of interventions as novel, or technologically superior (41). Evidence suggests that many proton centre websites promote the treatment as superior, without substantiation (42). However, decision-making is also shown in the wider literature to be a complex multifactorial process, involving the patient, their family and the healthcare team (43, 44). During the PBT decision-making process, patients and caregivers describe using a variety of sources to enhance understanding (31, 33) and previous systematic reviews describe that radiotherapy patients

utilise a mixture of web-based information, professional advice and anecdotal information from others (45-47) when making decisions. The relative rarity of PBT as a treatment method means there is not yet an abundance of information, and some patients lacked confidence in doctors' knowledge (33, 37), so turned to rare cancer support groups and the internet (33). There are reliable internet resources available, such as The Brain Tumour Charity's 'PBT fact-sheet', which has been developed with patients and carers and verified by specialists (48). However, if other internet resources used for decision-making are inherently biased or misleading, this could create ethical issues (49). Improving availability and quality of internet resources for patients considering PBT is therefore an area for future research and improvement.

Lack of available information about PBT and its likely outcomes created uncertainty for participants. When faced with uncertainty, study participants commonly demonstrated a positive, hopeful attitude towards the situation as a coping strategy (31, 34, 35, 37). Hope in the face of adversity is frequently demonstrated in qualitative cancer literature as a key coping strategy (50-53), aptly described by some as a 'fighting spirit' (51, 52). For PBT, this hopeful attitude was due to its' perceived superiority in the context of uncertain prognostic outcomes (31, 34, 35, 37).

The theme of living in a 'bubble' during PBT treatment was inextricably linked to instances where participants had travelled abroad or across-country to receive treatment. As of 2021, there were around 100 proton therapy centres worldwide, which are widely spread and some patients travel long distances to reach their centre (17). This raises the issue of equity of access for treatment; in this review, many of those considering PBT stated there are financial or social barriers to receiving treatment far from home, such as loss of income and lack of

childcare (31, 35, 36). This inequity is not unique to PBT– similar findings are observed for other advanced cancer therapies, such as cell immunotherapy, which is not widely available, but is subject to media sensationalism surrounding its’ novelty, making it desirable to patients despite low accessibility (54, 55). Addressing these inequities should be a priority of health providers for the future of these treatments.

For those who overcame the financial and geographical barriers to receive PBT, being away from the home environment had both positive and negative implications (31, 34, 35, 37). A previous review, focussed on travelling for cancer treatment, noted that on top of the general stresses of cancer treatment, patients and family members have difficulty adjusting to a new environment (24), which this review supports (31, 35). Adjustment was made easier by welcoming treatment centres with attentive staff and good organisation (31, 37). Interaction between patients and family groups, often facilitated by treatment centres, helped them to feel comforted by the shared experience, and this social support was missed by patients on return home (31, 34). There is evidence for the benefits of camaraderie and peer support between those with cancer in the wider literature (56, 57); peer support can empower patients to cope with treatment (58) and improves well-being (59). These findings could be applied by centres which provide new treatment modalities, such as PBT or immunotherapy, for which patients stay away from home to receive. The promotion of treatment environments which provide supportive hospitality and encourage peer camaraderie could significantly improve the patient experience.

Strengths and Limitations



This is the first systematic review of qualitative evidence on patient and caregiver experiences, perceptions and attitudes, specifically towards PBT. The review was limited by a low number of eligible studies, and the low quality of some of these studies. The decision to include both patient and parental views in the same synthesis may limit transferability of findings, however there was still value in considering both, given overall lack of available evidence and the consistency found between their experiences. Despite these limitations however, common themes were identifiable, with several practical implications for improving patient care in this evolving field of cancer treatment. Further high-quality qualitative research investigating PBT experiences is needed to inform the evidence on decision making and patient/family experiences of PBT.

#### Implications for Psychosocial Oncology

- The delivery of successful PBT services will depend on the ability of centres to provide a patient-centred experience. Without research to inform stakeholders and policymakers of challenges that are faced by patients and their families in decision-making, during and after treatment, the service will not be tailored to their needs.
- This review provides a first-glance view of understandings, experiences and how patients cope with treatment. From this review, suggestions that could improve patients' experience include:
  - Creating opportunities for patients and their families to engage with and support one another;
  - Prioritising the facilitation of a warm and welcoming treatment environment;
  - Scheduling radiotherapy treatments to fit around patients' daily lives;

- Improving availability and quality of accessible online and in-person PBT information.
- The small amount of current evidence limits the extractable findings, however as the evidence-base develops, further reviews can build on these findings and add new insights.

## Conclusions

Patients and their families who choose PBT for the treatment of cancer face several uncertainties due to the novelty of this treatment. This review has uncovered areas that can be targeted to improve the patient experience and reduce these uncertainties, such as adequate information provision, pleasant treatment environments and facilitating interaction between patients to form support networks. As PBT is more widely used for UK patients and globally, further areas to improve patient-centred care will emerge. Further in-depth qualitative primary research focused on PBT is needed, to expand the limited experiential evidence that is currently available and allow care improvements to be appropriately targeted.

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**Data Availability:**

Supplemental data can be shared upon reasonable request.

## Tables and Figures

Table 1: Inclusion and Exclusion Criteria

<b>Inclusion Criteria</b>	<b>Exclusion Criteria</b>
Qualitative methodology studies	Quantitative, or other methodology
Patients (all ages) with cancer and their families/caregivers. For patients under 18, 'caregivers': parents or whoever is responsible for looking after them. For adult patients, 'caregivers': family members and spouses/partners.	
Patients will have already received, or will be considering PBT (in any of its forms) for cancer treatment	Research of any other radiotherapy treatment besides PBT, such as internal radiotherapy
Published studies reporting on qualitative data	Conference proceedings, letters, posters, case reports, unpublished studies.
Data must refer to either participant perceptions or experiences of PBT.	

Table 2: Characteristic breakdown of included studies

FEATURE	Year Published	Country	Perspective	Cancer Type	Qualitative Methods	No. of participants	Methodology	n, CASP criteria met	Quality
<i>STUDY</i>									
<i>Cockle and Ogden (31)</i>	2016	UK	Parents	Brain	Semi-structured Interviews	10	Thematic Analysis	7	High quality
<i>Hague, C. et al. (32)</i>	2018	UK	Patients / family	Oropharyngeal	Focus Groups	33 patients 8 family	Thematic Analysis	2	Low Quality
<i>H-Yazdi and Meadows (33)</i>	2021	UK	Parents	Multiple	In-depth Interviews	27 (21 families)	Thematic Analysis	5	Medium Quality
<i>Langegard, U. et al. (34) and Mollerberg, M et al. (35)*</i>	2020	Sweden	Patients	Brain	Open-ended Interviews	22  19	Grounded Theory / Constant Comparative  Hermeneutical Analysis (Secondary Analysis of Langegard et al. <sup>(26)</sup> )	9	High Quality
<i>Nicholas, O.J. et al.(36)</i>	2020	UK	Patients	Oesophageal	Focus Groups	21	Thematic Analysis	5	Medium Quality
<i>Parkin and Girven (37)</i>	2005	US	Patients	Prostate	Descriptive Accounts	2	Descriptive	7	High Quality
<i>Powell, J.R. et al. (38)</i>	2019	UK	Patients/ Family Caregivers	Brain (Oligodendrioma)	Focus Groups	15	Descriptive	4	Low Quality
<i>Shah, A. et al. (39)</i>	2012	US	Patients	Prostate	Focus Groups	46	Thematic Analysis/Constant Comparative	8	High Quality

\*Langegard et al. (34) and Mollerberg et al. (35) are separate papers within the same qualitative study.

**Table 3: Distribution of characteristics across all participants**

	<b>Variable</b>	<b>Number of Studies</b>	<b>Number of Participants</b>	<b>Study References</b>
<b>Perspective</b>	Previous Experience of PBT	4	61	(31, 32-35, 37),
	Considering / views on PBT	4	123	(32, 36, 38, 39)
<b>Participant</b>	Adult Patient	6	124 (at least)	(32, 34-39)
	Parent	2	37	(31, 33)
	Family Member/Caregiver	2	8 (at least)	(32, 38)
<b>Cancer Type</b>	Brain (include Oligodendrioma)	3	47	(31, 34, 35, 38)
	Prostate	2	48	(37, 39)
	Oesophageal	1	21	(36)
	Oropharyngeal	1	41	(32)
	Multiple	1	27	(33)
<b>Country</b>	UK	5	114	(31-33, 36 38)
	US	2	48	(37, 39)
	Sweden	1	22	(34, 35)

(Due to being the same participant cohort, Langedard et al. (34) and Mollerberg et al. (35) have been counted as one study)

Table 4: CASP (28) checklist items met, by study.

Notes: see appendix for CASP template.

CITATION	<i>Cockle and Ogden (31)</i>	<i>Hague, C. et al. (32)</i>	<i>H-Yazdi and Meadows (33)</i>	<i>Langegard, U. et al. (34)</i>	<i>Mollerberg, M et al. (35)</i>	<i>Nicholas, O.J. et al.(36)</i>	<i>Parkin and Girven (37)</i>	<i>Powell, J.R. et al. (38)</i>	<i>Shah, A. et al. (39)</i>
<b>CASP Criteria</b>									
<i>Clear statement of aims</i>	✓		✓	✓	✓			✓	✓
<i>Appropriate qualitative methodology</i>	✓	✓	✓	✓	✓	✓	✓	✓	✓
<i>Appropriate research design</i>	✓		✓	✓	✓	✓	✓	✓	✓
<i>Appropriate recruitment strategy</i>	Maybe	✓		✓	✓		✓		✓
<i>Did data collection address the research issue?</i>	✓		✓	✓	✓	✓	✓	✓	✓
<i>Consideration of researcher-participant relationship</i>	Maybe			✓	✓		✓		
<i>Ethical consideration</i>	✓			✓	✓				✓
<i>Rigorous data analysis</i>	Maybe		Maybe	Maybe	Maybe				✓
<i>Clear statement of findings</i>	✓			✓	✓	✓	✓		✓
<i>Will the results help locally?</i>	✓		✓	✓	✓	✓	✓		
<b>Total CASP criteria met</b>	7	2	5	9	9	5	7	4	8
<b>Overall Quality</b>	High	Low	Medium	High	High	Medium	High	Low	High

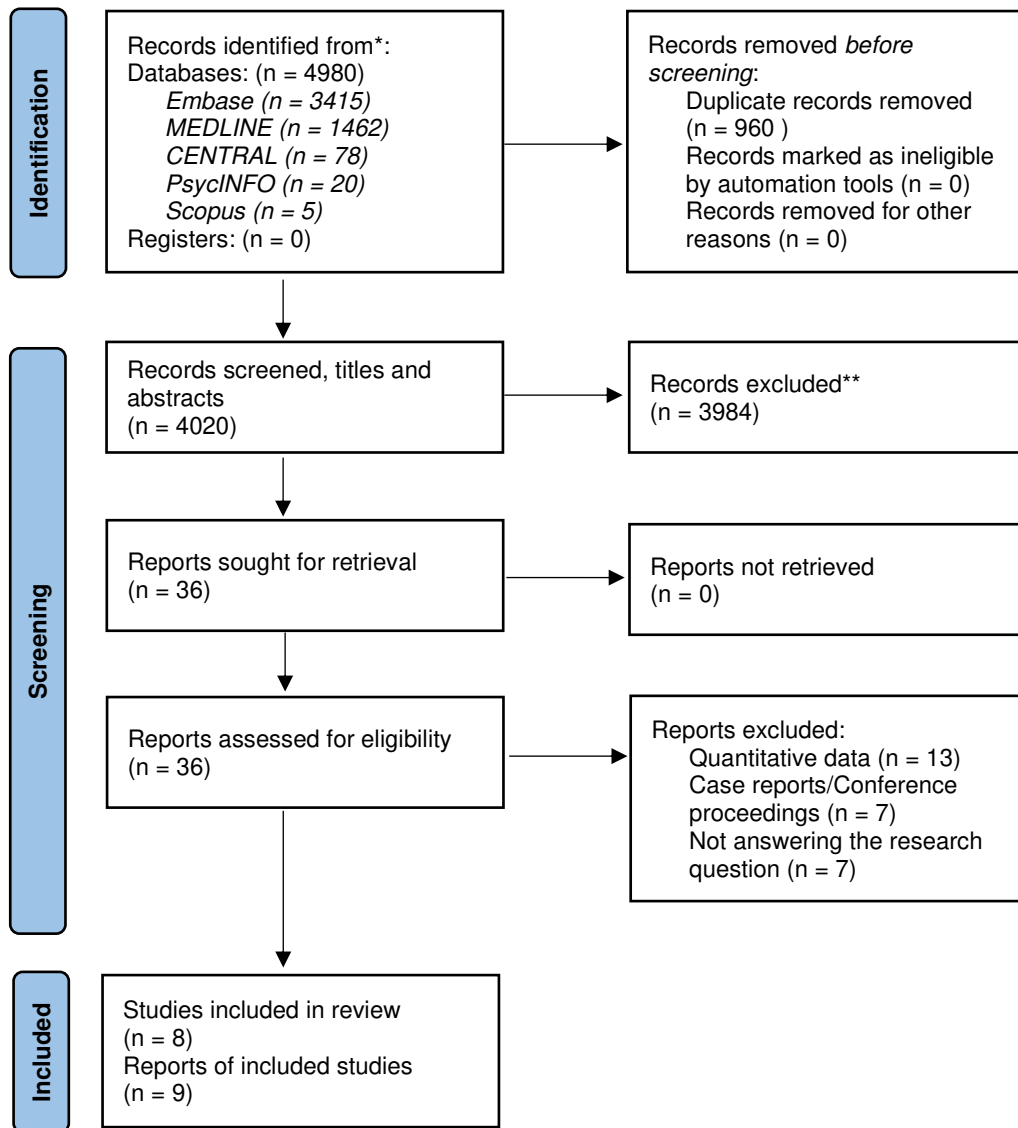


Figure 1: PRISMA 2020 diagram of systematic screening of records (25)

\*Final retrieval was eight studies, for which one had two separate papers, making nine total articles retrieved.



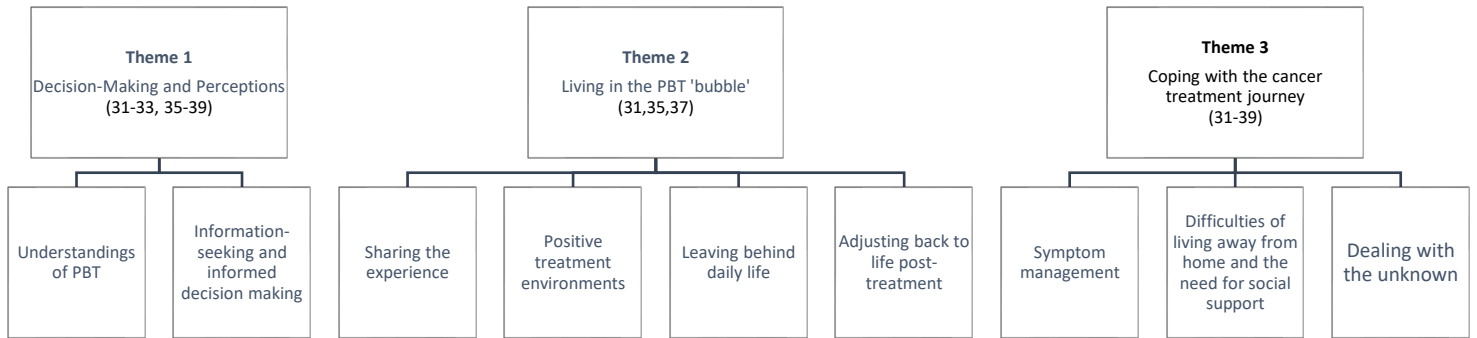


Figure 2: Generated themes and sub-themes

## Appendices

### Appendix 1 – Search Strategy

- 1 exp Proton Therapy/
- 2 Proton beam\*
- 3 proton minibeam\*
- 4 proton irradiation\*
- 5 proton radiotherap\*
- 6 proton radio-therap\*
- 7 exp Protons/
- 8 accelerated proton beam\*
- 9 accelerated proton\*
- 10 particle therap\*
- 11 hadron therap\*
- 12 (proton adj3 therap\*)
- 13 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12
- 14 exp Patient Satisfaction/
- 15 Patient-Centered Care/
- 16 "Quality of Health Care"/
- 17 (patient-centred adj2 care)
- 18 (patient centered adj2 care)
- 19 patient-reported experience measure\*
- 20 (patient\* adj3 report\*)
- 21 (patient\* adj3 expect\*)

22 (view\* or viewpoint\* or attitude\* or experience\* or opinion\* or expression\* or thought\* or focus group\* or interview\* or observation\* or perspective\* or understand\* or satisfaction\* or qualitative\* or perceive\* or perception\*)

23 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22

24 exp Neoplasms/

25 (neoplasm\* or cancer or carcinoma\* or tumour\* or tumor\* or malignanc\* or oncol\*)

26 (adenocarcinoma\* or adenoma\* or angiosarcoma\* or astrocytoma\* or carcinoma\* or cholangiocarcinoma\* or chondrosarcoma\* or chordoma\* or choriocarcinoma\* or craniopharyngioma\* or cytoma\* or ependymblastoma\* or esthesioneuroblastoma\* or fibrosarcoma\* or germinoma\* or glioblastoma\* or glioma\* or hemangioma\* or hemangiosarcoma\* or histiocytoma\* or hypernephroma\* or incidentaloma\* or leiomyosarcoma\* or leukaemia\* or leukemia\* or lipoma\* or liposarcoma\* or lymphangiosarcoma\* or lymphoma\* or medulloblastoma\* or melanoma\* or meningioma\* or mesothelioma\* or myeloma\* or myxosarcoma\* or neuroblastoma\* or neurofibrosarcoma\* or oligoastrocytoma\* or oligodendroglioma\* or osteosarcoma\* or paraganglioma\* or pheochromocytoma\* or plasmacytoma\* or pineoblastoma\* or pleomorphic xanthoastrocytoma\* or rhabdomyosarcoma\* or sarcoma\* or schwannoma\* or seminoma\*)

27 24 or 25 or 26

28 (view\* or viewpoint\* or attitude\* or experience\* or opinion\* or expression\* or thought\* or focus group\* or interview\* or observation\* or perspective\* or understand\* or satisfaction\* or qualitative\* or perceive\* or perception\*)

29 13 and 23 and 27

30 28 and 29

31 limit 30 to (english language and yr="1996 -Current")

MEDLINE

Appendix 2 – Data Extraction Form Template

General information		
	1 <sup>st</sup> reviewer -	2 <sup>nd</sup> reviewer
Data extracted by:		
Date:		
Data extraction checked by:		
Date:		
Citation:		
<b>Include:</b>		<b>Exclude:</b>
<b>Reason for exclusion:</b>		
Study Information		
Study Aim:		
Study Setting: <i>(location, country, context, where interview took place)</i>		
Study Design: <i>(Qualitative, mixed methods)</i>		
Perspective: <i>(those who are experiencing the situation – patients or parents for this review)</i>		
Population		
Study Population: <i>(no. of participants, age, gender, treatment)</i>		
Cancer Type reported:		
Inclusion Criteria:		
Exclusion Criteria:		
Methods		

Data Collection: <i>(Interviews, focus groups, survey free text data etc)</i>		
Role of the Researcher:		
Data Analysis: <i>(Analysis method used)</i>		
<b>Findings</b>		
Summary of study findings: <i>(Include key themes)</i>		
Quotes from study:		
Conclusions:		
<b>Notes</b>		
Further Comments:		
<b>Further Information</b>		
Ethical approval:		
Funding sources:		
Conflicts of interest:		

Appendix 3 – Critical Appraisal Form Template

<b>General information</b>		
	1 <sup>st</sup> reviewer -	
Appraised by:		
Date:		
Checked by:		
Date:		
Citation:		
<b>Include:</b>		<b>Exclude:</b>
<b>Reason for exclusion:</b>		
<b>Critical Appraisal: CASP Qualitative Checklist</b>		
<b>Section A: Are the results valid?</b>		YES/NO
1. Was there a clear statement of the aims of the research?		
2. Is a qualitative methodology appropriate?		
3. Was the research design appropriate to address the aims of the research?		
4. Was the recruitment strategy appropriate to the aims of the research?		
5. Was the data collected in a way that addressed the research issue?		YES
6. Has the relationship between researcher and		

participants been adequately considered?		
<b>Notes</b>		
<b>Section B: What are the results?</b>		<b>YES/NO</b>
7. Have ethical issues been taken into consideration?		
8. Was the data analysis sufficiently rigorous?		
9. Is there a clear statement of findings?		
<b>Section C: Will the results help locally?</b>		<b>YES/NO</b>
10. How valuable is the research?		
<b>TOTAL CASP CRITERIA MET</b>		<b>/10</b>

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