

Patient and caregiver return to work after a primary brain tumour

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Funding: Funding for this work was provided by Wellcome Trust Institutional Translational Partnership Award (TPA1026).

Conflict of Interest: No conflict of interest exists for any author.

Authorship: Conception and design: EN, IP and FWB. Collection and assembly of data: EN. Data analysis and interpretation: EN, IP and FWB. Initial manuscript draft: EN. Final manuscript: all authors. Final approval of manuscript: all authors.

Data Availability: Data are held securely by the research team and may be available upon reasonable request and with relevant approvals in place.

Acknowledgments: We would like to thank the patients and caregivers who have participated in our interview study for sharing their time and insights. We would also like to thank Sean Butler (SB) for his assistance with data transcription and analysis.

Accepted

Abstract

Background: Studies focusing on the return to work (RTW) experiences of patients with a brain tumour (BT) are scarce. We aimed to explore, in-depth, the occupational expectations, experiences, and satisfaction of patients who RTW after a BT diagnosis and treatment, those not able to, and their family caregivers.

Methods: This multicentre, cross-sectional study utilised semi-structured interviews and reflexive thematic analysis. Interviews were conducted with adults diagnosed with primary BT, in employment/self-employed before diagnosis, and currently in follow-up care; also their caregivers.

Results: In total, 23 interviews (17 patients/6 caregivers) took place. Five themes were developed: 1) Early (adjustments and) expectations: “*Thought I would be back at work the following Monday*”; pre-treatment patients wanted to be better informed about potential recovery time and side-effects. 2) Drivers to RTW: “*Getting my life back on track*”; RTW was seen as a symbol of normality, also dictated by financial pressures. 3) Experiences returning to work: “*It’s had its ups and downs*”, patients who had successfully returned were supported by employers financially, emotionally, and practically. 4) Required support: “*He had surgery and that was it*”, suggested support included a back-to-work scheme, and comprehensive financial support. 5) Caring and paid work: The “*juggling act*”, carer’s work was significantly impacted; often reducing/increasing their working hours whilst managing increasing caring demands.

Conclusions: Future research focused on RTW in neuro-oncology populations is needed. Interventions should be developed to improve employer/employee communication, and increasing knowledge about BT care and possibilities for RTW, to support patients and caregivers towards sustained employment.

Key words: Brain tumor; Caregivers; Return to Work; Surgery; Qualitative research

Accepted Manuscript

Introduction

In the United Kingdom (UK), over 11,000 adults are diagnosed each year with a primary brain tumour (BT).¹ Of concern in cancer in general is the effect of the disease and treatment on occupational productivity and work ability.² Workforce participation is an important contributor to economic and social engagement and is regarded by cancer survivors as providing self-worth and meaning, as well as having external worth through economic benefit and contribution to society.³ In other cancer populations, not returning to work and financial distress have been associated with a negative impact on patients' quality of life.^{4,5} In the UK, for most workers, employers are obliged to pay statutory sick pay (2023 weekly rate = £109.40) for the first 28 weeks of sickness absence.⁶

Patients diagnosed with a BT may experience disease-specific symptoms and side-effects of treatment can cause temporary or permanent damage and inability to work. For instance, cognitive limitations may cause issues with multi-tasking, organising work materials, and following instructions, all affecting return to work (RTW).⁷ A recent systematic review found few studies focusing on occupational outcomes of diagnosis and treatment in patients with a BT.⁸ When reported, the percentage of patients with a BT able to RTW varies greatly between tumour type 18.3%- 70.7%.⁹⁻¹² Amongst all cancer diagnoses, patients diagnosed with a BT have one of the largest reductions in employment and earnings.^{2,13} Yet, it is unknown what proportion of patients with a brain tumour expect to, want to, or need to RTW following their diagnosis. A qualitative study design is well suited to understand patients' values, feelings, and motivations underlying their occupational outcomes. Yet, we have only been able to identify one published, small-scale qualitative study focusing on experiences of patients with a BT.¹⁴ This study highlighted RTW requires patient's ability to engage in personal development and integral

support from health professionals and employers. However, this study only included experiences of four patients who had been able to RTW.

Furthermore, few studies have evaluated how providing care for a patient with a BT affects employment and work ability for caregivers. Caregivers provide extraordinary uncompensated care involving significant amounts of time and energy for months or years, which can be physically, emotionally, socially, and financially demanding.¹⁵ Because of providing care, caregivers can experience lost work hours and make adjustments to work that impact their finances.¹⁶⁻¹⁸ In the UK, caregivers by law can take (often unpaid) emergency leave. However, there is no legal obligation for employers to offer any carer's pay but some offer compassionate leave (paid or unpaid).¹⁹ Caregivers' vocational experiences can thus affect the caregiver, the patient, and wider family in the short and long term. Understanding caregivers' values, feelings, and motivations alongside patients', will help to inform and support both.

Therefore, we aimed to explore, in-depth, the occupational expectations, experiences, and satisfaction of patients who RTW after a BT, those not able to, and their family caregivers.

Methods

Study design

This multicentre cross-sectional study adopted a qualitative methodology involving semi-structured interviews and thematic analysis, underpinned by a reflexive approach.²⁰⁻²² The study was approved by the South West-Central Bristol Research Ethics Committee in September 2021 (21/SW/0113). The study was reported following the consolidated criteria for reporting qualitative research guidelines.²³

Setting and participants

Primary patients with a BT and caregivers were recruited between February-September 2022 from two sites: Leeds Teaching Hospitals NHS Trust and Lancashire Teaching Hospitals NHS Trust. Adult patients (≥ 18 years old) were eligible if they had been diagnosed with a primary BT, were currently in follow-up care, and had an employment contract or were self-employed at time of diagnosis. Adult caregivers were eligible if they were a partner, family member or close friend of the patient. Patients and caregivers were excluded if they were unable to understand or speak English or if the patient had cognitive deficits that would prevent completion of study procedures (as decided by the clinical team).

We used convenience and purposive sampling techniques to obtain a varied patient sample by: age, BT diagnosis (e.g., tumour type, location), treatment (e.g., adjuvant therapies), employment status before diagnosis (e.g., hours worked and self-employed patients), and occupations (e.g., manual work and office work).

Data collection

Eligible patients and caregivers were identified by their treating consultant during a follow-up clinic visit, and then approached by a researcher. Participants were given verbal and written study information and provided written or recorded verbal consent. Interviews were conducted by telephone or face-to-face, dependent on participant preference. Participants were interviewed individually; however, if preferred survivors and caregivers could be interviewed together. Data collection ceased when researchers felt theoretical saturation was achieved, meaning we had sufficient depth of understanding to build a theory and address the research questions.²⁴

An experienced qualitative researcher (EN), not involved in patient care, conducted all interviews. Two interview guides (one each for patients and caregivers, see supplementary information 1) were formulated based on relevant literature, with expert input from clinical perspectives (IP, SS), and patient and public involvement (PH). Enabling ongoing reflexive practice, reflective notes were made after interviews and regular discussions with the research team.

Analysis

Interviews were transcribed verbatim, and analysed using reflexive thematic analysis.^{21,22} The study employed a paradigmatic framework of interpretivism and constructivism. The first author (EN) read each transcript, though familiarisation with the data began when conducting the interviews. Transcripts were coded inductively to fully understand participant experiences but also deductively to find data to address research objectives. Initial codes were subsequently categorised into sub-themes and themes. This process was iterative with codes, subthemes and themes being constantly reviewed against the data.

A second coder (SB) helped sense-check ideas and explore interpretations of the data.^{20,21} To develop richer interpretations of meanings - reaching consensus of meaning was not a goal.

Results

In total, 21 patients and 11 caregivers were approached, 23 (17 patients; 6 caregivers) consented and took part. Two dyads were interviewed together. Interviews averaged 56 minutes (range 25–82).

Table 1 and 2 show participant characteristics. Patients were on average 32 months post-diagnosis and 24 months post-surgery. At the time of interview most patients had stable disease (58.8%). Most patients were in full-time employment before diagnosis (70.5%), others were employed part-time (7%) or self-employed (17.6%). Since treatment, under half returned to work

full-time (47.1%), and approximately a third had not returned to work (29.4%). Patients who had returned to work after surgery took 5-78 weeks (average 21 weeks).

Interview codes were merged to produce five themes and sub-themes (detailed in Table 3), and covered below. Throughout the results, we highlight important shared participant thoughts/experiences, and where appropriate the themes/results associated to particular participant characteristics (e.g. self-employed participants or those who have not returned to work). However, in qualitative research the focus is more on understanding the meaning and context of participants' experiences, rather than on measuring direct associations between participant variables.

1) Early (adjustments and) expectations: *“Thought I would be back at work the following Monday”*

Difficulties working prior to diagnosis

Difficulties at work started prior to diagnosis and treatment. Patients reported their inability to do their job was one of the first signs they were unwell, *“I could not get through the work...totally out of character for me”* [P3]. Problems with concentration, spatial awareness and processing speed were common, and were sometimes raised with colleagues/managers: *“I were speaking to my bosses saying “I don't know why I'm doing it [making mistakes], I've been doing this job like 15 years”* [P7] Other patients had to stop working immediately after their first seizure, especially if their role involved machinery or driving:

“Before he knew about the tumour, he had to stop driving because of the first witnessed fit. That was a huge blow then as suddenly he was out of work!” [C6]

Workplace considerations of emotional, practical, and financial needs

After diagnosis, patients quickly had discussions with their employers. Some employers were emotionally supportive from this point offering company counselling and paid leave:

“[manager] said– “you hand over in the next few days and you’re off work and there’s no argument! Spend a little time getting your head round things.” [P15]

Several employers proposed practical solutions to help support their employees, including flexible working (e.g., working from home) and changes in working roles (e.g., fewer responsibilities). The option to change working roles was particularly appreciated by patients who had manual, physical roles:

“[Manager] went “come off the production line”...so I learnt another job which wasn’t as busy...he could see I was struggling.” [P7]

However, not all patients felt offered support was genuine and little changed after telling their employers about their tumour diagnosis:

“My job role stayed exactly the same but [manager] said- if you need anything let me know, but it’s just a saying people say isn’t it really because you’re not going to!” [P10]

Employer support was not offered for workers on short-term/zero-hour contracts, who often lost their jobs at diagnosis:

“[My partner] messaged saying she’s got a brain tumour...and they wished me well and they said- we’ve got to find someone else unfortunately.” [P13]

For self-employed/business owners, responsibilities of work continued after diagnosis:

“I come back home [after diagnosis] and I had to deal with a lot of things, carry on, answer the phones for the business.” [P4]

Prior to treatment patients and caregivers were particularly grateful of financial discussions with employers. Being able to financially plan for after surgery, reduced uncertainties for patients and caregivers:

“The financial aspect...if that had been a problem, it would’ve caused a lot more stress, more worries and I don’t know what we’d have done!” [P1]

Managing expectations

After surgery, patients underestimated how long it would take them to RTW. Most based their expectations off conversations with their clinical team. Patients with low-grade tumours were told they should be able to RTW approximately 2-3 months after surgery. Although an estimate, this timeline set patient, caregiver, and employer expectations of when they would RTW.

Some patients experienced treatment complications (e.g., infections), meaning their proposed RTW date was unattainable. Many others stuck to the proposed RTW date, but felt they returned too soon:

“The surgeon said to me you can go back to work in 7 weeks, I thought goodie I want to be back at work. So, I went in 7 weeks...with hindsight I can see that was much too early!” [P17]

Patients felt unprepared for how they would feel after surgery and felt more information was warranted; *“I didn’t realise it would take me so long [to RTW]... that needs publicising somewhere.” [P11]* Specifically the prevalence of prolonged tiredness/fatigue after surgery needed highlighting:

“I thought I would be back at work the following Monday, but unfortunately not because basically the first 2 weeks after I got out of hospital I just basically slept.” [P9]

Others felt a more informed, flexible approach provided by their clinical team would be useful:

“We expect medics to be able to predict the future, and of course they can’t. I’d have liked a more nuanced approach from him talking about the range of possibilities -what I shouldn’t be doing, as well as what I might reasonably expect to do.” [P17]

2) Drivers to return to work: “Getting my life back on track”

Symbol of normality

Patients wanted to RTW to regain normality in their lives. After surgery and recovering at home, patients experienced a lack of structure to their days; *“I just needed routine!”* [P11]. Once side-effects of surgery and adjuvant therapies lessened, patients did not want to be dormant:

“I need to be doing something...otherwise you just sit and the day drifts away and you’ve done absolutely nothing.” [P9]

Patients felt their RTW symbolised they were ‘normal’ and ‘well’ again to others, especially family members:

“He wanted to get back [to work] and get back to normal and prove to everyone everything was fine.” [C5]

Financial stressors

For some patients their RTW was fundamentally motivated by financial security; *“I had no money...I was very poor.”* [P5] These patients said they restarted work before they ideally wanted to or felt ready to:

“6 weeks with no money...it pressures you into going back into work before you’re ready.” [P5]

This was especially true for patients who were not receiving financial support from their employers and self-employed patients:

“I’ll be honest with you I had to rush to go back to work because obviously your savings don’t last forever.” [P7]

Feeling you have to return (internal and external pressures)

Patients talked of their ingrained belief they should be working: *“It’s how I’ve been brought up...everyone needs to go to work.” [P2]*

Those who had not RTW found this adjustment challenging; *“I’ve only ever worked it’s a strange thing for me to not be working.” [P3]*

Patients with non-malignant BTs felt because their tumour was not cancerous, they ought to RTW:

“We weren’t sure what kind of brain tumour it was...I might die! But obviously now I know it’s not cancerous and it should all be gone I’m like- yeah carry on and work.” [P5]

One patient said they felt pressure from their workplace to RTW:

“You’re the mug that picks up every shift and obviously goes back to work after 5 weeks because they’re like- when are you coming back?” [P5]

Another felt the longer he was out of work, he would lose his reputation and clientele: *“Once you’re out of the game for a long period of time, it’s a lot harder to get back in”. [P16]*

3) Experiences returning to work: *“It’s had its ups and downs”*

Regaining sense of self

Patients and caregivers recalled mixed experiences if the patient had RTW. Positives highlighted by patients included regaining self-confidence. Re-connecting with work colleagues helped regain their sense of self:

“I was getting a bit unsure to who I was...my social interaction skills dropped...I withdrew...now I’m a lot more open, more likely to reach out and talk to people again. That’s come from work and interacting with people.” [P1]

Those who had not returned found the lack of socialisation mentally challenging:

“It’s made him quite depressed...he’s kind of stuck at home a little bit because he can’t drive and he can’t really go anywhere, it’s made him very isolated.” [C4]

Workplace environment challenges

Patients often needed adapted or additional equipment, such as larger computer screens due to sight issues. Patients reported long waits for necessary equipment, which delayed their RTW or made their job impossible. Some patients felt they did not get the support they needed from their workplace because it was not obvious (visible) they had been ill:

“Just because I look fine doesn’t mean I am fine...I think people thought I was lying...I’d always get the comment of- ‘there’s always people worse off’.” [P2]

Moreover, some patients felt undervalued or unimportant since their RTW:

“I’m just a number...they don’t care about you as an individual, you are literally someone who makes up their staffing levels and you’re an inconvenience to them.” [P10]

Adapting to the new me

Patients discussed the reality of going back to work, whilst dealing with physical, psychological, and cognitive impact of their tumour and treatment. Most prominently, patients experienced extreme fatigue, which often worsened after RTW. Patients who had not returned named fatigue as an explanation:

“I haven’t got energy, it’s about half of what it used to be. I sleep in the afternoon.” [P8]

Cognitive issues were common, mostly short-term memory loss, slow processing speeds, and poor concentration. These meant patients struggled working in busy/loud areas, or they were slower or unable to do work tasks, leading to reduced self-confidence:

“I couldn’t solve it, I had to turn round and say- ‘I can’t get to the bottom of this’...it knocked my confidence.” [P1]

Support valued to improve work ability

Participants highlighted valued support if they had been able to RTW. A phased RTW was described as key; *“My hours were short, simple, 7 till 10...to suit me and what I could cope with.” [P2]* Self-employed workers reported additional flexibility regarding picking their hours *“I could sort of work as hard as I wanted to.” [P11]*

It was important to patients who had not returned to work to find a job they were able to start on a part-time basis:

“I’d want to start off as part-time, see how I get on...say four hours a day, and then go home and rest.” [P13]

Patients were particularly grateful when employers allowed them to adapt their: role (e.g., lighter duties), workload (e.g., number of clients) and responsibilities. Not all patients were supported in this sense and felt this would have helped when returning:

“Being on lighter duties instead of [employer] thinking you were just going to spring back into your role...they forget you’re a person who’s just had surgery.” [P5]

The opportunity to work from home was highly valued, especially due to driving restrictions following diagnosis/seizures. Some patients said they would have to give up work (because of

the commute) if they were unable to work at home. Further benefits included quieter working space and the ability for short rests.

Patients highly valued regular and ongoing conversations with their employers/managers to discuss the RTW process, any support required (e.g., adaptations or occupational health provision) and future planning. These conversations were enhanced when employers had knowledge and understanding of their BT treatment and side effects:

“[My managers] partner had to have brain surgery, so he knows what I’m going through....it’s helped me speak to him and it’s helped him understand “ [P1]

However, not all patients felt their employers understood their experiences which hindered supportive conversations. Some patients received poor communication with their employers following RTW, causing anxiety. It was especially difficult for patients with regular changes in management:

“No one really understood me or what was going on, it was the case of repeating, answering the same questions and making sure someone understood my story.” [P2]

Re-thinking the future

Participants highlighted their RTW was only a part of the picture, as their career trajectories had been altered after diagnosis/treatment. Some patients not only wanted to RTW but to progress on their career path, which was often not recognised: *“I wanted to return to a career trajectory...getting back to work and advancing.” [P17]* Yet, career trajectories had been shattered, e.g., one self-employed patient had to sell their business [P4]. Others decided advanced, more demanding roles were now not desirable.

A shift in priorities was noted with some patients deciding to leave their current employment due to feeling undervalued and unsupported. Others felt a change of role/workplace would help them recover and improve their physical and mental well-being:

“I am going to leave, take a year off to a lighter job, to rest...get myself back to how I want to be.” [P10]

Similarly, participants discussed how their work/life priorities had changed since diagnosis/treatment. Patients said they realised: *“work isn’t everything”* [P1], *“it’s put so much in context”* [P6] and *“family comes first now”* [P11]. These feelings meant some decided to RTW with reduced hours, considered early retirement or became self-employed to have more control of their work/life balance; *“It’s a much less strenuous regime...I’m just doing odd bits of work.”* [P16]

A change in priorities was identified as one of the reasons for not returning to work:

“I used to have 5 jobs...running around like an idiot... not really getting anywhere, it was horrendous! Being diagnosed it’s made me think differently.” [P3]

However, most still wanted to RTW, but in their own time, with reduced pressure and to a job with more meaning to them: *“I’d rather do something to help.”* [P13]

4) Required support: “He had surgery and that was it”

Back-to-work scheme

Patients said they felt there needed to be more practical support to RTW, particularly those not supported by employers or unable to return to their occupation (e.g., driving jobs, machinery work). Suggestions included formal vocation packages that would:

“Help you back into work if you’ve been off long-term sick...help find a job you want to do...help these companies try and encourage you to go back in gradually.” [P12]

Named support included options of retraining, career guidance and interview support:

“I’m scared of having an interview I’m going to be absolutely shocking in...I was really good at interviews, but now I get brain fog.” [P16]

Furthermore, participants proposed more RTW information and guidance is needed for patients and employers:

“You could do with something- if you had a brain injury - what you can do and what you can’t do, how you’re affected and stuff like that!” [P12]

Finance and benefits support

Participants reported many challenges in seeking financial support, which delayed or prevented financial relief. First, participants had little knowledge of government financial support, mainly because they had never needed it:

“I’ve never claimed anything in my life, nothing, I’ve always worked...I didn’t even know this existed!” [P7]

Lack of knowledge also meant patients were discouraged to apply for financial support; *“we thought you’d have to pay it all back...we were wary.”* [C2]

Second, patients had little time between diagnosis and treatment to try to explore and organise financial support. After treatment patients were often too unwell to consider or apply for financial support: *“I couldn’t speak, I couldn’t even read!”* [P7]

Third, many patients reported challenges applying and receiving financial support, with little guidance available:

“You couldn’t speak to anybody with a pulse, it were all automated, sending me from one number to another, it was ridiculous...I’m waiting now because they sent me a form about 30 pages...then they sent me another one and that were 44 pages, it’s unreal!” [P3]

After applying, several patients were declined financial support or waited a long duration to receive provision; *“It took them nearly 18 month to get back to me...by that time I were back in work again!” [P12]*

Challenges in applying for financial support meant several patients did not claim any financial benefits and instead relied upon financial relief from family members or their own savings.

Most participants felt more financial advice is needed prior to treatment. Suggestions for improvement included a financial checklist –a resource given to patients of when/who to contact about access financial support, support groups to address financial difficulties and a support worker to provide advice/organise financial aid:

“If there was somebody you were able to ring up or speak to and say- this is our situation, what can we get or who can we speak to or how do you fill in the forms right!” [C4]

Most participants relied on their family members to seek/secure financial support. Providing this support can sometimes be overwhelming for caregivers: *“everything’s such a nightmare...you’re trying to think of everything”*. [C2] Formal support helped to alleviate pressure:

“The information I got yesterday from Citizens Advice, they’re very good actually...but it’s like anything, you’ve to wait!” [C2]

Patients who particularly needed financial support were those on short-term/zero-hour contracts, as their employers provided no financial aid: *“They were like- oh we can’t pay you so figure it out!” [P5]*

Equally, self-employed workers need support navigating their financial possibilities. One business owner's insurance did not consider their low-grade tumour a cancer or critical illness and refused cover, leading to the patient selling their business to ensure they could pay their mortgage.

5) Caring and paid work: The “juggling act”

Coping with the new caregiver role and paid work

Caregivers found it difficult to manage their paid work and new caring role:

“It was hard for her because she was trying to get me to hospital in the morning and still do her job...she'd do a few hours before she took me, do a few hours in hospital...she were working all hours.” [P12]

In some cases, caregivers stopped their paid work during/after treatment, as they felt they could not do both roles:

“I had to give up my job and because of his epilepsy and obviously the tumour, he had to give up his job. It was a massive worry neither of us would be working.” [C4]

Caring responsibilities could affect caregivers financially and practically but also their overall well-being:

“We went from being two separate people to essentially being the same person...we basically had to be together all the time -I stopped going into the office, I stopped going out...from diagnosis, we stayed in the house.” [C1]

Juggling aside, paid work seemed increasingly important to caregivers since their loved one's diagnosis. Caregivers discussed work being a needed break from their caring duties- *“for my mental health, I need that time at work.”* [C4] and providing routine for family life.

Valued caregiver workplace support

Caregivers were complimentary of their employers when they were understanding, supportive and provided flexible working to accommodate their new caring roles (e.g., to attend appointments). Caregivers found being encouraged to take leave during the patients' treatment especially valuable:

"My boss said to me the day [husband] was having his operation...just take the day off...you need time, time to sit in the corner of the room and cry." [C1]

However, most caregivers were not given carer leave and had to 'make-up their hours' or take annual leave:

"The day of the operation, I had to fight for that day to take him to hospital...I asked for some special leave and they said I think it's best if you take annual leave." [C3]

Caregivers also relied on changing their working hours/patterns to enable them to care for their loved one and continue their paid work. Further workplace changes included home working, which was particularly useful immediately after treatment:

"It helped me a lot being home at the same time. Certainly initially after the brain surgery, he needed somebody around, somebody watching him." [C5]

Some caregivers were also encouraged by their employers to lessen their work responsibilities (e.g. being excused from meetings). However, some caregivers felt unable to reduce their work responsibilities and take leave:

"I find it hard to take time off because of my workload and I don't get any cover. I did find it quite stressful...I wanted really to be off but I couldn't get in front enough with work." [C6]

Discussion

In this multicentre qualitative study, patients with a BT diagnosis had varied experiences returning to work. Patients who felt they had returned to work successfully, described being supported from diagnosis by their employer financially, emotionally, and practically. Therefore, indicating RTW success is somewhat at the mercy of employer relationships. We found ongoing communication with employers, who were informed about BTs (because of their own personal experiences), was integral. Therefore, creating awareness among employers about the abilities, work intention, and needs of patients with a BT would contribute to their RTW and work retention. Employers similarly express a need for better collaboration, communication, and information in supporting employees with cancer in general.²⁵ Employer and employee interests are interlinked and both need support.²⁵ For those with difficult employee/employer relationships, we believe legal advice should be freely available to provide nuanced assistance in work disputes and dismissal.

In our investigation, conversations with clinical teams were identified as the base of patients' knowledge. We recommend clinicians be prepared to raise the topic of work and more active in discussing work-related issues, providing signposting where needed. Before treatment patients wanted to be informed about recovery timeframes, post-treatment side-effects, rehabilitation options and financial benefits and provision. Patients with lower-grade or non-malignant BTs also need to be better informed about treatment side-effects and primed with realistic expectations regarding RTW. Many participants underestimated their recovery time and felt rushed back to work. Indeed, RTW has been scarcely investigated in low-grade glioma populations with a recent systematic review concluding RTW should be used systematically as a main outcome.²⁶ Regardless of prognosis, career trajectories were altered through diagnosis and treatment, with expectations and need for support changing throughout their journey. These complex conversations likely require a transdisciplinary approach involving both clinicians,

occupational health specialists and employers,²⁷ in which the general practitioner may also play a key role.²⁸

RTW was driven by wanting to gain normality, but also financial pressures. These motivations are commonly reported in studies on RTW after cancer,^{29,30} with work providing a sense of self-esteem and meaning,³¹ but financial toxicity playing a big role.³² Self-employed patients and those on short-term contracts were especially under strain as they were often financially unsupported. Most participants said their knowledge of financial support was extremely limited, and navigating, accessing, and securing financial aid was difficult. While financial resources are available from BT specific charities,^{33,34} our study indicates this support is not adequate or not being fully utilised. Future work should focus on ensuring available BT specific support meets their needs, making adaptations where necessary guided by the evidence base, and improving signposting to voluntary support services.

Furthermore, our results highlighted those wanting to RTW wanted vocational support and rehabilitation services. Yet, less than 2% of people with cancer access specialist RTW services.³⁵ We can assume this number is less in BT populations due to their complex late-effects. Survivors can be particularly frustrated and unhappy due to their reduced ability to work.³⁶ Therefore, more should be done at a governmental level towards vocational rehabilitation, including better specialist vocational rehabilitation services for people with complex health problems, including BTs.

We also explored caregiver experiences. Unpaid carers contribute substantial economic value to society. Caregivers approximately save the UK economy £132 billion per year.³⁷ Yet families interviewed were often doubly disadvantaged financially as caregivers' paid work was also significantly impacted. Many caregivers reduced or changed their working hours to manage increasing care demands. In BT caregivers,¹⁸ as well as in other cancer caregiver populations,³⁸⁻
⁴⁰ a similar impact on caregiver paid work and the family as a whole has been found. There is a

need for all caregivers to be offered flexible employment arrangements to better combine paid work and caregiving. Our findings highlight the need to develop or promote existing workplace educational resources for employees caring for a BT patient (e.g. employment rights when caring for someone with a BT),⁴¹ but also for employers to enhance their understanding of caregiver strain, particularly in a BT context.

Cancer and work is a growing field, with cognitive issues identified as a barrier to patient work productivity,³⁸ yet with very few studies including, or focusing on, neuro-oncology populations. Therefore, our study holds strength in its in-depth exploration of patients who did, and did not, RTW after a BT diagnosis, as well as their caregivers. Our sample, recruited from two sites, showed a broad range in age, diagnoses, and employment statuses. However, our sample has limitations. We had fewer, and a less varied sample of caregivers take part in interviews, which appeared to be due to time and competing caregiver demands. Additionally, all research participants were based in the UK, meaning results may be culturally tied or reflective of the UK's health and social care systems. In the future, more qualitative and quantitative research with work as a focus in neuro-oncology populations is required. Also including RTW, caregiver burden and income effects (for both patient and caregivers) should be used more systematically as a standard outcome measures in BT research. To support these patients and caregivers towards sustained employment, interventions need developing addressing stigma, improving communication, and increasing knowledge in general, about BT care and possibilities for RTW, work productivity and retention.

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Accepted Manuscript

Table 1 – Patient Characteristics

	S	Ethn	A	High	Tumo	G	Loc	Time	Tre	Time	Tum	Vocati	Ho	Sel	RT	Time
	e	icity	g	est	ur	rad	ation	since	at	since	our	on	urs	f-	W	me
	x	(self-	e	level		e		initial	ment	rece	stat	prior	or	em	after	from
		repor	of	educa				diagn	rec	tion	us	to	to	ploy	tre	res
		ted)	tion					osis	eiv			treat	diag	ed	at	till
									ed			ment	osis	ed	ment	RT
															W	W
																3
																months
P	M	White British	4 3	Univer sity degre e	Oligod endrog lioma	2	Pari etal lobe	1 yea r 1 month	R	4 month s	Rec ent gro wth- mor e treat ment bein g disc usse d	Softwa re consult ant	FT	No	Yes	3 month s
P	F	White British	2 6	Secon dary/ High school	Diffuse Astroc ytoma	2	Cer ebel lum	6 yea rs 4 month s	R, RR	3 yea rs 9 month s	Rec ent gro wth- mor e treat ment bein g disc usse d	Retail worker	FT	No	Yes – PT	3 month s/7 month s
P	F	White British	5 2	Natio nal Vocati onal Qualifi cation	Menin gioma	1	Rig ht Falc ine (Fro ntal lobe)	8 month s	R	6 month s	Stab le	Retail Manag er	FT	No	No	N/ A
P	M	Black Afric an and White Euro pean	4 7	Secon dary/ High school	Diffuse Astroc ytoma	2	Rig ht tem por al lobe	1 yea r 7 month s	R, RT, CT	11 month s	Stab le	Busine ss owner	FT	Yes	No	N/ A
P	F	White British	2 9	Diplo ma	Pilocy tic Astroc ytoma	1	Left Fro ntal lobe	4 yea rs 8 month s	R	6 month s	Stab le	Care suppor t worker	FT	No	Yes	1 month 1 we ek

P 6	M	White British	47	University Degree	Diffuse Astrocytoma	2	Right Parietal lobe	1 year 2 months	R, RT, CT	9 months	Stable	Senior Design Officer	FT	No	Yes	3 months
P 7	M	White British	36	Secondary/High school	Low grade glioma (unknown)	2	Unknown	2 years 7 months	R	1 year 10 months	Recent growth - more treatment being discussed	Production line operative	FT	No	Yes	4 months
P 8	M	White British	48	College/sixth form	Diffuse astrocytoma	2	Right Frontal lobe	3 years and 9 months	R	3 years 7 months	Recent growth - more treatment being discussed	Builder	FT	Yes	No	N/A
P 9	F	White Scottish	67	Unknown	Diffuse astrocytoma	2	Left Frontal lobe	11 months	R, RT, CT	11 months	Recent growth - watch and wait	Ticketing manager	FT	No	Yes	1 month 2 weeks
P 10	F	White British	29	University Degree	Meningioma	2	Cerebellum	8 months	R	5 months	Stable	Health care	PT	No	Yes - PT	2 months 2 weeks
P 11	M	White British	42	Secondary/High school	Diffuse astrocytoma	2	Right frontal lobe	3 years 1 month	R, RT, CT	2 years 7 months	Stable	Salesman/Company Director	FT	Yes	Yes	1 year
P 12	M	White British	49	Apprenticeship (Level 3)	Diffuse astrocytoma	2	Right frontal lobe	2 years	R, RT	1 year 5 months	Recent growth - Radiotherapy	Lorry driver	FT	No	Yes	1 year 6 months

P 13	F	White British	29	Secondary/High School	Glioblastoma	4	Temporal lobe	2 years 5 months	R, RT, CT	1 year 5 months	Stable	Administrator	PT	No	No	N/A
P 14	M	White Eastern European	33	Secondary/High School	Diffuse astrocytoma	2	Unknown	2 years 3 months	R, RT, CT	1 year 9 months	Recent growth more treatment being discussed	Forklift operator	FT	No	No – returned to education	N/A
P 15	M	White British	43	University degree	Oligodendroglioma	2	Left frontal lobe	1 year	R	4 months	Stable	Operations manager	FT	No	Yes	3 months, 3 weeks
P 16	M	White British	46	University degree	Oligodendroglioma	3	Frontal lobe	3 years	R, RT, CT	2 years 8 months	Stable	Lawyer	FT	No	Yes – gone self-employed (PT)	4 months
P 17	M	White British	59	University degree	Oligodendroglioma	3	Left posterior frontal lobe	10 years 5 months	R, RT, CT	9 years 8 months	Stable	Senior Manager	FT	No	Yes	1 month 3 weeks

F = Female, M= Male, R= Resection, RR= Re-resection, RT= Radiotherapy, CT= Chemotherapy, FT= Full time, PT= Part time, RTW = return to work, N/A=Not applicable

Table 2 – Caregiver characteristics

	S e x	Ethni city	A g e	Highest level of educatio n	Relationsh ip to patient	Patient tumour diagnosi s	Gra de	Careg iver vocati on	Patie nt retur ned to work	Patie nt tumo ur statu s	Care giver in paid work	Reason for caregiv er not returnin g to work
C 1	F	White British	43	Secondary/High school	Partner (P1)	Oligodendroglioma	2	Executive assistant	Yes	Recent growth- more treatment being discussed	Yes	N/A
C 2	F	White British	73	College/Sixth form	Mother (P3)	Meningioma	1	Health care	No	Stable	No	Retired
C 3	F	White British	61	Secondary/High school	Partner (P6)	Diffuse astrocytoma	2	Civil servant	No	Stable	No	Retired partly due to caring responsibilities
C 4	F	White British	33	College/Sixth form	Partner (P8)	Diffuse astrocytoma	2	Hospitality server	No	Recent growth- more treatment being discussed	No	Unable to work due to caring responsibilities
C 5	F	White British	59	University degree	Partner (P17)	Oligodendroglioma	3	Lecturer	Yes	Stable	Yes	N/A
C 6	F	White British	52	Diploma	Partner (P12)	Diffuse astrocytoma	2	Health care	Yes	Recent growth- more treatment being discussed	Yes	N/A

Table 3 – Themes, sub-themes and codes constructed from interview data

Themes	Sub-themes and codes
1) Early (adjustments and) expectations: <i>“Thought I would be back at work the following Monday”</i>	<p>Difficulties working prior to surgery</p> <p>Workplace considerate of emotional, practical and financial needs</p> <p>Managing expectations</p> <ul style="list-style-type: none"> - Underestimated recovery time - More information needed on symptoms and symptom management
2) Drivers to return to work: <i>“Getting my life back on track”</i>	<p>Symbol of normality</p> <ul style="list-style-type: none"> - Regaining routine - Challenge mind/active mind - Symbol of recovery to others <p>Financial stressors</p> <p>Feeling you have to return (internal and external pressures)</p>
3) Experiences returning to work: <i>“It’s had its ups and downs”</i>	<p>Regaining sense of self</p> <p>Workplace environment challenges</p> <ul style="list-style-type: none"> - Needing adapted/additional equipment - Invisible disability - Feeling undervalued <p>Adapting to the new me</p> <ul style="list-style-type: none"> - Managing post-treatment symptoms (e.g. fatigue) - Knocked confidence in completing work tasks <p>Support valued to improve work ability</p> <ul style="list-style-type: none"> - Phased return/reduced hours - Job role adjustments - Working from home - Effective and regular communication with employer <p>Re-thinking the future</p> <ul style="list-style-type: none"> - Adjusting to an altered career trajectory - Work to live: priority adjustment
4) Required support: <i>“He had surgery and that was it”</i>	<p>Back-to-work scheme</p> <p>Finance and benefits support</p> <ul style="list-style-type: none"> - Challenges in applying for financial support - Monetary consequences of not receiving adequate financial support (e.g. savings depleted) - Information and guidance about financial support - Financial support would relieve caregiver burden and stress
5) Caring and paid work: The <i>“juggling act”</i>	<p>Coping with the new caregiver role and paid work</p> <ul style="list-style-type: none"> - The emotions of the diagnosis - Work is escapism from their caring role <p>Valued caregiver workplace support</p> <ul style="list-style-type: none"> - Flexible/reduced working hours - Encourage leave during treatment - Reduced work responsibilities - Support network