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Experiences of work for people living with a grade 2/3 oligodendroglioma: a qualitative analysis within the Ways Ahead study

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ABSTRACT

Objectives This study aimed to explore the work experiences of people living with an oligodendroglioma.

Design This was a descriptive qualitative study. One-time semi-structured interviews exploring supportive care needs were conducted; work was discussed at various points throughout each interview. An inductive thematic analysis was undertaken.

Setting Participants were recruited across the UK through four National Health Service hospitals and the Brain Tumour Charity research involvement networks.

Participants 19 people with grade 2 or 3 oligodendroglioma (mean age 52 years; male n=11). At diagnosis, 16 participants were working, 2 studying and 1 retired. At the interview (mean time since diagnosis 9.6 years; range 1–18 years), seven participants were working, eight retired (four on medical grounds) and four unable to work due to illness.

Results Seven themes were constructed: (1) physical and cognitive limitations; (2) work ability and productivity; (3) work accommodations; (4) changing roles; (5) attitudes of clients and coworkers; (6) feelings and ambitions; and (7) financial implications. Fatigue, seizures and cognitive deficits influenced work ability. A stressful work environment could exacerbate symptoms. Changes in job roles and work environment were often required. Employer and coworker support were integral to positive experiences. Work changes could result in financial stress and strain.

Conclusions This study has highlighted, for the first time, influences on work experiences in this understudied population. These findings have implications for clinicians and employers, when considering the importance of work in rehabilitation for people with oligodendrogliomas, and the individually assessed adjustments required to accommodate them, should employment be desired.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ The qualitative approach allowed participants to speak freely, raising issues of importance to them, in relation to their work experiences.
⇒ Although work-related experiences were not the primary focus of the interviews, all participants spoke about it in detail, shedding light on a population currently under-represented in the literature on cancer and work.
⇒ Participants were recruited across the UK, and had worked in different capacities in different industries, enhancing the wider applicability of these findings.
⇒ As a result of COVID-19, participants were recruited through the Brain Tumour Charity networks, in addition to National Health Service hospitals; this raises the possibility that participants were self-selected and motivated to share their experiences.
⇒ Some people may not have felt well enough to take part in an interview, so it is possible that the experiences of people that are unable to work due to illness, were not comprehensively captured.

INTRODUCTION

For cancer survivors, returning to work is often considered a significant step on the path to recovery, indicating a return to normality.[1] For working-age survivors, resuming work after cancer treatment may, therefore, be an important goal. However, in part due to the ongoing impact of cancer symptoms on work experiences, such as work ability and performance,[2 3] cancer survivors have an increased risk of early retirement and unemployment.[1 4 5]

The clinical model of cancer and work developed by Feuerstein and colleagues outlines the factors influencing survivors' work outcomes (ie, health and well-being, symptoms, function, work demands and environment).[6] Experiences of work for cancer survivors are commonly influenced by the perceived importance and meaning of work, physical limitations and symptoms, employers' and coworkers' responses, self-esteem and identity and broader cultural/policy expectations.[7–11] However, to date, most research has focused on common cancers (eg, breast

cancer) and findings may not be generalisable across cancers.

People living with a brain tumour can experience a wide-range of general cancer-related (eg, fatigue; pain) and tumour-specific symptoms (eg, cognitive limitations; seizures; speech, language and communication impairments; personality changes; mobility issues).[12–14] These symptoms vary, depending on tumour location, often co-occur, and can deteriorate as the disease progresses.[15] As well as impacting quality-of-life,[16] such symptoms and impairments may present additional difficulties in the workplace.

Lower-grade gliomas (LGG) are usually diagnosed in working-age adults in their 30s or 40s.[17] They are rarely cured and typically recur or progress to a high-grade glioma.[18] Oligodendrogliomas, which are relatively uncommon tumours overall, but comprise a large proportion of LGGs, have a survival rate of 64% at 10 years.[17] People with oligodendrogliomas could, therefore, live for extended periods with their tumour, and, for numerous reasons (ie, social and financial), may want or need to (return to) work.[19]

Silvaggi *et al* reported poor rates of employment, return to work and work retention in a quantitative systematic review of a small number of very heterogeneous studies of work in people with brain tumours.[20] Beyond this, the work experiences of people living with a brain tumour is largely unexplored,[21] with no evidence for those with long-term prognosis, such as oligodendroglioma. Therefore, this study aimed to explore the work experiences of people living with an oligodendroglioma.

METHODS

Design

This descriptive qualitative study (part of the multimethod Ways Ahead study) used semi-structured interviews to collect data from people living with an LGG. The primary focus of Ways Ahead is to explore the needs of people with LGG to inform potential for a supported self-management programme.[22] The data analysed here pertained to people with oligodendrogliomas' experiences of work and related issues; adjusting to changes in life roles such as employment is a pertinent area of self-management. There were no deviations from the published protocol in this study. All participants provided informed consent prior to the interview. The Ways Ahead study is now completed; write-up of findings from each qualitative data set is in progress; with findings published on self-management strategies used by people living with a LGG.[23]

Patient and public involvement

People with LGG were involved in the design, conduct and reporting of our research, in accordance with the activities outlined in the study protocol[22]; for example, people with LGG were consulted on the appropriateness and sensitivity of language used in the participant information sheet (PIS), and the comprehensiveness of the interview topic guide.

Participants and recruitment

Individuals were eligible if they were resident in the UK, had a grade 2 or 3 oligodendroglioma diagnosis,[24] were aged ≥18 at diagnosis and in remission following completion of primary treatment, or stable under observation. Those who did not speak English sufficiently well to participate in an interview or were deemed by a health professional at collaborating National Health Service (NHS) sites to have severe psychosocial problems that risked participation causing further distress were ineligible.

Collaborating NHS sites and the Brain Tumour Charity networks were used to identify potentially eligible people with LGG. To ensure a range of ages, sex and times since diagnosis (<5 years, 5–10,>10 years), we used purposive sampling.

For NHS sites, health professionals identified people with LGG from medical records and provided a PIS by post or during a clinic visit. For the Brain Tumour Charity networks, a flyer advertising the study was distributed through email lists and online newsletters, with a link to a PIS. The PIS briefly introduced the researchers that would be conducting the interviews. To register interest in both recruitment pathways, people were asked to call or email the study team. For NHS recruitment, people could also permit the health professional to pass their contact details to the study team. Individuals were subsequently contacted (BR and LD) to confirm eligibility; for those who were eligible and willing to participate, the interview was scheduled at a time, date and remote method (ie, telephone or video call) convenient for the interviewee. Recruitment was conducted from August 2020 to May 2022.

Data collection

One-to-one semi-structured interviews were conducted by BR (male, MSc) and LD (female, PhD), who are researchers, both trained and experienced in qualitative research. To support participants who may have cognitive or communication impairments, we provided an interview topic overview in advance, and allowed ample time to consider and respond to each question.

Interviews followed a topic guide (online supplemental file 1), which was developed from literature review and expert knowledge and revised following discussions with a patient and public involvement panel, and health professionals (JL and SW). To begin, we asked participants to broadly reflect on life following diagnosis. We then explored how they were impacted by the tumour and its treatment (eg, cognitive, physical, psychological). We asked how this impact was managed and what, and when, support was received or needed. As appropriate, we used probing questions throughout to explore any challenges faced, affording the opportunity to raise any additional issues. Flexible use of the guide meant any new issues raised were added for exploration in subsequent

interviews. In this paper we focus on work experiences, which was one of the specific topics covered; all participants raised and discussed their work experiences at various points during the interview.

Participants were offered a £20 voucher to thank them for their time and given a post-interview sheet with details of charities and helplines, should they have any questions or concerns post interview. Interviews were audio-recorded and lasted 110 min on average (range 59–167 min). The researchers made field notes during each interview for their own reference.

Data analysis

Interviews were transcribed verbatim, anonymised and checked against audio-recordings for accuracy. For this analysis, we aimed to explore and understand work experiences. An inductive, data-driven approach was used in line with thematic analysis.[25 26]

Three trained researchers (HW, BR and LD) independently familiarised themselves with the data and generated initial codes, using NVivo, for a sample of transcripts (n=6 of 19). These codes were arranged into potential themes at the semantic level. Preliminary themes were discussed between the researchers to highlight any similarities and reach consensus on any differences. Themes were modified and refined, accordingly. Remaining transcripts were coded and analysed by HW and as analysis progressed, findings and uncertainties were discussed with the wider research team (BR, LD and LS). Final themes and subthemes were defined, named and are reported with illustrative quotes (table 1, online supplemental file 2). Reasonable data sufficiency was considered as the presence of sufficient data to support and understand the work experiences of people with oligodendrogliomas[27]; the richness of the collected data indicated that the sample size was adequate. Each participant received a summary of findings and had the opportunity to provide feedback.

RESULTS

Participant characteristics

Interviews were conducted with 19 of 26 people with oligodendrogliomas that registered an interest (5 recruited through NHS sites and 14 through the Brain Tumour Charity). Reasons for non-participation were: unable to confirm eligibility (n=5); and not completed primary treatment (n=2). Eleven participants were male, mean age at interview was 52 years (range 37–69 years) and average time since diagnosis was 9.6 years (range 1–18 years) (table 2). Ten participants were grade 2 and nine were grade 3 oligodendroglioma. Tumour location was primarily the frontal lobe (n=12).

At diagnosis, 18 participants (male n=10) were either working (n=16; full-time employee n=13, part-time employee n=2, self-employed n=1) or studying (n=2). At interview, only 7 participants (male n=4) were working (full-time employee n=3, part-time employee n=3, self-employed n=1), while others were retired (n=4), medically retired (n=4) or unable to work due to illness (n=4).

Overview of themes

Seven themes were constructed (table 1, online supplemental file 2): (1) physical and cognitive limitations, (2) work ability and productivity, (3) work accommodations, (4) changing roles, (5) attitudes of clients and coworkers, (6) feelings and ambitions and (7) financial implications. Physical and cognitive limitations played into all other themes, except financial implications.

Physical and cognitive limitations

Physical and cognitive limitations were commonly reported, though the impact on work varied. For some, they were an inconvenience, while others reported consequent loss of work and medical retirement. Subthemes were: 'Impact of fatigue', 'Impact of seizures' and 'Impact of cognitive and sensory deficits'.

Impact of fatigue

Fatigue was commonly described; presented as an internal battle between body and mind. Many participants conveyed its debilitating impact on work with words like 'zapping', 'exhausting' and 'awful'. The direct physical and cognitive implications of fatigue influenced the redundancy or retirement of some participants, as they were feeling 'utterly exhausted' and 'making mistakes'.

Impact of seizures

Several participants discussed the impact of seizures on work. For some the impact was small and manageable, though for others, seizures were a barrier to employment or were a major limitation, prompting changes in their duties. Some reported increased seizure activity following stressful work-related events, such as changing job roles. For a few participants, having understanding colleagues and clients helped; one participant said having seizures was 'fine because [the clients] were decent people'.

Impact of cognitive and sensory deficits

Many participants described the work impact of cognitive deficits (eg, memory problems, brain fog, concentration difficulties and visual impairments). Some formulated self-management strategies (eg, using calendars, note-taking). Busy, noisy or chaotic work environments could induce or exacerbate cognitive and sensory deficits, making it difficult to work. To ease symptoms, some reported periodically removing themselves from the environment.

Work ability and productivity

Some participants detailed factors contributing to reduced work ability and productivity. Subthemes were: 'Loss of skills or capacity and slower pace' and 'Uncertainty of limitations'.

Table 1 Example supporting quotes for all themes and subthemes, with participant ID number, sex, age range and employment status at interview*

Theme	Subtheme	Illustrative quotes
Physical and cognitive limitations	Impact of fatigue	"Well I eventually had to retire because I just couldn't carry on doing my job. In terms of fatigue, so I sleep a lot longer." - Pa33 (male, aged 41–50, medically retired)
	Impact of seizures	"When I switched into teaching, I did see, like, an increase in my seizures, which I assume is just due to stress – because if I get tired and stressed, I am more likely to get seizures." - Pa3 (male, aged 41–50, part-time)
	Impact of cognitive and sensory deficits	"I had, for some time, had issues with my balance, with nausea, dizziness, brain fog. I had to make notes of everything in a job that I was more than qualified to do." - Pa18 (female, aged 51–60, unable to work)
Work ability and productivity	Loss of skills or capacity and slower pace	"I couldn't drive. I couldn't work up ladders, work at height." - Pa30 (male, aged >60, unable to work)
	Uncertainty of limitations	"I don't know my limitations yet… I think it's a process of elimination, isn't it? "What can I do now? What am I good at? What can I do job-wise?"" - Pa20 (female, aged 41–50, unable to work)
Work accommodations	Employer support	"The managers, they just went with whatever I said. They said, say whatever you want, say whatever it is, we'll help as much as we can so I couldn't ask more than that really. There was no discrimination or anything like that." - Pa5 (male, aged 51–60, retired)
	Employer adjustments	"I had the neuropsychological test and effectively as a result of those, they recommended that I continue to work on a part-time basis. So, since that time I've been working a seven day fortnight at work which is nice because I get a long weekend every other week." – Pa15 (male, aged 51–60, part-time)
Changing roles	Change in responsibilities	"After I'd had my treatment, I went back to work again, my supervisor, said, "You're not putting out as much as you used to do so we're going to give you lighter jobs to do."" - Pa30 (male, aged >60, unable to work)
	Acquiring a new job	"I have applied for jobs, but then you've got to sit there and say, "Well, actually, if I black out, don't panic [laughs]."…"And I will need two days off, every three months – one for a scan, and one for a follow-up."…So they've been very reluctant to take me on." - Pa20 (female, aged 41–50, unable to work)
Attitudes and actions of clients and coworkers		"I think, to be honest, if you say you've got a brain tumour, they're pretty… that's something people understand… It's almost easier in a way because it sounds so terrible. People, you know, they tend to be quite sympathetic to that." - Pa10 (female, aged ≤40, part-time)
Feelings and ambitions	Ambition and perceptions of work	"Oh, now I'm going to change my life. I'm going to become fit and healthy. I'm doing this. I'm going to travel the world. I want to change my career… Actually, there are other things that are more important than proving myself in a career manner." - Pa3 (male, aged 41–50, part-time)
	Self-confidence and identity	"So because I wasn't working and getting any positive feedback, I was sitting at home thinking that I was useless, pointless." - Pa29 (female, aged 51–60, medically retired)
Financial implications	Financial awareness and independence	"To not be able to work and having the financial independence is quite hard…puts an awful lot of pressure. I mean my husband's been working two jobs." - Pa18 (female, aged 51–60, unable to work)
	Financial security and concerns	"My pension doesn't cover my bills. So, I supplemented with benefits. And you've got extra costs. So, as well as having a reduced income and less ability to earn because of, you know, your symptoms, I'm also diagnosed as palliative treated." - Pa17 (female, aged 51–60, medically retired)

*Additional supporting quotes for each theme and subtheme are available in online supplemental file 2.

Loss of skills or capacity and slower pace

Some participants described how executive deficits resulted in loss of skills (eg, decision-making), rendering them incapable of certain job roles. Others mentioned a loss of capacity, meaning some tasks (eg, being up ladders) became hazardous, leading to a change in responsibilities. Several participants reported only being able to work at a slower pace, which reduced work productivity, as tasks took longer to complete.

Uncertainty of limitations

Many participants reported being uncertain of their limitations, describing the substantial influence this had on work ability and productivity. For some, feeling uncertain of which tasks would be manageable, meant participants were hesitant about their capabilities to do their job. This was also prevalent in those seeking employment, with some participants wondering 'What can I do?'.

Table 2 Oligodendroglioma participant characteristics at time of interview (n=19)

Characteristic	n	Characteristic	n
Sex		Age	
Female	8	≤40	2
Male	11	41–50	5
Diagnosis*		51–60	8
Grade 2 oligodendroglioma	10	>60	4
Grade 3 oligodendroglioma	9	Dependents	
Treatment*		None	11
Surgery	17	One	3
Chemotherapy	13	Two	4
Radiotherapy	15	Three	1
Tumour location*		Relationship status	
Frontal	12	Married	14
Temporal	2	Single	2
Parietal	1	Widowed	2
Overlapping regions	1	Relationship	1
Not known	3	Employment status (at diagnosis)	
Tumour laterality*		Full-time employee	13
Right hemisphere	9	Part-time employee	2
Left hemisphere	9	Self-employed	1
Dominant hemisphere	10	Student	2
Non-dominant hemisphere	8	Retired	1
Not known	1	Employment status (at interview)	
	Mean (range)	Full-time employee	3
Time since diagnosis (years)*	9.6 (1–18)	Part-time employee	3
Full-time education (years)	15.6 (12–19)	Self-employed	1
		Retired	4
		Medically retired	4
		Unable to work	4

*Clinical and tumour-related details were self-reported for five participants.

Work accommodations

Accommodations at work were commonly reported. Subthemes were: 'Employer support' and 'Employer adjustments'.

Employer support

Following diagnosis, some participants described feeling uncertain about the future of work and the support they would receive from their employer. Some detailed supportive employers (eg, positive attitude, open communication) expressing appreciation and saying they felt 'lucky'. In contrast, other participants' employers were not supportive, making them feel 'unwanted', 'worried' and 'stressed', with some losing confidence in their ability to work.

Employer adjustments

Many participants' work experiences were influenced by adjustments agreed by their employers. For some, this involved temporary or permanent reductions in working hours. The one self-employed participant, however, perceived a need to work longer hours, describing reluctance and inability to reduce their workload.

Working from home was particularly valued, helping with time-management and addressing commuting challenges. It also provided a quiet work environment, which avoided unnecessary stress and 'brain flooding'. However, for some, role demands meant remote work was not viable.

Some participants reported employer willingness to accommodate, but felt employers lacked knowledge and understanding of adjustments required. This could result in an unsuitable work environment or the need for self-made adjustments (eg, noise-cancelling headphones). For one participant, this influenced their acceptance of voluntary redundancy.

Changing roles

Many participants experienced changing roles following diagnosis. Subthemes were: 'Change in responsibilities' and 'Acquiring a new job'.

Change in responsibilities

Some participants reported positive experiences with changing responsibilities, as it allowed them to complete more manageable tasks. Others expressed frustrations, describing difficulty with stepping-down from previous roles. For some, changing responsibilities induced more stress as though new tasks were easier, the workload was heavier.

Acquiring a new job

Following diagnosis, some participants speculated whether their career would or *should* change. Several highlighted anticipated or actual challenges with securing new employment due to their illness-related limitations. Some felt these limitations were the only barrier to them acquiring particular jobs.

Attitudes and actions of clients and coworkers

Most participants discussed support received from clients and coworkers, ranging from emotional (eg, boosting mood) to practical support (eg, transport to work). Practical support was particularly important for those who experienced seizures; for example, a few participants described coworkers taking them to hospital following a seizure. For some participants, coworkers' perceptions of brain tumours meant they expressed sympathy and showed understanding at work. However, some participants also reported awkwardness and frustration, perceiving coworkers' reactions to be uncomfortably emotional.

Feelings and ambitions

Feelings and ambitions relating to work were commonly discussed. Subthemes were: 'Ambition and perceptions of work' and 'Self-confidence and identity'.

Ambition and perceptions of work

Several participants reported changes in their work ambitions. Some described feeling initially more career-driven, before re-evaluating priorities and questioning the value of work. Largely due to fatigue, some considered ambitions of career progression to be unfeasible, if they wanted a good work-life balance. Others, however, outlined the personal value of work, including financial stability, social opportunities, and benefits of keeping busy.

Self-confidence and identity

Several participants discussed how (lack of) work affected their self-perception. Some used their profession to describe themselves and relate to people outside of work. For some, job loss was detrimental to self-confidence, with unemployment prompting a 'loss of identity' or feeling 'useless'. In contrast, meeting targets and proving capabilities evoked feelings of pride in those that maintained employment.

Financial implications

Financial implications were discussed by most participants. Subthemes were: 'Financial awareness and independence' and 'Financial security and concerns'.

Financial awareness and independence

Some participants highlighted increased financial awareness and related household discussions since their diagnosis and change in work circumstances. Several discussed feeling self-conscious about their financial contributions to the household; some experienced difficulties with losing financial independence, expressing the pressure this placed on their partner.

Financial security and concerns

Many participants outlined the importance of work for financial security. Those who received paid sick leave throughout treatment noted their relief. Several participants described financial concerns, often due to salary reductions associated with reduced working hours. For others, financial hardship was a consequence of medical retirement limiting their ability to earn. Some participants described feeling 'lucky' to be financially secure given their circumstances, expressing gratitude for financial support from partners, charities and employers.

DISCUSSION

Summary of findings

Seven themes were constructed in this, the first study of people with oligodendrogliomas' experiences of work. Individual-level factors, such as physical and cognitive limitations (particularly fatigue, seizures and cognitive deficits) and ambitions, and employer-level factors, such as employer understanding and accommodations, influenced work experiences. Employer and coworker support were integral to participants' overall work experiences, and financial implications were considered.

From diagnosis to interview (average time since diagnosis of 9.6, range 1–18 years), the number in employment fell from 18 to 7 participants, with those in full-time employment falling from 13 to 3 participants. This underlines the employment issues faced by people with oligodendrogliomas, who may live several years following diagnosis and treatment. Our findings give voice to their work experiences with the goal of improving understanding of the impact of an oligodendroglioma diagnosis on employment. The findings suggest the economic burden on people with oligodendrogliomas and their families may be sizeable and perhaps greater than other cancers due to the longer-term symptoms and impairments experienced.

Employers and accommodations

Our findings suggest that employer support generally influenced participants' perceptions of, and attitudes

towards, work. This supports findings that employer support and appropriate communication are key facilitators for work participation among survivors.[11] Still, despite employers' willingness, accommodations were often insufficient, with unsuitable work environments linked to (in)voluntary redundancy or retirement, as participants felt lost, unsupported and misunderstood. This may have been influenced by employers' lack of understanding of peoples' needs.[21] Similar to other studies, we found that employers would make inappropriate assumptions, prompting a 'trial and error' of workplace accommodations.[28 29]

It may be that specific workplace accommodations are needed for those with a brain tumour. For example, as shown here and elsewhere, noisy environments can cause brain flooding and concentration difficulties.[30] This highlights the need for quiet work environments, yet some employers do (or can) not provide them. To achieve appropriate employer support, future interventions may seek to 'educate' employers and encourage collaborative solutions with people with oligodendrogliomas (and perhaps, health professionals) to create a suitable work environment. However, it is difficult for employers to address the needs of survivors if individuals lack awareness of their own capabilities and limitations,[31] something that may be a particular issue in people with brain tumours who may underestimate cognitive, emotional and psychological changes.[32] This appears to be echoed in our finding that participants were often uncertain of their limitations.

Attitudes and actions of clients and coworkers

For people with brain tumours, tumour-specific symptoms (eg, seizures) may create challenging situations for coworker and/or client relationships. Therefore, perhaps unsurprisingly, coworkers had a critical influence on work experiences, providing many with practical and emotional support. Similar findings have been reported in other cancers.[9 33]

Similar to a study in head and neck cancer, participants expressed frustrations at feeling pitied by coworkers,[34] and felt uncomfortable when coworkers reacted emotionally. Building resilience in people with brain tumours and improving awareness and understanding of the consequences of living with a brain tumour across wider society may be important next steps.

Impact of physical and cognitive limitations on work ability and productivity

Participants' experiences of work were strongly impacted by their physical and cognitive impairments. Fatigue was particularly common, and one of the main contributors to mistake-making and inability to work, consistent with past reviews.[9 11 35] However, although fatigue is common in cancer survivors, it can be more severe and long-term in people with brain tumours,[36] exacerbated by physical and cognitive workplace demands.[37] Consideration of accommodations or adjustments for fatigue management (eg, frequent breaks) in (return to) work plans, is likely to be important for improving work outcomes for people with brain tumours.[38 39] Our findings also highlight that seizures can affect general employability, and work ability and relationships. This novel finding warrants further investigation of potential accommodations to minimise the implications of seizures in the workplace (eg, employer and coworker knowledge of what to do if a seizure occurs).

Cognitive impairments had a profound impact on work ability and productivity. The impact of memory problems was most frequently reported, consistent with studies investigating other cancers and brain tumours.[3 21 40] Tumour location, particularly frontal lobe, can exacerbate cognitive impairments.[41] Addressing and facilitating the management of cognitive impairments, especially in those with frontal lobe tumours, may be an important consideration for interventions to support people with brain tumours to achieve successful work outcomes.

Interestingly, our findings suggest there may be an 'interaction' between work and symptoms, as work-related stress or the work environment itself can intensify physical, cognitive and sensory difficulties, and vice versa, both influencing perceived ability to cope. Participants reported, temporarily or permanently, leaving the work environment to ease these symptoms. This finding appears to be novel and may be specific to brain tumours. Determining how work-related stress and unsuitable work environments influence the severity of symptoms and impairments, and vice versa, is important when considering what accommodations and adjustments are appropriate for each individual.

Feelings and ambitions

Our findings indicate that people with oligodendrogliomas' work ambitions and perceptions change following diagnosis and treatment. Some perceived less value in work than before diagnosis, consistent with other cancer survivors.[42–44] However, the life-limiting prognosis means these people may be even more likely than survivors of other cancers to re-evaluate their priorities and, for example, reduce working hours to prioritise family lives. Still, some participants worked for many years post diagnosis, expressing the importance of work for identity and self-confidence. This supports existing findings that work can help repair and shift identities from being a 'cancer patient'.[33 45] Other studies highlight the mental health benefits of working.[8 46] Thus, the personal importance of work for each individual should be considered in rehabilitation.

Financial implications

There is extensive literature on the financial burden experienced by people diagnosed with cancer and its consequences (including distress, debt and medication non-adherence)[47 48]; mitigating strategies include seeking to limit time off work, budgeting and support from family, and are influenced by individual circumstances (eg, being

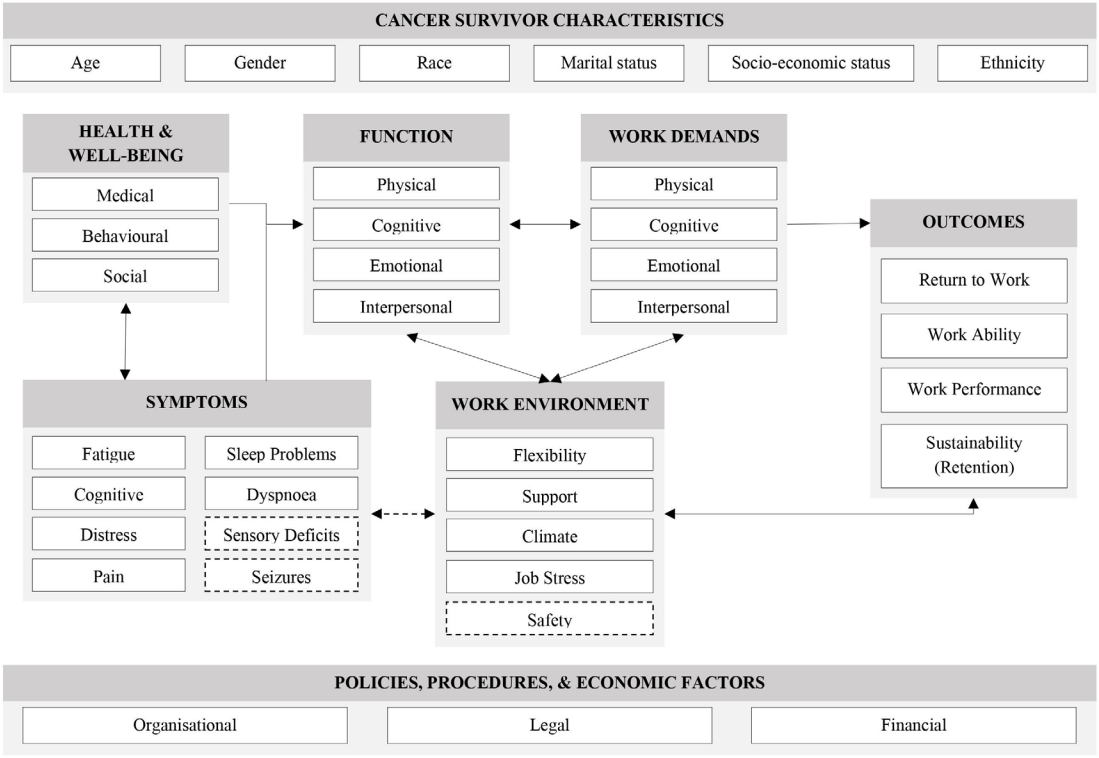

Figure 1 Cancer and work model with suggested revisions for people with oligodendrogliomas[a,b].
[a]Dashed lines indicate suggested revisions to the cancer and work model for greater applicability to people living with an oligodendroglioma. [b]Adapted by permission from Springer Nature Customer Service Centre GmbH: Springer Nature, Journal of Cancer Survivorship, Feuerstein, M., Todd, B. L., Moskowitz, M. C., Bruns, G. L., Stoler, M. R., Nassif, T., & Yu, X. (2010). Work in cancer survivors: a model for practice and research.

ready to return to work, access to social welfare benefits).[49] These findings were echoed in our study. Many participants felt fortunate to not have experienced major financial hardships, in large part due to support from their partners. However, participants desired to maintain financial independence and security, though often felt self-conscious about their financial contributions to the household and with some describing financial strain. An individual's support network and financial circumstances are, therefore, important considerations when determining the importance of facilitating (a return to) work.

Implications

While our findings largely support the factors outlined in Feuerstein *et al*'s clinical model of cancer and work,[6] our focus on people with oligodendrogliomas suggests some additions to this model (figure 1). First, the consequences of seizures and sensory deficits on work experiences suggests that they should be included in the 'symptoms' category. Second, the fatigue, seizures or capacity-related impairments experienced by many, emphasises the importance of a safe work environment. Irrespective of accommodations and support, certain work environments (eg, working at heights, culinary industry) may be unsuitable due to safety concerns, especially regarding seizures. Therefore, 'safety' should be added to the 'work environment' category. Third, we propose a feedback loop between 'work environment', 'symptoms' and 'function'. Our findings indicate that unsuitable work environments can exacerbate symptoms, which in turn impact functioning. Future research should explore how the proposed feedback loop manifests itself in different work environments to expand understanding of what accommodations or adjustments might be beneficial.

Strengths and limitations

The qualitative approach allowed participants to speak freely, raising issues of importance to them. Although work-related experiences were not the primary focus of the interviews, all participants spoke about it in detail, shedding light on a population currently under-represented in the literature on cancer and work. Further, participants were recruited across the UK, and had worked in different capacities in different industries, enhancing the wider applicability of our findings. We generated comprehensive data to understand the work experiences of people with oligodendrogliomas, with multiple quotes to support our findings; thus we are confident that we achieved reasonable data sufficiency.

Although some recruitment was through hospitals, as a result of the COVID-19 pandemic, participants were also recruited through the Brain Tumour Charity's networks. This raises the possibility that participants were self-selected and motivated to share specific experiences. Although approximately 15% of workers are self-employed,[50] we only had one self-employed participant.

Future research should seek to explore the perspectives of this group further. Finally, some people may not have felt well enough to take part; thus, it is possible the experiences of people with oligodendrogliomas, particularly those unable to work due to illness, were not comprehensively captured.

Conclusion

Our study explored, for the first time, work experiences of people with oligodendrogliomas. Individual-level and employer-level factors influenced work experiences. Employer and coworker support were integral to participants' work experiences. The proposed feedback loop between work environment, symptoms and functioning at work emphasises the importance of a suitable work environment. These are important considerations for clinicians and employers, when considering the importance of (returning to) work in the rehabilitation of people with oligodendrogliomas, and the adjustments necessary to accommodate this.

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Ways Ahead

Improving support for people with brain tumours

Topic guide for patient interviews

The direction and content of the interview, the order in which topics are covered, and the precise wording of questions and probes, will be determined by the issues and topics raised by, and the personal circumstances and experiences of, the interviewee. This topic guide therefore functions as an issue checklist for the interviewer.

Introductory questions:

Would you like to start by telling me a bit about yourself?

And when were you diagnosed with a brain tumour?

Topics to cover:

- Experiences of living with a brain tumour*
  - Transition from treatment
  - Physical impact
  - Psychological impact
  - Cognitive impact
  - Emotions relating to brain tumour and its recurrence
  - Managing medications and health appointments
  - Relationships
  - Parenthood and caring roles
  - Work
  - Driving and other means of transport
  - Hobbies and interests
  - Finances
  - Seeking support
  - Healthcare support
  - Self-perception and societal roles
  - Coping and self-efficacy
- Most important aspect affected
- Desired support and intervention design preferences

**For each topic, cover the following:*

- What the impact was
- How it was managed
  - Challenges with managing impact
- What support was received
- What support was needed
- When it was most impacted
- When the support was needed

Closing questions:

Is there anything you would like to tell me that we haven't already discussed?
Do you have any questions for me?

Ways Ahead Interview guide (Phase 1, P) V1, 31/10/2019, IRAS ID: 269814

Supplementary file 2. Supporting quotes for all themes and subthemes, with participant ID number, sex, age range and employment status at interview

Theme	Subtheme	Illustrative quotes
1) Physical and cognitive limitations	Impact of fatigue	• *"I was made redundant because I was making mistakes. I'd forget something crucial to a film shoot. I just generally didn't feel well… it's just that fatigue, exhaustion, utter exhaustion."* - Pa18 (female, ages 51-60, unable to work) • "*Well I eventually had to retire because I just couldn't carry on doing my job. In terms of fatigue, so I sleep a lot longer.'* - Pa33 (male, ages 41-50, medically retired) • *"I suppose I've noticed… I'm quite aware, during the week, of feeling myself getting more and more fatigued... But I kind of get to, like, about now, Thursday afternoon, and I'm like, "Oh [sighs], I really can't wait for the weekend…and then often, at the weekend, I will need to have, like, you know… a complete rest day"* – Pa3 (male, ages 41-50, part-time)
	Impact of seizures	• *"I could not take a train into Dover and then have a fit on the train and then… Well nobody would employ me, not one person. It can be spontaneous and it could be that I have a mild fit, but it's… Nobody would, I couldn't be in a restaurant, I couldn't be doing it."* - Pa19 (male, ages 51-60, self-employed) • *"It was a bit of an odd situation because I was going to client's sites, and I was having seizures every now and again… And they were sort of looking after me as I did work for them"* - Pa25 (male, ages 41-50, medically retired) • *"When I switched into teaching, I did see, like, an increase in my seizures, which I assume is just due to stress – because if I get tired and stressed, I am more likely to get seizures"* - Pa3 (male, ages 41-50, part-time)
	Impact of cognitive and sensory deficits	• *"I had, for some time, had issues with my balance, with nausea, dizziness, brain fog. I had to make notes of everything in a job that I was more than qualified to do."* - Pa18 (female, ages 51-60, unable to work) • *"But it was a long struggle to try and stay there 'cause… yes, I wasn't as on-the-ball as I used to be… and I'm a lot slower than I used to be"* Pa20 (female, ages 41-50, unable to work) • *"I used to have to go and sit in my car at work for ten minutes just to shut my eyes to stop the flashing lights… I couldn't even see my laptop, that's how bad it got."* - Pa18 (female, ages 51-60, unable to work) • *"If I've had a busy time at work, I feel much more foggier in my head than I would have imagined I would before."* – Pa3 (male, ages 41-50, part-time)
2) Work ability and productivity	Loss of skills, capacity, slower pace	• *"My higher executive functions are all damaged, again because of the right side, that's where it sits, which is all the decision-making… Things like discretion…It's a skill I would have used a lot in my job as a social worker…it's not the sort of job you can make mistakes, you know, you're talking about people's lives."* - Pa17 (female, ages 51-60, medically retired) • *"He was in no doubt that I was not capable of doing the safety critical work... there was some safety related stuff associated with it and he said, "I don't think, there's no way that she could do that.""*- Pa29 (female, ages 51-60, medically retired)

Theme	Subtheme	Illustrative quotes
		• *"I couldn't drive. I couldn't work up ladders, work at height."* - Pa30 (male, aged >60, unable to work)
	Uncertainty of limitations	• *"I don't know my limitations yet… I think it's a process of elimination, isn't it? "What can I do now? What am I good at? What can I do job-wise?""*- Pa20 (female, ages 41-50, unable to work) • *"Will I be able to work? All those kinds of things that the doctors say, "Well, you know, there's a 10% chance that this will happen or that will happen""* - Pa3 (male, ages 41-50, part-time) • *"I was diving. I was quite a well-known diver and I ran teams and everything. I said, "Is it alright going diving?" And the consultant went, "No, you can't go, no way." I thought. "Sod that. " So I carried on diving for three years. I just thought, "I'm in charge, this is my head, I'm in charge."… I'm not going to ignore what you say but I know my body…When it started to break my body up and give me fits and that I was like, oh maybe not, maybe this thing is in charge of you for some of time"* – Pa19 (male, ages 51-60, self-employed)
3) Work accommodations	Employer support	• "*They were very understanding about radiotherapy as well… I was incredibly lucky with my employers, incredibly lucky."* - Pa32 (female, ages 41-50, full-time) • "*The managers, they just went with whatever I said. They said, say whatever you want, say whatever it is, we'll help as much as we can so I couldn't ask more than that really. There was no discrimination or anything like that."* - Pa5 (male, ages 51-60, retired) • *"If they don't want me there, somewhere where they've known me for ten years… I think I talked to someone one day, expecting a bit of support, and I just got it in the neck… That just, like, rocked my confidence"* - Pa20 (female, ages 41-50, unable to work) • *"I've been very open all the way through. I've had great support from my head of teams, from HR so yes, I hope to return to work."* – Pa18 (female, ages 51-60, unable to work)
	Employer adjustments	• *"I was finding commuting quite difficult. I was working in an open plan office and the noise around me was quite high. It was very difficult to work in that environment really... I think probably the stress of the whole situation gets underestimated. I was fairly stressed out by the whole thing… certainly at the time that was leading to noise at work and the whole thing, brain flooding and quite difficult concentration problems and that sort of thing… I think if I knew I had somewhere to go the whole place that was quiet, an office or something like that I might still be working there now."* – Pa5 (male, ages 51-60, retired) • *"Initially, they didn't help me with any offers of the mobility scooter or whatever, I bought that out of my own pocket [laughter]. Maybe the private costing treatment that I had was kind of a recognition of the fact that they hadn't done much previously"* - Pa14 (male, aged >60, full-time) • *"Instead of working four days a week, I worked seven days a week. I've worked seven days a week ever since. I was working Sunday, in the morning, which I wouldn't have done… I can't write the report tomorrow. It's got to be done like last week it's got to be, because you've got to get all the team together to take the road apart. I've got to deliver."* - Pa19 (male, ages 51-60, self-employed)

Theme	Subtheme	Illustrative quotes
		• *"The company I worked for at the time was a small company. So, it was a company that they weren't really, particularly, bothered about where I worked. You know, they would say, "Oh, [person's name], works at home normally.""* - Pa25 (male, ages 41-50, medically retired)
		• *"I had the neuropsychological test and effectively as a result of those, they recommended that I continue to work on a part-time basis. So, since that time I've been working a seven-day fortnight at work which is nice because I get a long weekend every other week."* – Pa15 (male, ages 51-60, part-time)
4) Changing roles	Change in responsibilities	• *"After I'd had my treatment, I went back to work again, [name], my supervisor, said, "You're not putting out as much as you used to do so we're going to give you lighter jobs to do""* - Pa30 (male, aged >60, unable to work)
		• *"You go out to a site and you do the ecology work on it and then you come back and write the report... It's gone more and more and more and I'm probably 80, no 70% in the office now."* – Pa19 (male, ages 51-60, self-employed)
		• *"Being in my new position in this new role, I don't want stress let's just say and this job, even though it's not hard, probably not as hard as what I was dealing with before, it can be a bit more stressful because there's a lot more to deal with."* - Pa32 (male, ages 41-50, full-time)
	Acquiring a new job	• *"What does this mean for my life?... Do I need to change anything about my career or anything?"* - Pa3 (male, ages 41-50, part-time)
		• *"I have applied for jobs, but then you've got to sit there and say, "Well, actually, if I black out, don't panic [laughs]."..."And I will need two days off, every three months – one for a scan, and one for a follow-up."...So they've been very reluctant to take me on."* – Pa20 (female, ages 41-50, unable to work)
		• "*I've done the interview at the police three times and the last time round it was literally like I said, on the bleep test. They said you've done this so many times, you don't actually need to do the interview bit… just let them know that you've already been here and done that, so just to do that last bit. It's like a golden ticket to get halfway through."* - Pa26 (female, aged ≤40, part-time)
5) Attitudes and actions of clients and co-workers		• "*For me, it's by having a really good support network around me, really great friends and work co-workers who have become friends."* – Pa18 (female, ages 51-60, unable to work)
		• "*It was a bit of an odd situation because I was going to client's sites, and I was having seizures every now and again. And you know, they were perfectly fine because these were decent people. They were lawyers, but they were decent people. And they were sort of looking after me as I did work for them"* - Pa25 (male, ages 41-50, medically retired)
		• "*The work thing, co-workers at work were very supportive actually, one person in particular. She took me to A&E when I had the first seizure and she was incredibly supportive and I still, I still talk to her now."* - Pa5 (male, ages 51-60, retired)
		• *"I think, to be honest, if you say you've got a brain tumour, they're pretty… that's something people understand… It's almost easier in a way because it sounds so terrible. People, you know, they tend to be quite sympathetic to that."* - Pa10 (female, aged ≤40, part-time)

Theme	Subtheme	Illustrative quotes
		• *"If you're in a full time job, if you're able to carry on with it, if you've got a tumour, there was definitely- as there is with a lot of these things- awkwardness from some people, support from other people… people sort of didn't quite know how to deal with it. Apparently some people got upset which I didn't realise, those who knew me. Other people didn't know what to say to me when they saw me."* – Pa5 (male, ages 51-60, retired)
		• *"I think it was other people's reactions as well. I mean one of my bosses at the time, she wrote me this card, you know how people will send you a get well card and all that kind of thing. But her card was really intense. It was almost like, "You've just met [husband]," almost like I was going to die"* – Pa32 (female, ages 41-50, full-time)
6) Feelings and ambitions	Ambition and perceptions of work	• *"Oh, now I'm going to change my life. I'm going to become fit and healthy. I'm doing this. I'm going to travel the world. I want to change my career... Actually, there are other things that are more important than proving myself in a career manner"* - Pa3 (male, ages 41-50, part-time)
		• *"I want to work hard though. I want to work hard but I don't want to be working until stupid o'clock. With the work I do, it can get like that. It's almost like now I think it's not worth it."* – Pa32 (female, ages 41-50, full-time)
		• "*I enjoyed work. I loved getting to know so many people. And now, there's not much to do to be perfectly honest."* - Pa25 (male, ages 41-50, medically retired)
		• *"It means I'm writing and I'm think that has really helped my brain. I think if I was sitting down watching TV, oh I think I'd be all over the place. I think this focuses my brain into you've got to get that report, you've got to…"* - Pa19 (male, ages 51-60, full-time)
		• *"I would go upstairs to bed and would just zonk out, just completely zonk out. That never used to happen when I first started doing that job. It became a problem because I was having no home life. I would stay awake and do my job but that would be it. I would have no home life"* - Pa33 (male, ages 41-50, medically retired)
	Self-confidence and identity	• *"The fact that I lost my job in the initial diagnosis… it kind of kicks your confidence a bit. So I think the lack of work and everything else… a lot of big changes, I think."* – Pa20 (female, ages 41-50, unable to work)
		• "*You lose your identity. Yeah. I didn't have a job. I lost my home. I had to move house. My marriage broke down. So, loss was a huge thing. I lost my driving license. I lost my independence... I was a mother, I was a wife, I was a social worker…"* - Pa17 (female, ages 51-60, medically retired)
		• *"There were two other people who were just like me. One was a farmer… she was a chatter, and we had another lady who worked on building sites as a secretary, she doesn't take any nonsense either. We were having a laugh amongst everybody else."* Pa19 (male, ages 51-60, full-time)
		• "*So because I wasn't working and getting any positive feedback, I was sitting at home thinking that I was useless, pointless."* - Pa29 (female, ages 51-60, medically retired)
7) Financial implications	Financial awareness and independence	• *"I think we talk about money more now than we did before, when I was full-time… I am more self-conscious of, like… you know, I don't bring as much into the household as he does..."* - Pa3 (male, ages 41-50, part-time)

Theme	Subtheme	Illustrative quotes
	Financial security and concerns	• *"Handling your finances. Awareness that you might not be around for very long. So ensuring power of attorney, wills and crap like that, that took a long time to sort out"* – Pa16 (male, aged >60, retired) • *"To not be able to work and having the financial independence is quite hard…puts an awful lot of pressure. I mean my husband's been working two jobs"* - Pa18 (female, ages 51-60, unable to work) • *"I think I enjoyed the safety net of being in the employment of an organisation that was going to pay me my monthly salary whether I was fully active or still convalescing or something."* - Pa14 (male, aged >60, full-time) • *"My boss at the time, well he wrote to my mum and dad and said to them, "Don't worry about money." … It sounds like a fairy tale, doesn't it… I appreciate how lucky I was."* - Pa32 (female, ages 41-50, full-time) • *"We're quite comfortably off, and as long as the government keep paying my state pension, I seem to be getting paid more than I spend at the moment, which is quite nice, for the first time ever but there we go."* – Pa16 (male, aged >60, retired) • *"I've obviously gone from full-time to part-time, partly because of that. That's obviously had something of an impact on our family finances and things."* - Pa3 (male, ages 41-50, part-time) • *"My pension doesn't cover my bills. So, I supplemented with benefits. And you've got extra costs. So, as well as having a reduced income and less ability to earn because of, you know, your symptoms, I'm also diagnosed as palliative treated."* – Pa17 (female, ages 51-60, medically retired) • *"Finances impacts everything, doesn't it? You're worried, "Oh my God. We won't be able to keep up our repayments. Oh my God, we're not going to be able to do this or do that." Actually, when it comes down to it, it's a phone call, "What support can you give me?" If work can't help you, contact your local Macmillan team."* - Pa18 (female, ages 51-60, unable to work)