

Self-management strategies used by low- and intermediate-grade glioma patients: a directed content analysis

Ben Rimmer¹, Lizzie Dutton¹, Michelle Balla², Joanne Lewis³, Richéal Burns⁴, Pamela Gallagher⁵, Sophie Williams³, Vera Araújo-Soares^{1,6}, Linda Sharp¹

¹Newcastle University Centre for Cancer, ²Newcastle University, ³Newcastle upon Tyne Hospitals NHS Foundation Trust, ⁴IT Sligo, ⁵Dublin City University, ⁶University of Twente

 Ben.rimmer@newcastle.ac.uk

 <https://research.ncl.ac.uk/waysahead/>



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’¹.

- To self-manage, patients need a set of skills (e.g. problem solving, action planning), which interventions seek to equip them with.

- Self-management is not – and should not be – the sole responsibility of the patient².
- Patients require support from a network of health professionals, family and friends, and fellow patients.

Low- and intermediate-grade gliomas (LIGG) are rarely cured and almost always progress to a high-grade glioma, limiting life expectancy to around 5-15 years^{1,2}.

- Commonly diagnosed in young adults (30s and 40s).
- LIGGs experience a range of symptoms that could impact quality of life
 - *General cancer* symptoms (e.g. fatigue and pain)
 - *Tumour specific* symptoms (e.g. seizures, cognitive, and communication impairments)
- Living for extended periods with a terminal condition can impact people's ability to recuperate and resume everyday activities, i.e. work.

- Little is known about how LIGG patients self-manage their condition.
- Living for long periods with the emotional impact of an incurable condition, and tumour-specific impairments, may influence both what, and how, self-management strategies are used.
- Existing studies report small numbers of strategies and are limited by their inclusion of grade I tumours, and <6 months since diagnosis inclusion criteria^{1,2}.
- To inform intervention development, it is important to understand the self-management strategies used by LIGG patients.

Aim: To identify and explore the self-management strategies used by LIGG patients to manage the consequences 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 II astrocytoma, or Grade II or III oligodendroglioma diagnosis

Data collection:

- Remote semi-structured interviews

Data analysis:

- Directed content analysis using a self-management strategy framework developed in cancer^{2,3}

Diverse group of 27 LIGG patients
Interview length (minutes): 58-167, mean 104

General characteristics

- Male (n=16), Female (n=11)
- Age (years): 22-69, mean 51.1
- Employment: Full time (n=7), Part time (n=4), Retired (n=4), Retired (medical) (n=6), Unable to work (n=6)
- Education (years): 11-19, mean 15.7
- Relationship status: Married (n=21), Single (n=2), In a relationship (n=2), Widowed (n=2)

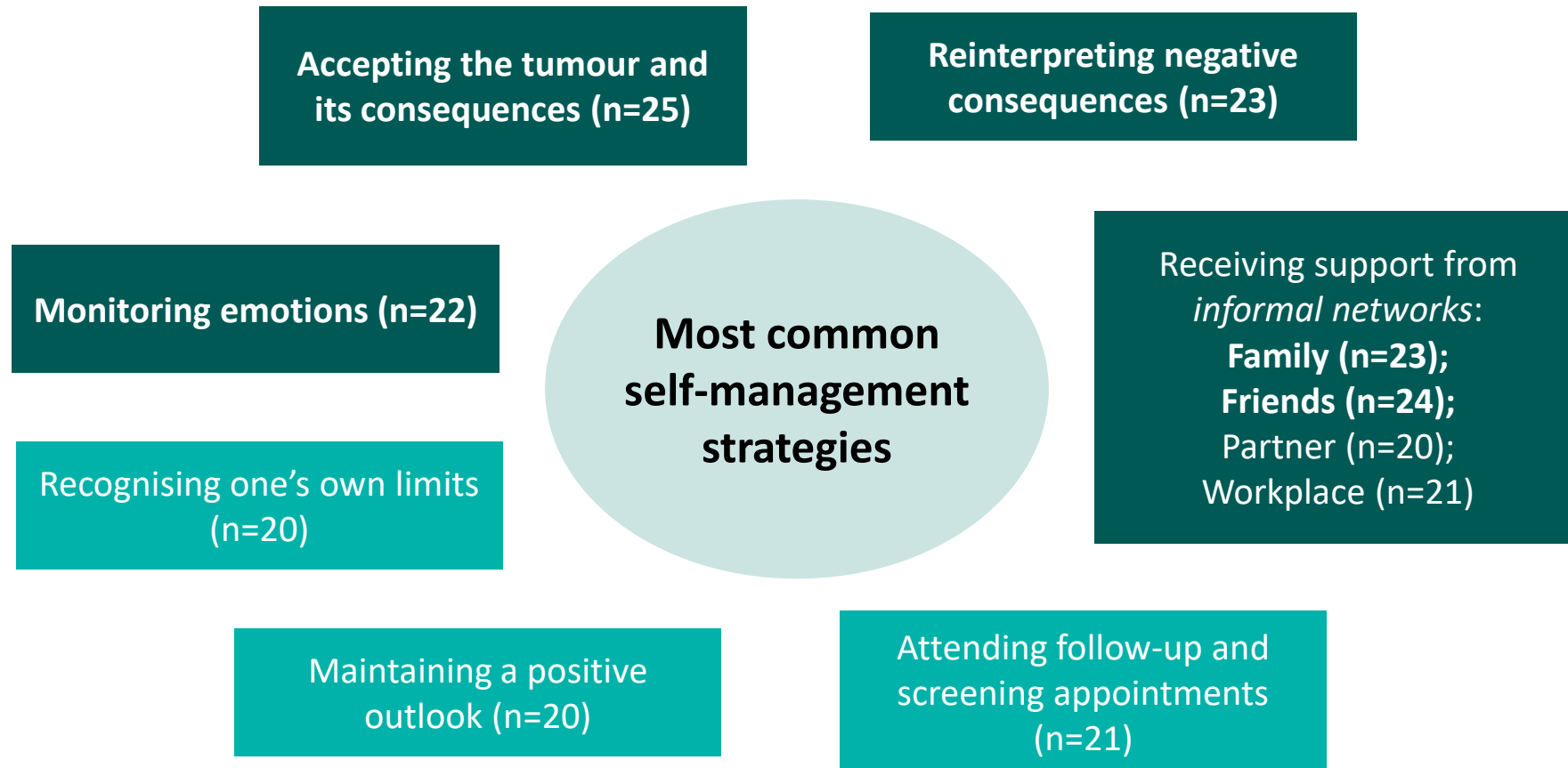
Tumour characteristics

- Tumour type: Grade II oligodendroglioma (n=10), Grade III oligodendroglioma (n=10), Grade II astrocytoma (n=7)
- Tumour location: Frontal (n=19), Parietal (n=3), Temporal (n=2), Overlapping regions (n=3)
- Hemisphere: Right (n=13), Left (n=14)
- Surgery: Yes (n=25), No (n=2)
- Radiotherapy: Yes (n=22), No (n=5)
- Chemotherapy: Yes (n=17), No (n=10)
- Time since diagnosis (years): 1-18, mean 9

Self-management strategy types

Acceptance (n=25)	Activity-based coping (n=19)	Adopting a healthy lifestyle (n=25)	Behavioural avoidance (n=8)
Cognitive avoidance (n=19)	Conserving emotional energy (n=12)	Conserving physical energy (n=17)	Creating a healthy environment (n=27)
Goal and action setting (n=25)	Managing others (n=21)	Meaning making (n=26)	Positive appraisal (n=25)
Proactive problem solving (n=18)	Reasoned decision making (n=23)	Seeking normality (n=22)	Self-monitoring (n=26)
Self-motivating (n=25)	Self-sustaining (n=11)	Using sense of humour (n=6)	Using support (n=27)

123 specific self-management strategies were reported
(median 39; range 19-54)



Creating a healthy environment

- Some expressed the importance of a strong patient-professional relationship.
- Many acquired knowledge about the tumour, treatment, and available support to learn how best to manage.
- Most obtained resources (e.g. dosette box, bus pass) and collected materials (e.g. charity information packs) to aid self-management.
- Some used skills for independent living, especially memory strategies.

“I’ve got a big calendar that I write everything on in the kitchen. I just keep on top of things that way” – Pa29

Using support

- Many sought support from formal networks (e.g. care team) to acquire information for, or assistance with managing their illness.
- Most received formal support (e.g. counselling) and used charity helplines and websites.
- Few sought support from informal networks, but most received practical and emotional support from friends, family, partners, and their workplace.
- Several shared advice and experiences with similar others.

“I used to go to work in the morning. My friends were just incredible. They set up a little rota to take me there” – Pa32

Meaning making

- Several acknowledged the importance of a strong support network.
- Many reported a desire to give something back (e.g. fundraising, research participation).
- Some acknowledged the severity of their illness history, managing by taking each day as it comes.
- Several felt a new appreciation for life and their health.

“I like to help people, if I can share their experience and bring my positive attitude into their life a little bit, then that’s good” – Pa16

Self-monitoring

- Most described awareness of their emotions (e.g. fear of tumour progression, anxiety, and short-temper), with some implementing strategies to control their emotions.
- Several patients actively monitored for symptoms of the tumour and its treatment (e.g. how it feels when they are fatigued).
- Many detailed awareness of environments that exacerbate symptoms, helping them to plan ahead.
- Most recognised their limits, engaging only in manageable activities.

*“My speech was slurred. I sat down and I thought, breathe deeply, keep calm, let’s see what happens, this might resolve itself”
– Pa14*

- Similar strategies and strategy types (i.e. Creating a healthy environment) used as head and neck cancer, and childhood cancer survivors.
 - LIGG patients use these strategies differently.
- Common theme of optimism and planning for the future among frequently reported strategies, despite limited life expectancy – linked with acceptance.
- Influential role of (in)formal support networks in supporting self-management.
 - Potential issues with help-seeking.
- Strategies used may be influenced by consequences of tumour (location) and its treatment.
- Similar engagement in self-management between patient tumour types, with one exception, ‘Reducing workload’.

Strengths and limitations

- Recruited across the UK
- Freedom of qualitative approach
- Facilitated inclusion of cognitive and communication impaired patients
- Interview demands may have influenced interest – potential underrepresentation of ‘lower functioning’ LIGG patients

This is the first study to explore the strategies used by LIGG patients to manage their health and well-being in the long-term.

LIGG patients use a wide variety of strategies in the long-term self-management of the consequences from their tumour and its treatment.

The findings will help inform the development of a supported self-management intervention for LIGG patients.

Integrating family and friends, where appropriate, could facilitate LIGG patients' effective engagement in self-management.

References

- Affronti ML, Randazzo D, Lipp ES, Peters KB, Herndon SC, Woodring S, Healy P, Cone CK, Herndon II JE, Schneider SM. Pilot study to describe the trajectory of symptoms and adaptive strategies of adults living with low-grade glioma. In *Seminars in oncology nursing* 2018 (Vol. 34, No. 5, pp. 472-485). WB Saunders.
- Barlow J, Wright C, Sheasby J, et al. Self-Management approaches for people with chronic conditions: a review. *Patient Educ Couns* 2002;48:177–87.
- Bauchet L. Epidemiology of diffuse low grade gliomas. *Diffuse low-grade gliomas in adults*. Springer, 2017: 13–53.
- Brown MC, Haste A, Araújo-Soares V, Skinner R, Sharp L. Identifying and exploring the self-management strategies used by childhood cancer survivors. *Journal of Cancer Survivorship*. 2021 Apr;15(2):344-57.
- Dixit K, Raizer J. Newer strategies for the management of low-grade gliomas. *Oncology* 2017;31:680–2.
- Dunne S, Mooney O, Coffey L, Sharp L, Timmons A, Desmond D, Goberman-Hill R, O'Sullivan E, Keogh I, Timon C, Gallagher P. Self-management strategies used by head and neck cancer survivors following completion of primary treatment: A directed content analysis. *Psycho-oncology*. 2017 (12):2194-200.
- Edvardsson T, Ahlström G. Illness-related problems and coping among persons with low-grade glioma. *Psycho-Oncology: Journal of the Psychological, Social and Behavioral Dimensions of Cancer*. 2005 (9):728-37.
- Pearce G, Parke HL, Pinnock H, et al. The prisms taxonomy of self-management support: derivation of a novel taxonomy and initial testing of its utility. *J Health Serv Res Policy* 2016;21:73–82.
- Rimmer B, Dutton L, Lewis J, Burns R, Gallagher P, Williams S, Araujo-Soares V, Finch T, Sharp L. Ways Ahead: developing a supported self-management programme for people living with low-and intermediate-grade gliomas-a protocol for a multi-method study. *BMJ open*. 2020;10(7):e041465.