



IPOS 2023
WORLD CONGRESS



Survivorship and quality of life

“It changes everything” Understanding
how people experience the impact of
living with a lower-grade glioma

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Ways Ahead was funded by...



Lower-grade gliomas (LGG) are a subgroup of malignant brain tumours that are rarely cured. They almost always progress to a high-grade glioma, limiting life expectancy to around 5-15 years.

- Commonly diagnosed in young adults (30s and 40s).
- Quantitative studies indicate that people with LGGs experience a range of symptoms and impairments that often impact quality of life.
 - *General cancer-related* symptoms (e.g. fatigue and pain)
 - *Tumour-specific* symptoms and impairments (e.g. seizures, cognitive, and communication impairments)

Quantitative data shows people with LGG may encounter challenges with daily living, such as strained relationships, or transport, financial, or work-related problems.

- There is a paucity of qualitative research to help us understand how people experience the impact of living with a LGG.
- Consideration of what the impact means to people (e.g. how are seizures impacting daily life) is important for recognising potential support needs.

Aim: To explore how people living with lower-grade gliomas experience the impact of their tumour and its treatment

Recruitment



Eligibility:

- Aged ≥ 18 years at diagnosis
- In remission following completion of primary treatment, or stable under observation
- Grade 2 astrocytoma, or Grade 2 or 3 oligodendroglioma diagnosis

Data collection:

- Remote semi-structured interviews, from August 2020 to May 2022

Data analysis:

- Inductive thematic analysis

Diverse group of 28 people with LGG
Interview length (minutes): mean 102 (range 54-167)

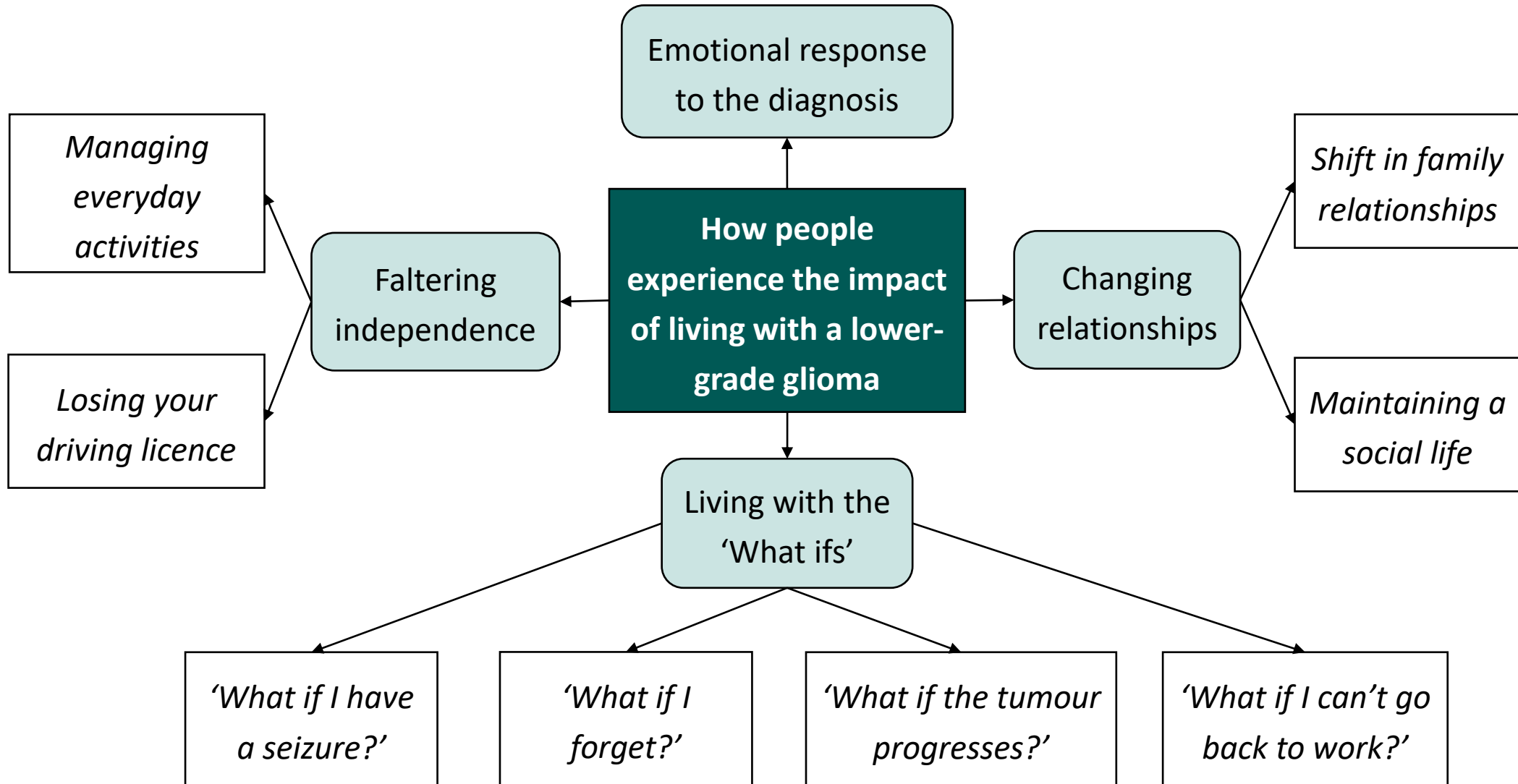
Personal characteristics

- **Sex:** male (n=16), female (n=12)
- **Age (years):** mean 50.4 (range 22-69)
- **Employment:** full time (n=8), part time (n=4), retired (n=4), retired (medical) (n=6), unable to work (n=6)
- **Education (years):** mean 15.8 (range 11-20)
- **Relationship status:** married (n=21), in a relationship (n=3), single (n=2), widowed (n=2)

Tumour-related characteristics

- **Tumour type:** grade 2 oligodendroglioma (n=10), grade 3 oligodendroglioma (n=9), grade 2 astrocytoma (n=9)
- **Tumour location:** frontal (n=18), parietal (n=3), temporal (n=3), overlapping regions (n=3), not known (n=1)
- **Hemisphere:** right (n=13), left (n=15)
- **Surgery:** yes (n=28)
- **Radiotherapy:** yes (n=22), no (n=6)
- **Chemotherapy:** yes (n=17), no (n=11)
- **Time since diagnosis (years):** mean 8.7 (range 1-18)

Overview of themes and subthemes



Emotional response to the diagnosis

- Participants described feeling significantly emotionally impacted upon receiving their diagnosis; with initial shock, and ensuing feelings of anxiety, stress, low mood, and depression.

“I’m a very, very positive person and with the first lot [of treatment], when I came around a bit and I was remembering things I wallowed for a while.” (Pa26, aged 37, female, grade 2 oligodendroglioma)

“When I was first diagnosed, it was such a shock and there was a huge sense of not knowing what was going to happen and a loss of any feeling of control over my life.” (Pa29, aged 51, female, grade 3 oligodendroglioma)

Changing relationships

Shift in family relationships

Maintaining a social life

- Participants emphasised the (largely emotional) impact of living with a LGG on their relationships with partners and family, and the impact of fatigue and cognitive impairment on engagement in social activities.

“I get on with things much as I used to really but emotionally, I’ve been flattened a bit by it all and I think that probably has had an impact on my family because I don’t think I’m a lot of fun sometimes.” (Pa28, aged 66, male, grade 2 astrocytoma)

“I get this sort of brain flooding. If we have a lot of people over for a meal or something it gets a bit, there’s too much going on, the brain has taken too much.” (Pa5, aged 56, male, grade 2 oligodendroglioma)

Faltering independence

Managing everyday activities

Losing your driving licence

- Participants highlighted how living with a LGG has impacted their independence, particularly with practical activities, such as exercise or transport, e.g. due to fatigue, seizures, and mobility issues.

“The rehabilitation can be soul destroying and you’re trying to get your life back and your personality back and everything is just so difficult and tiring.” (Pa36, aged 42, female, grade 2 astrocytoma)

“Because of the limitations of independence, relating to transport, I haven’t pursued hobbies or interests in the way that I have done maybe a year or two before surgery.” (Pa14, aged 66, male, grade 2 oligodendroglioma)

What if...I have a seizure?

- The anxiety about having a seizure influenced participants' approach to daily life, including avoiding public transport or certain physical activities (e.g. swimming).

"I am less willing to jog or cycle and worry about having a seizure when in the pool, because I think, "Well, if I did have a seizure while that was happening, I'd be in a much worse position."" (Pa3, aged 45, male, grade 2 oligodendroglioma)

What if...I forget?

- Participants highlighted how memory and attention deficits can have safety repercussions (e.g. leaving the front door open), and cause challenges for remembering medication and health appointments.

“Day-to-day, I’m leaving the house, I’ve got my bag, that’s all right, I can leave. I’ll leave, the door will be left open. And I’ll get out. And I’ll realise I haven’t got my keys. I haven’t got my phone. It’s a little bit of a joke sometimes because it’s so frequent.” (Pa17, aged 51, female, grade 3 oligodendroglioma)

What if...the tumour progresses?

- All participants spoke emotively about the worry surrounding future uncertainty due to the incurable nature of their diagnosis; this was worse at the time of scan appointments.
- This negatively impacted peoples' decision making for small (e.g. booking a holiday) and larger (e.g. having children) aspects of life.

"I was really afraid when in March, I booked a holiday for next August. I kept thinking, "Oh my God, will I get there?" I have to have blind faith that I'll be okay. So it changes everything. You have to learn to live with the changes, go with the flow."

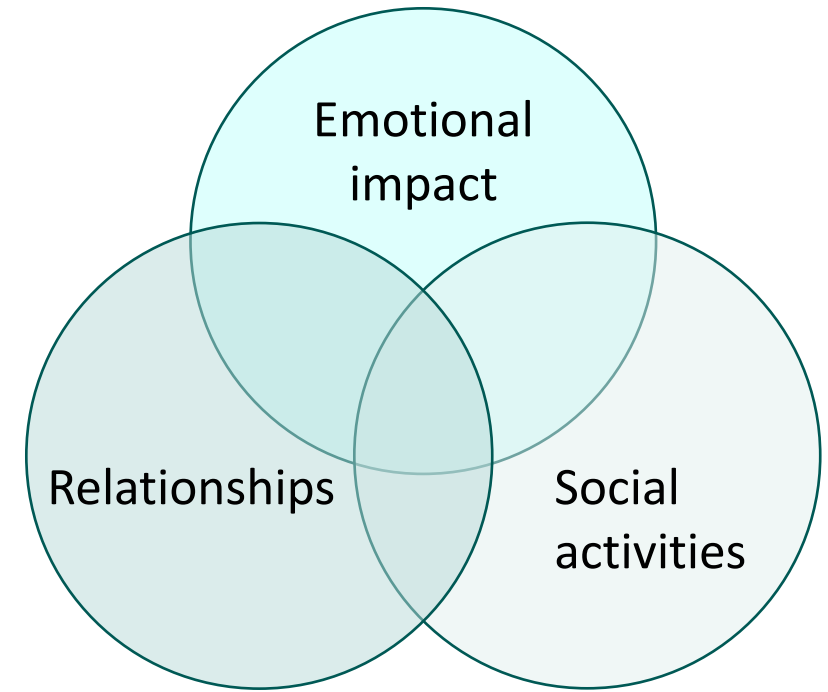
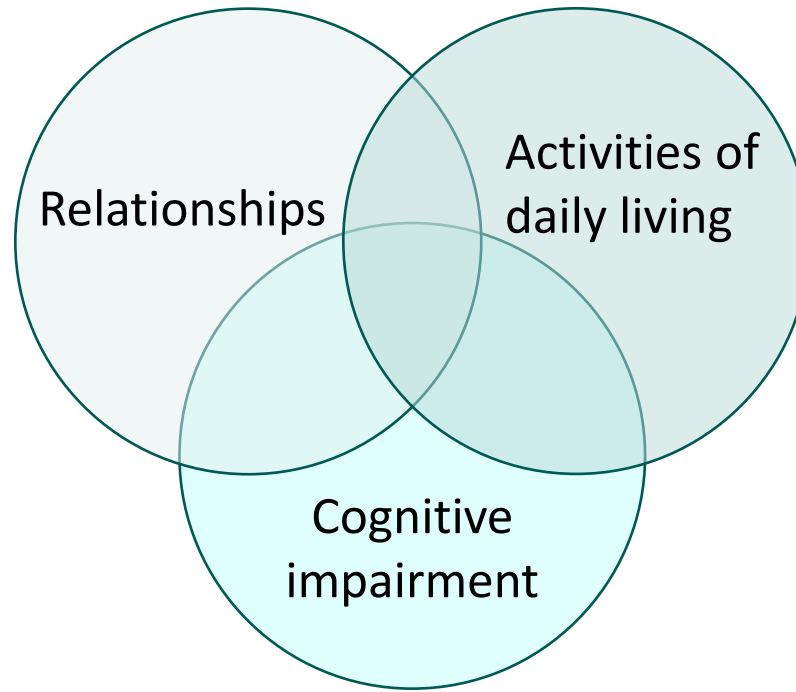
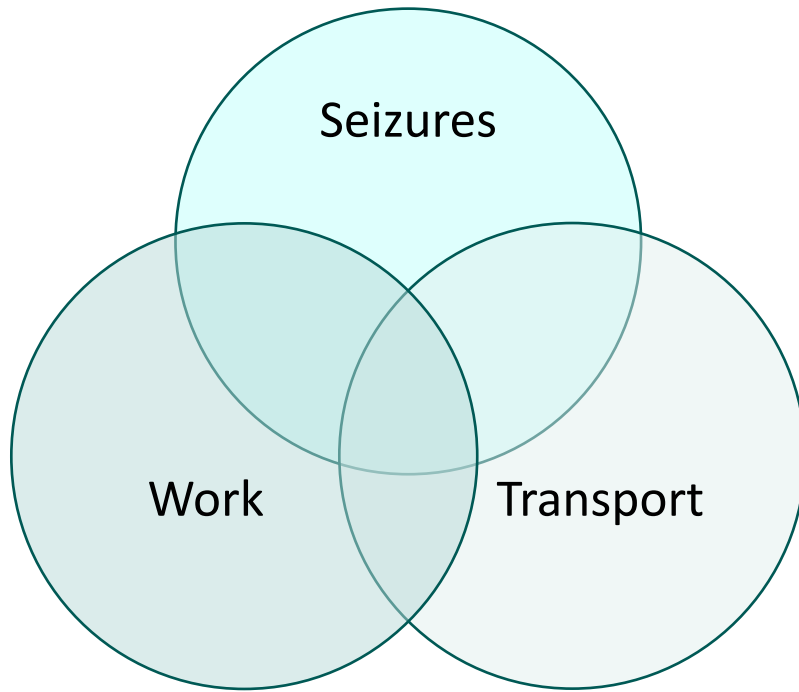
(Pa18, aged 55, female, grade 3 oligodendroglioma)

What if...I can't go back to work?

- Participants outlined the pressure of the financial consequences of employment changes. Those unable to, or taking time off work, described consequent feelings of increased loneliness, and less direction, purpose, and control over their life.

"To suddenly be told that you can't do anything... I lost confidence after losing my job because someone saw it [the diagnosis] as a reason for me not to be working anymore, and it kind of kicks your confidence a bit." (Pa20, aged 47, female, grade 3 oligodendroglioma)

The thematic results do not fully convey how these areas of impact can be interrelated.

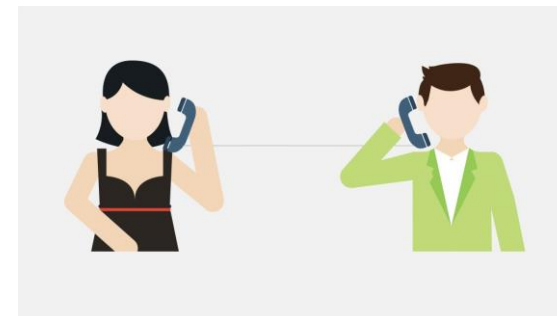


Strengths:

- Novel contribution to the evidence-base
- Diverse sample (e.g. age, sex, time since diagnosis)
- Flexibility of semi-structured interviews
- Support for people with cognitive and communication impairments
- Reasonable data sufficiency achieved

Weaknesses:

- Possible participation bias in charity recruitment, due to Covid-19
- Interview demands may have precluded participation of people with more impairment
- Remote interviews had varied influence on participant comfort



1

People with LGG can experience wide-ranging impacts on daily living and may have extensive supportive care needs.

2

We highlight, for the first time, how this impact is experienced and what it means to the daily lives of people with LGG.

3

Developing best practice recommendations for individual needs assessments (which contextualise symptoms by also capturing impact) could help recognise what is important to the person and what support might be helpful.

4

We know self-management can be helpful for people with cancer. Our findings suggest areas that a self-management intervention for people with LGG could focus on.

5

Future research should consider what may help or hinder an individual with LGG's ability, capacity, or willingness to engage with self-management.

Thank you for listening.

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