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

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Experiences of work for people living with a grade II/III 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 qualitative study. One-time semi-structured interviews exploring patient needs were conducted; work was discussed at various points throughout each interview. An inductive thematic analysis was undertaken.

Setting: Participants were recruited across the United Kingdom through four National Health Service hopsitals and the Brain Tumour Charity research involvement networks.

Participants: 19 grade II or III oligodendroglioma patients (mean age 52 years; male n=11). At diagnosis, 16 participants were working, two studying, and one retired. At 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 identified: physical and cognitive limitations; work ability and productivity; work accommodations; changing roles; attitudes of clients and co-workers; feelings and ambitions; 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 co-worker 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 under-studied patient group. These findings have implications for clinicians and employers, when considering the importance of work in a patient's rehabilitation, and the individually assessed adjustments required to accommodate them, should employment be desired.

Keywords: *oligodendroglioma, low-grade glioma, work, employment, qualitative*

Article summary

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 was not the primary focus of the interviews, all participants spoke about it in detail, shedding light on a patient group, currently underrepresented in the literature on cancer and work.
- Participants were recruited across the United Kingdom, 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 patients may not have felt well enough to take part in an interview, so it is possible that the experiences of patients 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 (i.e. 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 co-workers' responses, self-esteem and identity, and broader cultural/policy expectations[7–11]. However, to date, most research has focused on common cancers (e.g. 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 (e.g. fatigue; pain) and tumour-specific symptoms (e.g. 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.

Low-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]. Oligodendroglioma patients, could, therefore, live for extended periods with their tumour, and, for numerous reasons (i.e. 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 brain tumour patients[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 prognoses, such as oligodendroglioma. Therefore, this study aimed to explore the work experiences of people living with a low- or intermediate-grade oligodendroglioma.

Method

Design

This cross-sectional qualitative study (known as Ways Ahead) used semi-structured interviews to collect data from people living with a LGG. The primary focus of Ways Ahead is to explore the needs of LGG patients to inform potential for a supported self-management programme (*Supplementary file 1*)[22]; the data analysed here pertained to work and related issues. The study was approved by the Wales Research Ethics Committee (REC ref: 20/WA/0118). All participants provided informed consent prior to interview.

Patient and public involvement

Patients were involved in the design, conduct, and reporting of our research, in accordance with the activities outlined in the study protocol (*Supplementary file 1*)[22]; for example, patients 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 United Kingdom (UK), had a grade II or III oligodendroglioma diagnosis[23], 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 patients. 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 patients 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, patients were asked to call or email the study team. For NHS recruitment, patients 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 (i.e. telephone or video call) convenient for the interviewee. Recruitment was conducted August 2020-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 facilitate participation of those with 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 (*Supplementary file 2*), 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 (e.g. cognitive, physical, psychological). We asked how this impact was managed and what, and when, support was received or needed. As appropriate, we used probes 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 minutes on average (range 59 to 167 minutes). 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 identify and explore work experiences. An inductive, data-driven approach was used in line with the six-phases of thematic analysis[24,25].

Three trained researchers (HW, BR, 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, LS). Final themes and subthemes were defined, named, and are reported with illustrative quotes (*Table 2*). Reasonable data saturation was considered as the presence of sufficient data to support the emergent findings[26]. Each participant received a summary of findings and had the opportunity to provide feedback.

Results

Participant characteristics

Interviews were conducted with 19 of 26 oligodendroglioma patients 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 1*). Nine participants were grade II, nine grade III, and one grade II/III oligodendroglioma. Tumour location was primarily 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 seven 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 identified (*Figure 1; Table 2*): (1) physical and cognitive limitations, (2) work ability and productivity, (3) work accommodations, (4) changing roles, (5) attitudes of clients and co-workers, (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 (e.g. memory problems, brain fog, concentration difficulties and visual impairments). Some formulated self-management strategies (e.g. 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’.

Loss of skills or capacity and slower pace

Some participants described how executive deficits resulted in loss of skills (e.g. decision-making), rendering them incapable of certain job roles. Others mentioned a loss of capacity, meaning some tasks (e.g. 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*?'.

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 (e.g. 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 (e.g. 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 co-workers

Most participants discussed support received from clients and co-workers, ranging from emotional (e.g. boosting mood) to practical support (e.g. transport to work). Practical support was particularly important for those who experienced seizures); for example, a few participants described co-workers taking them to hospital following a seizure. For some participants, co-workers’ perceptions of brain tumours meant they expressed sympathy and showed understanding at work. However, some participants also reported awkwardness and frustration, perceiving co-workers’ 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 identified in this, the first study of low- and intermediate-grade oligodendroglioma patients' experiences of work. Patient-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 co-worker 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 seven participants, with those in full-time employment falling from 13 to three. This underlines the employment issues faced by oligodendroglioma patients, 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 oligodendroglioma patients and their families may be sizable 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 patient needs[21]. Similar to other studies, we found that employers would make inappropriate assumptions, prompting a 'trial and error' of workplace accommodations[27,28].

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[29]. 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 patients (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[30], something that may be a particular issue in brain tumour patients who may underestimate cognitive, emotional, and psychological changes[31]. This appears to be echoed in our finding that participants were often uncertain of their limitations.

Attitudes and actions of clients and co-workers

For brain tumour patients, tumour-specific symptoms (e.g. seizures) may create challenging situations for co-worker and/or client relationships. Therefore, perhaps unsurprisingly, co-workers had a critical influence on work experiences, providing many with practical and emotional support. Similar findings have been reported in other cancers[9,32].

Similar to a study in head and neck cancer, participants expressed frustrations at feeling pitied by co-workers[33], and felt uncomfortable when co-workers reacted emotionally. Building resilience in patients 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[9,11,34]. However, although fatigue is common in cancer survivors, it can be more severe and long-term in brain tumour patients[35], exacerbated by physical and cognitive workplace demands[36]. Consideration of accommodations or adjustments for fatigue management (e.g. frequent breaks) in (return to) work plans, is likely to be important for improving work outcomes for brain tumour patients[37,38]. 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 (e.g. employer and co-worker 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[3,21,39]. Tumour location, particularly frontal lobe, can exacerbate cognitive impairments[40]. Addressing and facilitating the management of cognitive impairments, especially in those with frontal lobe tumours, may be an important consideration for interventions to support brain tumour patients 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 oligodendroglioma patients' work ambitions and perceptions change following diagnosis and treatment. Some perceived less value in work than before diagnosis, consistent with other cancer survivors[41–43]. However, the life-limiting prognosis means these patients 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'[32,44]. Other studies highlight the mental health benefits of working[8,45]. Thus, the personal importance of work for each individual should be considered in rehabilitation.

Financial implications

The financial implications of work were notable in our findings. Many participants felt fortunate to not have experienced major financial hardships, in large part due to support from 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 brain tumour patients suggests some additions to this model (*Figure 2*). Firstly, the consequences of seizures and sensory deficits on work experiences suggests that they should be included in the 'symptoms' category. Secondly, 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 (e.g. 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. Thirdly, 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 was not the primary focus of the interviews, all participants spoke about it in detail, shedding light on a patient group, currently underrepresented 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.

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[46], we only had one self-employed participant. Future research should seek to explore the perspectives of this group further. Finally, some patients may not have felt well enough to take part; thus, it is possible the experiences of patients, particularly those unable to work due to illness, were not comprehensively captured.

Conclusion

Our study explored, for the first time, work experiences of oligodendroglioma patients. Patient-level and employer-level factors influenced work experiences. Employer and co-worker support were integral to participants’ work experiences. The 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 a patient’s rehabilitation, and the adjustments necessary to accommodate this.

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Data availability: The data that support the findings of this study may be available from the Chief Investigator (Professor Linda Sharp; linda.sharp@ncl.ac.uk) upon reasonable request.

Table 1. 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[a]		51-60	8
Grade II oligodendroglioma	9	>60	4
Grade III oligodendroglioma	9	***Dependents***	
Grade II/III oligodendroglioma	1	None	11
Treatment[a]		One	3
Surgery	17	Two	4
Chemotherapy	13	Three	1
Radiotherapy	15	***Relationship status***	
Tumour location[a]		Married	14
Frontal	12	Single	2
Temporal	2	Widowed	2
Parietal	1	Relationship	1
Overlapping regions	1	***Employment status (at diagnosis)***	
Not known	3	Full-time employee	13
Tumour laterality[a]		Part-time employee	2
Right hemisphere	9	Self-employed	1
Left hemisphere	9	Student	2
Dominant hemisphere	10	Retired	1
Non-dominant hemisphere	8	***Employment status (at interview)***	
Not known	1	Full-time employee	3
	Mean (Range)	Part-time employee	3
Time since diagnosis (years)[a]	9.6 (1-18)	Self-employed	1
Full-time education (years)	15.6 (12-19)	Retired	4
		Medically retired	4
		Unable to work	4

[a] Medical characteristics were self-reported for five participants.

Table 2. Supporting quotes for all themes and subthemes, with participant ID number, sex, age 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, aged 55, 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, aged 45, 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, aged 45, 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, aged 55, 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, aged 45, 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, aged 45, 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 55, 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, aged 47, 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, aged 55, 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, aged 45, 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, aged 51, 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, aged 51, medically retired) • *"I couldn't drive. I couldn't work up ladders, work at height."* - Pa30 (male, aged 61, 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 47, unable to work)

Theme	Subtheme	Illustrative quotes
		• *“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, aged 45, 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, aged 55, 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, aged 46, 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, aged 56, 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, aged 47, 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, aged 55, 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, aged 56, 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 66, 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, aged 55, self-employed) • *“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, [patient’s name], works at home normally.””* - Pa25 (male, aged 45, 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 (
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 61, unable to work)

Theme	Subtheme	Illustrative quotes
		• *"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, aged 55, 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, aged 46, 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, aged 45, 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, aged 47, 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 37, 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, aged 55, 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, aged 45, 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, aged 56, 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 37, part-time) • *"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, aged 56, 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, aged 46, 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, aged 45, part-time)

Theme	Subtheme	Illustrative quotes
		• *"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, aged 46, 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, aged 45, 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, aged 55, 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, aged 45, 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, aged 47, 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, aged 51, 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, aged 55, 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, aged 51, 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, aged 45, part-time) • *"Handling your finances. Awareness that you might not be around for very long. So enduring power of attorney, wills and crap like that, that took a long time to sort out"* – Pa16 (male, aged 69, retired) • *"I feel like I need to get back to work at some point. I don't know how I'm going to be. I'll probably have another notebook. If I need it, I'll use it. But yes, 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 55, unable to work)
	Financial security and concerns	• *"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 66, 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, aged 46, 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 69, retired)

Theme	Subtheme	Illustrative quotes
		• *"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, aged 45, 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, aged 51, 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, aged 55, unable to work)

Figure 1. Themes and related subthemes for experiences of work in people living with an oligodendroglioma

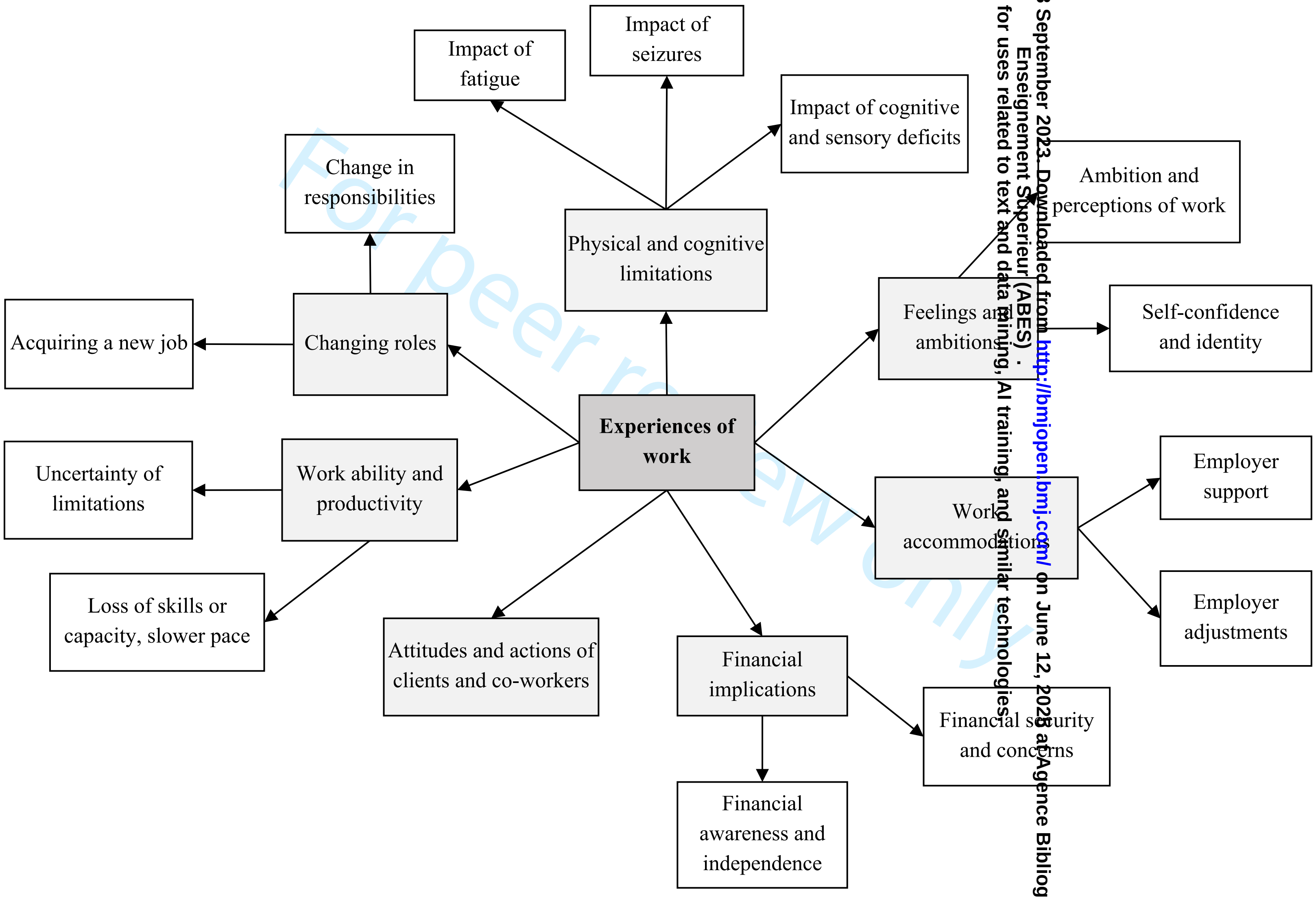
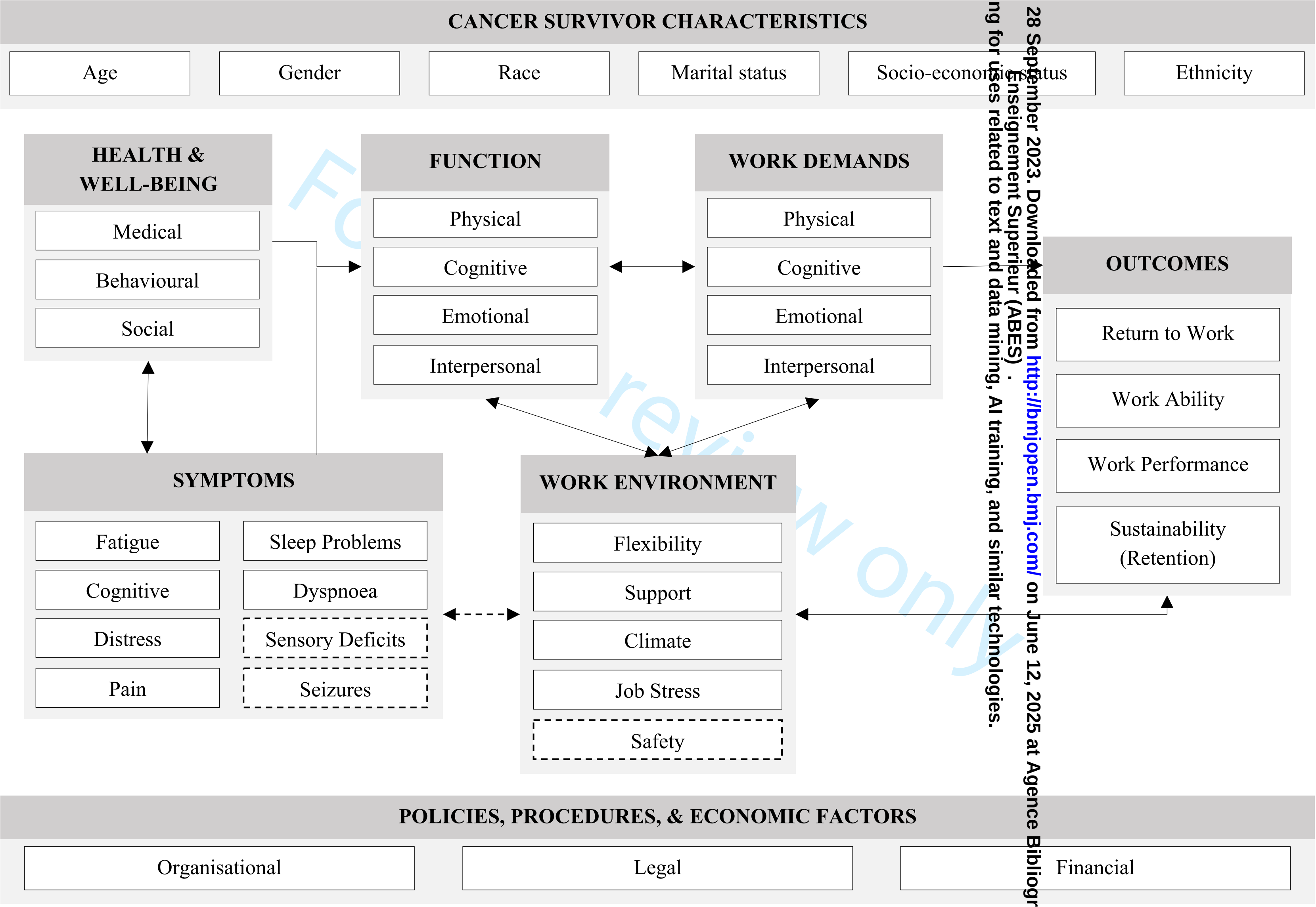


Figure 2. Cancer and work model with suggested revisions[a,b]



[a] Dashed lines indicate suggested revisions to the cancer and work model for greater applicability to people living with a brain tumour.

[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.

Open access Protocol

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Ways Ahead: developing a supported self-management programme for people living with low- and intermediate-grade gliomas - a protocol for a multi-method study

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ABSTRACT

Introduction Living with and beyond a diagnosis of a low- and intermediate-grade glioma (LIGG) can adversely impact many aspects of people's lives and their quality of life (QoL). In people with chronic conditions, self-management can improve QoL. This is especially true if people are supported to self-manage. Supported self-management programmes have been developed for several cancers, but the unique challenges experienced by LIGG survivors mean these programmes may not be readily transferable to this group. The Ways Ahead study aims to address this gap by exploring the needs of LIGG survivors to develop a prototype for a supported self-management programme tailored to this group.

Methods and analysis Ways Ahead will follow three sequential phases, underpinned by a systematic review of self-management interventions in cancer. In phase 1, qualitative methods will be used to explore and understand the issues faced by LIGG survivors, as well as the barriers and facilitators to self-management. Three sets of interviews will be conducted with LIGG survivors, their informal carers and professionals. Thematic analysis will be conducted with reference to the Theoretical Domains Framework and Normalisation Process Theory. Phase 2 will involve co-production workshops to generate ideas for the design of a supported self-management programme. Workshop outputs will be translated into a design specification for a prototype programme. Finally, phase 3 will involve a health economic assessment to examine the feasibility and benefits of incorporating the proposed programme into the current survivorship care pathway. This prototype will then be ready for testing in a subsequent trial.

Ethics and dissemination The study has been reviewed and approved by an National Health Service Research Ethics Committee (REC ref: 20/WA/0118). The findings will be disseminated through peer-reviewed journals, conference presentations, broadcast media, the study website, The Brain Tumour Charity and stakeholder engagement activities.

Strengths and limitations of this study

- Ways Ahead will develop an evidence-based and theoretically-informed supported self-management programme specifically designed to improve quality of life in adult primary brain tumour survivors.
- The methodological approach benefits from the use of recognised frameworks for systematic intervention development, and the incorporation of key stakeholder perspectives through all stages of intervention development, to optimise programme relevance, acceptability, usability and feasibility.
- The inclusion of an economic assessment at the development stages affords the opportunity to consider how the programme might integrate with existing pathways and to optimise its efficiency.
- The outcome of the study will be a prototype programme ready to be taken forward for testing. In the meantime, dissemination of findings may stimulate survivors to initiate new self-management strategies and encourage clinical teams to place greater emphasis on supporting self-management in brain tumour follow-up.
- While the findings will be specifically applicable to those with low- and intermediate-grade gliomas, some may be generalisable to other groups with brain tumours.

INTRODUCTION

Each year in the UK, more than 10 000 new primary brain tumours are diagnosed. Over the past 40 years, survival has doubled; 5-year survival is now 60% for those aged 15 to 39 years at diagnosis and 35% for those aged 40 to 49 years. These trends mean that there is a growing population of people, in particular younger adults, living with and beyond a primary brain tumour diagnosis.[1]

A brain tumour can have a devastating impact on an individual's life, and many of the problems and needs are specific to this form of cancer. Patients can experience a range of common cancer-related symptoms (e.g. fatigue, sleep disorders and pain) as well as others specifically related to the tumour and its treatment (e.g. cognitive limitations, seizures, visual impairment, changes in personality and behaviour, speech problems and mobility problems).[2–4] These symptoms can occur in clusters and get worse as the disease progresses.[5–7] Cognitive deficits, in particular, increase as the disease progresses, hampering communication and decision-making.[6] This can contribute to changing social roles, loss of independence and isolation.[4] Patients often experience significant distress, depression and anger.[8–10] These, in turn, adversely impact physical and psychosocial quality of life (QoL).[11 12]

As a result of the tumour, its treatment and treatment side-effects, those living with a brain tumour often have multi-faceted and complex supportive care needs. However, these needs often go unmet, in part due to poor communication with, and information from, healthcare providers, as well as low referral to and use of psychosocial services.[6 13 14] Given this burden, it is essential to identify effective ways to empower and support adults living with a primary brain tumour to manage the specific problems that they face, adjust to life after treatment, and optimise their well-being and QoL.

Self-management is an 'individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition'.[15] There is a large and growing evidence base indicating that self-management programmes can improve various clinical and psychosocial outcomes—including QoL, psychological well-being and healthcare utilisation—in people with long-term conditions.[16] However, to successfully self-manage, patients need a set of skills (such as problem solving, action planning/goal setting and communicating with healthcare providers) as well as the motivation and confidence to manage their condition. Self-management interventions seek to equip people with these skills and confidence, usually by improving self-efficacy.[17]

Self-management is not—and should not be—the sole responsibility of the patient.[18] They need support from a network of health professionals, family and friends, and fellow patients.[19] Thus, self-management programmes must consider what health professionals and health services can do to support people to self-manage, and how best to mobilise social resources.[20] Indeed, self-management strategies co-created with patients and providers are more likely to have positive effects.[16]

There is emerging evidence that both problem-focussed and adjustment-focussed programmes can improve cancer survivors' self-efficacy, social, physical and psychological well-being, and QoL.[21–26] However, the potential for self-management in adults living with a primary brain tumour has not been well investigated. The unique and complex needs of this group means that programmes developed for other conditions or cancers are unlikely to be suitable or easily transferable.

AIMS AND OBJECTIVES

Aim

The aim of the Ways Ahead study is to design an evidence-based and theoretically-informed supported self-management programme to improve QoL in adults living with a specific form of brain tumour—low- and intermediate-grade glioma (LIGG).

Objectives

The objectives of the Ways Ahead study are to:

1. Identify the characteristics and components of successful self-management interventions that have been tested in adult cancer survivors.
2. Identify self-management strategies currently used by people living with LIGGs.
3. Explore individual-level barriers to, and enablers of, self-management by people living with LIGGs.
4. Identify health system/service-level factors that would help or hinder implementation of a supported self-management programme for people living with LIGGs.
5. Co-produce a prototype for a supported self-management programme with survivors, informal carers and professionals.
6. Estimate the potential costs and benefits of implementing a supported self-management programme for LIGG survivors, and assess how this programme would change the current survivorship care pathway.

METHODS AND ANALYSIS

Overview of study design

Ways Ahead is a 3-year multi-method study (2019 to 2022), involving three sequential phases, underpinned by a systematic review (figure 1). We are following established frameworks for the systematic development of interventions.[27 28] In the first phase, three sets of semi-structured interviews will be conducted with patients, informal carers and professionals. These will identify barriers to, and enablers of, self-management, as well as self-management strategies currently used by people with LIGGs. The second phase will include co-production activities (namely workshops), in accordance with the sequential and systematic co-design approach of O'Brien *et al*.[29] These workshops will integrate evidence, expert knowledge and experience, and stakeholder involvement to develop a prototype for a supported self-management programme. For the third phase, an economic model of current care pathways will be developed and extended to incorporate the proposed supported self-management programme, to assess its acceptability and feasibility. These three phases will be underpinned by an updated systematic review of components and characteristics of supported self-management interventions which have been tested among adults living with cancer.

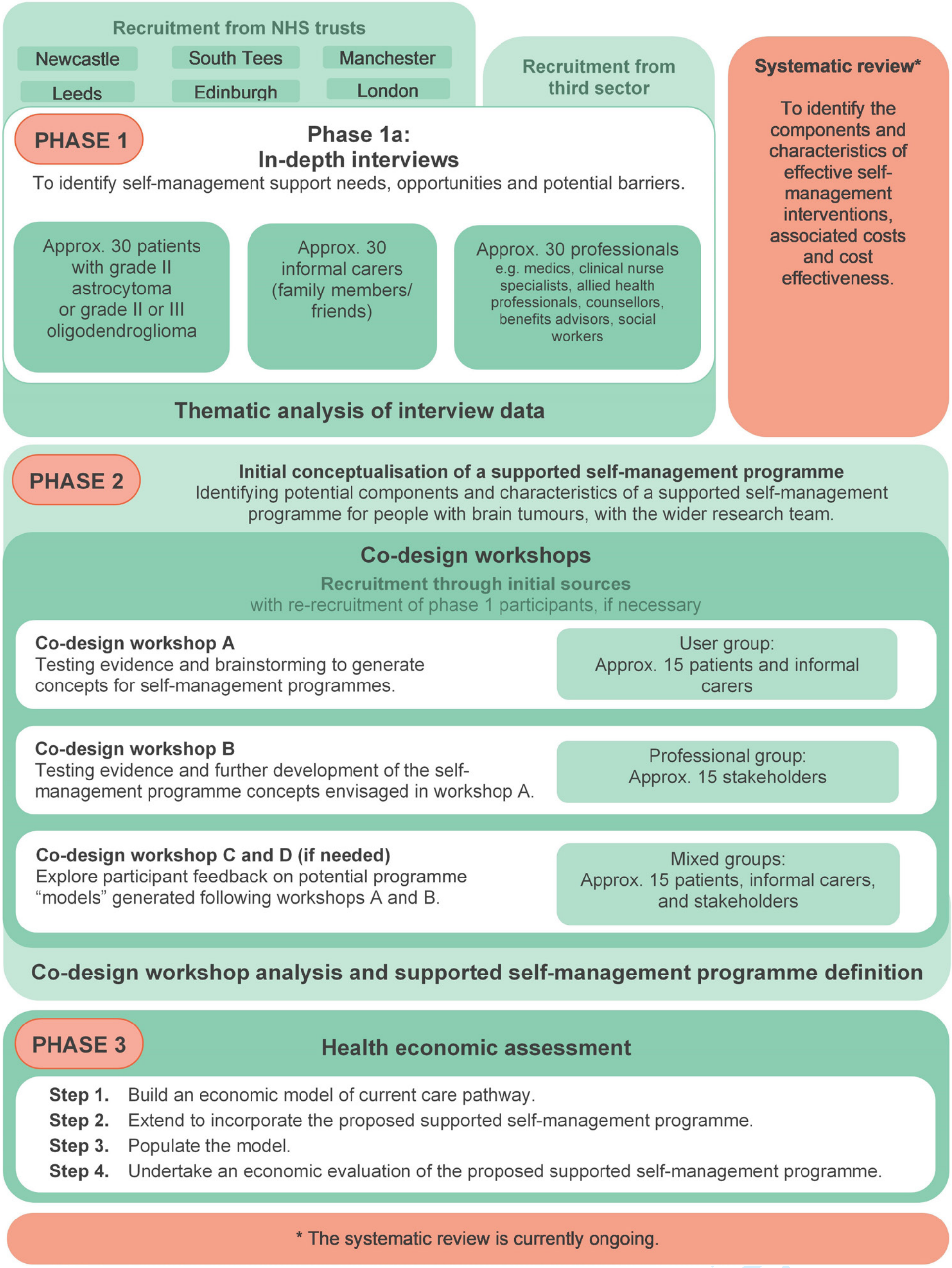

Figure 1 Flowchart illustrating the phases of the Ways Ahead study.

Table 1 summarises how the activities for each interview set and co-design workshop will be tailored to the different samples involved in this study.

Systematic review

The review, which has been registered with PROSPERO (CRD42019154115), will follow PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines.[30]

MEDLINE/Embase, CINAHL, PsycINFO, Cochrane Database of Systematic Reviews and Scopus will be searched for papers published in English, which evaluate: an intervention which is described as self-management or as seeking to develop self-management skills; targeted at adults diagnosed with cancer; during the survivorship phase (i.e. after completion of primary treatment and not at end-of-life); studies using design with a comparator (eg, controlled trials, feasibility or pilot studies with control groups, and pre–post design) will be eligible.

Abstracts and titles will be sifted independently by two team members. Full texts of articles deemed potentially eligible will be obtained and reviewed by two team members. Reference lists of eligible articles and relevant reviews will be searched to identify any articles missed. Eligible studies will be assessed for risk of bias using the Critical Appraisal Skills Programme checklist for randomised studies,[31] and the Joanna Briggs Institute tool for non-randomised studies.[32] The TIDieR (Template for Intervention Description and Replication)

Table 1 Summary of data collection activities for phases 1 and 2

Phase (component)	Description
P1 (patients)	The survivor topic guide will cover: the impact of the brain tumour on health and well-being; understanding and views of self-management; self-management strategies currently and previously used by the individual; other self-management strategies the individual might like to, or be willing to use; experience of formal and informal support for self-management; difficulties experienced with, and barriers to, self-management; and what would help the individual better self-manage.
P1 (informal carers)	The informal carer topic guide will cover: their views and attitudes towards self-management for their support recipient; their contributions to support the recipient's self-management; and barriers and facilitators to support the recipient self-managing.
P1 (professionals)	The professionals' topic guide will cover: views on main areas of unmet needs among LIGG survivors; potential for self-management among LIGG survivors; own experiences of patients who have used self-management; and what would be needed to successfully deliver supported self-management for LIGG survivors.
P2 (workshop A)	Workshop A with survivors and informal carers will generate ideas for what is needed to improve self-management in LIGG survivors and what support would be useful. Potential activities include presenting evidence statements based on the systematic review and phase 1, asking participants to review and prioritise these. To generate intervention design ideas, personas[66] ('characters' representing different people affected by LIGG) will be generated prior to the workshop. Workshop participants will be asked to consider what an intervention for each specific persona might involve (components, mode of delivery and so on). De Bono's 'Six hats' approach[67] may also be used to encourage participants to reflect on the needs and perspectives of patients, informal carers and professionals.
P2 (workshop B)	Workshop B with professionals and other stakeholders will follow a similar format to workshop A, and develop the ideas generated by survivors and informal carers. Participants will also discuss the feasibility of implementing the concepts from workshop A into current care pathways.
P2 (workshop C and D)	Workshop C and, if needed, D, with survivors, informal carers, professionals and stakeholders will seek participant feedback on supported self-management programme prototypes, developed following workshops A and B. Participants will discuss potential challenges around acceptability and feasibility of survivors' effectively engaging with the programme.

LIGG, low- and intermediate-grade glioma.

checklist will be used to describe the characteristics of the interventions; that is, systematically describe each intervention in terms of (i) mode of delivery (e.g. face-to-face or web-based); (ii) personnel delivering the support (e.g. healthcare professionals or lay educators); (iii) targeting (e.g. individually tailored or group-based); and (iv) intervention intensity, frequency and duration.[33] The PRISMS (Practical Reviews in Self-Management Support) taxonomy[18] will be used to abstract the self-management components of the interventions (e.g. information about condition/management, provision of equipment and social support). Data will be abstracted on health-related QoL (HRQoL), self-efficacy, as well as any other primary outcomes and any health economic outcomes. Narrative synthesis of eligible studies will be undertaken together with—if appropriate—meta-analysis, undertaken in RevMan, to identify which components or characteristics of the interventions are associated with improved HRQoL and self-efficacy.

Target population

The Ways Ahead study will focus on LIGGs, which are most commonly diagnosed in young adults in their 30s and 40s.[34–37] In almost all cases, LIGGs will progress to high-grade gliomas or recur: they are rarely cured.[38] Consequently, life expectancy following diagnosis with a LIGG is limited to around 5 to 15 years, depending on the subtype.[36 37 39] Living for extended periods with a terminal condition can affect people's ability to recuperate, cope with and resume everyday activities such as returning to work.[40] Therefore, the development of a supported self-management programme is likely to be particularly beneficial for this patient group, but to achieve this, their distinct experiences and needs must be understood.

Setting and eligibility criteria

Ways Ahead will be conducted in partnership with several National Health Service (NHS) trusts, including Newcastle upon Tyne Hospitals NHS Foundation Trust, Leeds Teaching Hospitals NHS Trust, The Christie NHS Foundation Trust, Salford Royal NHS Foundation Trust, South Tees Hospitals NHS Foundation Trust, Guy's and St Thomas' NHS Foundation Trust and NHS Lothian. The study will also collaborate closely with The Brain Tumour Charity.

Table 2 summarises the inclusion criteria for participants in each interview set.

In accordance with Dworkin's sample size policy,[41] each interview set will likely require 25 to 30 participants for reasonable saturation, though this cannot be entirely predetermined ahead of analysis.[42] Purposive sampling strata will be defined for each interview set to ensure sample

Table 2 Summary of eligibility criteria for each participant group

Group	Eligibility criteria
Patients	▶ Aged 18 years or older ▶ In remission or stable on a watchful waiting approach ▶ Have a grade II astrocytoma, or a grade II or III oligodendroglioma ▶ Have completed primary treatment (or be on observation) Exclude if they: ▶ Have severe psychological or social problems ▶ Have communication difficulties, cognitive impairment or memory difficulties so significant that they are unable to take part ▶ Are non-English speaking
Informal carers	▶ Aged 18 years or older ▶ Currently support, or have supported in the past 5 years, someone with LIGG (the index survivor need not have participated)
Professionals	▶ Are a member of a relevant multidisciplinary team, involved in the care of brain tumour patients ▶ Including, but not limited to, medics, nurses and allied health professionals ▶ **OR** Are involved in the support of brain tumour survivors outside of NHS care pathways ▶ Including, but not limited to, counsellors, benefits advisers and social workers

LIGG, low- and intermediate-grade glioma; NHS, National Health Service.

heterogeneity and elicitation of a broad range of views and experiences. The sampling strata for survivors and informal carers will be: time since diagnosis; treatment modality(ies); and gender. The sampling strata for professionals will be the clinical centre and discipline. We will also seek a maximum diversity sample of other professionals, in terms of organisation and role.

For phase 2, we will seek diversity among co-production workshop participants.

Recruitment procedures

Recruitment of survivors: phase 1

Identification and recruitment of survivors will happen in collaboration with healthcare professionals within the collaborating sites. Depending on site preference, two processes may be used.

Recruitment process 1: Potentially eligible survivors will be identified from their medical records and provided with an information sheet and reply slip, either face-to-face at a clinic visit, or by post. If the individual would like to take part or find out more information, they can return the reply slip to a member of clinic staff or post it to the study coordinator, and give permission for their contact details to be passed onto the study team or contact the study coordinator directly.

Recruitment process 2: Survivors may also be recruited via follow-up clinics. Information packs will be sent out, as above. Survivors will be informed that, at their next clinic visit, the researcher will be present and with their permission, will tell them more about the study and answer any questions. During the clinic conversation, the individual will be asked if they would be happy to take part and, if so, the interview will be scheduled. If they require more time to consider, the co-ordinator will telephone them in a few days for a final decision.

Recruitment of informal carers: phase 1

Survivors who have been interviewed will be asked to nominate someone who has been involved in helping care for/support them since diagnosis. The study team will provide the survivor with a carer study pack and ask them to pass it on to the carer. Informal carers may also be identified through collaborating sites, as healthcare professional sometimes know carers from their attendance to support a patient at a clinic visit.

Other recruitment routes for survivors and carers

If required, we will also use other routes to recruit patients and informal carers, including advertising through The Brain Tumour Charity's Research Involvement Network (RIN) and on the Ways Ahead study website. We may also post on relevant online forums and social media platforms.

Recruitment of professionals: phase 1

Healthcare professionals who are members of the brain cancer multidisciplinary teams at collaborating sites will be invited to interview. Those interested will be asked to call, email or return a reply slip using a prepaid envelope to the study team. We will also promote the study through The Brain Tumour Charity healthcare professional network and invite potentially interested healthcare professionals to contact the study coordinator by email or telephone.

Cancer support professionals will be identified through patient support organisations or charities (i.e. Maggie's Centre Newcastle, Brain Tumour Support, and The Brain Tumour Charity). We will write inviting them to be interviewed, with an information sheet attached. We will also allow for snowball sampling among this group.

Recruitment to phase 2

Recruitment for phase 2 co-production workshops will follow the same routes as phase 1. Participants from phase 1 will be invited to register their interest in taking part in phase 2, but we will also seek to include some survivors, informal carers and professionals who did not take part in phase 1.

Procedures

Table 1 provides a summary of the topics covered in each interview set, as well as the content of each workshop.

Phase 1: semi-structured interviews

Interviews will be conducted by research staff and take place either by phone, video call or face-to-face. Interviews will occur at a time and place convenient for the interviewee. Where possible, survivors and their informal carers will be interviewed separately so that each can be fully open and honest. Each interview is expected to last 60 to 90 minutes, or as long as the participant wishes. Once consent has been obtained, each participant will complete an 'About you' form, to collect some key demographic details such as age, education and employment status. The demographic questions asked vary appropriately for the survivors, informal carers and professionals.

Interviews will be informed by topic guides, which will be used flexibly to allow interviewees to raise issues they consider important. The interviewer will ask 'headline' open-ended questions for each area of interest on the topic guide; probes will then be used to explore issues in more depth. The topic guide may evolve as the interviews progress to examine emerging themes.

Phase 2: co-production workshops

Each workshop will take place in a neutral location and will be facilitated by members of the study team. It is expected that each workshop will last approximately 3 hours. Care will be taken to make sure participants understand that discussions taking place within the workshop are confidential. The researchers will ensure an atmosphere which is welcoming and non-judgemental, and it will be clear that all participants are treated as equals. Several activities will be used at each workshop (table 1) to engage participants, ensure workshops are interactive and interesting, and to facilitate discussion and interaction among participants.

Planned analysis

Analysis of the phase 1 interviews will occur in parallel with data collection to ensure that any new issues raised are explored in subsequent interviews. The first few interviews in each set will be independently coded by two team members, who will discuss and arrange the emerging codes and themes to be applied to the remainder of the interview set. Each interview set will be analysed separately using both inductive and deductive approaches. For inductive analysis, thematic analysis, within the framework approach, will be used.[43–45] For the more deductive phases, self-management strategies used by survivors and informal carers will be identified and classified following Yun *et al*[46] and Dunne *et al*.[47] The Theoretical Domains Framework (TDF)[48] will also be used to identify which domains influence the self-management behaviours of people with LIGG.

Normalisation Process Theory (NPT)[49] will be used to aid the analysis of professional interviews. This will identify key service/system issues, which might help or hinder implementation of a supported self-management programme. For analytical rigour, the classification of self-management strategies, belief statements to the TDF domains, and NPT constructs will be discussed and agreed within the team.

Findings from the interviews and the systematic review will be combined into a 'theoretical model' of supported self-management in LIGGs. This will identify which influences on self-management are potentially modifiable to determine what needs to be done to change survivors' self-management behaviours. The behaviour change wheel (BCW)[50] will be used to map the TDF domains within the theoretical model onto intervention functions that might be effective in changing self-management behaviours. Associated behaviour change techniques (BCT) will be identified from the BCT taxonomy,[51] that is, the techniques that can be used to overcome barriers to, and enhance enablers of, self-management.

As regards phase 2, the workshop outputs will be critically examined and evaluated to generate a design brief and intervention specification. This will detail the aim of the intervention, the design features it will include and how these will be operationalised, overall constituting the prototype intervention. A logic model, including a graphical and textual representation of how the intervention is intended to work, linking outcomes with processes and the underlying theoretical assumptions will be developed.[52]

Phase 3: health economic assessment

An early-stage health technology assessment will be undertaken to assess the feasibility of the prototype intervention. This will involve developing an Excel-based economic model that compares resource utilisation and outcomes from the routine survivorship care pathway (i.e. standard of care) with the proposed intervention. In order to understand the standard of care comparator pathway, a pragmatic review of cancer survivorship literature will be undertaken and combined with expert elicitation techniques from a range of stakeholders. This will involve overlap with phase 1 and 2 data collection methods as well as further independent evidence gathering, including focussed discussions or a brief survey with health professionals who care for patients with LIGGs.

The intervention pathway will include resource utilisation associated with the delivery and follow-up of the supported self-management programme. Expected clinical and QoL outcomes will also be included. The programme characteristics will be costed using a micro-costing framework, itemising each identified component of the implementation and sustainability of the programme. Resource utilisation consistent with the programme features will also be costed using national reference costing approaches. Expected changes to resource utilisation, and disease-specific and QoL outcomes will be explored through expert elicitation techniques guided by available evidence on self-management programmes for cancer survivors.

The disaggregated costs and benefits of implementing the self-management programme, compared with the current care pathway will be analysed and reported, consistent with a cost-consequence analytical framework. Costs will be reported in 2020 (£). A deterministic cost-effectiveness analysis will also be highlighted using average costs and effects across both the intervention and the current care pathways; the base case analysis will adopt an NHS healthcare payer perspective. Incremental cost-effectiveness ratios describing the ratio of cost difference to effectiveness difference for the range of outcomes identified will be estimated and reported for the base case analysis along with a series of sensitivity and scenario analyses, including the adoption of a societal cost perspective. The net benefit of the intervention will also be examined and a summary of the drivers of uncertainty in costs and benefits will be presented.

Patient and public involvement

A patient and public involvement (PPI) panel comprising brain tumour survivors and informal carers who support a brain tumour survivor has been established. We have also consulted members of The Brain Tumour Charity's RIN. Throughout Ways Ahead, patients will be consulted on the design and conduct of research activities, as well as the interpretation and dissemination of findings. To date, PPI input has been obtained on the protocol, study information sheets (including appropriateness and sensitivity of language), topic guides and the study website.

As the project progresses, the panel will be invited to: comment and reflect on findings from the interviews; identify what they see as the key messages that need to be disseminated to survivors, informal carers and the public; co-design the lay summary of findings; and advise on other dissemination activities. They will also be invited to contribute to the design of the supported self-management programme (via the co-production workshops).

ETHICS AND DISSEMINATION

Ethics and safety

All data from the interviews and workshops will be treated with strict confidence, anonymised, password protected and stored in secure facilities at the Population Health Sciences Institute at Newcastle University. Detailed information sheets will preface participation. Participants who provide informed consent (which will be written for face-to face interviews/workshops and audio-recorded when these take place remotely) and meet the inclusion criteria will be assigned a pseudonym. Any identifiable data will be stored securely behind the NHS firewall, using REDCap software, which is Health and Social Care Network (HSCN) compliant and only accessible to authorised members of the study team.

Dissemination plan

Study findings will be prepared for a range of stakeholder audiences. The study website has been established (https://research.ncl.ac.uk/waysahead/), which will be used to disseminate all outputs and materials.

For scientific dissemination, findings will be presented at relevant national and international conferences. Papers will be submitted to journals in neuro-oncology, cancer survivorship and psycho-oncology/behavioural science.

For lay dissemination, participants will have the option to receive a lay summary of the results. To reach patient and general populations, updates will be posted on the study website, with key messages (crafted together with the PPI Panel) highlighted. We will also embed podcasts within the website, with members of the team talking about the study, what it means and what survivors can do to self-manage. We will also seek to discuss the study findings with Brain and Central Nervous System Expert Advisory Groups in Cancer Alliances across different regions. Finally, we will hold a dissemination event for all stakeholders.

DISCUSSION

Little research has been conducted to understand people's everyday experiences of living with and managing a LIGG. Previous research has tended to combine people with low-grade and high-grade gliomas.[53–58] Since those with high-grade gliomas face different symptoms, significantly shorter life-expectancy and tend to be older, these findings are insufficient to inform an intervention aimed at LIGGs. To address this evidence gap, and inform the development of a supported self-management programme, this study will generate considerable empirical data on the experiences of those living with a LIGG, both survivors and informal carers.

To date, self-management interventions in cancer have tended to focus on either breast or prostate cancer survivors[59 60]—where prognosis is very good—or aimed, more broadly, at survivors of common types of cancer.[61] Far less is known about the self-management needs resulting from cancers with more complex/challenging outcomes, such as those experienced by people with LIGGs. Arguably, these groups need programmes specifically targeted to their complex needs and experiences, particularly since targeted self-management interventions have been found to be successful.[62]

It is also increasingly recognised that interventions which are systematically developed from the bottom-up, based on evidence and theoretically-informed are more likely to be effective.[27 28] By adopting this approach in the Ways Ahead study, we will be able to identify the factors affecting a patient's capacity to self-manage. From this, the theoretical constructs can be selected, and we can determine what BCTs are likely to be effective in addressing these constructs. Consequently, we can then evaluate why any behavioural changes have occurred in future testing of the prototype.

The Ways Ahead study responds to NHS England's recommendations that cancer patients be provided with information and education to prepare for self-management, including advice on healthy lifestyles, information on managing the long-term side effects of treatment, signposting to rehabilitation, work and other support services.[63] The study is also consistent with the objectives of the National Cancer Survivorship Initiative, which moved the focus of cancer care from treatment delivery to recovery, health and well-being,[64] and the English Cancer Strategy, which aspires to a recovery package being available to every person with cancer by 2020.[65]

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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?

COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the inter view or focus group?	
Duration	21	What was the duration of the inter views or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	
Software	27	What software, if applicable, was used to manage the data?	
Participant checking	28	Did participants provide feedback on the findings?	
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

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BMJ Open

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

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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 United Kingdom 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, two studying, and one retired. At 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: physical and cognitive limitations; work ability and productivity; work accommodations; changing roles; attitudes of clients and co-workers; feelings and ambitions; 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 co-worker 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 under-studied 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.

Keywords: *oligodendroglioma, lower-grade glioma, work, employment, qualitative*

Article summary

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 was not the primary focus of the interviews, all participants spoke about it in detail, shedding light on a population, currently underrepresented in the literature on cancer and work.
- Participants were recruited across the United Kingdom, 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 (i.e. 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 co-workers' responses, self-esteem and identity, and broader cultural/policy expectations[7–11]. However, to date, most research has focused on common cancers (e.g. 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 (e.g. fatigue; pain) and tumour-specific symptoms (e.g. 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 (i.e. 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 prognoses, such as oligodendroglioma. Therefore, this study aimed to explore the work experiences of people living with a oligodendroglioma.

Methods

Design

This descriptive qualitative study (part of the multi-method Ways Ahead study) used semi-structured interviews to collect data from people living with a 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. Ways Ahead was approved by the Wales Research Ethics Committee (REC ref: 20/WA/0118); there were no deviations from the published protocol in this study. All participants provided informed consent prior to interview. The Ways Ahead study is now completed; write-up of findings from each qualitative dataset 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 United Kingdom (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 (i.e. telephone or video call) convenient for the interviewee. Recruitment was conducted August 2020-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 (*Supplementary 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 (e.g. cognitive, physical, psychological). We asked how this impact was managed and what, and when, support was received or needed. As appropriate, we used probes 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 minutes on average (range 59 to 167 minutes). 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, 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, LS). Final themes and subthemes were defined, named, and are reported with illustrative quotes (*Table 1, Supplementary 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 (five 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 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 seven 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, Supplementary file 2*): (1) physical and cognitive limitations, (2) work ability and productivity, (3) work accommodations, (4) changing roles, (5) attitudes of clients and co-workers, (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 (e.g. memory problems, brain fog, concentration difficulties and visual impairments). Some formulated self-management strategies (e.g. 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'.

Loss of skills or capacity and slower pace

Some participants described how executive deficits resulted in loss of skills (e.g. decision-making), rendering them incapable of certain job roles. Others mentioned a loss of capacity, meaning some tasks (e.g. 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*?'.

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 (e.g. 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 (e.g. 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 co-workers

Most participants discussed support received from clients and co-workers, ranging from emotional (e.g. boosting mood) to practical support (e.g. transport to work). Practical support was particularly important for those who experienced seizures); for example, a few participants described co-workers taking them to hospital following a seizure. For some participants, co-workers' perceptions of brain tumours meant they expressed sympathy and showed understanding at work. However, some participants also reported awkwardness and frustration, perceiving co-workers' 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 co-worker 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 seven participants, with those in full-time employment falling from 13 to three. 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 sizable 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 co-workers

For people with brain tumours, tumour-specific symptoms (e.g. seizures) may create challenging situations for co-worker and/or client relationships. Therefore, perhaps unsurprisingly, co-workers 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 co-workers[34], and felt uncomfortable when co-workers 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 (e.g. 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 (e.g. employer and co-worker 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 (e.g. being 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*). Firstly, the consequences of seizures and sensory deficits on work experiences suggests that they should be included in the 'symptoms' category. Secondly, 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 (e.g. 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. Thirdly, 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 was not the primary focus of the interviews, all participants spoke about it in detail, shedding light on a population, currently underrepresented 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 co-worker support were integral to participants' work experiences. The 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.

Statements and declarations

Ethical approval statement: The study was approved by the Wales Research Ethics Committee (REC ref: 20/WA/0118).

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Competing interests: The authors declare that they have no competing interests.

Contributors: LS, JL, SW, PG, RB, VAS, and TF devised the Ways Ahead study and secured the funding. BR acquired ethical approval. BR and LD conducted the interviews. HW undertook the analysis, advised and supported by BR, LD & LS. HW drafted the manuscript, supported by BR. All authors reviewed, revised, and approved the final manuscript.

Data availability statment: The data that support the findings of this study may be available from the Chief Investigator (Professor Linda Sharp; linda.sharp@ncl.ac.uk) upon reasonable request.

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

Theme	Subtheme	Illustrative quotes
1) 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)
2) Work ability and productivity	Loss of skills, capacity, 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)
3) 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)
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)
	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)
5) Attitudes and actions of clients and co-workers		• *“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
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, 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)
7) 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)

[a] Additional supporting quotes for each theme and subtheme are available in *Supplementary file 2*.

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

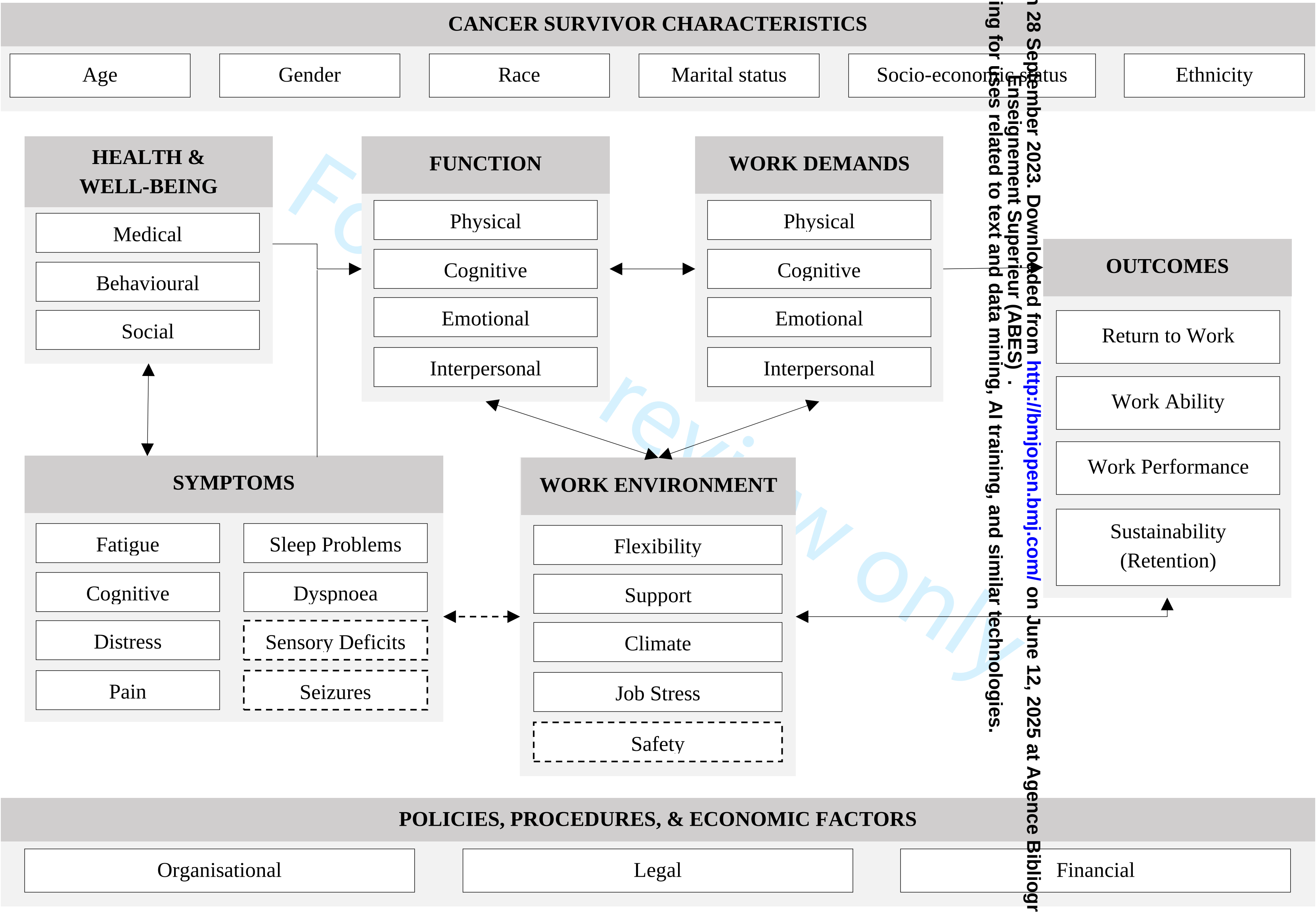
Characteristic	n	Characteristic	n
Sex		***Age***	
Female	8	≤40	2
Male	11	41-50	5
Diagnosis[a]		51-60	8
Grade 2 oligodendroglioma	10	>60	4
Grade 3 oligodendroglioma	9	***Dependents***	
Treatment[a]		None	11
Surgery	17	One	3
Chemotherapy	13	Two	4
Radiotherapy	15	Three	1
Tumour location[a]		***Relationship 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[a]		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)[a]	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

[a] Clinical and tumour-related details were self-reported for five participants.

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.


CANCER SURVIVOR CHARACTERISTICS
Age
Gender
Race
Marital status
Socio-economic status
Ethnicity
HEALTH & WELL-BEING
Medical
Behavioural
Social
FUNCTION
Physical
Cognitive
Emotional
Interpersonal
WORK DEMANDS
Physical
Cognitive
Emotional
Interpersonal
OUTCOMES
Return to Work
Work Ability
Work Performance
Sustainability (Retention)
SYMPTOMS
Fatigue
Sleep Problems
Cognitive
Dyspnoea
Distress
Sensory Deficits
Pain
Seizures
WORK ENVIRONMENT
Flexibility
Support
Climate
Job Stress
Safety
POLICIES, PROCEDURES, & ECONOMIC FACTORS
Organisational
Legal
Financial

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?

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)

COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the inter view or focus group?	
Duration	21	What was the duration of the inter views or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	
Software	27	What software, if applicable, was used to manage the data?	
Participant checking	28	Did participants provide feedback on the findings?	
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.