EMILY S. CARTER BSc Hons., PgCert

# CARING FOR INDIVIDUALS WITH A BRAIN TUMOUR

**Section A:** Caregiving Experiences of Carers for People with a Primary Brain Tumour: A Thematic Synthesis of Qualitative Studies Based on a Systematic Literature Search

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**Section B:** *'She Wasn't My Mum Anymore'* – Bereaved Young Peoples' Experiences of a Parental Brain Tumour: An Interpretative Phenomenological Analysis

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## Acknowledgements

Thank you to the participants who made this project possible through the courageous sharing of your stories. I share your vision of a world where brain tumours are better understood.

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To my friends, who made it very easy to forget I was undertaking a doctorate!

To Mum and Matt, for supporting me in so many ways.

And to my wonderful Dad, Richard. You will always be my inspiration.

# Summary of Major Research Project

**Section A:** This literature review explored the experiences of caregivers to people with a primary brain tumour (PwPBT). Ten qualitative papers were identified through a systematic search and analysed using thematic synthesis. Six themes were developed from the analysis: ‘Consumed by Caring’, ‘Impact and Isolation’, ‘Keeping Going, ‘Adapting to New Ways of Living, ‘Living with the Unknown, and ‘Finding The ‘Right’ Support’. Findings emphasise the continued importance of paying attention to the wellbeing of caregivers to PwPBT and thinking creatively to offer accessible support. Directions for future research are also discussed.

**Section B:** This study explored bereaved young peoples’ experiences of a parental primary malignant brain tumour (PMBT). Semi-structured interviews were conducted with nine young people and analysed using Interpretative Phenomenological Analysis (IPA). Results were organised into five group experiential themes: ‘The Emotional Impact’**,** ‘Seeing the Disease, Not My Parent’, ‘Stepping Up’, ‘Relationships: Strength or Strain’, and ‘A Changed Outlook’**.** Sub-themes were also explored. Findings highlighted this experience can have a far-reaching and long-lasting impact and indicated the importance of adequate support for young people whilst they navigate a parental PMBT. Implications for clinical practice and research are considered.

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# Section A:

## Caregiving Experiences of Carers for People with a Primary Brain Tumour: A Thematic Synthesis of Qualitative Studies Based on a Systematic Literature Search

Word Count*:* 8000 (201)

## Abstract

**Background.** A primary brain tumour (PBT) diagnosis carries a poor prognosis, and disease progression along with invasive treatment can result in significant functional and neuropsychological difficulties. Informal caregivers have a crucial role in supporting individuals with a PBT, and there is a need to understand the everyday caregiving experiences within this context.

**Aim.** This review aimed to carry out a systematic search of the literature to understand the caregiving experiences of carers to people with a PBT and identify implications for research and clinical practice.

**Design.** An electronic search of existing qualitative literature was conducted using four databases, yielding 10 studies based on inclusion criteria. A quality appraisal and thematic synthesis of the studies was carried out.

**Results.** Six themes were developed: 'Consumed by Caring', 'Impact and Isolation', 'Keeping Going', 'Adapting to New Ways of Living', 'Living With the Unknown', and 'Finding The 'Right' Support'. Each theme described a different aspect of the caregiving experience. Fifteen sub-themes were explored.

**Discussion & Implications.** Findings were discussed within the context of existing literature, and clinical implications, such as the need for flexible support for caregivers were considered. Recommendations for further research are also suggested.

**Key Words:** Primary brain tumour, brain cancer, caregiver, experience, qualitative methods.

# Introduction

## Primary Brain Tumours

Primary brain tumours (PBTs) are responsible for the most cancer deaths within people under 40, however, only 3% of UK government cancer research funding is spent on research to improve patient outcomes (Brain Tumour Charity, n.d.). The incidence of PBTs rises steadily from 20-25 years of age, and the diagnosis has a poor five-year survival rate of just 10% (Office for National Statistics, 2019). Gliomas are the most common type of PBT in adults and are graded according to their likely growth rate, from grade one (slowest) to grade four (fastest). Grades one and two tumours are considered ‘low grade’ and are typically benign or non-cancerous, whereas grades three and four are malignant and considered ‘high-grade’.

Treatment for a PBT usually involves invasive and intensive treatments: full or partial neurosurgical resection (if tumour site makes this possible), radiotherapy and chemotherapy. In cases of certain high-grade tumours (i.e., grade four glioblastoma multiforme) treatment is not curative and instead intends to prolong life. Regardless of whether the tumour is benign or malignant, the impact of a brain tumour and its treatment causes extensive challenges due to neuropsychological and functional changes; the emotional, physical, cognitive, and behavioural sequelae can significantly impact the quality of life for both people with a PBT (PwPBT) and their families (Ownsworth et al., 2015). PwPBT can experience changes in cognitive function (e.g., personality changes, impaired speech, visual-perception deficits); mental health, and their physical state (e.g., weight change, sensory and mobility loss, fatigue, seizures, changes in bodily functions) (Molassiotis et al., 2010; Piil et al., 2016). Standard care in Western countries emphasises outpatient treatment, and therefore early discharge from hospital (Heinsch et al., 2021). This can mean that informal caregivers play a key role in supporting their loved one through the disease trajectory (Ownsworth et al., 2015), particularly in contexts where health systems are under-resourced and over-stretched.

## Caregiving in the PBT Context

Literature focusing on caregivers of PwPBT suggests this group experience high levels of physical and mental stress and exhaustion, experience anxiety about future uncertainty and have an increased risk of illness (Edvardsson & Ahlstrom, 2008; Rimmer et al., 2023). Despite this, caregivers can struggle to attend to their own healthcare needs (Currie et al., 2015). In a clinical paper, Sullivan and Miller (2015) posit this is due to insufficient time and experiencing ‘appointment fatigue’ after attending many with the PwPBT. Caregivers for this group face unique challenges with managing PwPBTs’ behaviour, memory loss, reasoning, language and attention difficulties and mobility (Schubart et al., 2008). In a study exploring quality of life in caregivers, Fox and Lantz (1998) describe the experience of supporting a PwPBT as a constant battle of unexpected problems, caregiver burnout, need for resources and balancing hope with realistic expectations. Goebel & Mehdorn (2013), in longitudinal research examining anxiety and depression in PwPBT, further suggest that PBT caregivers have the highest psychological burden of carers to individuals with chronic illness.

A quantitative study exploring quality of life in PwPBT and their caregivers demonstrated found that assuming new caregiving responsibilities can lead caregivers of PwPBT to feel socially isolated with a lack of support (Petruzzi et al., 2012). Schubart et al. (2008) suggests new roles and responsibilities are acquired in attempts to compensate for disability and deterioration in PwPBT. Additionally, caregivers who communicate their loved one’s PBT diagnosis to family and friends can face stigma and further isolation, as support networks withdraw and avoid communication due to feeling overwhelmed (Schubart et al., 2008). Salander and Spetz (2002) found that relationships between caregivers and PwPBT can also experience strain due to changes in personality that occur as disease progresses. Aligned with this, Ownsworth et al. (2015) indicated that caregivers can feel as though the person with a PBT is not the person they used to know.

Despite literature indicating that caregiving for PwPBT can present challenges, studies have highlighted that the experience can also be positive and meaningful. Wasner et al. (2013), in a study examining caregiver needs, found the responsibility of providing care and having time together could be rewarding. Similarly, research has suggested other benefits for carers including greater resilience and strength, appreciation for life and stronger family relationships (Petruzzi et al., 2013; Stenberg et al., 2009). Nevertheless, conceptualisations of the detrimental impact on caregivers appear to dominate the literature.

## Conceptualising Caregiver Stress & Coping

Dominant conceptual models assume that the onset and progression of chronic illness and physical disability are stressful for both caregiver and person with the illness (Schulz & Sherwood, 2008). Subsequently, the transactional model of stress and coping (Folkman & Lazarus, 1984) offers a useful framework for understanding differences in subjective caregiving experiences. A central tenet of the model is that the individual appraisal of the event, rather than the event itself, is what leads to a situation being perceived as stressful or positive. The model suggests that individuals employ coping resources, such as problem-solving skills, social networks, general and specific beliefs (i.e., self-efficacy or existential beliefs), along with utilitarian resources (i.e., money or training) to manage the issue that is causing the stress (problem-focused coping) or regulate emotions (emotion-focused coping). This process of coping is proposed to mediate the effect of stress upon an individual. Notably, the model is criticised for not allowing an examination of the more positive and pleasurable caregiving experiences (Kelso et al., 2005).

## Rolland's (1994) Family Systems Illness Model

Given informal caregivers are primarily made up of spouses and adult children within families (Lambert et al., 2017), the family systems illness model (FSIM; Rolland, 1994) provides an additional relevant framework for understanding how caregivers may respond to a PBT diagnosis. The FSIM attends to three dimensions: i) psychosocial types of illness, ii) major developmental phases in the illness history and iii) key family system variables, including beliefs and culture.

The onset of a PBT diagnosis can be gradual but is often acute, which the FISM posits compresses affective and practical changes for caregivers into a short timeframe. Additionally, an acute illness onset requires caregivers to tolerate highly emotional situations, exchange roles flexibly, problem-solve and use outside resources. The FSIM suggests that with progressive illnesses, like PBTs, caregivers live with ongoing symptoms and relationship/role changes as the disease progresses. Strain and exhaustion are apparent with little opportunity for relief. Additionally, both the extent to which an illness alters a lifespan, and the degree of impairment caused, are proposed to influence the degree of caregiver psychosocial stress. Notably, cognitive impairment typically requires greater role reallocation (Rolland, 2005), and alters capacity for relational connections (Rolland, 2017). These ideas suggest the psychosocial impact of PBT on families is likely to be significant.

Rolland (1994) considered three-time phases of an illness in the FSIM: crisis, chronic and terminal, all of which have key developmental tasks for caregivers to navigate. In the crisis phase, they must socialise themselves to the illness, grieve loss of previous identity, accept permanency, develop flexibility, learn to live with symptoms and work with healthcare professionals (HCPs). In the chronic phase, caregivers seek to maintain semblance of normal life and avoid burnout, manage relationships between family and patient, sustain autonomy, adjust goals in the face of illness and sustain intimacy. In the terminal phase, tasks include coping with issues of death, loss and separation and reorganization of family beyond the loss. Rolland suggests optimal coping involves emotional openness, such as acknowledging the loss and saying goodbye, as well as dealing with practical tasks.

Within the model, Rolland (1994) also highlighted the key family and cultural beliefs that also shape illness narratives and coping strategies, including those about normality, the mind-body relationship, meaning attached to illness/symptoms, assumptions about illness cause and outcomes.

## Systematic Reviews into Caregiving for PwPBT

There have been limited reviews of literature surrounding caregiving for PwPBT, which have tended to focus on specific aspects of the experience or supportive care needs. Madsen and Poulsen (2010) reviewed needs for everyday life support in caregivers of malignant glioma across 14 studies. Findings suggested relative caregivers often take responsibility for PwPBTs' illness and survival which can lead to exhaustion and anxiety. It was highlighted caregivers lack information for how to manage neuropsychological difficulties at home, and valued support from support groups and specialist nurses. However, this review contained studies which were diverse in purpose and study design, with a focus on everyday support needs.

Further reviews have other specific focuses, examining existential distress amongst caregivers (Applebaum et al., 2016), quality of life outcomes (Custers et al., 2023), supportive care needs of carers and PwPBT together (Ford et al., 2012; Heinsch et al., 2021; Paterson et al., 2023), or how carers experience life after death of PwPBT (Piil et al., 2019).

## Aims and Rationale

Relevant reviews, such as the above, have focused on more specific aspects of a caregiving experience (i.e., everyday/supportive care needs or quality of life outcomes). Consequently, these do not capture the overall, more general experience of caregiving in day-to-day life which encompasses many other areas. The entirety of the experience is important to understand so that holistic support can be considered and developed where required. To the author's knowledge, there have been no reviews synthesising literature on the general experience of being a caregiver to a PwPBT. Considering the above, this review seeks to address the following question:

- What does research tell us about the experiences of caregivers to PwPBT?

Generating a better understanding of this experience could have useful clinical and research implications to improve support and outcomes for a group that have been historically overlooked within the literature (Goebel & Mehdorn, 2011).

## Methodology

### Inclusion & Exclusion Criteria

Studies were included if they focused on  the perspective of caregivers, rather than perspectives of PwPBT or HCPs. Where studies included multiple perspectives, only the accounts of caregivers were reviewed, providing these were presented separately within the results. Brain tumours were conceptualised broadly within the search to include studies looking at caregiving to individuals with both low and high-grade tumours. To align with the review aim, only qualitative studies were included, as these allow for an understanding of lived experiences (Harper, 2011). Additionally, drawing on a single methodology is suggested to provide greater consistency for analysing data, allowing more clear and coherent conclusions to be drawn (Harris & Crossley, 2021). Furthermore, all studies included were from peer-reviewed journals to enhance the credibility of the analysis.

**Table 1.**

*Inclusion and Exclusion Criteria*

| Inclusion Criteria | Exclusion Criteria |
|---|---|
| Participants are caregivers of adult primary brain tumour patients, or where studies also include patients themselves, caregiver data is presented separately. | Studies reporting solely experiences of brain tumour patients and/or healthcare professionals. |
| Qualitative research. | Caregiver data not presented separately within the results. |
| Focus on the caregiving experience. | Studies related to medical aspects of brain tumours. |
| Published in a peer-reviewed journal | Studies relating to caregivers of metastatic brain cancer or other cancers. |
| Contains rich accounts of caregiver experiences, through interviews or other qualitative methods. | Not available in English language.<br>Commentaries and theoretical or discussion papers. |
| Available in English language. | Quantitative research. |
| | PhD theses or other non-peer-reviewed work. |

## Literature Search

Following initial scoping searches using Google Scholar, an electronic search was completed in September 2023 across four databases: PsychInfo, MedLine, ASSIA and Web of Science. Search terms (Table 2) were informed by key papers identified in the scoping search and were combined with Boolean operators ‘AND’ and ‘OR’, along with truncations to ensure relevant papers were included in the results. Initial searches revealed numerous papers concerning paediatric brain tumours, so an additional Boolean ‘NOT’ operator was added for terms related to children.

**Table 2.**

*Search Terms*

| Boolean Operator | Search Terms | Field(s) |
|---|---|---|
| | "brain tumour" OR "brain tumor" OR "brain cancer" | All fields |
| AND | "caregiver*" OR "carer*" OR "family" OR "relative*" OR "spouse*" OR "widow*" | All fields |
| AND | "qualitative" OR "experience*" OR "interview*" | All fields |
| NOT | "paediatric" OR "pediatric" OR "child*" | All fields |

No date limits were applied to the search due to the limited scope of systematic reviews conducted in the area previously and to maximise the relevant papers identified.

References were exported to RefWorks, and duplicates were removed. Titles and abstracts were reviewed by the author, according to set inclusion/exclusion criteria (Table 1), before full texts were assessed for eligibility. The full search progress is illustrated in a PRISMA diagram (Figure 1). Forward and backward searching of reference lists for included papers was also completed; however, this did not yield any further results. Decisions to exclude or include papers based on the criteria were also discussed in supervision.

**Figure 1.**

*PRISMA diagram of Search Strategy*

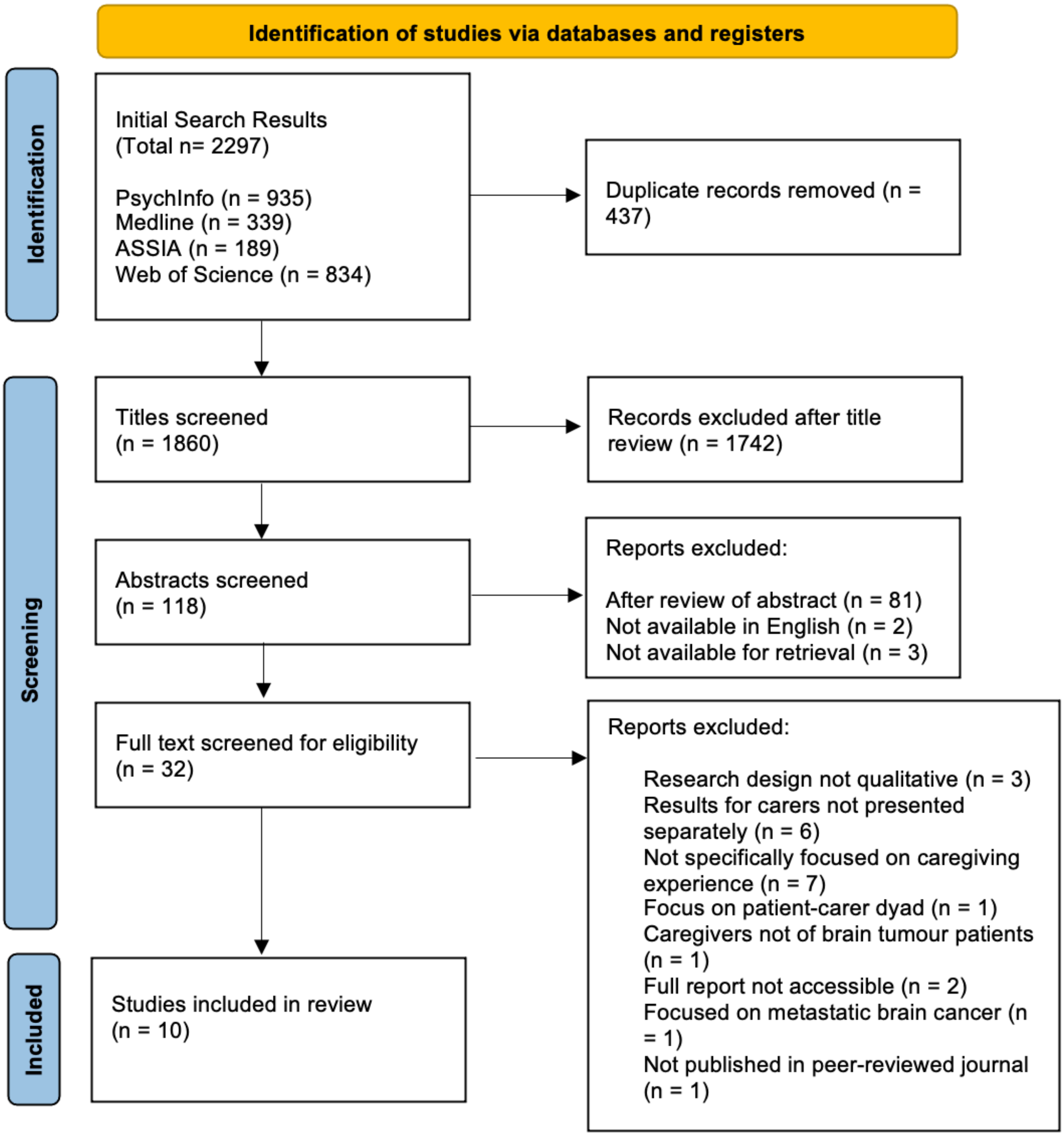

**Table 3.**

*Summary of Study Characteristics*

| Author (Date)<br>Location | Study Design | Research Aim(s) | Participants & Sampling Strategy | Care Recipient Brain Tumour Type | Data Collection | Method of Analysis | Main Findings |
|---|---|---|---|---|---|---|---|
| Wideheim et al. (2002)<br>Sweden | Qualitative | To describe what living with a highly malignant brain tumour is like from a family perspective. | **Participants:** 3 families comprising: 3 patients (2 men, 1 woman, aged between 25-88 years (M = 62) and 5 next of kin (2 partners, 2 parents, 1 adult child).<br>**Sampling Strategy:** Convenience sampling through neurology clinic. | Highly malignant glioma | Prospective interviews, occurring 2-3 weeks after surgery and 3-6 months after illness onset. | Inductive content analysis | Caregiver themes identified (categories):<br>Onset of learning diagnosis (deviant behaviour of patient, distancing, recognition of death).<br>Families' experiences of daily life (fear and anxiety, burden, support, return to a normal life, hope, prevent ill health, learn to cope with the grief).<br>Families' experiences regarding the encounter with staff and information |
| McConigley et al. (2010)<br>Australia | Qualitative | To articulate the experiences of family caregivers of people diagnosed with high-grade glioma and to describe their | **Participants:**<br>21 caregivers: 20 spouses and 1 parent. 4 males and 17 females. | Grade III – IV high-grade glioma diagnosed within the last year. | Semi-structured interviews | Grounded theory | A central theme 'Time of Rapid Change' and two sub-themes of 'Renegotiating Relationships' and |

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| | | information and support needs. | **Sampling Strategy:** Purposive sampling | | | | ‘Learning to be a Caregiver’ emerged.<br>What differed for participants compared to other cancer caregivers was the rapidity of change and need for immediate information and support to assist caring. |
| Kirby et al. (2021)<br>Australia | Qualitative | To better understand the everyday experiences of a group of home-based informal carers of people living with glioma in Queensland, Australia. | **Participants:** 32 caregivers: 11 male and 21 females. 17 partners, 5 parents, 4 children, 2 siblings, 4 friends. Age range 18-84 (M = 53.9)<br>**Sampling Strategy:** Convenience sampling through a metropolitan hospital. | 7 low-grade glioma<br>16 high-grade glioma | Semi-structured interviews | Systematic thematic analysis | Four themes were derived:<br>(i) The ‘need’ to be near the care recipient, and the implications for caregiver mobility;<br>(ii) the strong sense for responsibility of care, and the virtues of ‘good’ caring;<br>(iii) experiences of loneliness in the company of others,<br>(iiii) post-ponement of social connection and minimising the self. |
| Collins et al. (2014)<br>Australia | Qualitative | To provide an in-depth exploration of the needs and concerns of people caring for patients with primary malignant glioma.<br>To develop greater understanding of these care needs | **Participants:** 23 caregivers: 15 current and 8 bereaved; 17 spouses, 4 children, 2 others; Age 27-77 years (Mdn = 54).<br>**Sampling Strategy:** Convenience sampling from | Primary malignant glioma grades III-IV | Semi-structured interviews | Thematic analysis | Carers described challenges in three distinct domains:<br>i) The challenge of caring<br>ii) The lack of support available to carers<br>iii) The suffering of caring. |

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| | | during the patient's palliative illness phase.<br>Obtain insight into bereaved family members' experiences of caring for someone with primary malignant glioma. | neurosurgery, oncology and palliative care services of two metropolitan hospitals. Supplemented with purposive sampling. | | | | |
| Whisenant (2011)<br>USA | Qualitative | To explore the experience of informal caregivers of patients with a primary brain tumour by identifying themes of the caregiving experience specific to this population. | **Participants:**<br>20 caregivers: 12 male and 8 female; 17 spouses, 1 parent, 1 child, 1 other; Mean age 51 years.<br>Ethnicities: 2 African American, 16 White American, 2 Hispanic<br>**Sampling Strategy:**<br>Purposive sampling of informal caregivers of patients with PBTs being treated at a National Cancer Centre. | Grade II-IV primary brain glioma. | Interviews using Story Theory (Smith & Leihr, 2003) | Descriptive exploratory analysis method using The Model of Informal Caregiving Dynamics (MICD; Williams, 2005) to explore and inform analysis. | Caregivers used the six energy sources found in the MICD (Commitment, Expectation Management, Role Negotiation, Self-Care, Role Support & New Insight), but their use of these sources differed to other caregivers. |
| Francis et al. (2022)<br>Denmark | Qualitative | To investigate spouses' experiences of suffering in their role as main caregiver of a partner with a primary malignant brain tumour. | **Participants:**<br>10 caregivers living with and providing care for a partner in treatment for a PBMT.<br>7 women and 3 men. Age range 36-76<br>**Sampling Strategy:** | Primary malignant brain tumours. | Semi-structured interviews | Five-step hermeneutical analysis process (Brinkmann & Kvale, 2015). | Caregivers' experiences of suffering were interpreted into three themes:<br>i) Enduring every day life<br>ii) Being overlooked and hurt |

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| | | | Purposive sampling | | | | iii) Being acknowledged and feeling good<br><br>Concluded spouse caregivers are suffering from exhaustion and suppression of own emotions and need support to manage their hardship. This can be overlooked and hurts their dignity. Acknowledgement of this can be consoling and alleviate their suffering. |
| Sherwood et al. (2004)<br><br>USA | Qualitative | To explore the positive and negative aspects of caring for someone with a primary malignant brain tumour. | **Participants:**<br>43 caregivers: 40 female, 3 male.<br>27 spouse, 8 child, 8 other.<br><br>Ethnicities: 42 White American, 1 Other<br><br>**Sampling Strategy:**<br>Convenience sampling from two national brain tumour support group and an internet support group for the bereaved. | Glioblastoma multiforme, Astrocytoma Grades I-III, and other (not specified). | Self-report questionnaires | Content analysis | Six themes were identified from participant comments:<br><br>i) The work of caring<br>ii) Informal support<br>iii) Formal support<br>iiii) Information<br>v) Dealing with symptoms<br>vi) End of life |

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| Hricik et al. (2011)<br>USA | Qualitative | To examine how family members of patients with a primary malignant brain tumour transition into their caregiver role and how their perceptions of this change over time. | **Participants:** 10 family caregivers 8 female, 2 male. Aged 21-63 (M = 48)<br>Ethnicities: 10 White American<br>**Sampling Strategy:** Convenience sampling through neurosurgery and neuro-oncology clinics of regional medical centre. | Glioblastoma multiforme and Astrocytoma grades I-III | Interviews using open-ended questions. | Content analysis | Caregivers described difficulties from patients' tumour-related dysfunction and change in roles. Support from family/friends was crucial. Shock and fear were evident and carers were enmeshed in care situation. Difficulties communicating with healthcare providers were present.<br>Three major themes emerged when looking at changes over time:<br>i) Patient changes<br>ii) The New Normal<br>iii) Caregiver adjustments<br>iiii) Accessing support |
| Edvardsson & Ahlstrom (2002)<br>Sweden | Qualitative | To explore the experience of being the next of kin of an adult person diagnosed with a low-grade glioma. | **Participants:** 28 next of kin: 15 spouses/co-habitants, 3 live-apart partners, 8 parents, 1 sibling, 1 adult child; 20 female and 8 male; Aged 25-77 years (M = 52.5)<br>**Sampling Strategy:** Convenience | Low grade glioma.<br>2 patients had grade III glioma, however had a clinical picture corresponding to a low-grade tumour. | Interviews in 'conversational' form | Content analysis & Quantitative analysis to explore how themes differed amongst next of kin | Four main themes emerged:<br>i) Extremely stressful emotions<br>ii) Being invisible and neglected<br>iii) Changed roles and relations<br>iii) Enabling strength in everyday life. |

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| | | | sampling through patients of a previous study. | | | | |
| Piil & Jarden (2018)<br>Denmark | Qualitative | To explore the perspectives of newly bereaved caregivers to patients with high-grade glioma, regarding end-of-life caregiving and their bereavement experiences. | **Participants:** 8 bereaved caregivers. 6 female, 2 male. 28-60 years (M = 48)<br>**Sampling Strategy:** Convenience sampling through carers who had been bereaved whilst participating in a neuro-oncological rehabilitation study. | Glioblastoma multiforme (5) and Anaplastic Astrocytoma Grade III (1). | Semi-structured telephone interviews | Thematic analysis | Four main themes were highlighted:<br>i) Late-stage caregiving is comprehensive and taxing<br>ii) Releasing the responsibility of the caregiving role<br>iii) Feelings of grief and relief<br>iiii) Suggestions for clinical practice |

## Quality Appraisal

The Critical Appraisal Skills Programme (CASP) qualitative checklist (CASP, 2018) was used to assess the quality of the papers (Appendix A). The CASP checklist is a quality appraisal tool used in health-related qualitative evidence syntheses and is endorsed by Cochrane (Long et al., 2020). The tool consists of ten questions that address different aspects of qualitative methodology and was designed to evaluate study strengths and limitations. Each study included in the review was appraised individually using the CASP, and a summary of the results for the quality checklist is presented in Table 4.

## Approach to Synthesis

A thematic synthesis was conducted on the findings of all 10 studies, using the three-stage approach outlined by Thomas and Harden (2018). Data from ‘results’ or ‘findings’ sections within the studies were imported into NVivo Qualitative Data Analysis Software. This was followed by ‘free coding’ the findings on a line-by-line basis, inductively, to capture the meaning and content of each sentence. Codes were added to a ‘bank’ and new codes were developed where necessary. These were then ordered into ‘descriptive’ themes, to capture the meaning of groups of initial codes. The final stage involved the development of ‘analytical themes’ from these by ‘going beyond’ the data, which has been identified as a defining characteristic of synthesis (Britten et al., 2002; Thorne et al., 2004). Given that this involves a degree of researcher interpretation, a bracketing interview was undertaken prior to analysis to bring awareness to pre-existing knowledge and assumptions about the topic. Supervision was also used as a space to explore theme development.

## Position Statement

The lead researcher was a White-British, trainee clinical psychologist who had first-hand experience of being a caregiver to a family member with a brain tumour. It was acknowledged that this may influence preconceptions of the data and findings. Attention was paid to researcher reflexivity, to bring awareness to such assumptions and acknowledge and explore these. A bracketing interview prior to synthesis, use of a research diary and supervision allowed such beliefs to be identified and kept as separate as possible from findings.

# Results

## Selected Studies

Ten papers resulted from the systematic search (see Figure 1). Table 3 offers a summary of study characteristics. In summary, most studies were conducted in the USA and Australia, and participants were mostly female and a spouse/partner. The ages of caregivers ranged from 18-77. Ethnicity was sparsely reported by studies, but where it was, most participants were White.

## Quality Assessment

### *Aims and Methodology*

All studies included in the review clearly stated the aims of the research, and a qualitative methodology was appropriately chosen to address these, given they were focused on capturing caregiver experiences and perspectives.

### *Research Design & Data Analysis*

Whilst the research design for all studies was appropriate to meet the aims, most studies did not offer a rationale for why they had chosen a particular approach. The exception to this was Hricik et al. (2011), who provided a justification for the prospective, longitudinal design employed, recognising this would help to capture rich data and changes over time.

A range of approaches to qualitative analysis were employed and the process was at least partially described within the studies. Four papers used content analysis (Edvardsson & Ahlstrom, 2008; Hricik et al., 2011; Sherwood et al., 2004; Wideheim et al., 2002), three used thematic analysis (Collins et al., 2014; Kirby et al., 2021; Piil.& Jarden, 2018), one used descriptive exploratory analysis (Whisenant, 2011), one used a hermeneutic approach (Francis et al., 2022) and one used grounded theory (McConigley et al., 2010). Two papers gave clear examples of the theme development process (Edvardsson & Ahlstrom, 2008; Francis et al., 2022). Three papers detailed how analytic rigour was achieved by searching for contradicting, negative or atypical cases in theme development (Kirby et al., 2021), seeking feedback from an advisory group (Collins et al., 2014) or discussing emerging themes with stakeholders (Francis et al., 2022). All studies included verbatim quotes to support the accounts, but only one paper discussed how potential researcher bias was mitigated (Whisenant, 2011).

### ***Recruitment Strategy & Sample***

Recruitment strategies were at least partially described by all studies, with most studies using purposive sampling. This was justified by three studies for reasons including ensuring representation within the sample and a providing a broader scope for data collection (Francis et al., 2022; Kirby et al., 2021; Whisenant, 2011). There were potential biases within three studies' recruitment strategies, where participants had been involved in a related study or were recruited from a support group (Edvardsson & Ahlstrom, 2008; Piil & Jarden, 2018; Sherwood et al., 2004) These are significant as they may limit transferability of findings, as it perhaps reflects individuals who are more willing to engage in research. A few studies (Collins et al., 2014; Kirby et al., 2021; Wideheim et al., 2002) commented on why individuals did(not) choose to take part which means that, generally, the potential for selection bias is unclear.

The synthesis combined qualitative data from 10 studies and 199 caregivers overall. Most caregivers who participated across the studies were spouses/partners (*n* = 124), followed by parents (*n* = 26) and adult children (*n* = 18). Fewer participants were friends (*n* = 4) and siblings (*n* =3). Whilst demographic information was presented for most studies, English speakers (Collins et al., 2014) and White-American participants (Hricik et al., 2011; Sherwood et al., 2004; Whisenant, 2011) were most represented in certain studies, and recruitment took place at a single site (McConigley et al., 2010). This indicates a limitation with lack of diversity and results reflecting Western culture.

Some caregivers were classified more broadly into ‘living with’, ‘family’ or ‘other’ (*n* = 39), so it was unclear what relation they had to the PwPBT. Two papers provided information about participants’ geographical region (McConigley et al., 2010; Collins et al., 2014). Caregivers were supporting individuals who had a range of brain tumour grade classifications, but there were more studies that focused on high-grade brain tumours as opposed to low grade. Additionally, in two studies (Edvarsson & Ahlstrom, 2008; Piil & Jarden, 2018), more than one caregiver for the same individual were included within the samples, indicating there could be a skew within the results towards these experiences.

### ***Data Collection***

There was great variability in descriptions of the data collection process between studies. Most used a semi-structured interview, apart from Sherwood et al. (2004), who used a questionnaire, but only one study (McConigley et al., 2010) justified their choice. A questionnaire format arguably limited data quality, as the amount of content received varied significantly from a paragraph to numerous pages (Sherwood et al., 2004).

Many studies provided examples of at least one interview question or shared the topic guide and thematic areas covered (Collins et al., 2014; Edvardsson & Ahlstrom, 2008; Francis et al., 2022; Kirby et al., 2021; McConigley et al., 2010). Only one paper provided the full interview schedule (Hricik et al., 2011), however data was collected via telephone, which could have resulted in loss of contextual and non-verbal data (Novick, 2008). PwPBT were also present at interviews for some, but not all, carers (Collins et al., 2014), which may have limited what carers felt able to share.

### ***Relationship and Reflexivity***

Six papers made no reference to researcher reflexivity, which means that the potential for researcher bias is unclear. This is particularly significant for Piil and Jarden (2018), where researchers were neuro-oncology nurses, and it was unclear whether they had pre-existing relationships with participants. If so, this may have influenced the recruitment processes or research outcomes. The four studies that commented on researcher reflexivity did so to varying degrees, and in relation to different aspects of the research process. Wideheim et al. (2002), whilst not discussing reflexivity in relation to research design or data collection, stated that interviewers did not have a role within patient care to limit social desirability bias. However, it is plausible that interviewers could still be perceived as being connected to healthcare, given the topic of interest.  Kirby et al. (2021) discussed the relationship from an ethical perspective, stating that researchers were involved in the participants' care. Despite this, it was unclear whether this relationship was considered during the data analysis process. Francis et al. (2022) provided a more thorough reflection on the need for critical awareness of prejudices and experiences as oncology nurses and researchers, although it was unclear how this was achieved.

### ***Ethical Considerations***

Ethical issues were at least partially attended to within all papers. All referenced ethical approval from a relevant committee, and most documented informed consent from participants. Only one paper discussed seeking consent from the PwPBT who would be spoken about by the caregiver (Francis et al., 2022). Two studies mentioned how the sensitive nature of the research would be managed for participants (Wideheim et al., 2002; Sherwood et al., 2004), and one commented there was distress during interviews but did not indicate how this was addressed, (Francis et al., 2022) which raises ethical concerns. No papers mentioned providing participants with a debrief. One paper addressed possible coercion and stated that individuals were told participation was voluntary and would not affect their hospital care (Kirby et al., 2021), which is important as patients can feel dependent on a practitioner's goodwill for their ongoing care (Wilson et al., 2008).

### *Findings & Value of Research*

All papers clearly reported findings in the context of the original research question. Three studies provided indications of additional credibility, through use of more than one researcher (Collins et al., 2014; Hricik et al., 2011; Whisenant, 2011).

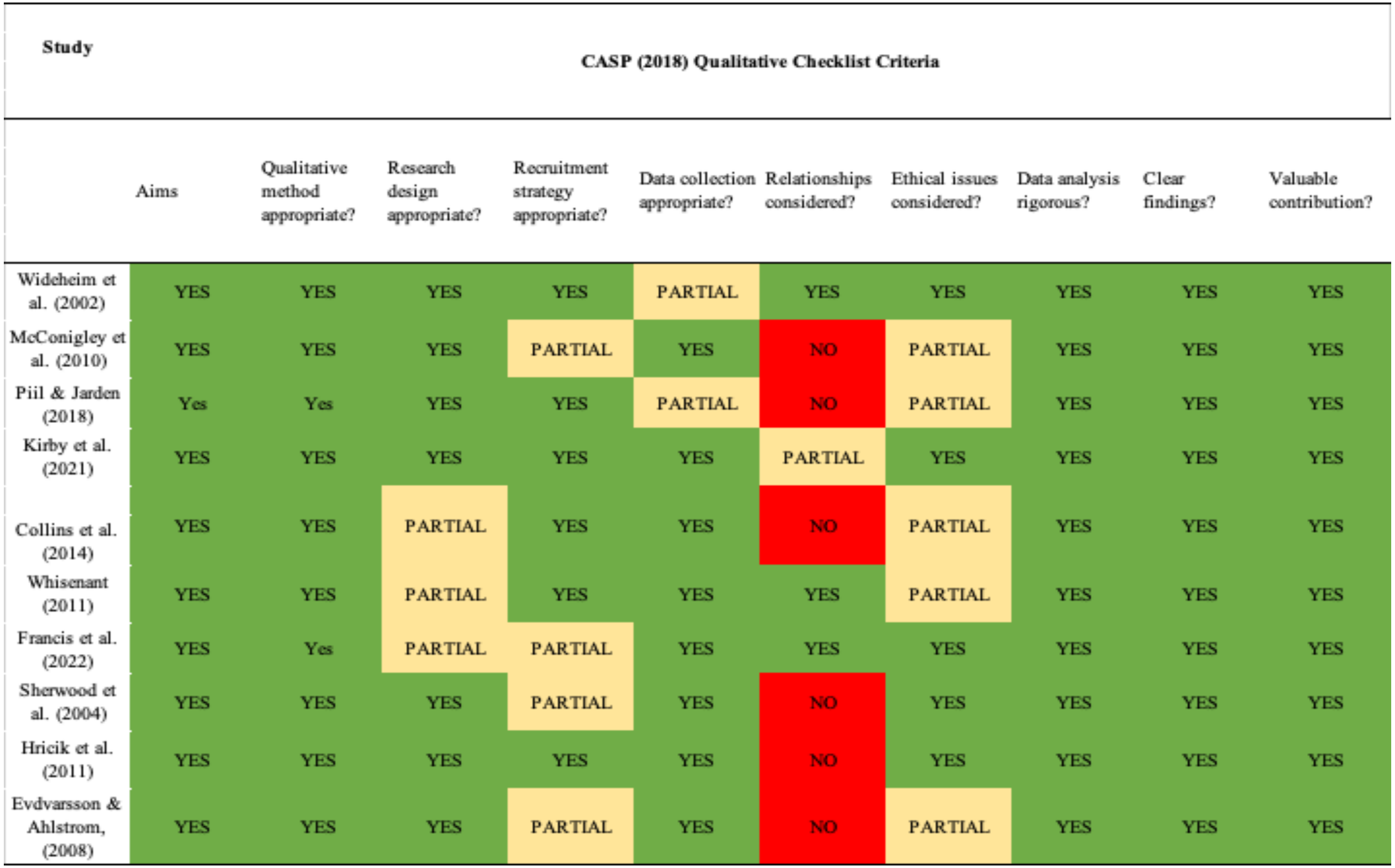
The value of research can be appraised by the extent to which studies detail how existing knowledge has been enhanced through findings, their implications, and whether results can be applied within different contexts (CASP, 2018). All studies partially addressed this by highlighting the implications of findings in clinical and/or social care settings and suggesting areas for future research. However, two studies made general statements rather than indicating directions for further research (Edvardsson & Ahlstrom, 2008; Francis et al., 2022).

### *General Critique*

All papers within the review had strengths and drawbacks, however, were deemed to be overall of acceptable quality to include in the review. There were strengths across studies in the reporting of aims, and appropriate use of a qualitative approach. Weaknesses in many studies were the omission of attending to ethical issues, lack of justification for research design and analysis methods, and consideration of relationships and researcher reflexivity.

The results of studies with areas of weakness or omission were interpreted with caution within the review.

**Table 4.**
*CASP (2018) Quality Checklist Results*



| Study | CASP (2018) Qualitative Checklist Criteria | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | Aims | Qualitative method appropriate? | Research design appropriate? | Recruitment strategy appropriate? | Data collection appropriate? | Relationships considered? | Ethical issues considered? | Data analysis rigorous? | Clear findings? | Valuable contribution? |
| Wideheim et al. (2002) | YES | YES | YES | YES | PARTIAL | YES | YES | YES | YES | YES |
| McConigley et al. (2010) | YES | YES | YES | PARTIAL | YES | NO | PARTIAL | YES | YES | YES |
| Piil & Jarden (2018) | Yes | Yes | YES | YES | PARTIAL | NO | PARTIAL | YES | YES | YES |
| Kirby et al. (2021) | YES | YES | YES | YES | YES | PARTIAL | YES | YES | YES | YES |
| Collins et al. (2014) | YES | YES | PARTIAL | YES | YES | NO | PARTIAL | YES | YES | YES |
| Whisenant (2011) | YES | YES | PARTIAL | YES | YES | YES | PARTIAL | YES | YES | YES |
| Francis et al. (2022) | YES | Yes | PARTIAL | PARTIAL | YES | YES | YES | YES | YES | YES |
| Sherwood et al. (2004) | YES | YES | YES | PARTIAL | YES | NO | YES | YES | YES | YES |
| Hricik et al. (2011) | YES | YES | YES | YES | YES | NO | YES | YES | YES | YES |
| Evdvarsson & Ahlstrom, (2008) | YES | YES | YES | PARTIAL | YES | NO | PARTIAL | YES | YES | YES |

## Thematic Synthesis

Six themes surrounding the experiences of caregivers for PwPBT were developed from the analysis. A full description of themes, sub-themes and supporting quotes from papers is presented in Appendix B. The themes are described below, with sub-themes highlighted in bold, and Table 5 represents which papers each theme and sub-theme were generated from.

### Theme One: Consumed by Caring

All papers discussed the **new roles and responsibilities** carers had assumed since the PBT diagnosis. These were either roles or responsibilities previously held by the PwPBT or tasks associated with caregiving specifically. Caregiving responsibilities competed with pre-existing roles, and some caregivers took time from work to provide care (Sherwood et al., 2004). Caregivers' new routines, roles and responsibilities needed to be established quickly, but it took time before these routines were considered 'normal' (Hricik et al., 2011). Carers who also had children at home reported increased challenges (Francis et al., 2011) and felt as though they had acquired an additional child due to the needs of the PwPBT, which detracted from time with offspring  (Sherwood et al., 2004; Collins et al., 2014). Balancing these demands meant letting go of former dreams and aspirations when things felt increasingly difficult (Edvardsson & Ahlstrom, 2008; McConigley et al., 2010).

Carers supported PwPBT by attending appointments, providing personal care, and managing medication (Collins et al., 2014; McConigley et al., 2010; Sherwood et al., 2004). Being a supportive presence and maintaining a positive attitude (Sherwood et al., 2004; Whisenant, 2011) was also important. Caregivers were also required to learn to gauge

PwPBTs' behaviour, as well as manage the emotions of concerned others (Collins et al., 2014; Whisenant, 2011).

*"I care for the kids 24/7. I've taken on a lot of the chores around the house that include lifting, taking out the garbage, cleaning the house, and I've taken care of the bills and dealing with the insurance company, and making sure he gets the medication filled."* (Hricik et al., 2011, p. 5).

*"The other problem I had was trying to balance caring for my husband while keeping life as normal as possible for our late teenage daughters"* (Sherwood et al., 2004, p. 69).

Most papers described a **lack of respite** experienced by caregivers, due to needing to be readily available to the PwPBT (Kirby et al., 2021; Wideheim et al., 2002) in a situation described as 'dependency and restricted freedom' (Edvardsson & Ahlstrom, 2008, p.587). Caregivers were also anxious to take respite due to concerns about the PwPBT; few had access to formal respite services, and some had no offers of informal respite from friends and family (McConigley et al., 2010; Sherwood et al, 2004).

*"Occasionally it overcomes you… It's relentless, it's nothing but relentless."* (Collins et al., 2014, p. 73).

Carers in three papers described **putting life on hold** when the PwPBT experienced significant neuropsychological changes (Collins et al., 2014; Edvardsson & Ahlstrom, 2008; Kirby et al.,2021). This meant sacrificing their social life, giving up work and financial security to attend to more immediate needs of the PwPBT (Collins et al., 2014; Kirby et al., 2021).

*" Of course I had to give up my job, because I had to be here at home all the time."* (Edvardsson & Ahlstrom, 2008, p. 588).

### Theme Two: Impact and Isolation of Caregiving

Caregivers across nine papers discussed the **impact on wellbeing** of providing care to PwPBT. Their investment in the role led to exhaustion and a sense that family life was falling apart (Francis et al., 2014; Sherwood et al., 2004). Carers reported psychological impacts: oscillating between emotions such as anger, frustration, entrapment, fear, shock, helplessness, and powerlessness (Collins et al., 2014; Edvardsson & Ahlstrom, 2008; Francis et al., 2011; Hricik et al., 2011; Kirby et al., 2021; Sherwood et al., 2004; Wideheim et al., 2002). Additionally, caregivers experienced insomnia, low mood, poor memory, and difficulty concentrating, which continued after the PwPBT had died (Francis et al., 2011; Piil & Jarden, 2018). Some caregivers felt a need to suppress their own feelings so that they did not burden others or upset the PwPBT (Edvardsson & Ahlstrom, 2008; Francis et al., 2011), which could impact physical health (Francis et al., 2011). Despite this, many papers commented on the challenge in accessing help to manage their wellbeing (Collins et al., 2014; Francis et al., 2011; McConigley et al., 2010;)

*"If I just throw in the reins and let go of how it actually feels, then I am not sure I can get hold of myself again and keep it all together. In one way or another, it is easier to just keep it in"* (Francis et al., 2011, p. 325).

Seven papers described the constant **anxiety and worry** that was associated with caregiving. Caregivers experienced worries surrounding the PwPBTs' health and the unknown future (Whisenant, 2011) as well as worries about treatment (Edvardsson & Ahlstrom, 2008; Wideheim et al., 2002). Carers were anxious anticipating death which could impact their ability to focus (Wideheim et al., 2002). Leaving the PwPBT at home was anxiety provoking, due to fear they may become distressed or have a seizure (Kirby et al., 2021). Caregivers were concerned about something happening to themselves which may impact their ability to care (Francis et al., 2011), and shared that they had developed a sensitivity to illness-related things, such as headaches, that could lead to anxieties about tumour progression (Edvardsson & Ahlstrom, 2008).

*"When I'm away I worry about what's going on with him. I won't let him go around the block without his mobile and I ring him to check that he's alright"* *(*McConigley et al., 2010, p. 477)

Four papers described the **isolation and loneliness** caregivers faced. A range of factors including demands of personal care, challenging logistics of travel and fear of being away from the PwPBT contributed to limited social mobility and interaction. Carers therefore spent most of their time within the home (Edvardsson & Ahlstrom, 2008; Kirby et al., 2021). Caregivers reported loneliness in relation to the lack of understanding from others and withdrew from their social activities (Collins et al., 2014; Kirby et al, 2021). The relationship with the PwPBT was also a source of loneliness, particularly when cognitive changes were apparent and there was a loss of reciprocity within the relationship (Collins et al., 2014; Edvardsson & Ahlstrom, 2008).

*'Indeed, several participants talked about withdrawing from social activities and shrinking social worlds, with caregiving circumstances meaning that participants "don't go to social things anymore"* (Kirby et al., 2021, p. 1928).

## Theme Three: Keeping Going

Carers across most papers described aspects of the role which sustained them. Four papers described **satisfaction and personal growth,** including the emotional rewards of feeling connected to/needed by the PwPBT (Whisenant, 2011). Some carers also commented on the gratefulness, honour, pride, and privilege they felt to be offering care, which allowed them to stay committed (Kirby et al., 2021; Sherwood et al., 2004). In one paper, carers also discussed the desire to meet the challenges that the role had presented them (Whisenant, 2011). Carers also took new insight and personal growth from their experiences, which allowed them to gain new knowledge and perspective, and appreciate each day (Sherwood et al., 2004; Whisenant, 2011). Notably, some reported that the ‘honeymoon’ phase of caregiving ended over time (Hricik et al., 2011).

*“[the care recipient] was the center of our world and our love poured out to her and it was returned many times over, she taught us much”* (Sherwood et al., 2004, p. 70).

Carers across five papers discussed **holding onto hope** during their journey. Hope was placed in the belief that the PwPBT would receive the best treatment and be an exception to the rule in the face of a poor prognosis. Hope was important for carers to maintain and demonstrate in front of the PwPBT (Wideheim et al., 2002). It appeared to be sustained by taking each day as it came, living in the present, frequent contact with HCPs and finding comfort in a higher power (Whisenant, 2011; Wideheim et al., 2001). Despite this, some caregivers acknowledged that attempts to negotiate hope in the face of increasing deterioration could feel like an emotional burden (Collins et al., 2014).

*“Because the worst thing you can do is to take away their last spark of hope”* (Wideheim et al., 2002, p, 241).

### Theme Four: Adapting to New Ways of Living

**Holding the PwPBT at the centre** of everything was discussed by caregivers in six studies. Caregivers wished to protect the PwPBT from their own worries about the future or disease recurrence, and shield them from unnecessary information that may be difficult for them to comprehend (Hricik et al., 2011; Wideheim et al., 2002). Additionally, caregivers needed to make decisions independently, when the PwPBTs’ cognitive abilities were significantly impaired (McConigley et al., 2010; Sherwood et al., 2004).

*I have been doing it [caregiving] with her so long now that I kind of know what needs to be done before she asks [and] I . . . anticipate what she will be wanting or needing.”* (Whisenant, 2011, p. 377)

Some carers also took on the role of an interpreter/advocate for the PwPBT when they were not able to make their wishes known (McConigley et al., 2010), but ensured they considered their perspective where possible (Whisenant, 2011). Caregivers spoke about putting the PwPBTs' best interests at the heart of difficult decisions they made, which sometimes involved discussion with HCPs (McConigley et al., 2010; Whisenant, 2011).

*"If I had tried to pressure her into signing up for disability, that would have been a bad deal. So, I didn't pressure her . . . and she made up her mind that she was going to [apply]."* (Whisenant, 2011, p. 377)

**Adjusting to a loss or change in the relationship** was a necessary task for caregivers within five papers. Neuropsychological changes in the PwPBT meant that communication abilities suffered which caused change in relationship dynamics (Kirby et al., 2021). For some spouse/partner caregivers, there was a perceived shift to assume a role alike to a parent as they took care of the PwPBT's personal tasks (Edvardsson & Ahlstrom, 2008). Furthermore, some carers felt they lost the sense of 'partnership' within the pre-existing relationship, and instead were facing a new phase of life on their own (Collins et al., 2014; McConigley et al., 2010). Further relationship changes were felt by caregivers who had children, who felt as though they were now a single parent, when adjusting to the impact of the diagnosis (Edvardsson & Ahlstrom, 2008).

Neuropsychological changes were a significant cause of concern for some carers who described difficulty and frustration managing personality, behaviour and diminished insight and inhibitions (Collins et al., 2014). Some caregivers perceived the PwPBT as a changed person when they experienced significant difficulty with their memory, and they had difficulties in 'reaching' them as before (Edvardsson & Ahlstrom, 2008). This was further compounded for some carers when the PwPBT could not understand the severity of their illness (Wideheim et al., 2002).

*"I was living with a psychotic and was terrified of what he might do to us or himself. He'd gotten lost in the neighborhood twice and had paralysis and rages."* (Sherwood et al., 2004, p. 71).

*"Everything was partnership and now it's not and it's very hard to get used to*" (McConigley et al., 2010, p. 476).

**Theme Five: Living with the Unknown**

Caregivers within nine papers discussed the experience and impact of **coping with daily uncertainty**. The nature of disease progression was a shock for caregivers (McConigley et al, 2010), who felt unprepared for the role due to the unpredictable deteriorations (Collins et al., 2014; Hricik et al., 2011). HCPs were unable to give caregivers definite answers about likely outcomes for the PwPBT, which led to a lack of security in daily life (Wideheim et al., 2002). Neurosurgery frequently contributed to further changes in cognition and functioning and was distressing to witness the aftermath of, as in some cases it was uncertain whether the individual would talk or move again (Edvardsson & Ahlstrom, 2008; McConigley et al., 2010). Additionally, impacts of treatment including steroids, radiotherapy and chemotherapy created visible changes in the PwPBT which were a reminder of the illness for caregivers (Wideheim et al., 2002).

*'It's so dreadfully hard because they can't give us the answer we want, the uncertainty's the worst part'* (Wideheim et al., 2002, p. 239).

Caregivers within five papers discussed the experience of **confronting death and entering grief**. Many carers faced the possibility of premature death when the PwPBT was diagnosed, which could leave a deep and lasting impression if life expectancy was short (Wideheim et al., 2002). Some carers discussed the need to prepare for death including making funeral arrangements and living wills, learning what to expect in final days/hours and beginning to prepare for life once the caregiving situation was over (Sherwood et al., 2004).

Feeling forced into giving up the caregiving role was a difficult decision for some carers who became unable to cope with the PwPBTs deteriorating condition (Piil & Jarden, 2018).

*"We know one day this thing will creep up on us and that's it – but you don't want to hear that, you want to keep going and tracking on until such time as well, it goes wrong I suppose."* (Collins et al., 2014, p. 72).

The lack of opportunity for meaningful goodbyes, in the context of cognitive decline, was a cause of sadness for caregivers as the PwPBT approached end of life (Collins et al., 2014). After death, the transition from a caregiver to a griever was particularly difficult for some carers who felt they had empty time to fill (Sherwood et al., 2004). Nevertheless, it could also be accompanied by a sense of relief (Piil & Jarden, 2018). Generally, the grieving period was discussed as being a challenging time; however, it was acknowledged that this process started long before death when changes in the PwPBT begun (Collins et al., 2014; Sherwood et al., 2004). Some carers described feeling traumatised after the death and experienced flashbacks to the caregiving experience long after the bereavement (Sherwood et al., 2004).

*"It was a relief in some ways, and I also think about the fact that we spent, in some way, a whole year saying goodbye"* (Piil & Jarden, 2018, p. 96).

### Theme Six: Accessing the 'Right' Support

Carers within nine papers discussed the **informal and formal support** they received from friends, family, and networks. Spontaneous help with everyday tasks, managing children and assistance with physical care were valued alongside feeling emotionally supported by others who understood (Francis et al., 2022; Hricik et al., 2011; McConigley et al., 2010; Sherwood et al., 2004; Whisenant, 2011). Caregivers felt secure within healthcare settings when they participated in decision making, felt well informed and able to ask questions (Edvardsson & Ahlstrom, 2008). It gave caregivers confidence when HCPs demonstrated awareness of the PBT impacting the whole family and considered carers' needs too (Edvardsson & Ahlstrom, 2008; Whisenant, 2011).

*"We have a strong family support, we have a strong church support, and it is all part of the equation."* (Whisenant, 2011, p. 379).

The **challenges of support** were documented by carers across seven papers. Firstly, some carers were unsure where to access support, and so defaulted to emergency departments for simple advice (Collins et al., 2014; McConigley et al., 2010). It was challenging for some to ask for support, due to feelings of guilt and they therefore attempted to manage things alone (Francis et al., 2022; Hricik et al., 2011; Sherwood et al., 2004). When professional support was obtained, this could be disappointing when carers felt overlooked, unheard, ignored, or misunderstood (Edvardsson & Ahlstrom, 2008; Francis et al., 2022; Sherwood et al., 2004). Caregivers also had experiences of family and friends withdrawing, and felt others were ignorant to the reality of their situation and the PwPBTs' declining health, where this was not always visible (Edvardsson & Ahlstrom, 2008; Francis et al., 2022; Kirby et al., 2021). Subsequently, any visits from close others could add to the burden for caregivers and cause anger and disappointment (Francis et al., 2022).

*"They have no idea of what I am doing, absolutely no idea, they are totally oblivious to it all"* (Francis et al., 2022, p. 324).

Caregivers across most papers described **figuring things out themselves**. The rapid changes in the PwPBT meant carers needed immediate access to information, as they were unsure about what to expect from tumour-related sequelae and felt unsure about how to care effectively (Collins et al., 2014; McConigley et al., 2010; Sherwood et al., 2004). Caregivers felt responsibility to obtain the information themselves, rather than relying on HCPs (Sherwood et al., 2004), however this could be difficult as it was not clear where to look or what questions to ask (McConigley et al., 2010).

*“You actually need an interpreter to be with you, you kind of need that middle person… That go to person like a librarian, who can say, ‘This is the information you need.’ You'd hit the next bump in the road and every time was different and every time I hit that bump I just didn't have that ‘go to’ person to ask.”* (Collins et al., 2014, p. 72).

**Table 5**.

*Theme Occurrence in Papers*

| Theme | Sub-Theme | Wideheim et al.(2002 | McConigley et al. (2010) | Piil & Jarden (2018) | Kirby et al. (2021) | Collins et al. (2014) | Whisenant (2011) | Francis et al. (2022) | Sherwood et al. (2004) | Hricik et al. (2011) | Edvardsson & Ahlstrom (2008) |
|---|---|---|---|---|---|---|---|---|---|---|---|
| **Consumed by Caring** | New Roles & Responsibilities | X | X | X | X | X | X | X | X | X | X |
| | Lack of Respite | X | X | | X | X | | | X | X | X |
| | Putting Life on Hold | | | | X | X | | | | | X |
| **Impact & Isolation** | Impact on Wellbeing | X | X | X | X | X | | X | X | X | X |
| | Anxiety and Worry | X | X | | X | | X | X | X | | X |
| | Isolation and Loneliness | | | | X | X | | X | | | X |
| **Keeping Going** | Rewards of Caregiving | X | | | X | X | X | X | X | X | X |
| | Holding onto Hope | X | | | X | X | X | | | | X |
| **Adapting to New Ways of Living** | Holding the PwPBT at the Centre | X | X | | | X | X | | X | X | |
| | Adjusting to Loss/Change | | X | | X | X | | | X | | X |

| | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | within the Relationship | | | | | | | | | | |
| **Living with The Unknown** | Coping with Daily Uncertainty | X | X | X | X | X | | X | X | X | X |
| | Confronting Death and Entering Grief | X | X | X | | X | | | X | | |
| **Accessing the ‘Right’ Support** | Informal and Formal Support | X | X | X | | X | X | X | X | X | X |
| | Challenges of Support | | X | | X | X | | X | X | X | X |
| | Figuring Things Out | X | X | X | X | X | | X | X | | X |

## Discussion

This review aimed to synthesise findings of qualitative studies that explored caregivers' experiences of caring for a PwPBT through a systematic review, quality appraisal and thematic synthesis. Six themes were developed from the synthesis: 'Consumed by Caring'; 'Impact and Isolation'; 'Keeping Going'; 'Adapting to New Ways of Living'; 'Adjusting to Uncertainty' and 'Accessing the 'Right' Support'. The findings are discussed below in the context of wider literature, and strengths and limitations of the present review are considered alongside clinical and research implications.

The theme 'Consumed by Caring' is consistent with previous research suggesting that caregivers acquire new roles and responsibilities, perhaps to compensate for declining abilities in the PwPBT (Petruzzi et al., 2012; Schubart et al., 2008). This theme also aligns with Rolland's (1994, 2005) FSIM which posits that carers experience role and relationship changes with progressive illnesses, particularly when cognitive impairment is present. The all-encompassing nature of the role reflects Rolland's (1994) ideas that a shortened lifespan can bring about greater psychosocial stress for caregivers.

'Impact and Isolation' faced by carers is supported by literature indicating that this group become socially isolated and experience a lack of support (Petruzzi et al., 2012), along with physical and mental health difficulties (Currie et al., 2015). Caregivers experienced loneliness and a lack of understanding from others, which is consistent with findings that support networks can withdraw at the magnitude of the diagnosis (Schubart et al., 2008). A lack of understanding may be intensified by the invisible nature of many PBT side effects, so PwPBT may appear 'well' on the outside (Brainstrust, 2021). The overall emotional impact on caregivers can be understood through Folkman and Lazarus' model (1984), in that carers appraise the situation as stressful, but can have limited social support as a means of coping to mediate the effects of stress.

The theme ‘Keeping Going’ builds on previous ideas that caring can be a positive experience (Wasner et al., 2013) that may be sustaining. Nevertheless, some caregivers discussed the ‘honeymoon’ phase of caring ending (Hricik et al., 2011), which suggests the rewards of caregiving and ability to hold hope may be harder to negotiate in face of increasing deterioration (Collins et al., 2014). This may be due to the proximity of death becoming closer, which aligns with the idea that hope is not a perpetually self-renewing resource and may at times be absent, particularly when odds are unfavourable (Folkman, 2010).

The theme ‘Adapting to New Ways of Living’ connects with the developmental tasks set out within stages of illness in the FSIM (Rolland, 1994). Caregivers adapted quickly and sacrificed aspects of their own life to manage the illness and attend appointments, which fits with the ‘crisis’ stage of the model where caregivers must develop flexibility, learn to work with HCPs and accept permanency of the illness. Adjustment to change within the relationship connects with Ownsworth et al.’s (2015) findings that PwPBT can be perceived as a different person, perhaps due to the neuropsychological impairment altering capacity for relational connections (Rolland, 2017).

The theme ‘Living with the Unknown’ indicated that carers of people with low-grade gliomas had anxiety about future uncertainty (Rimmer et al., 2023), suggesting this experience may be fitting for both low- and high-grade tumours alike. The theme also aligns with research indicating neuropsychological changes can be particularly difficult for caregivers to learn to adapt to in a short space of time (McConigley et al., 2010; Schubart et al., 2008). Caregivers were able to prepare for death, however struggled to have meaningful goodbyes (Collins et al., 2014), which is a key developmental task of the ‘terminal’ phase of the FSIM (Rolland, 1994). This may explain why some caregivers struggled with grief and continued to be affected after death (Sherwood et al., 2004). It is noted the FSIM does not account for the small number of caregivers outside of the family, such as friends, across the studies within this review. Furthermore, the FSIM suggests a linear model and was developed in the United States, so its applicability to the modern workings of the National Health Service may be limited. Further research is needed to determine how applicable the FSIM is for this group.

Research has found caregivers have a desire to be well informed about support options, along with what to expect and how to care for someone with a PBT (Ownsworth et al. 2015), which fits with the theme of 'Accessing the 'Right' Support'. This also connects with Madsen and Poulsen's (2010) review findings that caregivers lack information on how to manage neuropsychological changes at home. As well as taking responsibility for finding information (Sherwood et al., 2004), Madsen and Poulsen suggest that caregivers take responsibility for the illness, which together may offer an explanation for why caregivers were 'figuring things out themselves'.

Furthermore, findings are also supported by research that highlights PBT caregivers' needs for informal and formal support, which can be a challenge to access (Ownsworth et al., 2015; Sullivan & Miller, 2015). This raises the possibility that caregivers may not have capacity to attend their own appointments and could subsequently be discharged from services. Ownsworth et al. also found caregivers' expectations about timing and nature of support were subjective, suggesting there is not a 'one size fits all' approach.

## Strengths & Limitations

This review provided a summary of the experiences of caregivers to PwPBT and offered insights into the everyday realities of the role. Shared themes across the studies were presented.

The number of studies included in the review was small. Additionally, some samples were limited to representing White-American caregivers, or individuals recruited from single site/location, which may limit the generalisability of the findings. High-grade brain tumours were the most common PBTs within studies, and therefore results may be more reflective of caregiving experiences for more aggressive tumours.

The studies were heterogenous across many areas, which presents challenges with drawing reliable conclusions about the caregiving experience. For example, ‘caregiver’ was conceptualised differently across studies with participants including spouses, co-habitants, and children. Accordingly, these participants may assume different roles and responsibilities within their caregiver role. Furthermore, studies being from different countries infers that participants were describing an experience specific to their country’s own healthcare system, situated within a particular political, financial, and social context. Cross-culturally, there are differences in how informal caregivers perceive and respond to providing care (Andruske & O’Connor, 2020). This should be considered when interpreting conclusions.

Most studies were lacking on their consideration of researcher reflexivity which means the influence of the researcher’s position is unclear. Although attempts were made to mitigate this within the synthesis by prioritising higher quality studies, applicability of findings may be limited and should therefore be interpreted with caution. Furthermore, thematic synthesis may contribute to bias as there is a degree of interpretation required in theme developments.

## Clinical Implications

This review indicated caregivers for PwPBT can struggle with feeling overwhelmed within their role, which impacts their wellbeing. This highlights a need for commissioners to consider reviewing provisions for carers’ support within psycho-oncology services, which is limited (Macmillan Cancer Support, 2020). Research suggests even brief input, such as psychoeducation or skills training, can improve experiences of cancer caregivers (Molassiostis & Wang, 2022), so HCPs should consider how this could be offered within appointments where service provision allows.

Given there are numerous barriers to accessing formal support, services need to think creatively about their support offer. Initiatives such as flexible, community-based peer-led coaching support from ex-carers to current carers have been piloted and received positive feedback (St Christopher's Hospice, 2019). These could therefore be trialled elsewhere.

There appears a need for information to be provided to carers about the entire PBT experience, and it should be considered on an individual basis as to when and how this is offered. Cornwell et al (2012) found caregivers were less receptive to information in the early stages of illness; however, contrastingly, Schubart et al. (2008) suggest information seeking is highest immediately after diagnosis. This questions the idea that socialisation to the illness is necessary in the 'crisis' phase (Rolland, 1994) and implies there may be mixed preferences. Preferences for receiving information should be explored by HCPs early on in the illness journey.

Additionally, considering how to facilitate meaningful goodbyes in the context of cognitive decline could be a role for palliative care staff, as this has been shown to improve outcomes on measures of depression and complicated grief in cancer caregivers (Otani et al., 2017). This could be offered in creative ways such as video recordings or legacy letters.

## Research Implications

Given experiences may differ based on cultural/family beliefs about illness (Rolland, 1997), future research is needed to examine more diverse caregiving experiences, as the current review arguably reflects a more Western, White perspective. Future research could also seek to determine how the caregiving experience differs depending on age or family position, given not all caregivers are adults or spouses. Often, PwPBT can be diagnosed at child-rearing ages so young adult children may take on a caring role, which is a common occurrence in oncology (Justin et al., 2021). It would be interesting to explore what the experiences of this group are, given they are at a different part of the family life cycle (Carter & McGoldrick, 1988).

Studies included were limited in their attention to researcher reflexivity which threatens the integrity of qualitative research (Olmos-Vega et al., 2023). Future research should pay attention to this in a multi-dimensional way throughout the process, to bring awareness and transparency to the influence of subjectivity (Gentles et al., 2014). Researchers could offer, for example, a positionality statement, completion of a bracketing interview, and use of journaling and/or supervision to reflect on pre-existing knowledge and assumptions. Olmos-Vega and colleagues suggest these should be documented throughout the research manuscript for the reader's clarity.

## Conclusion

This review aimed to explore the experiences of caregivers to a PwPBT through a thematic synthesis of qualitative studies based on a systematic literature search. The results from the review revealed caregiving in this context can be all-consuming and impact carers' wellbeing. Caregivers to PwPBT must adjust to new ways of living, which can be isolating, but they can also encounter rewards in their role. Support for carers is vital, however there can be challenges to accessing this. Therefore, services should consider how they can be flexible to meet needs. Future research is needed to explore how this experience may differ for more diverse groups.

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# **Section B:** *"She Wasn't My Mum Anymore"'* – Bereaved Young Peoples' Experiences of a Parental Brain Tumour: An Interpretative Phenomenological Analysis

Word Count: 7990 (303)

**Proposed Journal:** Psych-Oncology

## Abstract

**Objective.** A primary malignant brain tumour (PMBT) diagnosis is common in adults of child-rearing age. It carries a poor prognosis and leads to significant neuropsychological and physical difficulties. Research with adult caregivers for individuals with a PMBT has suggested this role can be demanding, but no studies have explored what this experience is like for young people within the family. The aim of this research was to understand bereaved young peoples' experiences of a parental PMBT.

**Methods.** Individual, semi-structured interviews were conducted with nine young people who had been bereaved by a PMBT, to explore their experience of their parents' diagnosis and illness, along with how they experienced the impact on their wellbeing, friends and family relationships and identity**.** The data was analysed using Interpretative Phenomenological Analysis.

**Results.** Five Group Experiential Themes were developed from the data; 'The Emotional Impact'**,** 'Seeing the Disease, Not My Parent', 'Stepping Up', 'Relationships: Strength or Strain', 'A Changed Outlook'**.** Sub-themes were also explored.

**Conclusions**. The experience of a parental PMBT can have a significant emotional impact on young people, and result in changes in relationships and sense of identity. Implications for clinical practice and research are discussed.

**Key Words:** Young people, parental brain tumour, wellbeing, relationships, identity

# Introduction

Primary brain tumours are the most prevalent cancer in under 40s, yet amongst the most difficult to treat (Brain Tumour Charity, 2015). Malignant/high-grade PBTs (PMBTs), such as glioblastoma multiforme carry a poor prognosis with 5% five-year survival rate (Brain Tumour Charity, 2020). Experiences of neuropsychological, functional, and physical difficulties are clinical features of PMBTs and impact most individuals before treatment (Taphoorn & Klein, 2004). Neuropsychological changes depend on tumour location within the brain, but can include changes to personality, executive function, memory, attention, speech and language, emotional control, sensory processing, balance, and experience of hallucinations (Loon et al., 2015; Yamamoto et al., 2022; Hense et al., 2021).

Treatments for PMBTs often do not have curative intent and instead attempt to prolong life. Standard treatment  involves a combination of neurosurgical resection, radiotherapy and both concomitant and adjuvant chemotherapy. These are intensive and invasive treatments that can also lead to further neuropsychological challenges (Kapoor et al., 2019).

Rapid decline in an individual’s functioning often occurs following a PMBT diagnosis and continues steadily after. Individuals can experience a reduced quality of life, and a ‘psychological crisis’ can occur for the whole family (Taphoorn & Klein, 2004). This is likely influenced by the sudden illness onset, short disease trajectory, and myriad of associated difficulties that initiate a need to quickly learn caregiving tasks and renegotiate relationships (McConigley et al., 2010). This can be difficult: a systematic review of bereaved adult caregivers of people with PMBT (PwPMBT) suggested they face anticipatory grief, fatigue, emotional distress, reduced work capacity and an increased risk of depression (Sterckx et al., 2013). Within Western health contexts, where emphasis is placed on outpatient treatment (Heinsch et al., 2021), family caregivers play an important role in supporting PwPMBT through the entire disease course (Ownsworth et al., 2015). This may also include adolescent or adult children, given PwPMBT are often those of child-rearing age.

The World Health Organisation (2021) defines adolescents as individuals in the 10-19 age bracket, and 'young people' as those within the years of 10-24. These age ranges are characterised by significant biological, psychological, and social changes (Walsh, 2011), across developmental stages which Erikson (1950) defined as 'identity vs. role confusion' for adolescents and 'intimacy vs. isolation' for those within early adulthood. According to Erikson, the for adolescents is to explore independence and develop a sense of self through learning about goals, values, and beliefs. Those who are unable to explore different identities may be left with 'role confusion': a sense of uncertainty with who one is and where they fit in. Young adults are tasked with forming intimate, loving connections with others. Success at this stage leads to fulfilling relationships; however, struggling with interpersonal relations can result in loneliness and isolation.

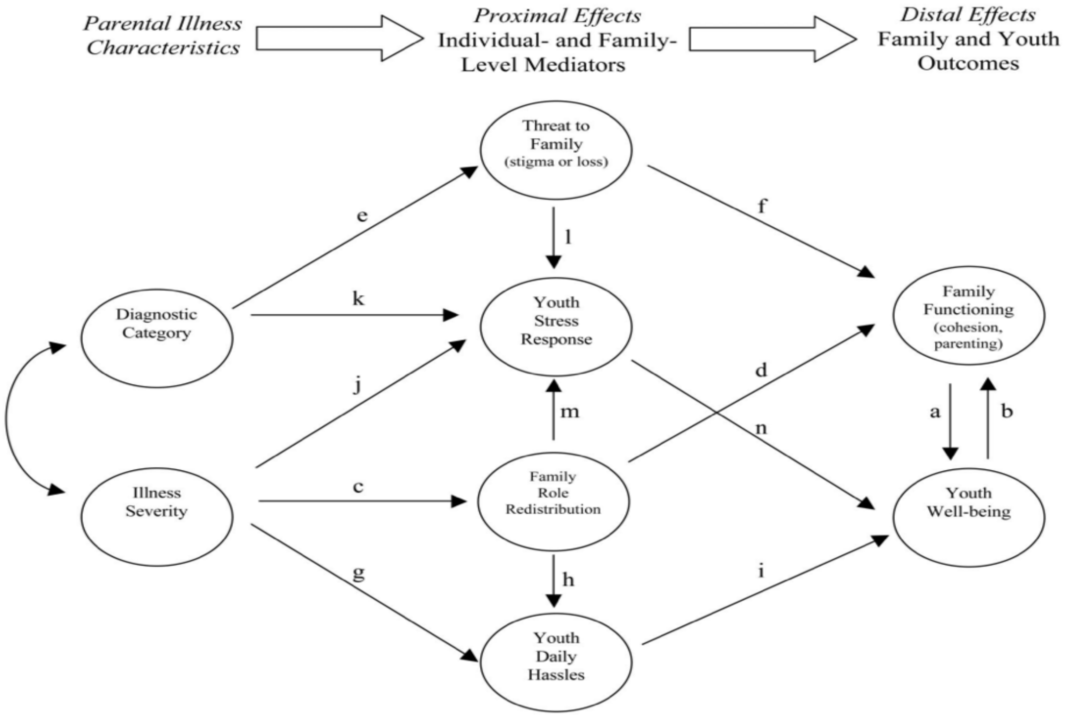
Adolescence is proposed as the most challenging stage of change and stress within the family life cycle (Carter & McGoldrick, 1988; 1989), as families must adapt in response to children growing up, searching for identity, and seeking independence. The family life cycle theory posits that unpredictable events (i.e., illness and death) create additional stress which is magnified when these events occur within a life cycle stage that is characterised by significant, predictable change, such as adolescence.

The impact of parental illness on young people has been documented as a stressful experience with threats to physical and mental health and development (Pederson & Revenson, 2005). Through the lens of attachment theory, this can be understood as parental PMBT threatening safety of a key attachment figure and creating an emotional 'protest' response in the young person (Bowlby, 1988). Pederson and Revenson developed a theoretical model of young peoples' adaptation to serious parental illness (Figure 1), which is based on stress and coping theories (e.g., Lazarus, 1999), but also attends to the interplay of family members' responses. Characteristics (i.e., severity) of a parent's illness are theorised to affect a young person's wellbeing and family functioning through various mediators. For example, family functioning is posited to be impacted through role-redistribution of individuals around an illness (i.e., other family members adopting the ill member's roles). Additionally, if the family views an illness as a threat to its identity (i.e., they see the illness as serious threat to the ill member's life), family functioning can become organised around an illness. This may disrupt relational dynamics and compromise normative development of the family system.

The model proposes that greater 'daily hassles' incurred by young people (i.e., increased chores due to role redistribution) may impact their wellbeing through interference with peer development. Additionally, the degree to which young people appraise illness as an uncontrollable, negative life event may also impact wellbeing through activating a stress response. This can be heightened if there are concerns about parental death. Furthermore, if illness impairs a parent's ability to fulfil their usual responsibilities, this may impact the parent-child relationship and in turn, a young person's wellbeing. Given this, the model indicates the impact of a parental PMBT could be significant for young people and their families, given it carries a poor prognosis and often a plethora of associated difficulties

The authors also consider other contextual mediators within the model: developmental stage, cultural norms, family attachment and coping styles, social support, and gender. The model is limited given that studies focusing on personal growth arising from parental illness were not considered, due to an overall dearth of literature in this area. However, research continues to highlight this can be an outcome for both individuals and overall family functioning (Ohanessian, 2007; Simseck Arslan et al., 2020).

**Figure 1.** *Family Ecology Model (Pederson & Revenson, 2005)*



*Note.* Letters indicate pathways of mediator effects. For further detail regarding the review of the empirical evidence for proposed pathways, please refer to the full paper.

Qualitative research has demonstrated the impact of parental terminal illness in young adulthood can be long-standing and far reaching. A study exploring retrospective experiences of adolescents who had a terminally ill parent identified super-ordinate themes of changing family dynamics, grappling with adolescence and adjustment to loss, barriers to feeling supported, and living with the consequences (Cafferky et al., 2018). Participants also highlighted areas of resilience and strength, again suggesting personal growth can occur.

Philips (2014) conducted a systematic review of 18 studies examining the experiences of parents diagnosed with a range of advanced cancers and their young adult children. It was found that they experienced challenges with wellbeing, which authors suggested may be due to their ability to empathise and understand illness ramifications. Young people incurred increased responsibilities and coped by seeking normalcy in life, talking to someone outside the family and searching for understanding. Positive gains from the experience were also discussed. Importantly, studies mainly included parents with breast and colorectal cancers, indicating results may not represent experiences with other cancers.

Reviewing 36 studies focusing on parental death in young adulthood, Farella Guzzo et al. (2021) suggest such bereavement can give rise to a range of emotional responses and impair functioning at home and school (Farella Guzzo et al., 2021). This suggests that young people may face further challenges that extend beyond the diagnosis period whilst they navigate grief. Social support and environment were indicated as important for coping during this time.

Whilst there is research examining how young people experience parental cancer and illness more generally; studies have not yet ascertained how they experience a parental PMBT. Research that has considered the impact of a PMBT on adult caregivers has demonstrated they can experience isolation, anxiety, exhaustion, strain in relationships and a sense that the PwPBMT is not the same person (Ownsworth et al., 2015; Petruzzi et al., 2012; Salander & Spetz, 2002). It is important for psychologists in oncology and palliative care settings to understand how young people experience a parental PMBT in order to improve services and support.

Considering this, this study will aim to answer the following questions:

a. What are bereaved young peoples' experiences of having a parent with a PMBT?
b. How do bereaved young people experience the impact, if any, of a parental PMBT on their psychological wellbeing?
c. How do bereaved young people experience the impact, if any, of a parental PMBT on their family/peer relationships?

d. How do bereaved young people experience the impact, if any, of a parental PMBT on their sense of identity?

## Method

### Design

A qualitative design was selected to allow for in-depth exploration of young peoples' experiences. Semi-structured interviews were conducted and analysed using Interpretative Phenomenological Analysis (IPA). IPA is an idiographic methodology adapted from phenomenological analysis and hermeneutics, used to gain insight into individual experience (Smith et al., 2009). IPA focuses on using an interpretive approach and a 'double hermeneutic' to allow the researcher to make sense of the participant's making sense of their own experiences (Smith & Osborn, 2009). IPA is well suited to addressing how caregivers for individuals with health conditions make sense of their role (Morrison & Williams, 2020) and therefore is appropriate for the study aims. IPA is rooted within critical realism (Bhaskar, 1978), which posits there are stable features of reality existing independently of human conceptualisation, and that differences in meanings individuals attach to experiences are possible as they experience different parts of reality (Fade, 2004). This aligns with the epistemological position of the lead researcher.

### Participants & Recruitment

Purposive sampling was used to recruit young people who had been bereaved by a parental PMBT, according to inclusion and exclusion criteria (Table 1). IPA typically uses smaller sample sizes, with six to ten participants suggested for doctoral research (Smith et al., 2022). Nine participants were recruited for this study, through distribution of a research advertisement (Appendix C) on social media pages dedicated to supporting bereaved young people and online support groups for individuals affected by a PMBT.

**Table 1.**

*Participant Inclusion and Exclusion Criteria*

| Inclusion | Exclusion |
|---|---|
| Young people whose biological parent, or primary caregiver holding parental responsibility, died of a primary malignant brain tumour. | Young people whose parent/caregiver had secondary brain metastases, but the primary cancer was within another area of the body. |
| Currently 1-15 years post-bereavement | Young people currently struggling to a significant degree with their mental health or bereavement, whereby participating in the study may exacerbate their distress. |
| Currently living in the UK | |
| Aged between 12-25 when the parent/caregiver was diagnosed. | |

A broad age range was used, as a more inclusive definition of young people has been recommended (Sawyer et al., 2018) to ensure policies and services are developmentally appropriate. Initially, the criteria was 1-5 years post-bereavement, but recruitment was unsuccessful. This was then expanded to align with studies focusing on bereavement that have obtained retrospective accounts from young people (i.e. Cafferky et al., 2018). A minimum of one year was proposed to ensure participants had had some time to reflect on their experience, and a maximum meant the experience was not too distant to be reliably recalled.

Excluding participants whose parent had secondary brain metastases ensured findings could be more reliably attributed to experience of a parental PMBT, rather than the impact of another cancer and treatment. To maximise homogeneity, participants were UK based, which also allowed for local safeguarding procedures to be actioned where necessary.

Participant demographic information is contained within Table 2. Current ages of participants ranged between 19-31 (*M* = 25), and between 13-25 (*M* = 19) when their parent was diagnosed with a PMBT. Years since bereavement ranged between 1-15 (*M* = 5).

**Table 2.**

*Participant Demographics*

| Pseudonym | Age | Gender | Ethnicity | Parent Who Died | Type of Brain Tumour | Age at Diagnosis | Years Since Bereavement |
|---|---|---|---|---|---|---|---|
| Sophie | 23 | Female | White-British | Mother | GBM4* | 13 | 8 |
| Ellen | 27 | Female | White-British | Mother | GBM4 | 23 | 4 |
| Jacob | 25 | Male | White-British | Father | GBM4 | 19 | 5 |
| Maeve | 22 | Female | White-British | Mother | GBM4 | 17 | 3 |
| Taylor | 29 | Female | White-British | Mother | GBM4 | 25 | 3 |
| Sam | 31 | Non-binary | White-British | Father | GBM4 | 23 | 7 |
| Abigail | 24 | Female | White-British | Father | GBM4 | 22 | 1 |
| Rachel | 29 | Female | White-British | Mother | Meningioma | 14 | 15 |
| Emma | 19 | Female | White-British | Father | GBM4 | 14 | 3 |

*Note.* *GBM4 = Glioblastoma Multiforme

## Procedure

Individuals who were interested contacted the researcher and were sent an information sheet (Appendix D) and invited to ask questions. Following this, if they remained interested in participating, a consent form (Appendix E) was sent and returned to the researcher prior to arranging a video-call interview. Participants were offered £10 for their participation.

### *Expert by Experience Consultation*

A request was posted within online support groups for an expert by experience (EBE) to review the interview schedule and study materials. One EBE was consulted and provided feedback that was incorporated, such the inclusion of a ‘warm up’ question and an opportunity to close the interview with a positive memory.

### *Data Collection*

Semi-structured interviews were used flexibly following the interview schedule (Appendix F), which allowed participants to have an important stake in what was discussed. Interview questions were open-ended to be less restrictive, and prompt questions were used to elicit further information where required. Participants were advised the interview would take approximately 60 minutes and would be voice recorded.

## Data Analysis

The IPA process followed guidance from Smith et al (2021). Interviews were manually transcribed by the lead researcher, before being read several times to allow for immersion within the data. Initial exploratory notes were made on each transcript, focusing on descriptive, linguistic, or conceptual aspects of data. These exploratory notes were then grouped thematically to create Personal Experiential Themes (PETs) and sub-themes. This process took place for each transcript, before PETs across the participants were grouped, considering convergence and divergence, to develop Group Experiential Themes (GETs). This involved the re-naming, moving, or dropping of certain PETs according to what best represented the entire dataset (Appendix G).

## Quality Assurance

Markers of high-quality IPA research (Nizza et al., 2021) were attended to throughout the process including holding idiographic focus and orienting to phenomenology, focusing on the experiential, being interpretative and using this to move beyond the descriptions and offer new insights into the phenomena.

Quality was also enhanced by attending to researcher reflexivity, a key component of qualitative projects that invites awareness of researchers' thoughts, feelings, and assumptions to then acknowledge and explore (Biggerstaff & Thompson, 2008). The lead researcher was a trainee clinical psychologist who identified as a White-British, middle-class female. She had lived experience of being bereaved by a parental PMBT in young adulthood, so acknowledged this may influence assumptions and expectations of the data. These were discussed within bracketing interviews with another trainee psychologist (Appendix H). These, alongside supervision and use of a research diary (Appendix I) brought awareness to pre-existing beliefs and knowledge so these could be considered before analysis (Carpenter, 2007) and kept be kept as separate as possible from outcomes (Berger, 2015; Smith et al., 2009). A transparent description of the analytic process was documented, and theme development was discussed with supervisors and a research consultant with topic expertise.

## Ethics

Ethical approval was granted by the Salomons Ethics Board (Appendix J). The research study was grounded in NHS (2021) values of Commitment to Quality of Care and Improving Lives.

Informed consent was obtained from all participants, or parents/carers if under 16, prior to participation. Participants were made aware of their right to withdraw from the research at any point up to one week after their interview, when analysis would have begun. Participants were informed their information would be anonymised and kept confidential unless there were safeguarding concerns, in which case this would be discussed with the research team and their doctor if necessary. Participant data was stored securely in password protected files.

Given the potentially distressing nature of the interview content, consideration was given to mitigating harm. Participants were informed about topic areas that may arise and the potential for sensitive issues to emerge. All participants were encouraged to let a trusted adult know they were taking part, for support. Participants were informed they could break, pass a question, or stop the interview at any point. The researcher discussed how participants could signal they were finding things challenging and ‘checked-in’ if there were signs of distress. Where distress occurred, the researcher responded in an empathetic way by suggesting a break, providing reassurance, and ensuring participants wished to continue. There was opportunity for a verbal debrief after the interview, if needed, to discuss arising issues. A written debrief form (Appendix K) was also provided to all participants which highlighted details of support information and contact details for concerns.

The researcher followed guidance from Butler et al. (2017) regarding taking care of their own wellbeing, given this was a topic area with personal resonance. This involved scheduling interviews a few days apart, taking breaks from analysis, using supervision and self-care.

## Results

Findings were organised into five GETS and 14 sub-themes (Table 3).

**Table 3.**

*Group Experiential Themes and Sub-Themes*

| Group Experiential Theme | Sub-Theme |
|---|---|
| **The Emotional Impact** | Living In a Nightmare |
| | *What's Going On?* |
| | Ongoing Grief |
| | Blocking It Out |
| **Seeing the Disease, Not My Parent** | *'They Were a Different Person'* |
| | Cherished Moments |
| | Unanswered Questions |
| **Stepping Up** | Taking on Responsibilities |
| | Holding Onto Normality |
| **Relationships: Strength or Strain** | Friends Can't Grasp It |
| | Feeling Let Down and Left Out |
| | Importance of Mutual Understanding |
| **A Changed Outlook** | Perspective Taking |
| | *Who Am I And What's Important Now?* |

## The Emotional Impact

### *Living In a Nightmare*

Many participants described how the experience of their parent having a PMBT was traumatic or surreal.

*'And also, just like it's a very out of body experience, I'd say. Because I'd say that a lot of it was like, is very traumatising.'* – Taylor

Taylor indicates the experience was emotionally overwhelming by implying she experienced a dissociative response, and her movement from past to present tense could reflect how she continues to feel traumatised, three years post-bereavement.

*'When it started to sink in, I just felt completely, I just felt helpless. And just like the whole situation was just devastating to go from such an intelligent, strong, sporty person, it was just, it was just completely, it felt like a nightmare. It was like living in a nightmare. And it just didn't feel real. Like sometimes it still doesn't feel real....'* – Abigail

Abigail's solemn tone and trailing off at the end of speech, captured the devastating nature of the change in her father when she likened the situation as a *'living in a nightmare'*. Others also echoed similar feelings:

*'I just remember thinking this can't be happening, I am not ready, I cannot lose my Mum, this isn't real. Yeah, it felt so, so surreal and just honestly horrifying....And just that feeling as well of total helplessness, there was nothing I could do. Yeah, it was just like my entire world came crashing down in a matter of moments.'* – Ellen

The impact of gradual bad news about diagnosis and deterioration seemed to move Emma into detachment, with a sense she was putting up a 'wall' to protect herself from further pain:

> *'I think at first, I was really, really upset. But then like I said, with the gradual bits of bad news, I kind of went from being upset and more just to kind of being numb.'* – Emma

***What's Going On?***

Many participants spoke of the confusion they felt trying to make sense of the initial changes they noticed in their parent, which seemed to add to anxiety.

*'It was so confusing…I just didn't understand that he was just not like him and it didn't make sense.'* – Abigail

'*And the doctor said, oh, you know, it could be anxiety. It could be you know, any sort of like mental health issues.'* – Taylor

Taylor alluded to initial reassurance given by medics, which may have contributed to a heightened emotional impact receiving a diagnosis. Speaking in a casual tone with the phrases *'you know'* and '*sort of'* highlight the lack of concern initially. Reassurance from doctors or attributing concerns to other common causes, was something echoed by other participants.

Rachel described how she was shielded from information by her parents, which seemed to lead to confusion when she felt excluded from school activities. Her parents minimised the severity of the situation, which she understood as attempts to protect their children. The extent of the confusion felt is conveyed by repetition and hesitancy with use of *'erm'* and *'I think'*.

*'...I asked Dad about that. And like, he just kept sort of brushing it off. And eventually he said, well, actually, we've said we don't want one at home because of Mum's headaches. So I think at that point that kind of felt like left out. Erm or, yeah, I just didn't really know what was going on. I think. Or, yeah, I just didn't really know what was going on, I think." –* Rachel

***Ongoing Grief***

Many participants acknowledged the grief they felt watching their parent deteriorate and change:

'*I felt that I was grieving before he even died because he wasn't the same person anymore'*- Abigail

*'…the anticipatory grief that I had to deal with first, bracing yourself for the death.'*- Maeve

Others described how they navigated grief after death:

'*So life has changed, so it's kind of hard to, like obviously I really, really miss him but it's kind of hard to feel that way because I feel like life has changed so much for the better since he passed away.'* – Emma

Emma seemed to acknowledge that she has managed grief without feeling overwhelmed, and is content with life. The disfluency in her speech seems to be an attempt to reassure the researcher that her father is still missed, and she feels obligated to stay connected to him.

Other accounts echoed a similar sentiment; Jacob implied that his grieving process was quick like his father's illness trajectory. His use of the adverb *'probably'* suggests uncertainty about his emotional experience, perhaps because he avoided dwelling on it.

*'I think because it was such a rapid onset and decline of his condition, I probably grieved in a somewhat similar manner. The funeral happened very quicky afterwards and me and my family got back to things quite quickly afterwards as well.'* – Jacob

### ***Blocking it Out***

Most participants described attempts made to avoid or suppress painful emotions experienced during their parent's illness.

*'I've stuck everything into a jar where it couldn't hurt me and I just put it in a shelf on my brain because I think if it's in a jar, it can't hurt me. I don't have to relive it.'* – Sam

Using of noun '*shelf*' suggests Sam attempted to create distance from the experience in their mind, perhaps by compartmentalizing the experience to protect themselves from emotional pain. Other participants described alternative attempts to block out emotional pain of the experience, such as dissociation and humour.

*'I don't think I coped very well. I think it was mostly not really being with it. A lot of the time, there was a lot of dissociating, which just comes back to bite you later.'* – Maeve

The verb '*bite*' implies that hurt was experienced later, unexpectedly, as a result of dissociation and was not a means of avoiding emotional pain entirely.

Emma implied the upset she experienced witnessing her father's struggles with mobility and aphasia was not something she outwardly showed, describing this as a *'frog in your throat kind of moment'.* However, she implied that humour helped her manage by stating it was *'something that we laughed at. And we found it a bit funny, and I think even he found it funny.'*

Jacob, who was a junior doctor at the time of his father's illness, highlighted how he used the practical task of updating family visitors as a way of managing difficult emotions

*'…he had lots of visitors. I was able to update them, reassure them, explain what was*

*happening and things like that. So I used that a lot to get by. I kind of avoided, avoided being swallowed up by the sense of despair and you know, impending massive change to life for me and my family. Remind me of the question and I'll stay on point.'* – Jacob

Jacob's use of '*swallowed up*' illustrates how he perceived despair as all-consuming if he let himself feel it. Talking about it possibly made him feel uncomfortable, reflected in his sudden request for a reminder of the question. Throughout the interview, Jacob used medicalized language and maintained a professional demeanour, possibly as a coping mechanism for discussing emotional topics.

## Seeing the Disease, Not My Parent

### *'They Were a Different Person'*

Many participants described how their parent seemed like a different person due to neuropsychological and physical changes. For Ellen, this was described as happening within just a few days:

*'She really deteriorated; she wasn't my Mum even after a few days of the diagnosis.'*

Participants highlighted the magnitude of change in their parents by comparing them to people living with dementia, or an elderly grandparent. Some observed increased anger or experiences resembling psychosis, which were difficult to know how to manage.

### *Unanswered Questions*

Many participants indicated there were difficulties getting a sense of closure before their parent died due to illness-related changes.

*'Before we knew exactly what was wrong he was changing, and it was too late to get any of those little things that would mean so much.'* – Abigail

Parents' communication difficulties made meaningful conversations impossible for many. Some were left with unanswered questions about parent's feelings and hopes for their future, and others expressed sadness at not being able to hear reassuring sentiments.

*'So, I think, you know, it's almost like if she had another disease that didn't affect her brain , that was a terminal illness, maybe we could have sat around and done like a memory box. Or I could have said, oh what do you think about me having children or something? But like, you never, that was never going to be possible.'* – Taylor

Taylor's harsh tone conveyed a sense of bitterness when considering what may have been possible if her mother had not experienced a PMBT.

### Cherished Moments

Some participants noted how the PMBT affected their relationship. Emma described it being '*nice'* to be relied on, perhaps due to being within a stage of early-mid adolescence meaning she was desiring more independence and authority at home.

*'And I used to like help him walk to the toilet and things like that, which kind of, in some ways made us a bit closer. And you know, rather than me relying on him, it was nice for him to rely on me.'* – Emma

More time spent with the parent during the illness was seen as an opportunity for '*cherished moments and a stronger relationship*' (Sophie). Maeve became a caregiver for her mother, who could no longer '*do the role anymore'* but still believed a '*mother-daughter relationship was still possible*', implying that family roles were fluid. It appeared new roles could exist alongside old ones, which themselves had changed. Maeve's age (17) being mid-late stage of adolescence may also be of significance, as she may have been through the process of negotiating independence. This perhaps allowed her to hold the 'both and' positions of appreciating closeness alongside autonomy.

This was not the case for all participants, such as Jacob, who expressed that he kept his relationship '*superficial'* with his father during the illness. This was in the context of having had a challenging dynamic previously, which they had not yet resolved.

*'And yeah, after he got diagnosed, I didn't make any strong effort to become closer to him….I didn't think too hard about it. I just kind of kept things superficial, honestly.'*- Jacob.

Use of '*honestly*' possibly reflects how Jacob expects to be met with disbelief at this statement by the researcher.

### Stepping Up

#### *Taking On New Roles & Responsibilities*

All participants discussed taking on additional responsibilities or acquiring new roles following their parent's PMBT diagnosis.

*'I'd come home in the evening, I'd set my sister up to do her homework for school, I'd put Mum into bed, I'd do the ironing so that we had school clothes the next morning. I'd cook dinner, I'd do the lunchboxes, and then I'd stay awake until my Mum went to sleep.'* – Sophie

Sophie's fast rate of speech reflected a sense of being rushed and overwhelmed at the number of responsibilities she acquired.

Emma described assuming these responsibilities for the sake of her younger siblings, while Rachel noted that adopting a 'motherly role' felt automatic for her.

*'That's where I kind of stepped up a bit and did a bit more just because all I could think about was that my brother and sister, when I was their age, I just had an easy childhood.'* – Emma

*'And it sounds really silly, but I just remember becoming an adult'* - Sophie

*'I took on that like sort of motherly role. Which at the time, I didn't really think about, it's just something that automatically happened.'* – Rachel

Maeve described taking on a 'carer' role. Use of the phrase '*kind of*' and '*like*', as well as highlighting the fact she was not an 'official' carer, could suggest a sense of unease about identifying with this role.

*'I kind of became like a carer. I was never like officially documented as one, like never signed up as like a young carer. But I did, I became a carer for a couple of months before she was moved to hospice.'* – Maeve

Demands of additional responsibilities appeared to be engulfing for many participants and meant aspects of life were put on hold.

*'It was all consuming though, my life completely went on hold and like, I had to defer my teacher training at Christmas time and every day was helping Mum.'* – Ellen

### ***Holding Onto Normality***

All participants described attempts to seek normality within their situation, which appeared to offer an escape and a sense of being young and 'normal'. For Jacob, pressure to continue with university studies was apparent until his father approached death, suggesting engagement with education remained a priority. Studying may have also offered a distraction from emotional pain.

*'I put quite a lot of pressure on myself to stay up to date, so I was, I did, I did work via PowerPoint slides, not attending any lectures or classes, until he became end stage, like palliative.'* – Jacob

Nevertheless, normality seemed difficult to obtain for many due to feeling guilty spending time away from their parent or not being able to switch off from the situation. This was due to being in constant '*crisis mode'* (Taylor) or feeling '*exhausted'* (Abigail).

*'But apart from that as I say it was every day, going to the hospital, coming home, maybe seeing a friend…trying to have some normality but also finding that really difficult.'*- Ellen

The word *'maybe'* indicates it that socialising was not able to be guaranteed or prioritised during her mother's illness.

## Relationships: Strength & Strain

### *Friends Can't Grasp It*

Most participants spoke about challenges of friends being unable to understand the situation, which led to strain in relationships.

*'I think it's changed, definitely changed a lot of my friendships because not many of my friends, really, I don't think any of them actually understand like, the gravity of it.'* – Abigail

Abigail's use of *'gravity'* implies her friends could not appreciate the extent to which she felt weighed down by the situation. Other participants implied feeling alienated by the experience, due to bereavement in adolescence/early adulthood being '*quite rare'* and something friends had '*no idea how to deal with'* (Sam). Rachel suggested a concern about burdening friends with information about the PMBT:

*'I probably didn't talk to friends about it early on because I didn't know how they'd respond. Like they might not want to talk about it. So I think there was almost a sense of guilt that I might put something onto them that was too much'* – Rachel

For Sophie, the situation seemed so incomprehensible to friends that she was not believed when she told them about her mother's PMBT, which led to the breakdown of the friendship.

*'My friend was like you're lying, your Mum isn't not well, you're making the whole thing up. And basically, said I was lying about the whole thing'* – Sophie

In contrast, Sam highlighted the supportive value of friendships at the time of the bereavement. Their statement implies that they felt some of them also 'died' when their father did, because of a lack of happiness in life:

*'Losing Dad kind of made our friendships stronger with one another, because when it felt like nothing and there was no hope and no joy…they brought me to life again'* – Sam

### *Feeling Let Down and Left Out*

Some participants discussed feeling disappointed or angry at responses from significant others or services. Rachel implied this has been felt in hindsight, perhaps having had time to reflect on the experience.

*'Family members…looking back now I feel like really angry about that like, they didn't ask questions like, how are you doing, which is very frustrating'.* – Rachel

Others indicated that they felt left behind by peers, which caused strain and disappointment.

*'And when I felt back to being a bit more normal, I sort of realised I feel a little bit out of the loop now. Everyone's got these lives without me. So it was yeah, it did definitely strain my friendships for sure'* – Ellen

Feeling '*out of the loop'* implies Ellen experienced a lack of connection with her peer group, or her social developmental somewhat stalled after being there to support her mother.

*'They came to the funeral but then it was almost like, moving on to the next thing, you know, And now like nearly four years on, I feel like people just don't remember or like don't think about it'* – Taylor

Feeling let down by support was not limited to family and friends, as others had unhelpful response from both schools and mental health services. Rachel indicated that even a simple check-in would have been appreciated by staff.

*"…like in the early stages, that was quite difficult, I think. I think, particularly because like school didn't sort of support me to do so or even acknowledge like what had happened or asked, like, how are you doing?"* – Rachel

*''I've been doing better after I'll say bullying, bullying, some of the talking therapies for 6 years…it took so, so long, but at the end of 2022 I finally got through to somebody… Like finally got through to somebody that, yes, I have depression and anxiety. That predates losing Dad. But I haven't been able to deal with losing Dad. And finally, getting somebody to listen to me and putting me into grief counselling"* - Sam

Sam alludes to feeling unheard by mental health services and feeling the need to '*bully*' them to listen to their request for grief counselling. Sam explained how mental health services initially offered stress management and cognitive behavioural therapy for pre-existing difficulties with anxiety and depression. This felt like an unhelpful lack of consideration for their experience of parental illness and bereavement.

### *Support Through Mutual Understanding*

Many participants found that relationships that offered shared understanding were supportive.

Seeing wider family members similarly emotionally affected by the situation appeared to be comforting, invite closeness and offer a sense of validation for participants' emotions:

*'And that you know, it's not just us going through it, it is them as well that are affected by it. Erm, so yeah that was the biggest thing for me, spending time with family and seeing how upset they were by it as well. And it also took my mind off it a bit, because you know, me and my cousins get on really, really well. And we're even closer after all of this'* – Emma

*"And I'm really close with my Mum's twin, and I think that massively helped because she was as close to her as I was, so we sort of shared the same… she had the same feelings"* – Sophie

Other participants indicated how pre-existing family relationships strengthened through the experience, perhaps due to relatives offering understanding that friends could not.

*"Me my brother and my sister are so close, so I feel like throughout the whole thing we really leaned on each other and supported each other. So I'd say if anything with them, it made our relationship even stronger and sort of made us even closer'* – Ellen

Some participants suggested the experience has shaped connections they pursue with others, including Maeve who discussed seeking supportive relationships through social media to find others in a similar position. *'Irrevocably changed'* indicates that Maeve views this as a permanent adjustment.

*'It has irrevocably changed my entire life…and the kind of friends that I make now because I need my friends to understand grief, otherwise, I just can't connect to them on a deeper level'* - Maeve

## A Changed Identity and Outlook

### *Perspective Taking*

Most participants described how the experience altered their life outlook.

*'And I just think it's given me a really good perspective on life. You know, there's now things that I look at and think it just doesn't matter. It's not a big deal'* – Emma

A sense of frustration was conveyed through a hard tone when discussing how peers complained about things that participants perceived as fixable in contrast to their situation that was not.

*"I tried to talk with my friends about it, or some of them, when they've been putting of plans or if they've just been talking about like, oh how do I explain it, just complaining about really pointless things that could be easily fixable, like complaining about one of their parents who like annoyed them or like I don't know, did something because they care about them. And I'm like well your parent is still here, just fix it with them"* – Abigail

Some participants also indicated elements of personal growth. Rachel appeared to be unsure how to describe this, suggesting it may be hard to conceptualise resilience alongside grief.

*'I think it's made me more, I don't know if resilience is the right word but like, I feel like if I can get through that then going forwards, I can probably deal with things'* – Rachel

### ***Who Am I and What's Important Now?***

Many participants discussed a loss of identity through the experience; Abigail reflected such shift felt like *'another reality'* which emphasises unfamiliarity.

"*I still do feel like I've lost part of myself, or like, I've always tried to describe it to people that have asked me how it feels. It's like I've kind of been put into another reality. And like I'm not living the same life anymore. I don't, I feel like the person I was when my dad wasn't ill is still part of me. But I don't feel like that person anymore'* – Abigail

Taylor echoed a similar sentiment, whilst suggesting the identity shift was permanent and starker when she had also transitioned from being a student to a working adult at a similar time.

'*…the person before my Mum died, like isn't going to come back, you know, and I think, especially because that was a different stage of life anyway.'* – Taylor

Most participants discussed how the experience had changed their outlook on what is important, including gaining a '*thirst for life'* after seeing someone die that '*still loved life and…didn't want to die'* (Emma). Jacob highlighted the desire to take life's opportunities, in a way that his father did not. Uncomfortableness at being confronted with his own mortality are indicated when Jacob avoids talking about his own death directly, but instead uses more colloquial language.

*'But the main thing is more kind of living and thinking more freely. Because yeah, I don't want to wait to do things or experience things, you know, until it's too late, kind of thing'* – Jacob

Maeve also described a shift in outlook and indicated this was something that not a conscious decision but rather something that felt forced.

*'Yeah, I think it's just changed my like entire worldview. Completely, I think I just completely had to shift the way that I thought about life' – Maeve.*

When thinking about the future, for some, a parental PMBT perhaps gave rise to concerns about genetic vulnerability themselves.

*'I'm quite paranoid about health. Paranoid about getting a brain tumour at some point'* – Ellen

Other participants alluded to sadness for what their parent would miss in the future, or how relationships could have evolved.

*'The biggest struggle for me after losing him was loving romantically again….wrapping my head around that when I fall in love with someone, I'm never gonna get to introduce them to my Dad'* – Sam

*'Most of the sorrow came from what he lost, what my mum and brothers lost. And you know, what he and I could have had if he'd stayed alive'* – Jacob

## Discussion

This study explored bereaved young peoples' experiences of having a parent with a PMBT and aimed to understand how their experiences impacted their identity, family and peer relationships and psychological wellbeing. Five GETS were developed: The Emotional Impact; Seeing the Disease, Not My Parent; Stepping Up; Relationships: Strength or Strain and A Changed Outlook. Findings are discussed in relation to psychological theory and literature, and limitations are considered. Implications for further research and clinical practice are suggested.

Participants described feeling distressed and traumatised by their parent's PMBT diagnosis and subsequent journey. This corroborates with literature suggesting many young people who lose a parent can experience this as trauma and may go on to develop difficulties with post-traumatic stress (McClatchey et al., 2009). For participants in the present study, this was perhaps exacerbated by initial reassurance from medical professionals that alarming initial symptoms were not concerning, which is documented in the research literature as being a typical experience (Ownsworth et al., 2011). Experiences of feeling devastated, helpless, and in disbelief align with research examining the experiences of adult caregivers to PwPMBT (i.e. Collins et al., 2014; Wideheim et al., 2002), and supports the idea that a 'psychological crisis' occurs for the entire family (Taphoorn & Klein, 2004). This may be because young people have enhanced abilities to empathise with their parent and understand the potential consequences of the diagnosis and their parents' pain (Phillips, 2014).

Participants struggling with their psychological wellbeing following the PMBT diagnosis aligns with Bowlby's (1988) theory that when security attachment figure is jeopardised, dependent offspring will have an emotional response. Similarly, Pederson and Revenson's (2005) family ecology model would suggest the illness was appraised as an uncontrollable and negative event that activated a stress response, which in turn impacted wellbeing. This may have been heightened given that PMBT carries a particularly poor prognosis, and participants 'seeing' the disease rather than their parent due to the visible change and decline. The model, however, does not explain differences in subjective appraisal of the PMBT, which was observed within some participants particularly in the initial stages.

Experiences with anticipatory grief, where participants felt they had 'lost' their parent due to cognitive changes, also mirror research findings with adult caregivers to PwPMBT that suggests the grieving process begins before death (Collins et al., 2014). For some participants, there was tension between grief and moving forwards with life. This alludes to the dual processing model of grief (Sroebe & Schut, 1999), which suggests oscillation between rebuilding life and acknowledging loss.

Attempts to avoid difficult emotions, and use of humour, could be understood as psychoanalytically defined defence mechanisms (Freud, 1984). Research has suggested defences are frequently observed in dealing with threats posed by cancer (Di Guiseppe et al., 2020). Defence mechanisms, whilst often viewed as pathological, can be understood as a meaningful adaptive effort through being protective and affect regulating (Freud, 1965; Hartmann, 1964). Use of defences may have minimised the impact of emotions, so participants were able to adapt and fulfil necessary roles and responsibilities.

Participants described shifts in roles and responsibilities, such as doing more at home or taking on parental roles. This connects with the family life cycle (Carter & McGoldrick, 1988), which suggests illness creates additional, unpredicted, stress for families that challenges established roles and relationships. This can mean responsibilities are, consciously or unconsciously, re-negotiated and certain members may do more, which is documented within research for adult caregivers (McConigley et al., 2010). Families were already navigating the predictable and stressful transition of adolescence in the life cycle, which may have compounded strain within relationships. Whilst participants did feel overwhelmed by their responsibilities, they contrastingly noted immediate family relationships to feel supportive and healthy, and gained a sense of closeness to their dying parent. This is consistent with research suggesting positive family functioning can develop from parental cancer (Ohanessian, 2007).

Participants feeling disconnected to, and misunderstood by, peers aligns with research suggesting there are barriers to feeling supported when a parent has terminal illness (Cafferky et al., 2018). Given it is a relatively uncommon experience, peers may be unsure how to respond or offer support which could be perceived as withdrawal or a lack of understanding. This may be particularly relevant for parental PMBTs where the illness may not always be visible to outsiders. A sense of disconnection from friends could denote ‘isolation’ (Erikson, 1950), due to additional responsibilities at home interfering with abilities to form and maintain relationships. Nevertheless, for some participants, friends provided a space to feel ‘normal’ and were described as a protective factor, which supports findings suggesting young people cope by seeking normalcy and talking to someone outside the family (Philips, 2014). These are perhaps ways of managing overwhelming emotions.

‘Role confusion’ (Erikson, 1950) may be represented by participants’ perceived loss of sense of self. This perhaps relates to putting elements of life on hold to support their parents, which prevented developmental tasks such as establishing autonomy and identity from being realised. Many participants expressed a change in outlook or acknowledged what had been gained from the experience, which supports research indicating resilience, strength and growth can occur through navigating parental illness (Cafferky et al., 2018; Philips et al., 2014; Simseck-Arslan et al., 2020). Notably, this was not the case for all participants, some of whom described their outlook as anxious or sad. This may have been influenced by availability of social support, or participants living with negative consequences (Cafferky et al., 2018) of the experience. Furthermore, a lack of closure or memories may have also influenced outlook.

### Strengths & Limitations

This study provided an insight into the experiences of young people that have been bereaved by a parental PMBT. Use of an EBE to review the interview schedule, as well as attention to markers of high-quality IPA (Nizza et al., 2021) and researcher reflexivity enhance the findings' credibility.

IPA requires a homogenous sample in relation to the area of interest. However, all participants were White-British within the UK, which means findings may not be transferable cross-culturally. Culture frames beliefs and attitudes towards family roles, illness, health, and death (Baider, 2012) and therefore there may be other experiences that are unaccounted for within the present study. Most participants were female, which may mean findings are skewed towards this perspective. This is notable given young adult female carers can experience more distress than boys (Fleitas Alfonzo et al., 2023). Participants were recruited via support groups for individuals impacted by a PMBT, which may signify they were struggling or more open to sharing experiences. Therefore, findings should be interpreted with caution.

The time since bereavement varied between participants, which is significant as participants are likely to have had different experiences in relation to the care, support and treatment they/their parent received during the period of illness in response to evolving NHS services. Additionally, stigma towards mental health (including grief), has reduced over time (Venters, 2018) suggesting those struggling could feel more able to seek support in more recent years. This, again, could mean participants' experiences, particularly in relation to their wellbeing, were shaped by the context of time, and as such may limit the transferability of findings.

Furthermore, most participants' parents had a glioblastoma multiforme, the highest-grade PMBT with the shortest prognosis. This may mean the results are more reflective of experiences with a more challenging diagnosis.

## Clinical Implications

During and after a parental PMBT diagnosis, the psychological wellbeing of young adult children needs attention. As a lack of dedicated funding towards family and carer support within psych-oncology services has been recognised (Macmillan Cancer Support, 2020), commissioners should review service provisions to ensure young people can be adequately supported. Support should be flexible and person-centred, given needs can change as a parent's illness progresses (Bergerson et al., 2022) and young people may be reluctant to access psychological support (Sheffield et al., 2004). Therefore, consideration should be given to distribution of signposting literature, including organisations to find mutual understanding. Alternatively, books (e.g., Johnson, 2011) could be recommended to offer indirect support around living alongside a parental PMBT in an accessible way.

Results from the current study indicate young people affected or bereaved by a parental brain tumour may be traumatised. Complexities arising from this can impact a young person's everyday life in a multitude of ways, including social and educational functioning (UK Trauma Council, n.d.). This highlights the importance of recent recommendations to extend trauma-informed care in the context of cancer to family members supporting individuals with a diagnosis (Davidson et al., 2023). Trauma-informed interventions should be individualised and reduce the risk of re-traumatisation (Dhawan & LeBlanc et al., 2023; Kazak et al., 2005) for young people. This could include creating safe environments, providing elements of control, and offering psychosocial support that integrates knowledge of trauma. Such an approach may help to reduce poor long-term outcomes and increased risk of mental health difficulties in future (Cohen et al., 2002).

Preservation of normality is important, so there is a role for HCPs to signpost families to respite/care service. This would enable young people, as well as adults, to have time to socialise, and engage with ‘normal’ developmental tasks to allow them to stay connected to their identity.

Ideas could be taken from bereavement and dementia literature regarding making memories where there is cognitive decline, as dementia too involves a deteriorating process which wears away personality, cognition, and skills (Hundt, 2014). This could include photographs and memory books if conversations are not possible.

## Future Research

Future research should seek to understand how young peoples’ experiences of a parental PMBT can vary cross-culturally, by capturing a wider range of experiences. Similarly, it may be useful to understand how experiences may differ according to other aspects of diversity, such as gender or age. Ascertaining an understanding of how young people being of a same or different gender to the parent with a PMBT may influence psychological wellbeing could also be of interest, given research has found girls with unwell mothers reported greater difficulties than girls with unwell fathers and boys with unwell mothers or fathers (Compas et al., 1994).

Researchers could also move beyond the understanding of experiences and explore the information and support needs of this group, and pilot interventions towards this.

## Conclusion

This study explored bereaved young peoples’ experiences of a parental PMBT and highlighted their challenges with psychological wellbeing, as well as changes in relationships, roles, and responsibilities. This mirrors experiences of adult caregivers to PwPMBT. The study also identified challenges with feeling supported by peers; however, finding connections that offer understanding and normality was important. Findings indicated young people grapple with identity after the experience, but also obtain a changed outlook and new perspective on life. It is vital for psychological wellbeing of young people to be attended to, and for HCPs to consider creative ways to support them through the process. Future research should seek to understand how this experience may differ according to diversity.

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# Section C: Appendices of Supporting Material

## Appendix A: CASP Qualitative Studies Checklist

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## Appendix B: Themes, Sub-Themes, Code Examples, and Illustrative Quotes

| Theme | Subtheme | Code Examples | Illustrative Quote(s) |
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| **Consumed by Caring** | New Roles and Responsibilities | 'Assuming additional roles'<br>'Balancing caring with other responsibilities'<br>' | "I care for the kids 24/7. I've taken on a lot of the chores around the house that include lifting, taking out the garbage, cleaning the house, and I've taken care of the bills and dealing with the insurance company, and making sure he gets the medication filled" (Hricik et al., 2011)<br>"What has been difficult for me has been the amount of additional work that fell in my lap: taking care of financial things, taking care of insurance, taking care of the worries of all of that." (Whisenant, 2011) |
| | Lack of Respite | 'Difficulty getting respite'<br>'Lack of respite' | "It would have been nice if the family members especially would have offered to take over and give me a night off. If I needed to be away for work, they were there, but it would have been nice to have been able to just go out to a movie or something with my then 9-year-old daughter" (Sherwood et al., 2004)<br>"Few of the caregivers had accessed formal respite services" (McConigley et al., 2010) |
| | Putting Life On Hold | 'Giving up work'<br>'Changing priorities' | "All participants talked about putting aspects of their life on hold, or sacrificing their own social lives, aspirations or financial security, for the sake of their recipient's more immediate needs." (Kirby et al) |

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| | | | “Of course I had to give up my job, because I had to be here at home all the time.” (Edvardsson & Ahlstrom, 2008) |
| **Impact and Isolation** | Impact on Wellbeing | ‘Decline in physical or mental health’<br>‘Struggling with exhaustion’ | “It was common among the spouse caregivers to experience insomnia, distress, lack of energy, poor memory, and difficulty concentrating on everyday matters.” (Francis et al., 2022)<br>“Caregivers overwhelmingly described the work of providing care as mentally and physically exhausting.” (Sherwood et al., 2004) |
| | Anxiety and Worry | ‘Worry about the care recipient’<br>‘Sensitivity to illness-related things’ | “Well, I suppose it’s all this worry about [X] when he’s home. He’s sort of out there in front, in the forefront of your thoughts sort of all the time.” (Wideheim et al., 2002).<br>“Symptoms like headache or slight memory problems, or being close to the anniversary of surgery, aroused thoughts about brain tumour or the possibility of the patient’s getting worse” (Edvardsson & Ahlstrom, 2008) |
| | Isolation and Loneliness | ‘Limited social mobility and interaction’<br>‘Loneliness and isolation’ | “Some next of kin did not dare to be away from home, whereby they were prevented from travelling or even going to work, and this led to a sense of isolation” (Edvarddson & Ahlstrom, 2008)<br>“Carers frequently reported they had lost their support network, who had ‘dropped off’ while they were consumed by the daily tasks of caring.” (Collins et al., 2014) |
| **Keeping Going** | Satisfaction and Personal Growth | ‘A gift to provide care’ | “Although taking on the caregiver role was difficult, caregivers stressed positive |

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| | | ‘Improved relationship with the PwPBT’ | aspects of caring. The majority perceived the opportunity to provide care as a gift.” (Sherwood et al., 2004)<br>“I’d say definitely closer than before. We definitely cherish each other more and tell each other that we love each other” (Hricik et al., 2011) |
| | Holding Onto Hope | ‘Holding hope’<br>‘Uplifted by improvements’ | “Hope was placed in the results of the treatment and in the possibility of one’s own sick relative being an exception to the rule. When the patient appeared to be feeling better, the next of kin felt better too and gained a sense of assurance. The next of kin kept up their hopes by being constantly in touch with the doctors, asking questions particularly when new symptoms appeared” (Wideheim et al., 2002)<br>“They instead, emphasised the importance of always maintaining hope” (Collins et al., 2014) |
| **Adapting to New Ways of Living** | Holding the PwPBT at The Centre | ‘Listening to patient perspective’<br>‘Advocating for the patient’ | “Caregivers also took on a role of ‘interpreter’ and advocate when the patient was not able to make their wishes known.” (McConigley et al., 2010)<br>“Forcing of information upon patients was another thing to which some of the next of kin reacted negatively. They also believed that it was unnecessary that the patient should receive information about things that might happen” (Wideheim et al., 2002) |
| | Adjusting to Loss/Change within the Relationship | ‘Change in patient abilities’ | “From that moment [of diagnosis], everything was different… As the seizures |

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| | | ‘Change in roles and relations’ | progressed, she started losing more of her abilities – she lost the ability to eat, to drink, to stand, to walk” (Collins et al., 2014)<br>“For others, the care recipient's personality or behavioural changes not only indicated the progression of illness but also a shift in the relationship” (Kirby et al., 2021) |
| **Living with The Unknown** | Coping with Daily Uncertainty | ‘Uncertainty about disease progression’<br>‘Concern about disease progression’ | “The staff urge the family to live in the present to bear the burden of such a serious diagnosis and the uncertainty it involves.” (Wideheim et al., 2002)<br>“Caregivers and patients also needed to make plans for the future and reassess priorities, knowing that life expectancy was unpredictable” (McConigley et al., 2010) |
| ‘ | Confronting Death and Entering Grief | ‘Recognition of death’<br>‘Coping with grief’ | “This encompassed making funeral arrangements, living wills, knowing what to expect in the final days and hours, and being prepared for life after the care situation was over.” (Sherwood et al., 2004)<br>“Overall there was much grief, and this was sustained into bereavement. Bereaved carers spoke of the long ‘catch-up’ period after the patient died, in which they finally had time and space to process the immense losses.”(Collins et al., 2014) |
| **Accessing the ‘Right’ Support** | Informal and Formal Support | ‘Emotional support from others’<br>‘Feeling closer to others who understood’ | “There was a strong feeling of being closer to relatives and friends or fellow-workers who increased in social importance by showing a much-appreciated understanding of the next of |

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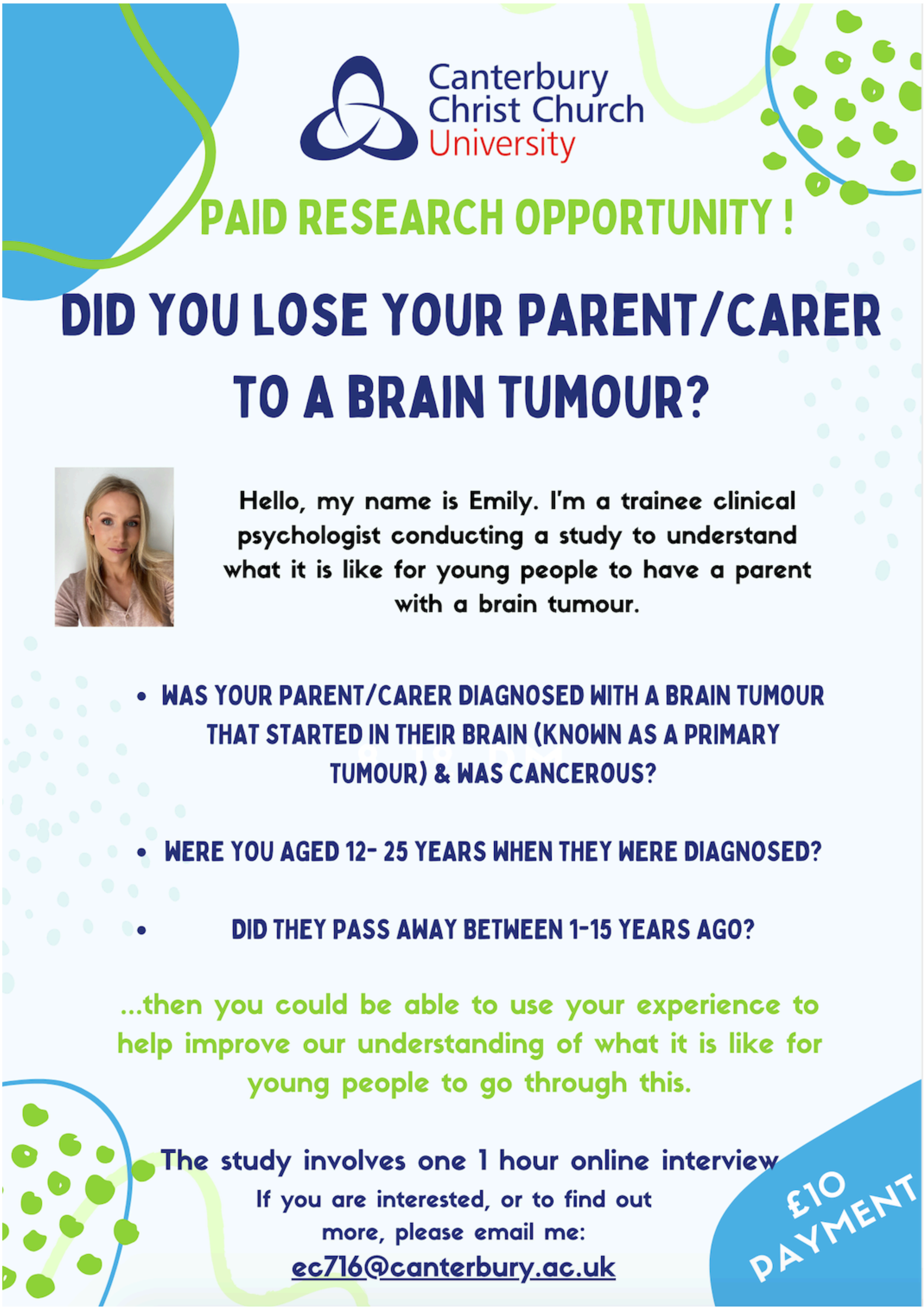
| | | | kin's situation and were good listeners." (Edvardsson & Ahlstrom, 2008)<br>"Assistance in providing physical care was the most readily available and easiest for caregivers to request from friends and family." (Sherwood et al., 2004) |
| | Challenges of Support | 'Lack of understanding from others'<br>'Disappointment in others' | 'I realize that my doctors were very upset to see that there was nothing they could do to save my husband, but I felt that they were consoling themselves rather than giving me information to help me get through the day-to-day care. I don't think they had a clue how difficult it was' (Sherwood et al., 2004)<br>"The spouse caregivers experienced that some friends and family members appeared oblivious to their partner's declines with remarks that their partner looks fine and seems well, although the partner had severely changed behaviour" (Francis et al., 2022) |
| | Figuring Things Out Themselves | 'Difficulties finding information'<br>'Responsible for researching information' | "Caregivers sought information about how to provide care and about what to expect. Information was difficult to obtain because they did not know what questions to ask or where to look for information" (McConigley et al., 2010)<br>"They were also responsible for researching information on the disease and its treatment" (Sherwood et al., 2004) |

## Appendix C: Study Advertisement



Canterbury
Christ Church
University

PAID RESEARCH OPPORTUNITY !

DID YOU LOSE YOUR PARENT/CARER TO A BRAIN TUMOUR?

Hello, my name is Emily. I'm a trainee clinical psychologist conducting a study to understand what it is like for young people to have a parent with a brain tumour.

- WAS YOUR PARENT/CARER DIAGNOSED WITH A BRAIN TUMOUR THAT STARTED IN THEIR BRAIN (KNOWN AS A PRIMARY TUMOUR) & WAS CANCEROUS?
- WERE YOU AGED 12- 25 YEARS WHEN THEY WERE DIAGNOSED?
- DID THEY PASS AWAY BETWEEN 1-15 YEARS AGO?

...then you could be able to use your experience to help improve our understanding of what it is like for young people to go through this.

The study involves one 1 hour online interview

If you are interested, or to find out more, please email me:

ec716@canterbury.ac.uk

£10 PAYMENT

**Appendix D: Participant Information Sheet (Young Person)**

Salomons Institute for Applied Psychology
One Meadow Road, Tunbridge Wells, Kent TN1 2YG
www.canterbury.ac.uk/appliedpsychology

## Information about the research v2 – Nov 2022

# Bereaved Young People's Experiences of a Parental Brain Tumour

Hello. My name is Emily Carter and I am a trainee clinical psychologist at Canterbury Christ Church University. I would like to invite you to take part in a research study. Before you decide whether to take part, it is important that you understand why the research is being done and what it would involve for you.

This research is supervised by two Clinical Psychologists, Dr Tamara Leeuwerik and Dr Jocelyne Kenny. Dr Ndidi Boakye, Clinical Neuropsychologist will also provide consultation about the project.

Talk to others about the study if you wish.

Part 1 of this information sheet tells you the purpose of this study and what will happen to you if you take part.

Part 2 of this information sheet gives you more detailed information about how the study is conducted.

### Part 1

### What is the purpose of the study?

The purpose of the study is to understand bereaved adolescent's experiences of having a parent who had a cancerous brain tumour. We know that young people are affected in different ways when a parent has any type of cancer. However, brain tumours can sometimes cause symptoms which might affect a person's memory, concentration, personality, and ability to do everyday things, which can impact those around them. Research so far hasn't looked at what this might be like for young people when their parent is affected. We hope that by furthering our understanding of this experience, support services for young carers of brain tumours and those who have been bereaved by a brain tumour can be developed and improved in the future.

### Why have I been invited?

To find young people to take part in the study I am sharing an advertisement with young people/parents and carers who have connections with social media groups offering support to those affected by a brain tumour, and in mail-outs sent by brain tumour charities. Those that are interested or would like to find out more will be handed this information sheet. You have been invited to take part as your parent was diagnosed with a cancerous brain tumour whilst you were an adolescent, and they have sadly passed away between one and fifteen years ago. There will be 8-10 adolescents taking part in this study.

### Do I have to take part?

It is up to you to decide whether to join the study. If you agree to take part, I will then ask you to sign a consent form. You are free to withdraw from the study at any time up until one week after your interview, without giving a reason.

### What will happen to me if I take part?

If you decide you would like to take part, you or your parent/carer can contact me by email or telephone. You can ask me any questions you might have about the study.

We would then arrange to meet online once (via Zoom or Microsoft Teams) at a time that suits you. When we meet, I will give you a consent form and we can talk this through together. If you are under 16, I will need your parent/carer to consent on your behalf so it’s important they are there for the beginning of our meeting. If they are not available, I can speak with them over the telephone and give them the consent form to sign beforehand. If you are over 16, you can consent to participating in the study yourself. It’s up to you if you’d like to tell a parent/carer about the study, but we would encourage you to.

We recommend to all participants that you ensure a parent/carer or trusted adult is available after the study for you to check-in with if you need to. All participants will be required to provide details of their GP surgery in case of any safeguarding concerns, and we encourage over 16s to prove details of their parent/carer if they are willing to.

We will then have a conversation alone about your experiences. I’ll ask questions about what this was like for you and what might have changed. I’ll record our conversation using a digital voice recorder so I can listen back to it when completing my research. Our conversation will last up to 60 minutes. We can stop earlier or have a break in the middle if you wanted to. After I have asked you the questions, there can be time for us to talk at the end if you want to, which will not be recorded.

Once the research is completed, I will share my findings with you, if you would like me to, so you can understand what the key findings were and how this research may be helpful in shaping experiences of others.

### Expenses and payments

As a token of thanks for your participation, you will be paid £10 for your time.

### What will I be asked to do?

During the online interview, I will ask you questions. These questions will gather some more information about you and the parent you lost, before going on to asking about your personal experience of having a parent with a cancerous brain tumour, and how this impacted you. Specifically, you will be asked about the impact on your relationships (friends and family), how you felt at the time, and how things might have impacted how you see yourself as a person.

### What are the possible disadvantages and risks of taking part?

There is a possibility that, quite naturally, you might feel upset when thinking and talking about what it was like when your parent had a brain tumour and having lost them. The interview questions or process may also trigger upsetting memories or thoughts that you had not anticipated. At the beginning of the interview, we will discuss how is best for me to check in with you throughout the interview to see how you are managing. The focus on the interview is around you and your experiences, and if you feel uncomfortable asking any questions you can say ‘pass’ and we will move onto something else. If you feel upset after taking part in the study, you let me know. If I notice you becoming distressed, I will check-in with how you are feeling and how I can support you in that moment. If you feel you might need further support after the interview, you should speak to your GP or some of the support services below:

Childline – 0800 1111 https://www.childline.org.uk/
Child Bereavement UK – 0800 02 888 40 https://www.childbereavementuk.org/
Cruse Bereavement ‘Hope Again’ Youth Support - https://www.hopeagain.org.uk/

In the unlikely event that you become seriously distressed after the interview and feel unable to keep yourself safe, we would encourage you to visit your local A&E department who will be able to provide some immediate support.

### What are the possible benefits of taking part?

Lots of people find talking about their experiences and thinking about changes can be valuable. We cannot promise the study will help you but the information we get from this study might help improve the support young people who care for, or have been bereaved by, a parent with a cancerous brain tumour.

### What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2.

### Will information from or about me from taking part in the study be kept private?

Yes, the things we talk about will be kept private between us and I won’t tell your parent/carer what we spoke about during the conversation. The only time I would need to share information with your parent/carer or a third party (i.e., GP) is if you say anything which makes me worried about your safety, or the safety of anyone else. Where possible we will have a conversation about information sharing prior to it happening.

This completes part 1.

*If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.*

## Part 2

### What will happen if I don’t want to carry on with the study?

You can stop taking part in the study at any time up until one week after your interview, as I will then be using it for analysis. We would like to use the information we have collected about you up to you deciding you would like to stop taking part, if possible. If you would rather we didn’t, you can request that your data and recording is removed from use within the study. You will still receive payment for your time.

**What if there is a problem?**

**Concerns and Complaints**

If you have any concerns about any aspect of the research, you should ask to speak with me and I will do my best to address your concerns. You can contact me by leaving a message on the 24-hour voicemail phone number 01227 927070. Please leave a contact number and say the message is for me, Emily Carter, and I will get back to you as soon as possible.

If you remain unhappy and wish to complain formally, you can do this by contacting Dr Fergal Jones, Clinical Psychology Programme Research Director, Salomons Institute for Applied Psychology: fergal.jones@canterbury.ac.uk

**Will information from or about me from taking part in the study be kept confidential?**

- Your information will be treated with care, in line with General Data Protection Regulations (GDPR) and you will not be identifiable from any records kept about you.
- Our conversation will be recorded on a digital recorder, and then transferred onto a password protected, encrypted USB stick that is only accessible and used by the research team. The recording and any data will be named with a code so people can't tell it's you.
- The data held about you will only be used for the purpose of the study. Following completion of the research, the data will be kept in a locked cabinet for 10 years in case I need access to it again. You have a right to access the data held about you and
- The only time when I would need to pass on information from you to someone else would be if, because of something you told me, I were to become concerned about your safety or the safety of someone else.

**What will happen to the results of the research study?**

The results of the study will be shared with you as a participant. Once I have finished writing the report of the results, I will contact you to share the findings with you. If you would prefer I did not do this, you can let me know during our interview. I intend to publish the report in a research journal. You will not be identifiable in any report/publication, but anonymised quotes from your interview may be used in the reports.

**Who is sponsoring and funding the research?**

This research is funded by Canterbury Christ Church University.

**Who has reviewed the study?**

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by The Salomons Ethics Panel, Salomons Institute for Applied Psychology, Canterbury Christ Church University.

**Further information and contact details**

If you would like to speak to me and find out more about this study, or participating in research more generally, the best way to contact me is via email: ec716@canterbury.ac.uk.

Alternatively, you can leave a message for me on a 24-hour voicemail phone line at 01227 927070. Please say that the message is for me, Emily Carter, and leave a contact number so that I can get back to you. If you have any concerns during the process, please use the same number.

**You will be provided with a copy of this information sheet and a signed consent form to keep if you take part in the study.**

**Appendix D: Participant Information Sheet (Parents)**

Salomons Institute for Applied Psychology
One Meadow Road, Tunbridge Wells, Kent TN1 2YG
www.canterbury.ac.uk/appliedpsychology

## Information about the research for Parents/Carers – v3 April 2024

# Bereaved Young People's Experiences of a Parental Brain Tumour

Hello. My name is Emily Carter and I am a trainee clinical psychologist at Canterbury Christ Church University. I would like to invite your young person to take part in a research study. Before you decide together whether they would like to take part, it is important that you understand why the research is being done and what it would involve for them.

This research is supervised by two Clinical Psychologists, Dr Tamara Leeuwerik and Dr Jocelyne Kenny. Dr Ndidi Boakye, Clinical Neuropsychologist, will also provide consultation about the project.

**Part 1** tells you the purpose of this study and what will happen to your young person if they you take part.

**Part 2** gives you more detailed information about the conduct of the study.

## Part 1

### What is the purpose of the study?

The purpose of the study is to understand bereaved adolescents' experiences of having a parent who had a cancerous brain tumour. We know that adolescents are affected in different ways when a parent has any time of cancer. However, brain tumours can sometimes cause symptoms which might affect a person's memory, concentration, personality, and ability to do everyday things, which can impact those around them. Research so far hasn't looked at what this might be like for young people. We hope that by furthering our understanding of this experiences, support services for young carers of brain tumours and those who have been bereaved by a brain tumour, can be developed, and improved in the future.

### Why has my young person been invited to take part?

To find young people to take part in the study I am sharing an advertisement on social media, including pages offering support to those affected or bereaved by a brain tumour, and with relevant charities, hospices and support groups who are promoting the study.

Your young person has been invited to take part as their parent was diagnosed with a cancerous brain tumour whilst they were between the ages of 12 and 25, and they have sadly passed away between one to fifteen years ago. There will be 8-10 adolescents taking part in this study.

**Do they have to take part?**

It is up to you to decide together with your young person whether they would like to join the study. If you both agree for them to take part, I will then ask you to sign a consent form on their behalf. They are free to withdraw from the study at any time up until one week after their interview, without giving a reason.

**What will happen to young people who take part?**

If you decide together that your young person would like to take part, you can contact me by email or telephone. You can both ask me any questions you might have about the study.

We would then arrange to meet together online once (via Zoom or Microsoft Teams) at a time that suits you. When we meet, I will give you a consent form and we can talk this through together. You will provide consent on their behalf if your child is under 16 years, or if over 16, they can consent to participating in the study themselves. All participants will be required to provide details of their GP surgery in case of any safeguarding concerns. We recommend that all participants ensure a parent/carer or trusted adult is available for them to check in with during or after the study if needed.

I will then conduct an interview with your young person, alone, about their experiences. This may be after our initial conversation or on another suitable day. I'll ask questions about what this was like for them and what might have changed following their parent/carer's diagnosis. I'll record our conversation using a digital voice recorder so I can listen back to it when completing my research. The interview will last up to 60 minutes, but can be stopped earlier if requested, and we are able to take breaks. After the interview there can be time for us to talk at the end about anything that feels important, which will not be recorded.

Once the research is completed, I will share my findings with participants, if they wish to receive these, so they can understand what the key findings were and how this research may be helpful in shaping experiences of others.

**Expenses and payments**

As a token of thanks for their participation, young people will be paid £10 for their time.

**What will young people be asked to do?**

During the online interview, young people will be asked questions by the researcher. These questions will gather some more information about them and the parent/carer they lost, before going on to asking about their personal experience of having a parent/carer with a cancerous brain tumour, and how this impacted them. Specifically, they will be asked about the impact on their relationships (friends and family), feelings, and how their experiences might have impacted their identity.

**What are the possible disadvantages and risks for young people taking part?**

There is a possibility that, quite naturally, young people may feel upset when thinking and talking about what it was like when their parent/carer had a brain tumour and their loss. The interview may also 'open doors' for participants that they did not anticipate, in that they may become upset in relation to a certain question or part of the interview process. At the beginning of the interview, we will discuss how is best for me to check in with them throughout the interview to ensure they are managing. If they feel uncomfortable answering any questions, they can 'pass' and we will move on to something else. At the end of the interview, there will be an opportunity for us to talk about how they are feeling. If they are distressed during or after the interview, they will be encouraged to let me know, and if I observe this, I will offer reassurance and support. If you, or your young person, feel they might need further support after the interview, you should speak to their GP or some of the support services below:

Childline – 0800 1111 https://www.childline.org.uk/
Child Bereavement UK – 0800 02 888 40 https://www.childbereavementuk.org/
Cruse Bereavement 'Hope Again' Youth Support - https://www.hopeagain.org.uk/

In the unlikely event that they become seriously distressed after the interview and feel unable to keep themselves safe, we would encourage you to visit your local A&E department to access some immediate support.

**What are the possible benefits for young people taking part?**

Lots of people find talking about their experiences and thinking about changes can be valuable. We cannot promise the study will help young people directly, but the information we get from this study might help improve the support that other young people who care for, or have been bereaved by, a parent with a cancerous brain tumour.

**What if there is a problem?**

Any complaint about the way you or your young person have been dealt with during the study or any possible harm you may have suffered will be addressed. The detailed information on this is given in Part 2.

**Will information from or about my young person taking part in the study be kept confidential?**

All data collected about a young person before and during the interview will be kept confidential between the young person and the research team. Information will not be shared with parents/carers or third parties (i.e., GP) unless there is a concern about an individual's wellbeing. Where this is necessary, a conversation will happen between the young person and researcher prior to information sharing, where possible.

This completes part 1.

*If the information in Part 1 has interested you and your young person and you are considering their participation, please read the additional information in Part 2 before making any decision.*

## Part 2

**What will happen if young people want to withdraw from the study?**

Young people can stop taking part in the study at any time up until one week after their interview, as it will then be used for analysis. If possible, I would like to use the information we have collected about them up to the point they decide they would like to stop taking part. If you would rather this did not happen, didn't you or the young person can request that their data and recording is removed from use within the study. Young people will still receive payment for their time if they withdraw at any point.

**What if there is a problem?**

## Concerns and Complaints

If you have any concerns about any aspect of the research, you should ask to speak with me, and I will do my best to address your concerns. You can contact me by leaving a message on the 24-hour voicemail phone number 01227 927070. Please leave a contact number and say the message is for me, Emily Carter, and I will get back to you as soon as possible.

If you remain unhappy and wish to complain formally, you can do this by contacting Dr Fergal Jones, Clinical Psychology Programme Research Director, Salomons Institute for Applied Psychology: fergal.jones@canterbury.ac.uk

## Will information from or about young people taking part in the study be kept confidential?

- Information collected will be treated with care, in line with General Data Protection Regulations (GDPR) and young people will not be identifiable from any records kept about them.
- Our interview conversation will be recorded on a digital recorder, and then transferred onto a password protected, encrypted USB stick that is only accessible and used by the research team. The recording and any data will be named with a code so it is anonymised.
- The data held about young people will only be used for the purpose of the study. Following completion of the research, the data will be kept in a locked cabinet for 10 years in case access I require access in future. Young people have a right to access the data held about them.
- As above, the only time when I would need to pass on information from a young person to someone else would be if, because of something they told me, I were to become concerned about their safety or the safety of someone else.

## What will happen to the results of the research study?

The results of the study will be shared with participants if they wish to receive these, which will be discussed in the interview. If young people wish to receive findings they will be contacted once the research report is written. I intend to publish the research report in a research journal. Young people will not be identifiable in any report/publication, but anonymised quotes from interviews may be used in the reports.

## Who is sponsoring and funding the research?

This research is funded by Canterbury Christ Church University.

## Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect participant's interests. This study has been reviewed and given favourable opinion by The Salomons Ethics Panel, Salomons Institute for Applied Psychology, Canterbury Christ Church University.

## Further information and contact details

If you would like to speak to me and find out more about this study, or participating in research more generally, you can leave a message for me on a 24-hour voicemail phone line at 01227 927070. Please say that the message is for me, Emily Carter, and leave a contact number so that I can get back to you. If you have any concerns during the process, please use the same number.

**You will be provided with a copy of this information sheet and a signed consent form to keep if your young person takes part in the study.**

## Appendix E: Consent Form

Canterbury Christ Church University

Salomons Institute for Applied Psychology
One Meadow Road, Tunbridge Wells, Kent TN1 2YG

Ethics approval number: ETH2122-0306
Version number: v3 April 2024
Participant Identification number for this study:

# CONSENT FORM

Title of Project: **Bereaved Young People's Experiences of a Parental Brain Tumour**

Name of Researcher: Emily Carter

Please initial box

1. I confirm that I have read and understand the information sheet dated April 2024 (version 3) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to stop taking part in the study at any time up until one week after my interview, without giving any reason, and still be paid for my time. ☐

3. I understand that data collected during the study may be looked at by the project supervisors/consultants, Dr Tamara Leeuwerik, Dr Jocelyne Kenny and Dr Ndidi Boakye. I give permission for these individuals to have access to my data. ☐

4. I agree to the use of audio recording during the interview, with possible use of quotations of my interview answers in the report. ☐

5. I agree that anonymous quotes from my interview and other anonymous data may be used in published reports of the study findings. ☐

6. I agree for my anonymous data to be used in further research studies ☐

7. I agree to take part in the above study. ☐

Name of Participant____________________ Date________________

Signature ___________________

GP Name & Practice ______________________ GP Contact Details ____________

Name of Parent/Carer *(Optional if over 16)*

Name: ____________________ Contact number:___________________

(*To be completed by researcher)*

Name of Person taking consent ______________ Date_____________

Signature ____________________

## Appendix F: Interview Schedule

Could you please introduce the parent you will be talking to me about today?

Could you tell me about the time your (parent) first became unwell?

What was this like for you?
- Prompt: How did you feel? What did you think? What did you do?

Can you tell me about the time when your (parent) became more seriously unwell with their brain tumour?
- How was your parent affected by their brain tumour (i.e. cognitively, physically, personality, emotionally).
- How quickly did things progress?

What was this like for, you?
- Prompts: How did you feel? What did you think? What did you do?

When your (parent) was diagnosed with the brain tumour, how did this affect you emotionally?
- Prompts: How do you remember feeling? How did you cope? How were you feeling after they passed away? How do you feel nowadays?

How would you describe your relationships with your family members after your (parent) was diagnosed with a brain tumour?
- Prompt: Did you experience any changes in relationships with your family members after your (parent) became ill?

How would you describe your relationships with your friends after your (parent) was diagnosed with a brain tumour?
- Prompt: Did you experience any changes in relationships with your friends after your (parent) became ill?

How would you describe your relationship with your (parent) after they were diagnosed with a brain tumour?
- Did you experience any changes in the relationship with X whilst they had a brain tumour?

How has your (parent's) diagnosis impacted how you see yourself?
- Prompt: How would you describe yourself? What changed when X was diagnosed with their brain tumour?

How do you look back now on having gone through the experience of [parent] being diagnosed with a brain tumour and sadly passing away?

- Prompt: Has it changed your perspective on anything? How has the experience of their illness affected your grieving process?

Optional: Would you like to conclude the interview with you telling me about positive memory of your parent?

## Appendix G: GETS, Sub-Themes and Related PETS

| **Group Experiential Theme** | **Sub Theme** | **Examples of Related Personal Experiential Themes** |
|---|---|---|
| The Emotional Impact | Living in a Nightmare | 'Trauma something never felt before'<br>'Too traumatic to think about'<br>'Burning anger at what happened' |
| | *What's Going On?* | 'A minimised situation'<br>'Uncertainty in the experts'<br>'There's nothing to worry about'<br>'Knowing something wasn't right' |
| | Ongoing Grief | 'Loving life but missing Dad'<br>'Losing her before she had gone'<br>'Doing okay after death' |
| | Blocking It Out | 'Hiding behind liaison role'<br>'Shutting feelings away at first'<br>'Avoidance – protection from the pain' |
| Seeing the Disease, Not My Parent | *'They Were a Different Person'* | 'Incomprehensible change in Mum'<br>'Upsetting personality changes'<br>'She wasn't Mum anymore' |
| | Cherished Moments | 'Attunement and closeness'<br>'Bonds and barriers in relationship with Dad'<br>'The role of optimism' |
| | Unanswered Questions | 'A lack of closure and memories'<br>'Impact on making memories'<br>'Not knowing what Mum wanted' |
| Stepping Up | Taking on Responsibilities | 'Stepping up to support Mum'<br>'Taking on parental responsibilities'<br>'Maturing fast'<br>'Feeling responsible' |
| | Holding onto Normality | 'Continuing with normality'<br>'Wanting things to stay the same'<br>'Keeping going with studies'<br>'Wanting to be normal' |

| | | |
|---|---|---|
| Relationships: Strength or Strain | Friends Can’t Grasp It | ‘Friends just can’t understand’<br>‘The conversation killer’<br>‘Friends couldn’t understand the gravity’<br>‘Blamed and not believed’ |
| | Feeling Let Down and Left Out | ‘No one to talk to’<br>‘Feeling left out by friends’<br>‘Disappointed by others distance’<br>‘Others moved on without me’ |
| | Importance of Mutual Understanding | ‘Needing people that can understand’<br>‘Shifting energy into supportive relationships’<br>‘When you’ve seen behind the curtain’ |
| A Changed Outlook | Perspective Taking | ‘Putting trivial things into perspective’<br>‘New perspectives on patient care’<br>‘Thinking and doing differently’<br>‘Learning I can bounce back’ |
| | *Who Am I and What’s Important Now?* | ‘Doing what’s important’<br>‘Making a difference’<br>‘Who am I now this is over?’<br>‘A thirst for life’ |

## Appendix H: Abridged Bracketing Interviews

*This has been removed from the electronic copy.*

## Appendix I: Abridged Research Diary

*This has been removed from the electronic copy.*

## Appendix J: Ethical Approval from Salomons Ethics Board

*This has been removed from the electronic copy.*

## Appendix K: Debrief Form

Salomons Institute for Applied Psychology
One Meadow Road, Tunbridge Wells, Kent TN1 2YG

Ethics approval number:
Version number: v3 April 2024
Participant Identification number for this study: 01

# DEBRIEF SHEET

Title of Project: **Bereaved Young People's Experiences of a Parental Brain Tumour**

Name of Researcher: Emily Carter

Thank you for your time in taking part in the above study, your participation is much appreciated. This project hopes to understand bereaved adolescent's experiences of the impact of a parental brain tumour on their relationships, wellbeing, and identity. It is hoped that the results of this project will help improve understanding of the support that is required for young people caring for, and bereaved by, a parental brain tumour.

I encourage you to speak with a trusted adult about your participation following your interview if you feel able to.

### Data Storing & Withdrawal

Your data will be now be securely stored and destroyed once no longer required, as detailed in the information sheet you received.

You have the right to withdraw from the study up to one week following the date of your interview, as your data will then be used for analysis. Please contact me on the number below if you would like to withdraw your data from the study.

### Contact Details & Further Information

If you would like to speak to me following your participation in this study, you can leave a message for me on a 24-hour voicemail phone line at 01227 927070. Please say that the message is for me, Emily Carter, and leave a contact number so that I can get back to you. You can also email me on ec716@canterbury.ac.uk.

If you feel that you might need further support after taking part in this interview, you should speak to your GP or some of the support services below:

- Childline – 0800 1111 - https://www.childline.org.uk/
- Child Bereavement UK – 0800 02 888 40 - https://www.childbereavementuk.org/
- Cruse Bereavement 'Hope Again' Youth Support - https://www.hopeagain.org.uk/
- The Samaritans – 116 123 https://www.samaritans.org/
- Shout – text 85258 https://giveusashout.org/

If you are feeling highly distressed, or feel unable to keep yourself safe, we would encourage you to visit your local A&E department to access some immediate support.

**Concerns & Complaints**

If you have any concerns about any aspect of the research, you should ask to speak with me, and I will do my best to address your concerns. You can contact me by leaving a message on the 24-hour voicemail phone number 01227 927070. Please leave a contact number and say the message is for me, Emily Carter, and I will get back to you as soon as possible.

If you remain unhappy and wish to complain formally, you can do this by contacting Dr Fergal Jones, Clinical Psychology Programme Research Director, Salomons Institute for Applied Psychology: fergal.jones@canterbury.ac.uk

**Sharing of Project Results**

If you have consented to be contacted to receive information about the results of the study, I will contact you when the project has finished to share these.

*Thank you again for your participation.*

## Appendix L: Jacob's Coded Transcript

*This has been removed from the electronic copy.*

## Appendix M: Jacob's PETs, Sub-Themes and Experiential Statements

| **Personal Experiential Theme** | **Sub-Theme** | **Experiential Statement** |
|---|---|---|
| **Continuing with Normality** | Keeping Going with Studies | 328. Put pressure on self to continue with studies even when involving brain tumours<br>171. Even though concern increased, it was important to carry on with studies<br>129. Balancing of carrying on with studies at uni and supporting Mum<br>331. Continued with studies until Dad was end of life stage<br>782. Pressure to continue with studies meant returning to normality was easier |
| | Wanting Things to Stay the same | 557. Didn't want things to change so hobbies and everyday activities stayed the same<br>554. Wanted friendships to stay the same for a sense of normality<br>595. Social life was important as a university student |
| | The Role of Optimism | 289. Had optimism that Dad would come out of hospital<br>65. Initial symptoms did not create concern until Dad in hospital<br>342. Sense of optimism after initial diagnosis so carried on as normal |
| **Relationships and Lost Futures** | Sadness for What Could Have Been | 462. Sadness about lost opportunities for building relationship with Dad<br>260. Sadness for what family members had lost<br>599. Acknowledgement of how relationship with Dad could have developed<br>397. Sadness for Dad and his experience of illness at a young age<br>225. Aware that Dad was sad he would not see his children's future |
| | Maintaining A Superficial Relationship | 604. A superficial relationship with Dad was maintained throughout illness<br>601. Not motivated to become closer with Dad after diagnosis<br>584. Relational challenges in adolescence meant building a relationship with Dad was just beginning<br>457. Hadn't rebuilt relationship with Dad from teenager years - didn't feel like big loss |
| | Stepping Up to Support Mum | 313. Travelled from Uni to support Mum practically |

| | | |
|---|---|---|
| | | 796. Supporting Mum personal and practically continued after death<br>434. Stepped up to responsibilities as was the eldest brother<br>439. Had to be strong  in front of Mum |
| **Response to Emotions** | Hiding Behind Liaison Role | 356. Used role of liaising with family to avoid painful feelings<br>413. Had to hold it together to update family members<br>442. Dealing with other family members helped avoid despair at situation<br>384. More emotions felt when unable to avoid within liaising role<br>370. Found ways to deal with emotions - liaising with family<br>369. Felt emotional and stressed underneath a strong outward presentation |
| | Doing Okay after Death | 470. Family in a better place than preceding illness<br>714. Family have adjusted well after death<br>776. Grieving process mirrored illness trajectory - got back to normal quickly<br>798. Felt emotionally stable after death<br>681. Don't think of self as deeply affected or changed by experience<br>451. Expect surprise from others that things are okay now<br>468. Sadness has been dealt with<br>793. No significant changes in sense of self meant going back to normal was easier |
| | Letting Guard Down with Friends | 551. Felt supported and listened to by friends when needed<br>799. Showed moments of grief with friends<br>392. Able to show emotions with friends |
| **Thinking and Doing Differently** | New Perspectives on Patient Care | 746. Difficult experiences with Dad's care have influenced delivery of information at work<br>749. Increased conscientiousness to achieve comfort and pain control for own patients<br>693. Job as medic has allowed normalisation of experience as part of life |
| | Doing What's Important | 649. Ways of living now influenced by Dad's missed opportunities<br>642. Changed outlook on life due to awareness of uncertainty and unpredictability<br>646. Since bereavement doing more of what’s important, spending more liberally<br>651. Future not guaranteed so live in the moment |

| | | |
|---|---|---|
| | | 762. Living and thinking more freely |

## Appendix N: Feedback Report for Ethics Panel

## Feedback Report for Ethics Panel

### Research Summary

**Title:** '*She Wasn't My Mum Anymore*'- Bereaved Young Peoples' Experiences of a Parental Brain Tumour: An Interpretative Phenomenological Analysis

**Background:** Primary malignant brain tumours (PMBTs) are one of the most common cancers in the under 40s and often difficult to treat. PMBTs often result in significant neuropsychological, functional and physical changes for an individual due when the disease progresses, or as a result of invasive treatment. Research has examined experiences of adult caregivers to people with a PMBT (PwPMBT) and indicated this group can face challenges to their physical and mental wellbeing, isolation, anticipatory grief and struggle to access their own healthcare support. The impact of a PMBT can affect a whole family, yet research has not yet explored what the experiences may be of young people who have a parent with a PMBT.

**Aims:** This study explored bereaved young peoples' experiences of having a parent with a brain tumour, seeking to answer the following questions:

e. What are bereaved young peoples' experiences of having a parent with a PMBT?
f. How do bereaved young people experience the impact, if any, of a parental PMBT on their psychological wellbeing?
g. How do bereaved young people experience the impact, if any, of a parental PMBT on their family/peer relationships?
h. How do bereaved young people experience the impact, if any, of a parental PMBT on their sense of identity?

**Method:** Semi-structured interviews were conducted with nine young people who had been bereaved by a parental PMBT and analysed using Interpretative Phenomenological Analysis (IPA). This is a qualitative methodology that seeks to understand the experiences and meaning that individuals attribute to events and is often used in healthcare research.

**Analysis:** From the data analysis, five group experiential themes were developed, and sub-themes were also explored:

- **'The Emotional Impact':** This theme discussed participants' emotional response to their parent being diagnosed with a PMBT, their experiences of grief and attempts to manage emotions.
- **'Seeing The Disease, Not My Parent'**: This theme explored how changes within the parent, as a result of the PMBT, were often difficult to navigate. Certain opportunities for making memories and chances for conversations were not possible anymore, but participants made efforts to make the most of the time they had left with their parent.
- **'Stepping Up'**: This theme relates to participant's taking on of additional responsibilities at home in response to illness, whilst also seeking to maintain semblances of normality.

- **‘Relationships: Strength or Strain’**: This theme discussed how friend and family relationships evolved over the course of their parents’ illnesses.
- **‘A Changed Outlook’:** This theme discussed how participants identity had shifted following the experience of a parental PMBT, including new perspectives and outlooks.

**Conclusion**: The findings highlighted the challenges with psychological wellbeing that young people can experience, and changes in relationships, roles and responsibilities which mirrors experiences of adult caregivers to PwPMBT. The study also identified challenges within peer relationships due to lack of understanding; however, finding connections that offer a sense of mutual understanding was important. Findings indicated young peoplecould grapple with their identity after the experience, but also obtain a changed outlook and new perspective on life. It is vital for psychological wellbeing of young people to be attended to following a parental PMBT diagnosis, and for HCPs to consider creative ways to support them through the process. Opportunities for young people to engage with typical developmental tasks should also be facilitated, through contact with respite and care services. Future research should seek to understand how this experience may differ according to aspects of diversity, or examine support and care needs for this population.

## Appendix O: Feedback Report for Participants

## Feedback Report for Participants

### Research Summary

**Title:** '*She Wasn't My Mum Anymore'*- Bereaved Young Peoples' Experiences of a Parental Brain Tumour: An Interpretative Phenomenological Analysis

**Background:** Primary malignant brain tumours (PMBTs) are one of the most common cancers in the under 40s and often difficult to treat. Due to it's location in the brain, a PMBT can often cause significant changes for individuals which are compounded by invasive treatments to prolong life. Research has examined experiences of adult caregivers to people with a PMBT and indicated this group can face challenges to their physical and mental wellbeing, isolation, anticipatory grief and struggle to access their own healthcare support. The impact of a PMBT can affect a whole family, yet research has not yet explored what the experiences may be of young people who have a parent with a PMBT.

**Aims:** This study explored bereaved young peoples' experiences of having a parent with a brain tumour, seeking to answer the following questions:

a. What are bereaved young peoples' experiences of having a parent with a PMBT?
b. How do bereaved young people experience the impact, if any, of a parental PMBT on their psychological wellbeing?
c. How do bereaved young people experience the impact, if any, of a parental PMBT on their family/peer relationships?
d. How do bereaved young peo-ple experience the impact, if any, of a parental PMBT on their sense of identity?

**Method:** Semi-structured interviews were conducted with nine young people who had been bereaved by a parental PMBT and analysed using Interpretative Phenomenological Analysis (IPA). This is a qualitative methodology that seeks to understand the experiences and meaning that individuals attribute to events and is often used in healthcare research.

**Analysis:** From the data analysis, five group experiential themes were developed, and sub-themes were also explored:

| Group Experiential Theme | Sub-Theme |
|---|---|
| **The Emotional Impact** | Living In a Nightmare |
| | *What's Going On?* |
| | Ongoing Grief |
| | Blocking It Out |
| **Seeing the Disease, Not My Parent** | *'They Were a Different Person'* |
| | Cherished Moments |
| | Unanswered Questions |
| **Stepping Up** | Taking on Responsibilities |
| | Holding Onto Normality |
| **Relationships: Strength or Strain** | Friends Can't Grasp It |
| | Feeling Let Down and Left Out |
| | Importance of Mutual Understanding |

| | |
|---|---|
| **A Changed Outlook** | Perspective Taking<br>*Who Am I And What's Important Now?* |

- **'The Emotional Impact':** This theme discussed participants' emotional response to their parent being diagnosed with a PMBT, their experiences of grief and attempts to manage emotions.
- **'Seeing The Disease, Not My Parent'**: This theme explored how changes within the parent, because of the PMBT, were often difficult to navigate. Certain opportunities for making memories and chances for conversations were not possible anymore, but participants made efforts to make the most of the time they had left with their parent.
- **'Stepping Up'**: This theme relates to participant's taking on of additional responsibilities at home in response to illness, whilst also seeking to maintain semblances of normality.
- **'Relationships: Strength or Strain':** This theme discussed how friend and family relationships evolved over the course of their parents' illnesses.
- **'A Changed Outlook'**: This theme discussed how participants identity had shifted following the experience of a parental PMBT, including new perspectives and outlooks.

**Conclusion**: The findings highlighted the challenges with psychological wellbeing that young people can experience following a parental PMBT diagnosis, which can be long-standing after a bereavement. The study also found changes in relationships, roles and responsibilities occur, which mirrors experiences of adult caregivers to people with a PMBT. Challenges were identified within peer relationships due to lack of understanding; however, finding connections that offer a sense of mutual understanding was important. Findings indicated young people could grapple with their identity after the experience, but also obtain a changed outlook and new perspective on life. Future research should seek to understand how this experience may differ according to aspects of diversity, or examine support and care needs for this population.

**Clinical Implications:**

- It is vital for psychological wellbeing of young peop[le to be attended to following a parental PMBT diagnosis. It is important that services are set up to be able to offer support for families and children, as well as the person with the PMBT. Given that individuals differ in their needs for support and can sometimes be reluctant to access this, healthcare professionals should consider creative ways to support young people through the process, such as connecting with support organisations, or books/websites.
- Opportunities for young people to engage with 'normal' activities (education, socialising, hobbies etc.) should also be facilitated, through healthcare professionals supporting families to access respite and care services.
- Healthcare professionals and social workers should consider how they can support memories to be made, even when changes arise due to the PMBT that make this possible. This could include memory books, video tapes etc.

Thank you for your participation within this research. If you would like to discuss the findings with me, or receive a copy of the full report, please get in touch with me.