

Experiences of work for people living with a grade II/III oligodendroglioma: a qualitative study

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- Commonly diagnosed in young adults (30s and 40s)
 - Patients experience a range of general and tumour-specific symptoms (e.g. seizures, cognitive problems, communication impairments) that impact quality-of-life and functioning
 - Rarely cured and almost always progress to a high-grade glioma, limiting life expectancy to around 5-15 years^{1,2}
- Living for extended periods with a terminal condition can impact people's ability to recuperate and resume everyday activities, including work
 - Lack of knowledge of the work experiences of this group

To explore the experiences of work for people living with low- or intermediate-grade (oligodendro)glioma, using qualitative data from the Ways Ahead study

Equality Act 2010

Prohibits discrimination against people with “disabilities” in the workplace.

Cancer is specifically defined as a disability in this Act.

Requires employers to make reasonable adjustments for those with disability.



Ways Ahead

Improving support for people with brain tumours

Designing an evidence-based and theoretically informed supported self-management programme for adults living with low- and intermediate-grade gliomas

1

Identify problems and supportive care needs.

2

Identify self-management strategies currently used.

3

Explore individual-level barriers and facilitators to self-management.

4

Explore the role of informal carers and health professionals in supporting self-management.

5

Identify health service-level barriers and facilitators to providing self-management support

6

Co-produce a prototype for a supported self-management programme.

Eligibility for the current study

- diagnosis of grade II or III oligodendroglioma
- aged ≥ 18 at diagnosis
- in remission following completion of primary treatment, or stable under observation
- spoke English sufficiently well to participate in an interview
- did not have severe psychosocial problems, such that participation risked further distress

- Volunteers recruited through patient network, or screened for eligibility and approached by health professionals
- Purposive sampling to ensure a range of ages, sex, and times since diagnosis (<5 years, 5–10, >10 years)



Data collection

- Semi-structured interview by telephone or video-call
- Topic guide covered impact and experiences of living with tumour, including impact on work
- Interviews lasted mean of 110 minutes (range 59-167)

Analysis

- Inductive thematic analysis
- Focus on any mentions of work, employment or related issues (e.g. finances) in transcripts

Characteristics of participants

- 19 people with grade II/III oligodendroglioma were interviewed

Sex	Females	8	Current age	<40	2
	Males	11		40-49	5
				50-59	8
		60+		4	
Treatment	Surgery	17	Dependents	None	11
	Chemotherapy	13		1 +	8
	Radiotherapy	15			
Time since diagnosis	Mean=9.6 yrs	1-18 yrs	Marital status	Married/cohabiting	14
				Single	2
				Widowed	2

Work status of participants

Working status	At diagnosis	At interview
Full-time employee	13	3
Part-time employee	2	3
Self-employed	1	1
Student	2	-
Retired	1	4
Medically retired	-	4
Unable to work	-	4

Themes identified

Physical and
cognitive
limitations

Work ability and
productivity

Work
accommodations

Changing roles

Attitudes of
clients and co-
workers

Feelings and
ambitions

Finances

Physical and cognitive limitations

- Fatigue, seizures, cognitive & sensory deficits were common
- Impact on work varied. For some, they were an inconvenience; others reported loss of work and medical retirement
- Work stress, or challenging work environments, could induce or exacerbate cancer-related symptoms such as seizures

I was made redundant because I was making mistakes. I'd forget something crucial....

But it was a long struggle to try to stay there cause...I am a lot slower than I used to be

No one would employ me, not one person....it could be that I [just] have a mild fit, but it's....Nobody would....

- Deficits in executive functions resulted in loss of skills
- Loss of capacity meant that, for some, work tasks became hazardous, leading to change in responsibilities
- Participants described feeling uncertain about their limitations and wondered “*what can I do?*”

My higher executive functions are all damaged...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

Will I be able to work?

He was in no doubt that I was not capable of doing the safety critical work

Work accommodations

- Some participants described supportive employers and felt “*lucky*”
- Others felt “*unwanted*” and lost confidence to work
- Employers were sometimes described as willing but lacking knowledge and understanding of adjustments required

The managers, they just went with whatever I said. They said, say whatever you want, we'll help as much as we can

If they don't want me there, somewhere where they have known me for 10 years.... I spoke to someone expecting a bit of support and I just got it in the neck

Changing roles

- Some participants described positive experiences of changing responsibilities as it allowed them to do more manageable things
- Others were frustrated and found difficulty stepping down from previous roles, or found new responsibilities resulted in more stress and heavier workload
- Some experienced difficulties in changing employers

Being in my new position in this new role...even though it's not hard, probably not as hard as what I was dealing with before, but it can be more stressful because there's a lot more to deal with

I have applied for jobs, but then you've got to sit there and say, "Well...if I black out, don't panic"

Attitudes of clients and co-workers

- Most participants described support – emotional and practical - from co-workers and clients
- Others said co-workers didn't know how to react to them. Some said co-workers didn't understand a brain tumour was a type of cancer, so they overestimated participants' abilities

For me, it's having a really good support network around me, really great friends and co-workers who have become friends

There was definitely awkwardness from some people...[they] didn't quite know how to deal with it

Feelings and ambitions

- Several participants described changed work ambitions. Some were initially more career focused, then re-evaluated priorities
- Others accepted career progression was not feasible, due to fatigue
- Some described how no longer working affected their self-perception, describing a “*loss of identity*” or feeling “*useless*”

I enjoyed work. I loved getting to know so many people. And now, there's not much to do to be perfectly honest

So, because I wasn't working and getting any positive feedback, I was just sitting at home thinking I was useless, pointless

Finances

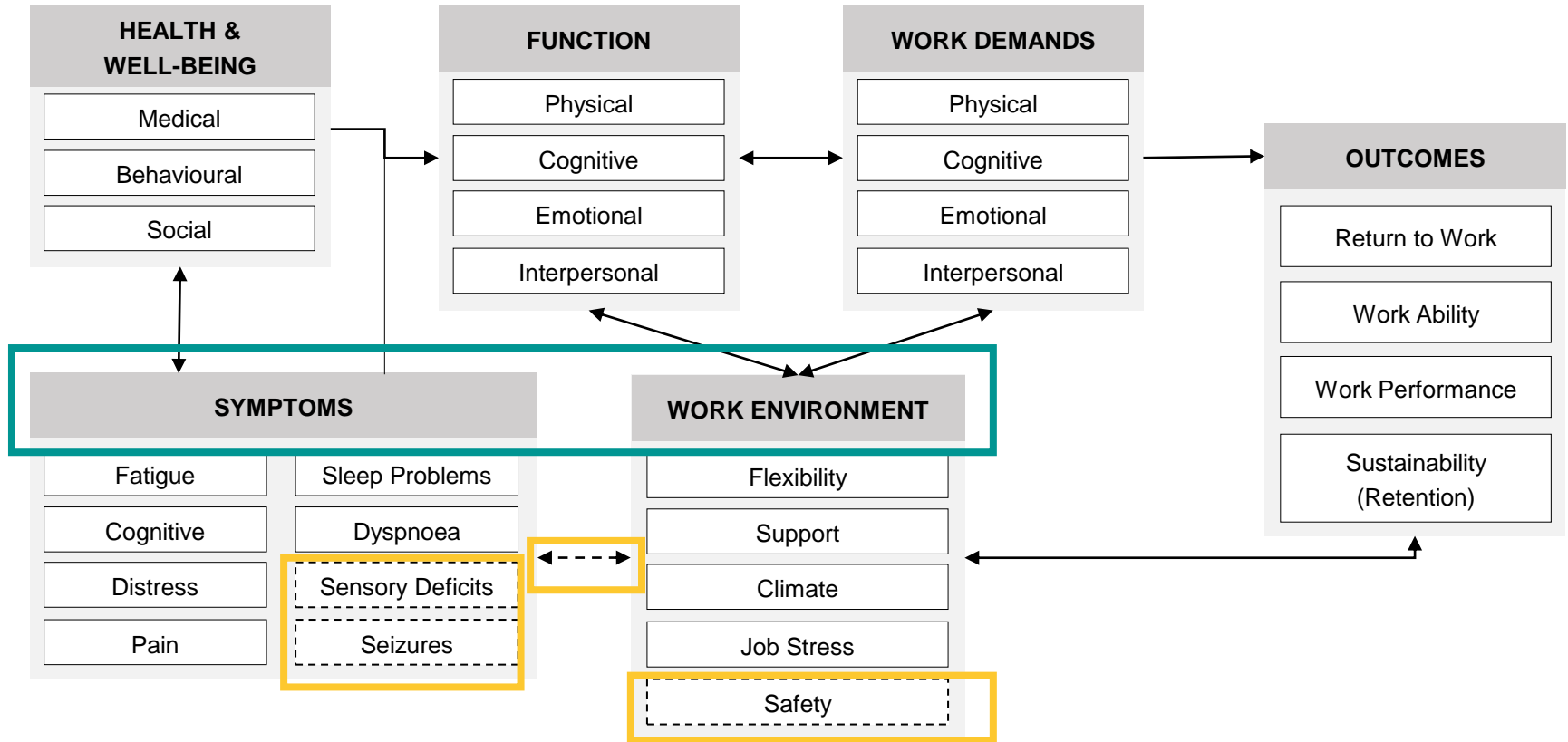
- Some participants described feeling “*lucky*” to be financially secure given their circumstances
- Others described financial worries and hardships
- Some experienced difficulties with losing financial independence and felt self-conscious about their financial contributions to the household

I feel like I need to get back to work at some point. I don't know how I'm going to be.... To not be able to work and [not] having financial independence is quite hard...puts an awful lot of pressure.... I mean my husband's been working two jobs.

- Physical and cognitive limitations had a profound impact on work experiences in this patient group. The nature of the cancer-related symptoms (eg seizures) mean certain work environments may be unsafe for this patient group.
- Work stress or challenging work environments could exacerbate tumour-related symptoms.
- Employers, co-workers and clients had a critical influence on work experiences – both positive and negative.
- Changes in work responsibilities were sometimes welcomed, but sometimes unwelcome or challenging.
- Financial stress - and feelings of financial strain - often resulted from work changes due to the brain tumour.

Implications for cancer and work model

CANCER SURVIVOR CHARACTERISTICS



POLICIES, PROCEDURES, & ECONOMIC FACTORS



Strengths

- Sheds light on work experiences of a neglected population
- Participants varied in ages, and the types of job roles and settings in which they (had) worked

Limitations

- Work was not primary focus of the study
- Recruiting through charity may mean participants were particularly motivated to take part
- Only one self-employed participant

- This study explored - for one of the first times - work experiences of those with oligodendrogliomas
- Cancer-related symptoms heavily influence work experiences, ability and productivity
- Employers and co-workers have key role in influencing work experiences
- “Feedback loop” between work environment, symptoms and functioning at work emphasises importance of a work environment for this group
- Findings may be of value for health professionals who manage these patients, patients and their families

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