The unmet needs of adults living with grade II and III brain tumours: Implications for supported self-management

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Conflict of Disclosure

• The authors declare that there is no conflict of interest.

Background

Grade II and III brain tumours can have a prolonged, negative impact on quality of life, with inevitable progression and mortality.

- Grade II and III oligodendrogliomas
- Grade II astrocytomas
- Younger adults: 30s and 40s (Bauchet, 2017)
- Average life expectancy: 5 to 15 years (*Dixit et al., 2017*)
- Living for extended periods with a terminal condition can affect people's ability to 'return to normal' (Affronti, 2018).

Aim

To understand what problems people living with low- and intermediate-grade gliomas experience following primary treatment.

Purpose

To inform the co-design of a supported self-management programme for adults living with low- and intermediategrade gliomas, as part of the Ways Ahead project.

Method

Recruitment

- The Brain Tumour Charity (UK)
- NHS (UK)
 - Newcastle upon Tyne Hospitals
 - The Christie
 - NHS Lothian
 - ❖ South Tees Hospitals

Eligibility

- Grade II or III oligodendroglioma or grade II astrocytoma
- Adults aged ≥18 years at diagnosis
- Completed primary treatment
- Currently stable

Data collection

- Semi-structured interviews, covering:
 - Cognitive impact
 - Physical impact
 - Psychological impact
 - ❖ Social and role impact
 - Functional impact

Proposed analysis

• Thematic analysis (Braun and Clarke, 2006)

Sample

23 patients interviewed

Tumour type

- Grade II oligodendroglioma (n=11)
- Grade III oligodendroglioma (n=9)
- Grade II astrocytoma (n=3)

Treatment

- Surgery (n=22)
- Radiotherapy (n=17)
- Chemotherapy (n=14)

Years since diagnosis

Mean = 9; Range: 0-18

Age at diagnosis

Mean = 43; Range: 22-67

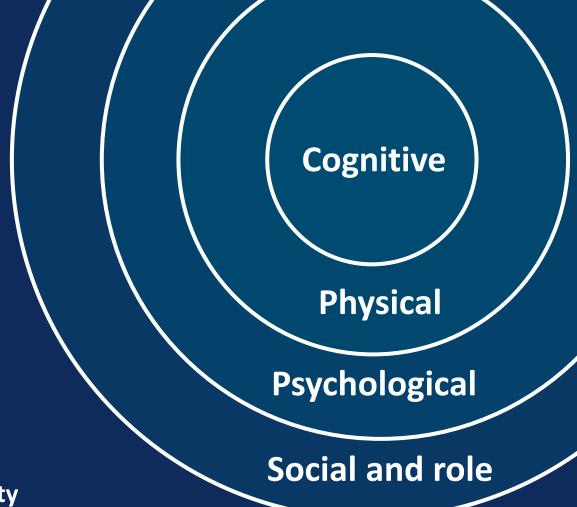
Sex

- Male (n=14)
- Female (n=9)

Unmet needs

Influenced by:

- Tumour type
- Tumour location
- Disease stage
- Extent of disability



Cognitive

Speech
Communication
Memory
'Brain fog'
Slowness
Concentration
Personality change

Physical

Weakness
Gait changes
Seizures

Psychological

Anxiety

Guilt

Depression

Acceptance

Self-image

Confidence

Fatigue

Social and role

Relationships

Work

Travel

Caregiving

Finances

Hobbies and interests

What next?

We are also asking patients about:

- Self-management strategies
- Barriers and facilitators to self-management
- How they would like support to be delivered

Interviews with family members and health professionals are underway to comprehensively understand how these patients can be better supported.

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References

- Bauchet L. Epidemiology of diffuse low grade gliomas. Diffuse lowgrade gliomas in adults. Springer, 2017: 13–53. 37
- Dixit K, Raizer J. Newer strategies for the management of low-grade gliomas. Oncology 2017;31:680–2.
- Affronti ML, Randazzo D, Lipp ES, et al. Pilot study to describe the trajectory of symptoms and adaptive strategies of adults living with low-grade glioma. Semin Oncol Nurs 2018;34:472–85.
- Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol 2006;3:77–101.