Living with a lower-grade glioma: Exploring the potential for supported self-management

This thesis is submitted in fulfilment of the degree of

Doctor of Philosophy in Applied Psychology

(*Staff, part-time*)

Ben Rimmer

Population Health Sciences Institute

May 2025

Acknowledgements

Firstly, I would like to thank my friend, Ben Morrison for bringing the job advert for this project to my attention, without which I may not have become involved in this work.

I would like to mention my ‘cancer team’ colleagues Morven Brown, Jennifer Deane, and Fiona Menger, who provided invaluable guidance and support in my first few years at Newcastle University. For this reason, Fiona went on to become one of my supervisors and has provided excellent support throughout this PhD.

I would like to thank Catherine Exley for the patience and flexibility afforded to me as I balanced the completion of this PhD with work on a new research project.

I am grateful to all members of the Ways Ahead project team, as I have learned a lot from their varied expertise. This includes Lizzie Dutton, Michelle Balla, and Iakov Bolnykh, who each assisted with the conduct of this project, and Sophie Williams, Joanne Lewis, Tracy Finch, Pamela Gallagher, Vera Araújo-Soares, and Richéal Burns, who provided multidisciplinary expertise and support that elevated the outputs from this project. Full details of how each member of the Ways Ahead project team contributed to this work can be found in *Appendix A*.

A particularly special mention goes to my lead supervisor, Linda Sharp who has been a great support since I started at Newcastle University, providing me with countless training and development opportunities, and seamless collaboration on all the outputs from the Ways Ahead project. My development as an academic has thrived in large part due to the support received from Linda and the confidence gained from this over the years.

To my wife, Sophie, thank you for providing a soundboard for me to discuss all the challenges faced throughout the completion of this PhD, and for helping me celebrate all the victories along the way or provide motivation at times when I needed it.

Finally, an honourable mention for my dog, Oatie, who slept patiently under my desk for the countless days working from home on this PhD. The many dog walks always cleared my head and helped me through the write-up process, making him an unsung hero.

I dedicate this PhD to my son (due June 2025) whose imminent arrival gave me the motivation to get this PhD finished in time to start the next chapter of my life.

I also dedicate this PhD to my late Grandad, Eddie Rimmer, who tracked and read all my publications as and when they were published but passed away before the PhD was finished.

Abstract

Background: Lower-grade gliomas (LGG) are a subgroup of primary malignant brain tumours. People with LGG may live long-term with tumour-specific symptoms and impairments (e.g. seizures, cognitive impairment), alongside the uncertainty of an incurable condition. Supported self-management can improve clinical and psychosocial outcomes, such as quality-of-life (QoL). However, the self-management experiences of people with LGG are unclear. This thesis aimed to understand the lived experiences of people with LGG and the potential for supported self-management, from multiple perspectives.

Methods: A quantitative systematic review of health-related QoL in people with LGG was followed by three semi-structured interview sets. These comprised purposive samples of people with LGG (n=28), informal caregivers (IC) (e.g. partners) (n=19), and healthcare professionals (HCP) who support adults with brain tumours (n=25). Participants were recruited across the United Kingdom, through four National Health Service hospitals and the Brain Tumour Charity. Interviews were audio-recorded, transcribed, then analysed using inductive thematic analysis, framework method, or directed content analysis.

Results: Findings are reported across six publications. People with LGG experience extensive QoL impacts (e.g. seizures, fatigue), with considerable implications on day-to-day life (e.g. work, relationships). They show willingness to self-manage but several factors (e.g. knowledge, health status) influence their ability to self-manage effectively. ICs provide wide-ranging support (e.g. practical, healthcare advocacy) but experience difficulties with preserving the care recipient’s independence. HCPs can empower people with LGG and ICs with the necessary tools and information, though challenges (e.g. identifying support needs, HCP collaboration) hinder the implementation of self-management support.

Conclusions: This thesis provides novel and comprehensive understanding of the need, and potential for, supported self-management in people with LGG. These insights could extend to other brain tumours or progressive neurological conditions. Overall, this represents critical groundwork for the development and implementation of person-centred self-management support, to improve the QoL of this underserved population.

Declaration

I declare that this thesis is my own work and that the work of others has been correctly acknowledged. This submission is in accordance with the good academic conduct University and School guidance.

I declare that I have not previously submitted any part of this thesis for a degree or other qualification in this or any other University. This thesis contains collaborative work; my independent contributions have been outlined in the appropriate co-authorship forms, which can be found in *Appendix A*.

I confirm that the word count is within the range (>10,000 words) advised by my School and Faculty.

Signature:

Date: 15.05.2025

Abstract word count: 299

Narrative word count (excluding embedded published papers, contents, appendices, and references): 21,032

Outputs during PhD candidature

This thesis comprises the following six publications, submitted for the degree of Doctor of Philosophy in Applied Psychology:

1. **Rimmer, B.,** Bolnykh, I., Dutton, L., Lewis, J., Burns, R., Gallagher, P., Williams, S., Araújo-Soares, V., Menger, F., & Sharp, L. (2023). Health-related quality of life in adults with low-grade gliomas: a systematic review. Quality of Life Research, 32(3), 625–651. https://doi.org/10.1007/s11136-022-03207-x
2. **Rimmer, B.,** Balla, M., Dutton, L., Williams, S., Lewis, J., Gallagher, P., Finch, T., Burns, R., Araújo-Soares, V., Menger, F., & Sharp, L. (2024). "It changes everything" Understanding how people experience the impact of living with a lower-grade glioma. Neuro-Oncology Practice, 11(3), 255-265. https://doi.org/10.1093/nop/npae006
3. **Rimmer, B.,** Balla, M., Dutton, L., Lewis, J., Brown, M. C., Burns, R., Gallagher, P., Williams, S., Araújo-Soares, V., Finch, T., Menger, F., & Sharp, L. (2024). Identifying and understanding how people living with a lower-grade glioma engage in self-management. Journal of Cancer Survivorship, 18(1), 1837–1850. https://doi.org/10.1007/s11764-023-01425-x
4. **Rimmer, B.,** Balla, M., Dutton, L., Williams, S., Araújo-Soares, V., Gallagher, P., Finch, T., Lewis, J., Burns, R., Menger, F., & Sharp, L. (2024). Barriers and facilitators to self-management in people living with a lower-grade glioma. Journal of Cancer Survivorship. https://doi.org/10.1007/s11764-024-01572-9
5. **Rimmer, B.,** Balla, M., Dutton, L., Burns, R., Araújo-Soares, V., Finch, T., Lewis, J., Gallagher, P., Williams, S., Menger, F., & Sharp, L. (2024) "It's a delicate dance" How informal caregivers experience the role and responsibilities of supporting someone living with a lower-grade glioma. Neuro-Oncology Practice, *12*(2), 340–350. https://doi.org/10.1093/nop/npae096
6. **Rimmer, B.,** Finch, T., Balla, M., Dutton, L., Williams, S., Lewis, J., Gallagher, P., Burns, R., Araújo-Soares, V., Menger, F., & Sharp, L. (2024) Understanding supported self-management for people living with a lower-grade glioma: implementation considerations through the lens of normalisation process theory. Health Expectations, 27(3), e14073. https://doi.org/10.1111/hex.14073

The following publications represent closely related work that I have been involved in during my PhD candidature (see published abstracts in *Appendix B*). They add important context to the six thesis papers:

1. **Rimmer, B.,** Dutton, L., Lewis, J., Burns, R., Gallagher, P., Williams, S., Araújo-Soares, V., Finch, T., & Sharp, L. (2020). 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, 10(7), e041465. http://dx.doi.org/10.1136/bmjopen-2020-041465
2. **Rimmer, B.,** & Sharp, L. (2021). Implementation of Self-Management Interventions in Cancer Survivors: Why Are We Not There Yet? Journal of Cancer Education, 36(6), 1355–1358. https://doi.org/10.1007/s13187-021-02021-2
3. **Rimmer, B.,** Crowe, L., Todd, A., & Sharp, L. (2022). Assessing unmet needs in advanced cancer patients: a systematic review of the development, content, and quality of available instruments. Journal of Cancer Survivorship, 16(5), 960–975. https://doi.org/10.1007/s11764-021-01088-6
4. **Rimmer, B.,** Brown, M. C., Sotire, T., Beyer, F., Bolnykh, I., Balla, M., Richmond, C., Dutton, L., Williams, S., Araújo-Soares, V., Finch, T., Gallagher, P., Lewis, J., Burns, R., & Sharp, L. (2023). Characteristics and Components of Self-Management Interventions for Improving Quality of Life in Cancer Survivors: A Systematic Review. Cancers, 16(1), 14. https://doi.org/10.3390/cancers16010014
5. **Rimmer, B.,** Balla, M., Dutton, L., Lewis, J., Burns, R., Gallagher, P., Williams, S., Araújo-Soares, V., Finch, T., & Sharp, L. (2024). ‘A Constant Black Cloud’: The Emotional Impact of Informal Caregiving for Someone with a Lower-Grade Glioma. Qualitative Health Research, 34(3), 227–238. https://doi.org/10.1177/10497323231204740
6. Murrell, A. J., **Rimmer, B*.,** Dutton, L., Lewis, J., Burns, R., Gallagher, P., Williams, S., Araújo-Soares, V., Finch, T., & Sharp, L. (2023). The Nature and Quality of Support from Informal Networks for Informal Caregivers of Low-Grade Glioma Patients: A Qualitative Analysis within the Ways Ahead Study. European Journal of Cancer Care, 2023(1), 4149412. https://doi.org/10.1155/2023/4149412
7. Walker, H., **Rimmer, B*.,** Dutton, L., Finch, T., Gallagher, P., Lewis, J., Burns, R., Araújo-Soares, V., Williams, S., & Sharp, L. (2023). Experiences of work for people living with a grade 2/3 oligodendroglioma: a qualitative analysis within the Ways Ahead study. BMJ Open, 13(9), e074151. https://doi.org/10.1136/bmjopen-2023-074151

*These publications were secondary qualitative analyses completed by Masters in Public Health students under my co-supervision.

During my PhD candidature I have presented at national and international conferences; the titles of each presentation are detailed below:

- International Psycho-Oncology Society (IPOS) 2021 conference:
    - **Rimmer, B.,** Crowe, L., Todd, A., Sharp, L. Unmet needs in advanced cancer patients: a systematic review of the development, content, and quality of available instruments. In: IPOS 2021 Abstracts Booklet, Journal of Psychosocial Oncology Research and Practice: June 2021 - Volume 3 - Issue S1 - p e054 (Oral)
    - Clarke, N., Brown, M., Dutton, L., **Rimmer, B.,** Sharp, L. Supported self-management in cancer survivors: potential in more challenging groups. In: IPOS 2021 Abstracts Booklet, Journal of Psychosocial Oncology Research and Practice: June 2021 - Volume 3 - Issue S1 - p e054 (Symposium)
- Multinational Association of Supportive Care in Cancer (MASCC) 2021 conference:
    - **Rimmer, B.,** Bolnykh, I., Dutton, L., Sharp, L. Quality of life in adults with low-grade gliomas: a systematic review. In abstracts for MASCC/ISOO Annual Meeting 2021. Support Care Cancer 29, 1–261 (2021). https://doi.org/10.1007/s00520-021-06285-8 (Oral)
    - **Rimmer, B.,** Dutton, L., Lewis, J. et al. Unmet needs of adults living with grade II and III brain tumours: implications for supported self-management. In abstracts for MASCC/ISOO Annual Meeting 2021. Support Care Cancer 29, 1–261 (2021). https://doi.org/10.1007/s00520-021-06285-8 (Oral)
- National Cancer Research Institute (NCRI) 2021 festival:
    - **Rimmer, B.,** Bolnykh, I., Dutton, L., Menger, F., Sharp, L. Quality of life in adults with low-grade gliomas: a systematic review. In abstracts for NCRI festival 2021 (https://abstracts.ncri.org.uk/) (Poster)
    - Dutton, L., **Rimmer, B.,** Lewis, J., Burns, R., Gallagher, P., Williams, S., Araujo-Soares, V., Finch, T., Sharp, L. Self-management support needs and barriers for adults living with grade II and III brain tumours: findings from the Ways Ahead study. In abstracts for NCRI festival 2021 (https://abstracts.ncri.org.uk/) (Poster)
- British Psycho-Oncology Society (BPOS) 2022 conference:
    - **Rimmer, B.,** Balla, M., Dutton, L., Lewis, J., Williams, S., Burns, R., ... & Sharp, L. (2022). Self-management strategies used by low-and intermediate-grade glioma patients: a directed content analysis. In Psycho-Oncology (Vol. 31, pp. 10-11). 111 River St, Hoboken 07030-5774, NJ USA: Wiley. (Oral)
    - **Rimmer, B.,** Dutton, L., Lewis, J., Williams, S., Burns, R., Gallagher, P., ... & Sharp, L. (2022). Barriers and facilitators to the provision of support for adults living with a brain tumour: a qualitative study of healthcare professionals. In Psycho-Oncology (Vol. 31, pp. 22-23). 111 River St, Hoboken 07030-5774, NJ USA: Wiley. (Poster)

- British Psycho-Oncology Society (BPOS) 2023 conference:
    - **Rimmer, B.,** Balla., M., Dutton, L., Williams, S., Araújo-Soares, V., Gallagher, P., Finch, T., Lewis, J., Burns, R., Menger, F., Sharp, L. (2023) Barriers and facilitators to self-management in people living with a low-grade glioma. In abstracts for BPOS 2023 conference (https://www.delegate-reg.co.uk/bpos2023/programme) (Oral)
    - **Rimmer, B.,** Balla, M., Dutton, L., Burns, R., Araújo-Soares, V., Finch, T., Lewis, J., Gallagher, P., Williams, S., Menger, F., Sharp, L. (2023) "It's a delicate dance" How informal caregivers experience the role and responsibilities of supporting someone living with a low-grade glioma. In abstracts for BPOS 2023 conference (https://www.delegate-reg.co.uk/bpos2023/programme) (Poster)
- International Psycho-Oncology Society (IPOS) 2023 conference:
    - **Rimmer, B.,** Balla, M., Dutton, L., Lewis, J., Burns, R., Gallagher, P., Williams, S., Araújo-Soares, V., Finch, T., Sharp, L. "A constant black cloud" the emotional impact of informal caregiving for low-grade glioma patients. In: IPOS 2023 Abstracts Booklet. Journal of Psychosocial Oncology Research and Practice 5(S1):e111, September 2023. (Oral)
    - **Rimmer, B.,** Dutton, L., Williams, S., Lewis, J., Gallagher, P., Finch, T., Burns, R., Araújo-Soares, V., Menger, F., Sharp, L. "It changes everything" understanding how people experience the impact of living with a low-grade glioma. In: IPOS 2023 Abstracts Booklet. Journal of Psychosocial Oncology Research and Practice 5(S1):e111, September 2023. (Oral)
    - **Rimmer, B.,** Brown, M., Sotire, T., Beyer, F., Bolnykh, I., Balla, M., Richmond, C., Dutton, L., Sharp, L. Characteristics and components of self-management interventions for improving quality of life in cancer survivors: a systematic review. In: IPOS 2023 Abstracts Booklet. Journal of Psychosocial Oncology Research and Practice 5(S1):e111, September 2023. (Oral)
    - **Rimmer, B.,** Murrell, A.J., Dutton, L., Lewis, J., Burns, R., Gallagher, P., Williams, S., Araújo-Soares, V., Finch, T., Sharp, L. The nature and quality of support from informal networks for informal caregivers of low-grade glioma patients: a qualitative analysis within the Ways Ahead study. In: IPOS 2023 Abstracts Booklet. Journal of Psychosocial Oncology Research and Practice 5(S1):e111, September 2023. (Poster)

I have also disseminated this work to key stakeholder groups; this included making the findings accessible for lay audiences. Key dissemination activities are listed below:

- Recorded a podcast episode for the Brain Tumour Charity's 'Let's talk about brain tumours' podcast – Episode 51 'A spotlight on the Ways Ahead project': https://spotify.link/IVwXrkSB9Db
- Contributed to three blogs on the Brain Tumour Charity's website, disseminating project outputs for a lay audience:
    - https://www.thebraintumourcharity.org/news/research-news/the-ways-ahead-project-finding-better-ways-to-support-people-with-their-diagnosis/

  - https://www.thebraintumourcharity.org/news/research-news/it-changes-everything-the-impact-of-living-with-a-lower-grade-glioma/
  - https://www.thebraintumourcharity.org/news/research-news/its-a-delicate-dance-the-impact-of-caring-for-someone-with-a-lower-grade-glioma/
- Invited keynote speaker to open the session on ‘Self-management in brain tumours’ at National Brain Tumour Day 2024 in Uppsala, Sweden
- Twice invited speaker to present findings on self-management and quality of life in people with lower-grade gliomas at the European Association of Neuro-Oncology (EANO) 2025 educational day and meeting in Prague, Czech Republic.
- Presented findings at Northeast Speech and language therapy research update meeting, July 2022
- Presented findings to Northeast aphasia study group, July 2022
- Presented findings at a Newcastle University Centre for Cancer seminar, November 2021
- Presented findings as a guest lecture on ‘The importance of qualitative methods in healthcare research’ to Masters students at Atlantic Technological University (2022 and 2023)

Finally, this work informed the development of a recently awarded NIHR grant for the following call: RfPB Under-represented disciplines and specialisms highlight notice: Allied Health Professionals

- **Co-applicant:** National Institute for Health and Care Research (NIHR208175) – REsearching Speech and Language Therapy for adults living with brain tumours (RESuLT_BT): awarded 17.02.2025, 24 months, £197,190.

Contents

List of abbreviations

HCP = Healthcare professional

HGG = High-grade glioma

HRQoL = Health-related quality of life

IADL = Instrumental activities of daily living

IC = Informal caregiver

ICF = International classification of functioning, disability, and health

LGG = Lower-grade glioma

NCI = National Cancer Institute

NHS = National Health Service

NICE = National Institute for Health and Care Excellence

NIHR = National Institute for Health and Care Research

NPT = Normalisation process theory

PIS = Participant information sheet

PP = Published paper

PPI = Patient and public involvement

PRISMS = Practical reviews in self-management support

QoL = Quality of life

TIDieR = Template for intervention description and replication

List of tables

Chapter 1: The prospects for supported self-management for people with lower-grade gliomas

1.1 Background and rationale

1.1.1 The landscape of cancer 'survivorship'

Continuous advances in the treatment of cancer, screening and early diagnosis initiatives, and an ageing population, means there is a growing number of cancer survivors (i.e. people living with or beyond cancer[1]) in developed countries[2,3]. Although prognoses are improving, cancer survivors can face long-term physical and psychosocial consequences of the diagnosis and its treatment (e.g. fatigue, motor dysfunction, anxiety and depression)[4,5]. This has lasting implications for their health and well-being, with the potential to impact occupational roles (e.g. work retention)[6] and social relationships[7]. Combined, the lasting effects and growing number of cancer survivors influence the substantial, and increasing, burden of cancer survivorship on health services[1].

In 2010, the National Cancer Survivorship Initiative[8] was established in the United Kingdom to understand where support is needed for people living with and beyond cancer and identify the best ways to meet these needs. This initiative was driven by the recognition that past 'models' of patient follow-up care were clinically focused on the detection of cancer recurrences, neglecting the long-term consequences of a cancer diagnosis and its treatment[1,9]. This inspired a goal to support cancer survivors to live as healthy as possible, for as long as possible, with five proposed shifts in care towards: (1) greater focus on recovery, health and well-being after cancer treatment; (2) holistic assessment with personalised care planning; (3) supported self-management that recognises individual needs and preferences; (4) tailored support that facilitates early recognition of the consequences of cancer and its treatment; and (5) routine measurement of patient-reported outcomes[8]. These interests are reflected internationally. Since its inception in 2007, the international Journal of Cancer Survivorship has been an influential platform for evidence related to cancer survivorship. An overview of the Journal's outputs indicate traction for the proposed shifts in follow-up care, with a surge in published research (between 2007 and 2020) investigating quality of life (QoL), care plans, physical activity, symptom management, and psychosocial care[10]. Still, it is crucial to identify where gaps persist, to recognise where more can still be done to improve support for people living with and beyond cancer.

1.1.2 Introducing self-management

This thesis was inspired by the vision to shift from clinical approaches to follow-up care towards empowering people to engage in self-management[8]. In cancer, self-management has been defined as the "*awareness and active participation by the person in their recovery, recuperation, and rehabilitation to minimise the consequences of treatment, promote survival, health and well-being*"[11]. Social cognition theories suggest that self-management is underpinned by an individual's self-efficacy (i.e. their belief in their capacity to execute the necessary behaviours)[12]. The ways that people can engage in self-management are extensive, including the use of support (e.g. community support groups), equipment/resources (e.g. medication organisers), acquiring knowledge and information (e.g. leaflets about their condition), and self-monitoring (e.g. awareness of health and emotions); this is explored further in chapter 4.

Though people need to be willing and motivated to engage in self-management, self-management constitutes a collective activity and should not be the sole responsibility of the individual[13]. This is because cancer survivorship can come with healthcare demands (e.g. managing medication and follow-up appointments), long-term effects on health and well-being, and the need to re-establish (or establish new) routines and social roles[14]. Further, cancer and its treatment can leave people feeling vulnerable, with threats to their self-identity and self-confidence[15]. Hence, supported self-management is important because self-efficacy (and thus, self-management) can be empowered through training, education, and skill development[12]. Therefore, this thesis focuses on *supported* self-management, acknowledging that healthcare professionals (HCPs), and informal caregivers (IC) (i.e. close family and friends that provide ongoing care and support, without pay) have important roles in facilitating self-management. What these roles are, and how the responsibilities are experienced is explored further in chapters 5 and 6.

1.1.3 Current and future directions for supported self-management

Improving support for self-management is of great interest to clinical and research communities. To illustrate the multi-dimensional nature of supported self-management, the practical reviews in self-management support (PRISMS) taxonomy[16,17] presents 14 different ways that self-management can be supported (e.g. provide information about condition and its management; training for psychological strategies). This framework can be used to aid researchers with the design and description of a self-management intervention, ensuring that such interventions equip people with the set of skills (e.g. problem solving; action planning) required to self-manage[18]

Existing self-management interventions often focus on addressing the physical effects of, or adjustment to, the diagnosis and its treatment. There is a growing evidence base, including several systematic reviews, to support the effectiveness of self-management interventions for improving outcomes, such as QoL and self-efficacy in cancer survivors[19–21]. There is also a systematic review in non-cancer populations, which suggests that self-management interventions can reduce healthcare utilisation (e.g. hospitalisation rates), without compromising health outcomes[22]. While the presented evidence suggests that supporting self-management could be worthwhile[23], there is substantial heterogeneity in the active ingredients of self-management interventions[24]. This has implications for understanding what makes an intervention effective and hinders translation into clinical practice.[1]

A report from the 2019 National Cancer Institute (NCI) cancer survivorship workshop[25] suggests that more needs to be done for the promotion and support of self-management. In 2021, a ‘call to action’ for self-management in cancer care identified six priority actions to ensure self-management support is integrated as part of high quality, person-centred care, with the aim to optimise health outcomes and expedite recovery[18]: (1) Prepare patients, survivors, and caregivers for active involvement in care; (2) Embed self-management support into everyday practice and care pathways; (3) Train healthcare providers with knowledge and skills for providing self-management support; (4) Foster accountability for self-management support as a performance metric in value-based care; (5) Advance evidence on the effectiveness of self-management and self-management support in cancer populations; and (6) Expand reach and access to self-management support programmes across care sectors. In addition, Foster et al.[26] presented several ‘pressing questions’ requiring investigation to inform policy and practice for supported self-management in cancer care (e.g. effectiveness, type and timings of support, identifying those in need of support). This shows the extensive groundwork required to inform the development and implementation

---

[1] Chapter 6.1.2 expands on how a systematic review from Ways Ahead on the characteristics and components of self-management interventions for cancer survivors aimed to overcome this[27] (*Appendix B.4*).

of supported self-management in cancer care. However, current efforts have largely focused on breast or prostate cancer survivors[27], informing a need to research rare and underserved cancers to understand and address disparities among cancer survivors[25].

1.1.4 Incidence and burden of primary brain tumours

Brain tumours can be malignant (approx. 30% of new cases) or non-malignant (approx. 70%)[28]. They comprise over 100 histologically distinct subtypes, as classified by the fifth edition of the World Health Organisation classification of tumours of the central nervous system[29]. Global cancer statistics report that in 2022, there were an estimated 20 million new cancer diagnoses, worldwide. Approximately 321,000 (1.6%) of these were new diagnoses of primary malignant brain and central nervous system tumours; this is modest compared to the most common cancers, such as lung (12.4% of new diagnoses), breast (11.6%), and colorectal (9.6%)[30]. The age-standardised incidence rates of malignant brain tumours in 2022 were 3.9 (males) and 3.1 (females) per 100,000 population[30], further indicating the rarity of this type of cancer.

The cornerstone of treatment for malignant brain tumours is surgical resection, where possible, with subsequent standard of care being a combination of chemotherapy and radiotherapy[31]. It is important to note that these tumours are considered incurable, meaning that treatment can only prolong survival[31]. This is distinct from other cancers, which are typically treated with curative intent if diagnosed at an early enough stage. In cancer, chemotherapy and radiotherapy treatment modalities have been associated with wide-ranging side effects, including fatigue, nausea, and diarrhoea[32,33]. A brain tumour diagnosis can lead to several, often tumour-specific, symptoms and impairments, such as seizures, cognitive impairment, mood and personality changes, speech, language, and communication difficulties, and headaches[34–36]. Thus, people with brain tumours could be vulnerable to both the consequences of cancer (and its treatment) and an acquired brain injury. These deficits can be focal and influenced by the tumour location; the impact of life with a brain tumour is expanded in chapter 3. Overall, the potential symptom burden experienced by people with brain tumours suggests that the challenges they face are likely to be different - at least to some extent - to other cancers. For example, impaired cognitive function (e.g. memory, concentration deficits) could affect medication management, or seizures could influence ability to drive. This raises two questions about self-management interventions for people with brain tumours: (1) are existing interventions for cancer survivors applicable to the needs of people with brain tumours; and (2) are such interventions accessible for people with substantial impairments?

1.1.5 Focusing on people with lower-grade gliomas

There are several types of primary brain tumour, including, for example, gliomas, embryonal tumours, meningiomas, and haematolymphoid tumours[29]. The most common malignant tumours are gliomas[28], which can be grade 2, 3 or 4, distinguished by their expected prognosis and resectability; grade 4 tumours (e.g. glioblastoma) are highly malignant and expected to lead to death in relatively short periods of time[29]. In this thesis, the focus is on ‘lower-grade gliomas’ (LGG), which account for approximately 15% of all gliomas[28], encompassing here grade 2 astrocytoma and grade 2 or 3 oligodendroglioma[29].

People with LGG are typically diagnosed in their 30s and 40s[37], at a crucial time in working and family lives. Since treatment with curative intent is not available for these tumours[31], a LGG diagnosis will eventually progress to a high-grade glioma (HGG)[38]. Still, following diagnosis, people with LGG can continue to live for five to 15 years, depending on the tumour subtype, with shorter progression-free survival for people with astrocytomas, compared to oligodendrogliomas[28,39]. People with LGG may, therefore, live long-term with a ‘terminal’ diagnosis, including the effects of the condition and its treatment, which could impact their ability to recuperate and resume daily activities[40]. For example, the age at diagnosis, and potentially long-term prognosis, means returning to work may be a priority for people with LGG, for personal, social, or financial reasons[41], yet their ability or desire to return to work may be hindered by the symptom burden and uncertainty regarding their prognosis. This makes people with LGG distinct from other 'curable' cancers, and people with HGG, who typically have much shorter prognoses[42]. A survey of HCPs' views on the rehabilitation needs of people with brain tumours suggested that poor survival prognosis was a prominent challenge linked to self-management[43]. Consequently, the potential need for long-term management of the impact of living with a LGG suggests that supported self-management may be a worthwhile consideration for this population. However, first it is important to identify the extent to which people with LGG have the capacity to engage in self-management and develop an understanding of the challenges they face around self-management.

Despite general progress in directions for follow-up care and the understanding of QoL in cancer survivors[10], clarity in this understanding is lacking for people with LGG, particularly concerning their lived experiences. Further, there is a paucity of evidence concerning self-management in people with brain tumours, with minimal evidence specifically focused on people with LGG. Where evidence exists, qualitative studies have reported a narrow focus on coping[44], adapting[40], or access to support services[45], and explored a limited time since diagnosis (i.e. <6 months)[40] or included multiple types of brain tumours with varying prognoses[44,45]. Therefore, there is a pertinent gap to explicitly understand the need and potential for supported self-management in people with LGG. It is a necessity to shed light on the lived experiences of this currently underserved population, so that research and clinical communities can work to understand and improve their QoL.

1.2 Thesis overview

1.2.1 Research questions

This thesis will address the following three research questions:

1. What are the lived experiences of people living with a LGG?
2. To what extent is self-management feasible for people with LGG?
3. How can self-management be supported for people with LGG?

1.2.2 Aims and objectives

The overall aim of this thesis was to understand the lived experiences of people with LGG and the potential for supported self-management, from multiple perspectives. Within this, the specific objectives were to identify and understand:

1. The impact of life with a LGG.

2. How people with LGG currently engage in self-management.

3. The current and potential roles of ICs and HCPs in supporting self-management for people with LGG.

4. The challenges faced by ICs and HCPs in supporting self-management for people with LGG.

1.2.3 Supporting chapters and papers

The thesis is formed of seven chapters, including six core published papers (PP) (*Table 1*).

Table 1. Core published papers

Paper	Title	Journal[a]	Article type (interview set)	Research objective(s)
PP1	Health-related quality of life in adults with low-grade gliomas: a systematic review.	Quality of Life Research	Systematic review of quantitative studies	1
PP2	"It changes everything" Understanding how people experience the impact of living with a lower-grade glioma.	Neuro-Oncology Practice	Qualitative (People with LGG)	1
PP3	Identifying and understanding how people living with a lower-grade glioma engage in self-management.	Journal of Cancer Survivorship	Qualitative (People with LGG)	2
PP4	Barriers and facilitators to self-management in people living with a lower-grade glioma.	Journal of Cancer Survivorship	Qualitative (People with LGG)	2
PP5	"It's a delicate dance" How informal caregivers experience the role and responsibilities of supporting someone living with a lower-grade glioma.	Neuro-Oncology Practice	Qualitative (ICs of people with LGG)	3, 4
PP6	Understanding supported self-management for people living with a lower-grade glioma: implementation considerations through the lens of normalisation process theory.	Health Expectations	Qualitative (HCPs and People with LGG)	3, 4

[a]Full details are provided on page iv.

Throughout this thesis, seven additional published papers are alluded to, where appropriate, to provide additional context; the abstracts of the additional papers are presented in *Appendix B*. This thesis, including all 13 core and additional papers, was informed by work on the multi-method Ways Ahead project[46] (*Appendix B.1*). The subsequent chapters are organised as follows.

Chapter two outlines the methodology of the Ways Ahead project to provide an overview of how this work was conducted.

Chapter three aims to examine the impact of life with a LGG, through a systematic review of quantitative studies on health-related quality of life (HRQoL) in people with LGG, and a qualitative analysis of how people experience the impact of life with a LGG. This chapter includes **PP1**[47] and **PP2**[48].

Chapter four explores how people with LGG currently engage in self-management, through qualitative analyses that identify the different self-management strategies that are used, and the barriers and facilitators to engagement in self-management. This chapter includes **PP3**[49] and **PP4**[50].

Chapter five looks to understand how ICs experience the role and responsibilities of supporting people with LGG, through a qualitative analysis of the types of support provided, challenges faced, and implications for the care recipient's self-management. This chapter includes **PP5**[51].

Chapter six considers the challenges of implementing self-management support for people with LGG, through the lens of normalisation process theory (NPT). This involves a qualitative analysis which explores the alignment in experiences and perspectives of HCPs and people with LGG. This chapter includes **PP6**[52].

Chapter seven presents a discussion of the body of work, including a summary of the main findings, overall strengths and limitations, future research and clinical implications, and conclusions.

Chapter 2: Methodology of the Ways Ahead project

This chapter focuses on the qualitative phase of the Ways Ahead project[2], which involved people with LGG, ICs, and HCPs who support people with brain tumours. This work provided the data included in PP2-PP6[48–52]. This work was descriptive in design, with a constructivist worldview[53], and sought to advance an area where little is known by recognising the diverse and subjective experiences of participants[54]. Ways Ahead was reviewed and approved by the Wales Research Ethics Committee (REC ref: 20/WA/0118); Health Research Authority ethical approval documentation can be found in *Appendix C*.

I commenced the Ways Ahead project with an academic background in Health Psychology and experience in qualitative research on QoL in cancer survivorship, though limited knowledge on the clinical aspects of brain tumours; I reflect on the implications of my role and experience in chapter 7.2.3. Patient and public involvement (PPI) was consistently considered throughout Ways Ahead, engaging the Brain Tumour Charity research involvement network and Maggie's centre brain tumour network ("Maggie's Brains") to ensure PPI opportunities were widely accessible. Details of the conducted PPI activities are presented in section 2.4.

The chapter is organised as follows: participant eligibility; participant recruitment; data collection; PPI.

Disclaimer: In the initial stages of the project, I worked alongside a Research Associate, Dr Lizzie Dutton. Their involvement included early PPI activities (specified in section 2.4) and conduct of some semi-structured interviews (n=19 of 72). For full details of how each member of the research team contributed to the Ways Ahead project, see *Appendix A*.

2.1 Participant eligibility

People with LGG could take part without their IC also taking part (or having any IC); likewise, ICs could take part without their care recipient having taken part.

People with LGG:

People with LGG were eligible if they:

- Were aged 18 years or older at diagnosis.
- Resided in the United Kingdom.
- Had a grade 2 astrocytoma or grade 2 or 3 oligodendroglioma, based on histology or molecular features[29].
- Had completed primary treatment or were stable under observation.

People with LGG were excluded if they:

- Were non-English speaking to the extent that they were unable to take part in an interview, as an interpreter was not used.
- Were judged by their clinical team to have severe psychological or social problems, which meant that an interview would risk causing further distress.

---

[2] PP1[47] was a systematic review of quantitative studies; full methods can be found at: https://www.crd.york.ac.uk/PROSPERO/view/CRD42021231368

- Were judged by their clinical team to have cognitive and communication impairments that were so significant, they would be unable to take part in an interview.[3]

Informal caregivers:

Informal caregivers were eligible if they:

- Were aged 18 years or older.
- Resided in the United Kingdom.
- Were family-members or friends who currently, or had in the past five years, informally cared for someone with a LGG (specifically, a grade 2 astrocytoma or grade 2 or 3 oligodendroglioma[29]).
    - Individuals who were a caregiver in the past five years, but who were bereaved at the time of recruitment, were therefore eligible.

Healthcare professionals:

Healthcare professionals were eligible if they:

- Practiced within the United Kingdom.
- Were a member of a relevant multidisciplinary team, involved in the care and support of adults with brain tumours.
    - This included, but was not limited to, Consultant Clinical Oncologists, Clinical Nurse Specialists, and Allied Healthcare Professionals (e.g. Occupational Therapist, Speech and Language Therapist).
- **OR** were involved in the support of adults with brain tumours outside of National Health Service (NHS) care pathways.
    - This included, but was not limited to, social workers, benefits advisors, and counsellors.

2.2 Participant recruitment

The Ways Ahead project was adopted on the National Institute for Health and Care Research (NIHR) Clinical Research Network portfolio (Central Portfolio Management System ID: 44917; *Appendix C*). Site set-up and collaboration was arranged with four NHS sites across the United Kingdom: Newcastle upon Tyne Hospitals NHS Foundation Trust; The Christie NHS Foundation Trust; South Tees Hospitals NHS Foundation Trust; and NHS Lothian. Each NHS site had an established multidisciplinary team to support people with brain tumours, and a relevant clinical site lead. Recruitment was facilitated through additional collaboration with the Brain Tumour Charity to recruit through their networks.

For both recruitment pathways (i.e. NHS sites and the Brain Tumour Charity), an invitation letter and participant information sheet (PIS) was shared with potentially eligible individuals; this provided a brief introduction to the study and the researchers conducting the interviews, as well as contact details for the study team. There were different PIS for each participant group to portray differences in why the person was being asked to take part, what taking part involves, and benefits and risks to taking part. To register an interest in taking part, individuals were asked to call or email the study team; each person was subsequently called to confirm eligibility, afford the

---

[3] There were no people with LGG excluded based on severe psychological, social, cognitive or communication problems.

opportunity to ask questions, and if eligible and willing to proceed, arrange a convenient date and time for interview. Individuals could request a call back if they needed more time to process the information and decide whether to take part. Interview arrangements were confirmed in an email to support those with memory difficulties.

Purposive sampling was used to ensure sample heterogeneity and elicit a broad range of views and experiences. Recruitment was conducted between August 2020 and May 2022; recruitment continued until the study team judged that sufficient data had been generated across each interview set to support and understand each research question[55].

Detailed below is how the purposive sampling strata and participant recruitment varied for each interview set; see *Appendix D* for examples of the invitation letters and PIS.

People with LGG:

The purposive sampling strata for people with LGG were age, sex, diagnosis, and time since diagnosis (1-5, 6-10, >10 years). This helped capture the views of people with different subtypes of LGG, diagnosed at different points in their working and family lives, and at different timepoints in the management of their condition. For recruitment through NHS sites, people with LGG were identified from their medical records and given a PIS by a healthcare professional. For recruitment through the Brain Tumour Charity, a study advertisement was disseminated through their research involvement networks with the PIS attached.

Informal caregivers:

The purposive sampling strata for ICs were age, sex, and relationship with care recipient (e.g. spouse, sibling, parent). This helped capture the experiences of ICs from a broad range of relationship dynamics. To be sensitive in the language used, individuals were approached using the terms ‘family-member or friend’ (rather than ‘carer’). For recruitment through NHS sites, known ICs of people with LGG were given a PIS by a healthcare professional. Recruitment through the Brain Tumour Charity was the same as for people with LGG.

Healthcare professionals:

Since people with LGG require multidisciplinary management, the purposive sampling strata for HCPs were healthcare profession and geographical location (clinical centre). This helped capture the perspectives of many relevant disciplines and understand how HCPs’ perspectives and healthcare services might vary across the United Kingdom. For recruitment through NHS sites, the principal investigator at each site gave the PIS to HCPs within their respective multidisciplinary teams. For recruitment through the Brain Tumour Charity, a study advertisement was disseminated through their HCP network with the PIS attached.

2.3 Data collection

One-to-one semi-structured interviews were conducted remotely via telephone or video call (e.g. Zoom or Teams), as per participant preference. Since data collection occurred during the COVID-19 pandemic, face-to-face interviews were not an option; the impact of COVID-19 on Ways Ahead is discussed in chapter 7.2.2. Immediately prior to each interview, audio-recorded consent was acquired. This confirmed that participants understood, for example, that the interview would be audio-recorded and anonymised quotes may be used in research and publications. Once consent was obtained, each participant completed an ‘About you’ form to collect key demographics; the demographic questions asked varied appropriately for each interview set.

Each interview set followed a topic guide, which were informed by the literature and expert knowledge, and modified following discussions with HCPs within the study team. The topic guides for people with LGG and ICs were modified further following review by a brain tumour PPI panel (which included people with brain tumours, n=3; and ICs n=3), ensuring comprehensive coverage of relevant topics across each topic guide (details below). Throughout data collection, each topic guide was used flexibly, with variation in the order of topics, depending on what the participant chose to speak about; probing questions were used, where necessary, to explore topics further. Participants were afforded opportunities to raise any additional issues of importance to them; any new issues raised were added to the relevant topic guide and explored in subsequent interviews. During each interview, field notes were taken for reference.

Detailed below is how data collection procedures varied for each interview set; see *Appendix D* for an example of the consent form, demographics and medical record forms, and post-interview sheet, as well as each final topic guide.

People with LGG:

The demographics collected from people with LGG encompassed age, sex, employment and relationship status, years of education, and number of dependents, as well as clinical and tumour-related information of diagnosis (date), tumour location and laterality, treatment (dates), IDH1-mutation and 1p19q codeletion status. Participants recruited through the Brain Tumour Charity were asked for their main treatment hospital and consultant; with participant consent, the treating hospitals of all people with LGG were asked to confirm the clinical and tumour-related information.

To support participants who may have had cognitive impairments (e.g. memory and processing speed limitations), an interview topic overview was offered in advance. In the interview, ample time was allowed for the participant to consider and respond to each question.

To begin the interview, participants were invited to broadly reflect on life following diagnosis. Then, their experiences of different areas of functioning that may have been affected by the tumour and its treatment (e.g. cognitive, physical, emotional) and the impact on aspects of day-to-day life (e.g. work, hobbies, relationships) were explored. For each area, participants were asked how they were impacted, how this was managed and any related challenges, and what and when support was needed or received. At the end, participants were asked for initial thoughts on desired support and design preferences for a self-management intervention. Finally, each participant was asked if they wanted to tell the interviewer anything else. After each interview, participants were offered a £20 voucher to thank them for their time, and a post-interview sheet with information about project next steps and details of relevant charities and helplines, should they require support. Interviews were a mean of 102 minutes long (range 54-167 minutes).

Informal caregivers:

The demographics collected from ICs encompassed age, sex, employment and relationship status, years of education, number of dependents, and relationship to the care recipient.

To begin the interview, participants were invited to broadly reflect on their experiences of supporting someone with a LGG. Then, their views on how the care recipient has been impacted by the tumour and its treatment, and their own impact and support needs across several areas (e.g. emotions, family, transport) were explored. For each area, participants were asked about their caregiving responsibilities and any challenges faced, as well as what, and when, they or the care recipient needed or received (in)formal support. At the end, participants were asked for initial thoughts on desired support and design preferences for a self-management intervention. Finally, each participant was asked if they wanted to tell the interviewer anything else. After each interview, ICs were also offered a £20 voucher to thank them for their time, and a similar post-interview sheet, with wording adjustments to be appropriate to ICs. Interviews were a mean of 85 minutes long (range 54-110 minutes).

Healthcare professionals:

The demographics collected from HCPs encompassed healthcare profession, geographical region, and years working with people with brain tumours.

To begin the interview, participants were invited to broadly reflect on their role in supporting people with brain tumours. Then, their views on the support needs of people with LGG, how these needs are identified, and what support is available following primary treatment, were explored. Participants were also asked about their perception of, and role in supporting, self-management, and whether they face any challenges in providing support. Self-management was defined in the interview for participants who were not familiar with the term. At the end, participants were asked for initial thoughts on design preferences for a self-management intervention. Finally, each participant was asked if they wanted to tell the interviewer anything else. After each interview, HCPs were thanked but not reimbursed for their time, and verbally informed about project next steps. Interviews were a mean of 72 minutes long (range 48-93 minutes).

2.4 Patient and public involvement

PPI activities were carefully planned across design, analysis, and dissemination stages of the project, so that the research was being conducted *with* the public, not *for* them.

Design:

Dr Dutton received input from people with brain tumours and ICs on the acceptability of the protocol and importance of the research questions, appropriateness and sensitivity of the PIS. I followed this up by seeking input on the relevance and comprehensiveness of the topic guides, and accessibility of the project website. Following each PPI input, appropriate modifications were made and feedback outlining the changes was shared with the charity networks to keep people informed on how their suggestions have been actioned.

Analysis:

Upon completion of data collection, the interview findings were sense checked in two face-to-face and one online discussion group with people with brain tumours and ICs. In these groups, findings were presented, then people were invited to reflect on the findings and identify what they saw as key messages for dissemination. These discussions helped to co-create a lay summary of interview findings that has been disseminated across the Brain Tumour Charity and Maggie’s centre networks.

Dissemination:

I have continued to maintain the project website (research.ncl.ac.uk/waysahead/) to provide a platform for people to learn more about the project and keep updated with progress and outputs. In addition to the summary of findings, I have collaborated with the Brain Tumour Charity to release three blogs and a podcast episode to disseminate the project outputs for a lay audience (see ‘Outputs during PhD candidature’). The podcast episode included an interview-style conversation with a person living with a brain tumour, about the project aims, findings, and projected impact.

Chapter 3: The impact of life with a lower-grade glioma

This chapter introduces the impact of living with a brain tumour, both on HRQoL and the implications on day-to-day life, before considering when people may require support. This is important for developing an understanding of the challenges that people with LGG may need to learn to self-manage. The first publication (PP1[47]) presented in this chapter is a systematic review of quantitative studies, which aimed to examine HRQoL in adults with LGG. The second publication (PP2[48]) presents qualitative findings from interviews with people with LGG within Ways Ahead, which aimed to explore how people experience the impact of living with a LGG.

The chapter is organised as follows: introduction to the impact of living with a brain tumour; PP1; PP1 commentary; PP2; PP2 commentary; chapter summary.

3.1 The impact of living with a brain tumour

3.1.1 Health-related quality of life

HRQoL is a multidimensional construct that reflects an individual's level of control over their health, and ability to function in day-to-day life; this is more focused than QoL which concerns an individual's overall well-being[56]. HRQoL has been defined in cancer as "*the subjective perceptions of the positive and negative aspects of cancer patients' symptoms, including physical, emotional, social, and cognitive functions and, importantly, disease symptoms and side effects of treatment*"[57]. In people with limited survival expectations, minimising the potential adverse consequences of the cancer and its treatment on HRQoL is a crucial consideration[58].

As introduced in chapter 1.1.4, people with brain tumours can experience wide-ranging, often tumour-specific, symptoms and impairments. HRQoL can be measured with generic measures (i.e. applicable across multiple cancers or other populations, such as SF-36[59], EORTC QLQ-C30[60]) or those specifically developed for people with brain tumours (e.g. EORTC QLQ-BN20[61], FACT-Br[62]). In a consensus meeting held by a NCI neuro-oncology working group of researchers in 2018, it was determined that the core patient-reported outcomes for people with brain tumours should be pain, difficulty communicating, perceived cognition, seizures, symptomatic adverse events, physical, role, and social functioning[63]. This consensus improves the quality and generalisability of research into HRQoL by standardising the priority constructs for patient care in people with brain tumours[64]. The perceived ability to function in day-to-day life for people with brain tumours has been significantly associated with these core outcomes (e.g. cognitive and motor impairment)[65]. In PP1[47], I present the rationale for developing a comprehensive, synthesised understanding of HRQoL in people with LGG.

3.1.2 Implications for day-to-day life

There are various means to highlight the impact of a brain tumour; while sustaining HRQoL is of high importance, it is not the only useful outcome for indicating levels of functioning and well-being in people with brain tumours. For a more comprehensive understanding of people's QoL, it is valuable to also consider their abilities to engage in basic activities of daily living (e.g. dressing, bathing) and instrumental activities of daily living (IADL)[66]. IADLs pertain to the activities that allow an individual to live independently in a community, such as cooking, cleaning, transportation, managing finances[67]. Recently, the EORTC IADL-BN32[68] was developed to measure IADLs in people with brain tumours; this contains seven sub-scales across a wide range of IADLs (e.g. domestic life, technology literacy). An example question includes "Have you had difficulty managing your own medication?"; this provides useful context for a person's ability to self-manage. The assessment of IADLs should be complementary to HRQoL assessments, as findings showed that people with cognitive impairments had significantly more IADL problems compared to those without such impairment[68]. Hence, identifying problems or challenges with IADL that an individual experiences could help contextualise what QoL means to that individual.

The international classification of functioning, disability, and health (ICF) is the international standard for describing health and disability[69]. Within this, the domains comprise ‘environmental factors’ (e.g. ‘relationships’, ‘services’, ‘systems’) and 50 categories of ‘activities and participation’. Khan et al.[70] found that people with brain tumours report problems with 44 of these categories, most commonly, ‘handling stress’, ‘driving’, ‘doing housework’, and ‘remunerative employment’. These problems have been linked with HRQoL, particularly the presence of seizures, and have ramifications for people feeling able to live independently[71,72]. Beyond this, people with brain tumours often need to rebuild social connections following their diagnosis, due to loss of pre-illness networks (e.g. work colleagues)[73]. Thus, both functional impairments and changes in environment can have implications for maintaining social networks. Understanding the extent of the impact on social functioning is important because loss of social groups has been associated with higher levels of depression and anxiety in people with brain tumours[74]. In PP2[48], I present the rationale for why there is a need to understand how QoL is experienced, covering issues such as cognitive function and seizures, and what it means to the daily lives of people with LGG (e.g. work, relationships, social activities).

3.1.3 When an impact becomes a support need

A support need is when something needs to be managed and/or requires adjustment; for example, if an individual needs to take more breaks to manage their fatigue, then fatigue would become a support need. Still, these can be considered *met* or *unmet* needs. A *met* need is when the support required to manage the problem has been sufficiently fulfilled, or the problem is mild enough to be self-managed without ‘formal’ (external) support. Alternatively, an *unmet* need is when support is required but not yet fulfilled, and the individual feels unable to self-manage. Support needs can relate to medical or non-medical matters, spanning the physical, psychological, social, or economic consequences of living with a cancer diagnosis. The support required could pertain to a need for information about the condition, self-management strategies, or access to specialist professionals. There are different approaches to assessing the support needs of people with brain tumours; needs can be inferred through HRQoL measures[75,76], or explicitly indicated through completion of measures to assess unmet needs[77]. However, current approaches have limitations, particularly concerning their ability to contextualise the problem in relation to the implications on day-to-day life, as expanded in chapter 7.4.1. The areas and contexts in which people with LGG may require support are explored in PP1[47] and PP2[48].

3.2 PP1: Health-related quality of life in adults with low-grade gliomas: a systematic review

Rimmer, B., Bolnykh, I., Dutton, L., Lewis, J., Burns, R., Gallagher, P., Williams, S., Araújo-Soares, V., Menger, F., & Sharp, L. (2023). Quality of Life Research, 32(3), 625–651.

Quality of Life Research (2023) 32:625–651
https://doi.org/10.1007/s11136-022-03207-x

REVIEW

Health-related quality of life in adults with low-grade gliomas: a systematic review

Ben Rimmer[1] · Iakov Bolnykh[2] · Lizzie Dutton[1] · Joanne Lewis[3] · Richéal Burns[4] · Pamela Gallagher[5] · Sophie Williams[3] · Vera Araújo-Soares[1,6] · Fiona Menger[7] · Linda Sharp[1]

Accepted: 18 July 2022 / Published online: 6 August 2022

Abstract

Purpose Low-grade glioma (LGG) patients may face health-related quality-of-life (HRQoL) impairments, due to the tumour, treatment and associated side-effects and prospects of progression. We systematically identified quantitative studies assessing HRQoL in adult LGG patients, for: aspects of HRQoL impacted; comparisons with non-cancer controls (NCC) and other groups; temporal trends; and factors associated with HRQoL.

Methods MEDLINE, CINAHL, Embase, PubMed, and PsycINFO were systematically searched from inception to 14th September 2021. Following independent screening of titles and abstracts and full-texts, population and study characteristics, and HRQoL findings were abstracted from eligible papers, and quality appraised. Narrative synthesis was conducted.

Results Twenty-nine papers reporting 22 studies (cross-sectional, $n = 13$; longitudinal, $n = 9$) were identified. Papers were largely good quality, though many excluded patients with cognitive and communication impairments. Comparators included high-grade gliomas (HGG) ($n = 7$); NCCs ($n = 6$) and other patient groups ($n = 3$). Nineteen factors, primarily treatment (n = 8), were examined for association with HRQoL. There was substantial heterogeneity in HRQoL instruments used, factors and aspects of HRQoL assessed and measurement timepoints. HRQoL, primarily cognitive functioning and fatigue, in adult LGG patients is poor, and worse than in NCCs, though better than in HGG patients. Over time, HRQoL remained low, but stable. Epilepsy/seizure burden was most consistently associated with worse HRQoL.

Conclusion LGG patients experience wide-ranging HRQoL impairments. HRQoL in those with cognitive and communication impairments requires further investigation. These findings may help clinicians recognise current supportive care needs and inform types and timings of support needed, as well as inform future interventions.

Keywords Low-grade glioma · Health-related quality-of-life · Survivorship

Plain English Summary

Low-grade gliomas are brain tumours most commonly diagnosed in working-aged adults. Brain tumour patients can experience numerous symptoms, such as communication impairment and mobility issues, which can impact their quality of life. Patients with low-grade gliomas have a longer life expectancy than patients with other, high-grade brain tumours, though they are rarely cured. Therefore, it is important to understand how their quality of life is impacted in the extended periods living with a low-grade glioma. We looked at which aspects of health-related quality of life

---

✉ Ben Rimmer
ben.rimmer@newcastle.ac.uk

[1] Population Health Sciences Institute, Newcastle University, Newcastle University Centre for Cancer, Ridley Building 1, Newcastle upon Tyne, NE1 7RU Newcastle, England

[2] Faculty of Medical Sciences, Newcastle University, Newcastle, England

[3] Newcastle Upon Tyne Hospitals NHS Foundation Trust, Newcastle, England

[4] Department of Health and Nutritional Sciences, Sligo, IT, Ireland

[5] School of Psychology, Dublin City University, Dublin, Ireland

[6] Faculty of Behavioural, Management and Social Sciences, Department of Health Technology and Services Research, University of Twente, Twente, The Netherlands

[7] School of Education, Communication and Language Sciences, Newcastle University, Newcastle, England

were impacted; how health-related quality of life compared with other patient populations; whether health-related quality of life changed over time; and whether any factors (e.g. age) influenced health-related quality of life. We found that low-grade glioma patients experience wide-ranging health-related quality of life impairments, particularly fatigue and cognitive impairment, that remains poor, but does not change much over time. Though better than in high-grade gliomas, health-related quality of life was worse than in people without cancer and was influenced by several factors, most frequently seizures. This means low-grade glioma patients may live for long periods with poor health-related quality of life. Our findings may help clinicians recognise what these patients' supportive care needs are, and what support is needed.

Introduction

Worldwide, in 2020, there were approximately 300,000 new brain and central nervous system tumours diagnosed [1]. Gliomas – which may be high- or low-grade—are the most common malignant tumour of the brain [2]. Low-grade gliomas (LGG) account for approximately 15% of all gliomas, with an incidence rate of around 1/100,000; they are mostly diagnosed in adults in their 30 s and 40 s [3]. Depending on the subtype, life expectancy of LGG patients is limited to about 5–15 years [3, 4]. However, LGGs are rarely cured, and typically recur or progress to a high-grade glioma (HGG) [5]. Thus, LGG patients may live for extended periods with a 'terminal' condition.

Health-related quality-of-life (HRQoL) is a multidimensional construct that comprises the ability to perform everyday activities, as well as patient satisfaction with levels of functioning and disease control [6]. Brain tumour patients can experience an array of symptoms, often occurring in clusters and deteriorating as the disease progresses [7]. These include general cancer-related symptoms (e.g. fatigue, pain), and tumour-specific symptoms (e.g. cognitive limitations, seizures, speech, language, and communication impairments, personality changes and mobility issues) [8–10]. These symptoms can contribute to changes in social roles, daily functioning, and loss of independence, which adversely impact physical and psychosocial HRQoL [10, 11].

Studies suggest there are numerous factors (e.g. age, tumour location, and time since diagnosis), that could influence brain tumour patients' HRQoL [12]. Gaining a comprehensive understanding, from across the literature of how these factors are associated with HRQoL and how HRQoL changes over time, may help to ascertain in whom, what, and when, support is necessary and identify target areas for future interventions.

It is, however, difficult to distinguish the extent these problems are experienced by LGG patients. One issue is sample heterogeneity; studies often group patients with LGGs, HGGs, and other primary brain tumours [13–15]. This limits our understanding of the HRQoL impact of living long-term with a tumour that is still likely to progress. Further, much of the evidence comes from treatment trials. Trial populations are often highly selected and have a lower risk profile than 'real-world' patient populations [16]. Treatment modalities (e.g. surgery, radiotherapy, and chemotherapy) have been associated with HRQoL in LGG patients [17–19]. Thus, HRQoL impairments may be due to the tumour or its treatment. Consequently, there is a need to better understand the 'real world' impact of an LGG on HRQoL, outwith the trial context.

We, therefore, conducted a systematic review to examine how HRQoL is impacted in adults with an LGG, by establishing: (1) which aspects of HRQoL are impacted; (2) how HRQoL compares with other populations; (3) temporal trends in HRQoL; and (4) factors associated with HRQoL. Our secondary aims were to assess quality of, and identify gaps or limitations in, the available evidence.

Methods

This systematic review was registered with the Prospective Register for Systematic Reviews (PROSPERO) (CRD42021231368) and conducted and reported in accordance with the Preferred Reporting Items for Systematic Review and Meta-Analysis (PRISMA) guidelines [20].

Definition

For the purposes of this review, we defined HRQoL as "*the subjective perceptions of the positive and negative aspects of cancer patients' symptoms, including physical, emotional, social, and cognitive functions and, importantly, disease symptoms and side effects of treatment*."[21] Hereafter, '*global HRQoL*' indicates total scores, while '*specific (aspects of) HRQoL*' indicates functioning and symptoms.

Eligibility criteria

A paper was eligible if: (1) it was a primary, peer-reviewed research article, available in English; (2) participants were adults (≥ 18-years old), diagnosed with an LGG; (3) data were from an observational study conducted in a '*real-world*' setting (i.e. in routine practice, outwith the clinical trial context); (4) an instrument was used to quantitatively assess HRQoL, with evidence of content validity or other psychometric properties. Papers which focused on a single issue (e.g. psychological wellbeing) were eligible if the issue was framed, in the paper, as an aspect of HRQoL.

A paper was excluded if: (1) the sample was heterogenous (e.g. included HGGs) and LGGs were not a distinct group; (2) the HRQoL findings were not reported; (3) participants were adult survivors of childhood diagnoses (< 18-years); or (4) data were from a trial directly investigating specific treatments (e.g. impact of radiotherapy).

Search strategy

On 10th December 2020, we searched five electronic databases from inception: MEDLINE, Embase, PsycINFO, CINAHL, and PubMed. The search strategy concerned two key concepts: LGG and HRQoL. Assisted by a Senior Library Assistant, a combination of Medical Subject Headings and keywords were formulated, informed by the literature (Supplementary Table S1). LGG was searched using general terms and specific tumours, in line with the 2016 WHO classification of tumours of the central nervous system [22]. The 2021 WHO classification update [23] succeeded initial database searches, though our search strategy still encompassed LGGs, as they are now classified. HRQoL was searched using general terms and terms for HRQoL instruments that were previously reported to have been used in brain tumour patients [24] (although studies did not have to have used these instruments to be eligible). The search strategy was adapted accordingly for each database (Supplementary Table S2).

Reference lists and forward citations of eligible papers and relevant reviews were hand-searched to identify additional papers not retrieved through the database searches. The search was updated on 14th September 2021.

Paper selection

Once duplicates were removed, B.R and I.B independently screened titles and abstracts, followed by full texts of papers considered potentially eligible by either reviewer. The process was blinded until both reviewers completed each stage of screening. Discrepancies at paper selection were resolved through discussion with co-authors (L.D and L.S).

Data extraction and quality appraisal

Data extraction was conducted and cross-checked (shared between B.R and I.B), using a structured form. The following data were extracted: *general:* name of first author, year published, country; *study population:* eligible population, sample size, participant characteristics, namely, age, sex, ethnicity, socio-economic status (SES), Karnofsky performance status (KPS), tumour type and location, genetic markers, treatment, time since diagnosis/treatment; *study design:* design, comparator/control populations, HRQoL measurement timepoints, HRQoL instrument(s) used and specific aspects of HRQoL assessed, clinical and epidemiological factors examined for association with HRQoL; *findings:* global HRQoL, specific HRQoL, HRQoL in comparators/controls, HRQoL over time (e.g. mean scores), and factors associated with HRQoL (e.g. correlation coefficients).

If more than one paper reported the same sample, then characteristics and findings were pooled as one study. Corresponding authors were contacted to request relevant missing information. No reply within three weeks meant data extraction decisions were informed by the available published material. Discrepancies at data extraction were resolved through discussion between co-authors (B.R and I.B).

Included papers were quality appraised and cross-checked (shared between B.R and I.B), using the 12-item critical appraisal checklist, established by Dunne et al. [25] in a previous systematic review on quality-of-life in cancer survivors. Items included '*main features of population/design described*' and '*measures relevant, validated, and described adequately*'. Each item was scored 0 (no), 1 (partial) or 2 (yes). Potential scores ranged from 0–24, with 0–8 indicating '*low quality*', 9–16 '*acceptable quality*', and 17–24 '*good quality*'.

Data synthesis and analysis

Eligible studies were included in a narrative synthesis [26]. This was structured around the study population, design, quality appraisal, and HRQoL assessment, namely: global and specific HRQoL, population comparisons, temporal trends, and associated factors. Aspects of HRQoL which are included in the relevant instrument(s), but which were not reported by authors, were abstracted as 'not reported'.

To interpret HRQoL, we used previously reported reference values; these were available for EORTC QLQ-C30 [27], EQ-5D [28], and FACT-G [29]. Otherwise, judgements were based on interpretations of the original authors; here, to ensure consistency, a value interpreted as '*poor*' in one study, was considered '*poor*' across all other studies which used the same instrument (there were no instances of different interpretations for values by authors of the papers). To synthesise the interpreted values for specific aspects of HRQoL, studies were grouped when different studies/instruments reported a dimension with the same (e.g. fatigue) or similar label (e.g. emotional wellbeing/functioning). In the synthesis, papers were "weighted" equally irrespective of the quality appraisal results.

Results

Search results

Database searches identified 3295 papers, with 2037 remaining following deduplication. Full texts of 132 papers were assessed for eligibility, with 26 papers deemed eligible. Hand searches identified three additional papers. Twenty-nine papers reporting on 22 studies were included [12, 30–57] (Fig. 1).

Study population

Studies were conducted across 13 countries: three each in the Netherlands [12, 30–32, 44, 48] and USA [33, 36, 37, 39], two each in China [42, 54–56], Italy [35, 45], India [34, 46], Japan [47, 53], and Norway [38, 41], and one each in Australia [52], Finland [50, 51], Germany [49], South Korea [43], Sweden [40], and Turkey [57] (Table 1; Supplementary Table S3). Sample size ranged from 15 to 260. Mean age was typically late 30 s and 40 s. Sex ranged from 24 to 73% female. Only Affronti et al. [33] reported ethnicity, for a predominantly white (93%) sample. Eleven studies reported SES [12, 35, 36, 39, 42, 44, 45, 48, 49, 54, 57] assessed through education, employment, or insurance status. Nine studies reported KPS [12, 33, 38, 41, 47–49, 54, 57]; scores ranged 60–100, but were mostly ≥ 80.

Tumour details included: grade ($n = 5$ studies) [31, 43, 52, 54, 57]; type ($n = 12$) [31, 33, 36, 40–42, 44, 45, 47, 49, 52, 53], predominantly astrocytoma, oligodendroglioma, and oligoastrocytoma; laterality ($n = 13$) [31, 33, 35, 36, 38, 39, 42, 44, 45, 49, 52, 54, 57]; and location ($n = 12$) [31, 33, 35, 36, 39, 42, 44, 45, 47–49, 57], largely frontal lobe. Four studies reported genetic markers [33, 42, 45, 53]. Sixteen studies reported treatment [12, 33, 35, 36, 38, 40–42, 44, 45, 47, 48, 50, 52, 54, 57], including chemotherapy, radiotherapy, and extent of surgical resection. Time since diagnosis/treatment at which HRQoL was assessed ranged from point of diagnosis to 20-years since treatment. Heterogeneity was common within studies; e.g. participants in Correa et al. [36] ranged from six- to 118-months (9.83 years) since treatment.

Study design

Thirteen studies were cross-sectional [34, 35, 39–44, 46–49, 53] and nine longitudinal [31, 33, 37, 38, 45, 51, 52, 54, 57], assessing HRQoL at several (albeit varied) timepoints (*Table*

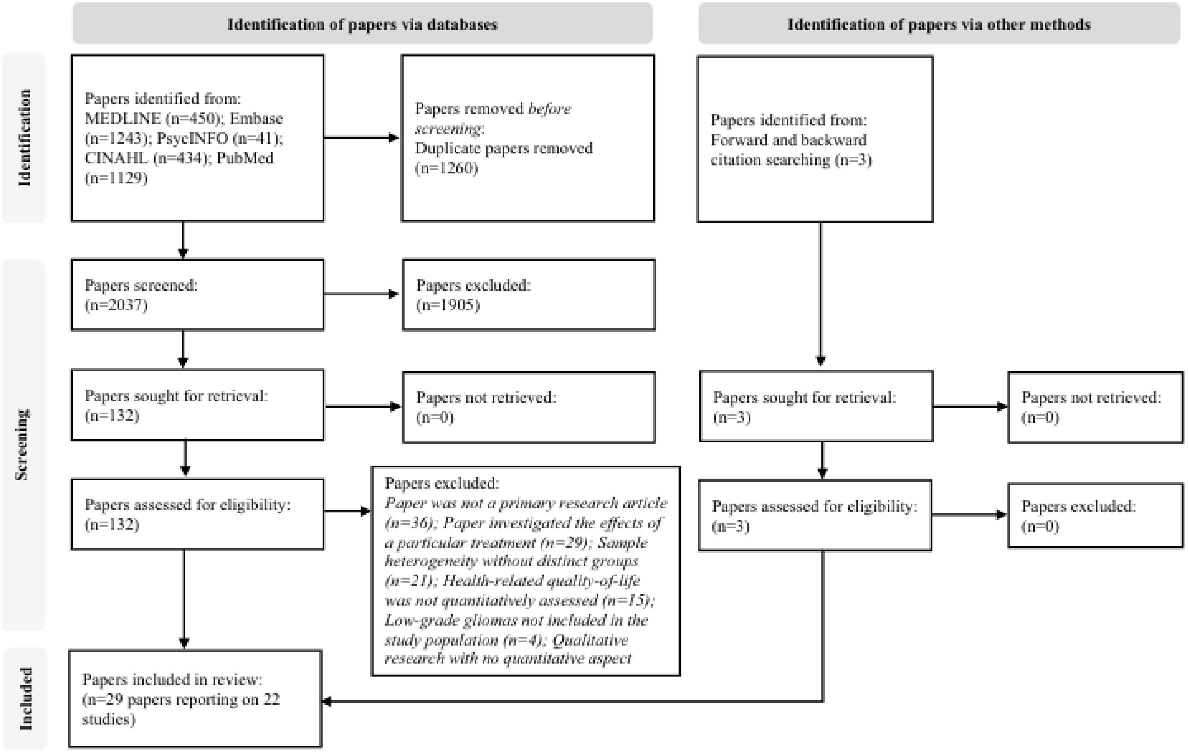


Fig. 1 PRISMA flow diagram of paper selection for quantitative studies that assessed health-related quality-of-life in low-grade glioma patients

Table 1 Population characteristics of included quantitative studies that assessed health-related quality of life in low-grade glioma patients

Study (Country)	Sample size	Mean age (SD)[g]	% Female	Tumour type	Tumour location	Treatment	Time since diagnosis/treatment
Aaronson (2011); Boele (2014; 2015); Ediebah (2017) (Netherlands)[12, 30–32]	T1: 195, T2: 65[a]	40.8 (11.6)	38.5%	Grade I (10.8%), Grade II (89.2%); Astrocytoma (71.3%), Oligodendroglioma (22%), Oligoastrocytoma (6.7%)	*Location:* frontal (24.1%), temporal (16.9%), parietal (9.7%), occipital (2.6%), mixed (45.6%), other (1%); *Laterality:* left (43.6%), Right (44.6%), Bilateral (4.6%)	Biopsy (43.1%), Resection (56.9%); Radiotherapy: yes (53.3%), no (46.7%)	*Since diagnosis:* mean 5.6 (SD 3.7) years
Affronti (2018) (USA) [33]	15	40 (11)	73%	Diffuse astrocytoma (53%), Infiltrating glioma (7%), Well-differentiated oligodendroglioma (40%)	Bilateral multifocal (7%), Left frontal (20%), Right frontal (53%), Right parietal (20%)	Biopsy (33%), Gross total resection (67%); Postsurgical temozolomide (40%)	*Since diagnosis:* 2 months at initial assessment
Budrukkar (2009) (India) [34]	71	NR[h]	NR[h]	NR	NR	NR	NR
Campanella (2017) (Italy) [35]	50	40 (10.9)	54%	NR	*Location:* frontal (60%), temporal (30%), parietal (10%); *Laterality:* right (50%), left (50%)	Surgery (100%), Radiotherapy (10%), Chemotherapy (10%), Both (4%)	*Since treatment:* mean 40.3 months, range 12–181 months
Correa (2007; 2008) (USA) [36, 37]	T1: 40, T2 and T3: 25[b]	41.5 (9.4)	37.5%	Oligodendroglioma (47.5%), Astrocytoma (22.5%), Oligoastrocytoma (25%), Not available (5%)	*Location:* frontal (37.5%), fronto-parietal (30%), temporal-parietal-occipital (27.5%), cortical/subcortical (5%); *Laterality:* right (57.5%), left (42.5%)	Resection (90%), Radiotherapy (30%), Chemotherapy (10%), No adjuvant therapy (60%)	*Since diagnosis:* median 71 months (27–142) (treated), 22 months (3–82) (untreated); *Since treatment:* median 38 months (6–118)
Drewes (2018) (Norway) [38]	40	46.7 (16.2)	32.5%	NR	*Laterality:* right (45%), left (40%), bilateral/midline (15%)	Preoperative corticosteroids (10%), Gross total resection (45%), Subtotal resection (42.5%), Biopsy only (12.5%)	*Since treatment:* 1–3 days before treatment at initial assessment

Table 1 (continued)

Study (Country)	Sample size	Mean age (SD)^g	% Female	Tumour type	Tumour location	Treatment	Time since diagnosis/treatment
Gabel (2019) (USA) [39]	21	42.7 (13.6)	23.8%	NR	*Location:* frontal (23.8%), parietal (9.5%), temporal (19%), occipital (4.8%), insular (19%), other (23.8%); *Laterality:* left (42.9%), right (47.6%), midline (9.5%)	NR	NR
Gustafsson (2006) (Sweden) [40]	39	47 (14)	31%	Astrocytoma ($n = 23$), Oligodendroglioma ($n = 8$), Oligoastrocytoma ($n = 4$), Ependymoma ($n = 3$), Other ($n = 1$)	NR	Surgical resection ($n = 29$), Radiotherapy ($n = 23$), Chemotherapy ($n = 8$)	*Since diagnosis:* mean 16 years (< 1 to 47)
Jakola (2012) (Norway) [41]	55	41 (13)	45%	Astrocytoma (53%), Oligodendroglioma (29%), Oligoastrocytoma (18%)	NR	Biopsy (18%), Resection (82%), < 6 months post-op radiotherapy (26%), Radiotherapy (46%), < 6 months post-op chemotherapy (16%), Chemotherapy (33%), Later/repeat resection (22%)	*Since treatment:* mean 7 years
Jiang (2019) (China) [42]	219	41.5 (10.9)	38%	Astrocytoma ($n = 103$), Oligodendroglioma ($n = 56$), Oligoastrocytoma ($n = 60$)	*Location:* frontal (64%), non-frontal (36%); *Laterality:* right (38%), left (54%), bilateral (8%)	Resection: complete (83%), incomplete or biopsy (17%); Adjuvant therapy: yes (30%), no (70%)	*Since diagnosis:* > 3 months; *Since treatment:* 3 months
Kim (2020) (South Korea) [43]	45	NR^h	NR^h	Grade I ($n = 13$), II ($n = 32$)	NR^h	NR^h	*Since diagnosis:* > 3 months

Table 1 (continued)

Study (Country)	Sample size	Mean age (SD)[g]	% Female	Tumour type	Tumour location	Treatment	Time since diagnosis/ treatment
Klein (2003) (Netherlands)[44][c]	156 (21, 21, 33, 24, 24, 33)	35.8 (10.1), 37.7 (11.5), 43.4 (11.7), 43.5 (12.2), 45.7 (13.2), 41 (8.5)	57%, 38%, 32%, 30%, 42%, 33%	Astrocytoma (81%, 71%, 56%, 70%, 67%, 79%), Oligodendroglioma (14%, 24%, 35%, 26%, 33%, 12%), Oligoastrocytoma (5%, 5%, 9%, 4%, 0%, 9%)	*Location:* frontal (33%, 43%, 68%, 33%, 58%, 34%), parietal, occipital (24%, 24%, 9%, 29%, 0%, 30%), temporal (19%, 19%, 23%, 38%, 38%, 30%), deep structures (14%, 9%, 0%, 0%, 0%, 0%), other (10%, 5%, 0%, 0%, 4: 6%); *Laterality:* right (52%, 29%, 47%, 52%, 50%, 39%), left (43%, 62%, 53%, 48%, 42%, 58%), bilateral (5%, 10%, 0%, 0%, 8%, 3%)	Surgery: biopsy (38%, 33%, 52%, 57%, 33%, 55%); resection (62%, 67%, 48%, 43%, 67%, 45%); Radiotherapy (57%, 57%, 56%, 61%, 42%, 58%)	*Since diagnosis:* > 1 year; *Since treatment:* > 1 year
Leonetti (2021) (Italy) [45]	80	39.7 (11.3)	42.5%	Astrocytoma (30%), Oligodendroglioma (28.75%), Ganglioglioma (17.5%), Other (23.75%)	*Location:* frontal (51.2%), insular (18.2%), temporal (12.5%), parietal (16.3%), other (1.3%); *Laterality:* right (53.8%), left (46.3%)	Surgery (100%), Radiotherapy (52.5%), Chemotherapy (57.5%)	From point of diagnosis to 12 months post-surgery
Mahalakshmi (2015) (India) [46]	54	NR[h]	NR[h]	NR[h]	NR[h]	NR	*Since diagnosis:* 3 months
Okita (2015) (Japan) [47]	50	Median 39 (22–76)	32%	Astrocytoma (72%), Oligodendroglioma (6%), Oligoastrocytoma (22%)	*Location:* frontal (47.6%, 52.6%, 60%); temporal (19.1%, 36.8%, 10%); parietal (23.8%, 0%, 20%)[d]	Radiotherapy (78%), Chemotherapy (60%)	*Since treatment:* 0–4 years ($n=21$), 5–9 years ($n=19$), 10–20 years ($n=10$); median 5.8 years (0–20.2 years)
Reijneveld (2001) (Netherlands) [48]	24	38.2 (10.6)	37.5%	NR	*Location:* frontal ($n=4$), temporal ($n=7$), parietal ($n=7$), occipital ($n=3$), midline ($n=3$)	Stereotactic biopsy ($n=6$), surgery ($n=17$), unknown ($n=1$)	*Since diagnosis:* mean 5.5 years (SD 3.7 years)

Table 1 (continued)

Study (Country)	Sample size	Mean age (SD)[g]	% Female	Tumour type	Tumour location	Treatment	Time since diagnosis/treatment
Ruge (2011) (Germany) [49]	33	44.4 (11.2)	51.5%	Astrocytoma (90.9%), Oligodendroglioma (6.1%), Oligoastrocytoma (3.0%)	*Location:* frontal (33.3%), temporal (54.5%), parietal (6%), subcortical (6%); *Laterality:* left (55.5%), Right (45.5%)	NR	NR
Salo (2002); Mainio (2006) (Finland) [50, 51]	19	Male: 49.4 (12.9) Female: 48.8 (13.7)	52.6%	NR	NR	Surgery 100%	NR
Teng (2021) (Australia) [52]	167; 1: 64, 2: 51, 3: 25, 4+: 27[e]	40.85 (13.47)	46.1%	Grade II diffuse glioma (86.23%), Grade I pilocytic astrocytoma (9.58%), other (4.19%); Grade I (11.98%), Grade II (88.02%)	*Laterality:* right (47.31%), left (40.72%), midline (7.78%), unknown (4.19%)	Resection: biopsy (19.16%), partial (7.19%), subtotal (36.53%), gross-macroscopic (29.34%), unknown (7.78%); Radiotherapy (31.14%), Chemotherapy (13.17%)	*Since treatment:* mean 60.66 (SD 110.48) months
Umezaki (2020) (Japan) [53]	31	NR[h]	NR[h]	Diffuse astrocytoma ($n=11$), Oligodendroglioma ($n=16$), Oligoastrocytoma ($n=3$), Diffuse glioma ($n=1$)	NR[h]	NR[h]	NR[h]
Wang (2018); Li (2019a; 2019b) (China) [54–56]	260	Median 42 (18–67)	44.20%	Grade I (23.5%), Grade II (76.5%)	*Laterality:* left (45.8%), right (52.7%), bilateral (1.5%)	Excision: total (48.8%), subtotal (43.5%), biopsy (7.7%); Surgery (33.5%), surgery and radiotherapy (57.3%), surgery and chemotherapy (3.8%), surgery, radiotherapy, and chemotherapy (5.4%)	*Since treatment:* 1 month

Table 1 (continued)

Study (Country)	Sample size	Mean age (SD)[g]	% Female	Tumour type	Tumour location	Treatment	Time since diagnosis/treatment
Yavas (2012) (Turkey) [57]	43; T1: 43, T2: 43, T3: 42, T4: 41, T5: 39, T6: 37, T7: 30, T8: 21[f]	18–29 (20.93%), 30–39 (39.53%), 40–49 (20.93%), 50–59 (13.95%), 60–69 (4.65%)	37.2%	Grade I (9.3%), Grade II (81.4%), Not other classified low grade (9.3%)	*Location:* frontal (48.8%), parietal (16.3%), temporal (27.9%), occipital (7%); *Laterality:* left (41.9%), right (58.1%)	Excision: total (23.3%), subtotal (65.1%), inoperative (11.6%); Radiotherapy (100%)	*Since treatment:* initial assessment at end of radiotherapy

NR = *Not reported*

[a] T1 = mean 6 years, T2 = mean 12 years since diagnosis

[b] T1 = baseline, T2 = 6 months, T3 = 12 months follow-up

[c] Sample stratified into six levels of epilepsy burden (level 1 = epilepsy free – level 6 = > 6 seizures in the last year)

[d] Stratified by: Years since treatment 0–4, 5–9, 10–20

[e] Number of surveys completed by participants within the sample

[f] T1 = baseline, T2 = 1–3 months, T3 = 6 months, T4 = 12 months, T5 = 18 months, T6 = 24 months, T7 = 30 months, T8 = 36 months since treatment

[g] Where mean age was not reported, medians and age groups are detailed

[h] This demographic was not reported separately for low-grade gliomas

Table 2 Study characteristics of included quantitative studies that assessed health-related quality of life in low-grade glioma patients

Study	Quality appraisal (score)[a]	Study design	Comparator/ control	Measurement time points	HRQoL instrument(s) used	Factors examined for association with HRQoL
Aaronson (2011); Boele (2014; 2015); Ediebah (2017) [12, 30–32]	Good (21); Good (18); Good (21); Good (19)	Longitudinal	Non-Hodgkin's lymphoma, chronic lymphocytic leukaemia, non-cancer controls	T1 = mean 6 years, T2 = mean 12 years since diagnosis	SF-36, BN20	Age, cognitive function, education, epilepsy burden, sex, time since diagnosis, treatment, tumour location
Affronti (2018) [33]	Acceptable (15)	Longitudinal	NR	T1 = 2 months, T2 = 4 months, T3 = 6 months since diagnosis	FACT-Br, FACIT- fatigue, FACT-Cog	Genetic markers
Budrukkar (2009) [34]	Acceptable (16)	Cross-sectional	High-grade glioma, benign tumour	Single time point (pre-adjuvant therapy)	QLQ-C30, BN20	Age, education, KPS, sex, socio-economic status, treatment, tumour location
Campanella (2017) [35]	Good (18)	Cross-sectional	Non-cancer controls	Single time point (> 1-year post-surgery, mean 3.35 years)	PWB	Age, cognitive function, education, epilepsy burden, sex, time since treatment, treatment, tumour location
Correa (2007; 2008) [36, 37]	Acceptable (15); Acceptable (15)	Longitudinal	NR	T1 = Baseline, T2 = 6 months, T3 = 12 months follow-up	FACT-Br	NR
Drewes (2018) [38]	Good (21)	Longitudinal	High-grade glioma	T1 = initial assessment (1–3 days before first surgery) T2 = 1 month, T3 = 6 months since treatment	EQ-5D	Treatment
Gabel (2019) [39]	Good (17)	Cross-sectional	High-grade glioma	Single time point (at diagnosis and initial clinic visit)	NIH-PROMIS, Neuro-QoL	NR[b]
Gustafsson (2006) [40]	Good (17)	Cross-sectional	NR	Single time point (mean 16 years since diagnosis)	QLQ-C30	Age, coping, marital status, sex, time since diagnosis[c]
Jakola (2012) [41]	Good (17)	Cross-sectional	NR	Single time point (mean 7 years since treatment)	QLQ-C30, BN20, EQ-5D	Tumour location
Jiang (2019) [42]	Good (17)	Cross-sectional	NR	Single time point (3 months since treatment)	SF-36	Post-traumatic stress disorder
Kim (2020) [43]	Good (17)	Cross-sectional	High-grade glioma	Single time point (not specified)	FACT-G	NR[b]
Klein (2003) [44]	Good (18)	Cross-sectional	Non-cancer controls	Single time point (not specified)	SF-36	Epilepsy burden

Table 2 (continued)

Study	Quality appraisal (score)[a]	Study design	Comparator/ control	Measurement time points	HRQoL instrument(s) used	Factors examined for association with HRQoL
Leonetti (2021) [45]	Good (18)	Longitudinal	High-grade glioma	T0 = 1 week pre-surgery, T1 = 1 month, T2 = 3 months, T3 = 6 months, T4 = 12 months since surgery	SF-36	Age, cognitive function, education, genetic markers, sex, treatment, tumour location
Mahalakshmi (2015) [46]	Good (19)	Cross-sectional	High-grade glioma	Single time point (3 months since diagnosis)	QLQ-C30, BN20	NR[b]
Okita (2015) [47]	Good (17)	Cross-sectional	NR	Single time point (G1: 0–4; G2: 5–9; G3: 10–20 years since treatment)	QLQ-C30, BN20	Age, history of recurrence, KPS, time since treatment, treatment
Reijneveld (2001) [48]	Acceptable (15)	Cross-sectional	Suspected low-grade glioma, non-cancer controls	Single time point (> 6 months since diagnosis)	SF-36, BN20	NR
Ruge (2011) [49]	Good (19)	Cross-sectional	Non-cancer controls	Single time point (at diagnosis)	SF-36	Age, cognitive function, depression, duration of symptoms, KPS, seizures, tumour location
Salo (2002); Mainio (2006) [50, 51]	Acceptable (16); Acceptable (15)	Longitudinal	NR	T1 = Pre-surgery, T2 = 1 year, T3 = 5 years post-surgery	Sin-tonen's 15D Nottingham Health Profile	NR
Teng (2021) [52]	Acceptable (16)	Longitudinal[d]	Non-cancer controls	Multiple timepoints completed at 6 monthly intervals, stratified by time since surgery and divided into 12 monthly intervals	QLQ-C30	Time since treatment[c]
Umezaki (2020) [53]	Good (19)	Cross-sectional	High-grade glioma	Single time point (not specified)	QLQ-C30, BN20	NR[c]
Wang (2018); Li (2019a; 2019b) [54–56]	Good (21); Good (20); Good (20)	Longitudinal	NR	T1 = 1 month, T2 = 1 year post- surgery	FACT-Br	Age, coping, depression, marital status, post-traumatic growth, post-traumatic stress disorder, seizures, sex, socio-economic status, time since treatment, treatment, tumour location, tumour type

Table 2 (continued)

Study	Quality appraisal (score)[a]	Study design	Comparator/ control	Measurement time points	HRQoL instrument(s) used	Factors examined for association with HRQoL
Yavas (2012) [57]	Acceptable (15)	Longitudinal	NR	T1 = pre-adjuvant therapy, T2 = 1–3 months, T3 = 6 months, T4 = 12 months, T5 = 18 months, T6 = 24 months, T7 = 30 months, T8 = 36 months since treatment	QLQ-C30, BN20	Treatment

BN-20 European Organisation for Research and Treatment of Cancer Quality of life Questionnaire Brain Neoplasm, *EQ-5D* EuroQoL 5 dimension, *FACT-Br* Functional Assessment of Cancer Therapy – Brain, *FACT-Cog* Functional Assessment of Cancer Therapy – Cognitive function, *FACT-G* Functional Assessment of Cancer Therapy – General, *FACIT-Fatigue* Functional Assessment of Chronic Illness Therapy – Fatigue, *G* Group, *NIH-PROMIS* National Institutes of Health—Patient-Reported Outcomes Measurement Information System, *Neuro-QoL* Quality of Life in Neurological Disorders, *NR* Not reported, *PWB* Psychological wellbeing scale, *QLQ-C30* European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire Core, *SF-36* Short Form 36 health survey questionnaire, *T* Timepoint

[a] Where more than one paper reports the same study, quality appraisal scores are given for each individual paper

[b] Factors were not examined separately in low-grade gliomas

[c] Health-related quality-of-life patient reported outcome measures were examined as factors

[d] Participants could enter the study cohort at any point during follow-up and were then followed over time

2). Thirteen studies included a comparator and/or control group, comprising: HGG patients ($n = 7$) [34, 38, 39, 43, 45, 46, 53], non-cancer controls (NCC) ($n = 6$) [12, 35, 44, 48, 49, 52], or benign brain tumour [34], suspected LGG [48], or non-Hodgkin's lymphoma (NHL)/chronic lymphocytic leukaemia (CLL) patients [12].

Thirteen different general, cancer-related, brain tumour-specific, or unidimensional HRQoL instruments were used, predominantly: EORTC QLQ-BN20 ($n = 8$) [12, 34, 41, 46–48, 53, 57], EORTC QLQ-C30 ($n = 8$) [34, 40, 41, 46, 47, 52, 53, 57], SF-36 ($n = 6$) [12, 42, 44, 45, 48, 49], FACT-Br ($n = 3$) [33, 36, 54], and EQ-5D ($n = 2$) [38, 41]. Eleven studies used multiple HRQoL instruments [12, 33–35, 39, 41, 46–48, 50, 53, 57], often combining general (e.g. SF-36) or cancer-related (e.g. QLQ-C30), with brain tumour-specific (e.g. QLQ-BN20) instruments. The HRQoL instruments used, specific dimensions assessed by each, and their scoring, is detailed in Supplementary Table S4. Fourteen studies assessed global HRQoL [33, 34, 36, 38, 40, 41, 43, 46, 47, 51–54, 57] with one of the six instruments (e.g. FACT-G) with a possible global HRQoL score. Once grouped, frequently assessed HRQoL dimensions included: physical ($n = 19$ studies) [12, 33, 34, 36, 39–49, 52–54, 57], social ($n = 18$) [12, 33, 34, 36, 40–49, 52–54, 57], emotional ($n = 13$) [33, 34, 36, 39–41, 43, 46, 47, 52–54, 57], and cognitive functioning ($n = 10$) [33, 39–41, 46, 47, 52, 53, 57], as well as pain ($n = 17$) [12, 34, 38–42, 44–50, 52, 53, 57], and fatigue ($n = 10$) [33, 34, 39–41, 46, 47, 52, 53, 57].

Quality appraisal

Quality appraisal scores ranged from 15 to 21 of a possible 24, with 20 papers considered '*good quality*' [12, 30–32, 35, 38–47, 49, 53–56] and nine '*acceptable quality*' [33, 34, 36, 37, 48, 50–52, 57] (Table 2; Supplementary Table S5). Aaronson et al. [12], Boele et al. [31], Drewes et al. [38], and Wang et al. [54] were the highest quality papers, each scoring 21. Primary reasons for lower scores included: failure to clearly document participant eligibility and recruitment (e.g. 11 papers (eight studies) excluded cognitively and/or communication impaired patients without detailing how this was determined) [12, 30–32, 38, 40, 42, 44, 46, 53, 57]; and lack of a control and/or comparator group.

Health-related quality-of-life findings

Health-related quality-of-life

The dimensions measured and how scores are determined across the 11 multidimensional and two unidimensional HRQoL instruments reported in the studies is quite different (Table 2; Supplementary Table S4). HRQoL values were not reported for all potential instrument dimensions in 13 studies [34–36, 41–46, 48–50, 52]; below, the denominator is the number of studies that reported a value for a specific dimension.

Global HRQoL

Thirteen (of 14) studies reported poor global HRQoL in LGG patients (i.e. QLQ-C30 score 61.9–74) [33, 34, 36, 38, 40, 41, 43, 46, 47, 52–54, 57] that was significantly worse than in NCCs ($n = 1$ of one) [52], though significantly better than in HGG patients ($n = 4$ of five) [34, 38, 43, 46] (Table 3; Supplementary data).

Specific HRQoL – functioning

Seventeen studies reported values for functioning aspects of HRQoL in LGG patients [12, 33, 34, 39–42, 44–49, 52–54, 57]. Poor functioning was reported across numerous HRQoL aspects. Cognitive functioning was poor in seven (of 10) studies [33, 34, 39–41, 52, 57], and significantly worse than NCCs in one (of one) of these [52]. Poor emotional functioning was reported in five (of 11) studies [33, 34, 40, 52, 54] and was significantly worse than NCCs in one (of one) of these [52]. General health perception was poor in four (of five) studies [12, 42, 48, 49]; four (of four studies with an NCC group) found it was significantly worse in LGG patients than in NCCs [12, 44, 48, 49]. Poor vitality was reported in four (of five) studies [12, 42, 48, 49]; three (of four studies with an NCC group) found it was significantly worse than in NCCs [12, 44, 48], as well as suspected LGGs in one (of one) of these [48].

Compared to NCCs, studies also reported significantly worse physical functioning ($n = 4$ of five) [12, 44, 49, 52] and emotional role functioning ($n = 3$ of four) [12, 44, 49] in LGG patients. Compared to HGG patients, of seven studies, only Mahalakshmi et al. [46] found significant differences, namely that LGG patients reported better emotional, physical, and social functioning.

Across studies, functioning aspects with the worst scores were cognitive functioning ($n = 6$) [39, 41, 46, 47, 52, 57], functional wellbeing ($n = 2$) [33, 54], general health perception ($n = 2$) [42, 49], social functioning ($n = 2$) [34, 53], vitality ($n = 2$) [12, 48], role functioning [40], and SF-36 mental [44] and physical [45] component scores. Still, '*worst scores*' is a function (in part) of instrument used and what study authors choose to report, as cognitive functioning was either not assessed or reported in seven of the 11 studies that reported another aspect as having the worst score.

Specific HRQoL – symptoms

Fourteen studies reported values for HRQoL symptoms [12, 33, 34, 39–42, 46–50, 53, 57]. Considerable symptom

Table 3 Health-related quality-of-life key findings

Study	Global HRQoL[a]	Specific HRQoL	HRQoL over time[a]	Findings vs comparators[a]
Aaronson (2011); Boele (2014; 2015); Ediebah (2017) [12, 30–32]	NA	*Function:* poor general health perception, mental health, physical role functioning, physical and mental components scores, and vitality *Symptom:* high levels of communication deficit, drowsiness, future uncertainty, and suffering from headaches	LGG patients had significantly worse physical component scores ($P < 0.01$) and physical functioning ($P < 0.01$) at long-term follow-up (mean 12 years) compared to mid-term follow-up (mean 5.6 years since diagnosis). No other significant differences were observed. Authors state that most LGG patients maintained a stable level of HRQoL	Compared with NCCs, LGG patients had significantly less bodily pain ($P < 0.01$), but significantly worse emotional role functioning, general health perception, mental component score, physical functioning, physical role functioning, social functioning, vitality (all $P < 0.01$), and mental health ($P = 0.043$). No significant differences between LGG patients and NHL/CLL comparators were observed
Affronti (2018) [33]	Poor	*Function:* poor brain cancer subscale scores, emotional and functional wellbeing. High perceived cognitive impairments, impact of perceived cognitive function, and poor perceived cognitive abilities *Symptom:* high levels of fatigue	LGG patients with either IDH mut or TERT mut (genetic markers) consistently reported lower global HRQoL, and higher levels of fatigue, depression, and distress from two to six months since diagnosis. *No significant differences as this was a pilot study*	NA
Budrukkar (2009) [34]	Poor	*Function:* poor cognitive, emotional, and social functioning *Symptom:* high levels of appetite loss, communication deficit, fatigue, insomnia, motor dysfunction, nausea/vomiting, pain, seizures, and suffering from headaches	NA	Compared with HGGs, LGG patients reported significantly better global HRQoL ($P = 0.015$). No significant differences between LGG patients and benign tumour comparators were observed
Campanella (2017) [35]	NA	*Function:* average psychological wellbeing	NA	Compared with NCCs, LGG patients scored significantly higher on the environmental mastery subscale of psychological wellbeing ($P < 0.01$)
Correa (2007; 2008) [36, 37]	Poor	NR	No significant changes over time in FACT-Br were observed	NA
Drewes (2018) [38]	Poor	NR	No significant differences in EQ-5D index scores were observed between all three time points	Compared with HGGs, LGG patients scored significantly higher on the EQ-5D at six months since treatment ($P < 0.01$)
Gabel (2019) [39]	NA	*Function:* high Neuro-QoL cognitive function and PROMIS physical function impairments *Symptom:* high PROMIS pain interference and sleep disturbance impairment	NA	Compared with HGGs, LGG patients experienced significantly greater distress related to pain intensity ($P = 0.01$) and declining physical function ($P = 0.05$)
Gustafsson (2006) [40]	Poor	*Function:* poor cognitive, emotional, and role functioning *Symptom:* high levels of dyspnoea, fatigue, financial difficulties, insomnia, and pain	NA	NA

Table 3 (continued)

Study	Global HRQoL[a]	Specific HRQoL	HRQoL over time[a]	Findings vs comparators[a]
Jakola (2012) [41]	Poor	*Function:* poor cognitive functioning *Symptom:* high levels of communication deficit, fatigue, future uncertainty, and motor dysfunction	NA	NA
Jiang (2019) [42]	NA	*Function:* poor emotional and physical role functioning, general health perception, mental health, physical functioning, social functioning, and vitality *Symptom:* high levels of bodily pain All eight dimensions were significantly worse in LGG patients with PTSD	NA	NA
Kim (2020) [43]	Poor	NR	NA	Compared with HGGs, LGG patients had significantly better global HRQoL ($P < 0.01$)
Klein (2003) [44]	NA	*Function:* poor physical and mental component scores that were increasingly worse in those with greater epilepsy burden	NA	Compared with NCCs, LGG patients had significantly more bodily pain, and worse emotional and physical role functioning, general health perception, physical functioning, vitality, (all $P < 0.01$), and social functioning ($P = 0.013$)
Leonetti (2021) [45]	NA	*Function:* high prevalence of poor physical and mental component scores	The prevalence of LGG patients with low SF-36 mental and physical component scores reduced incrementally from pre-surgery to one-year post-surgery, though statistical tests were not reported	No significant differences between LGG patients and HGG comparators were observed
Mahalakshmi (2015) [46]	Poor	*Symptom:* high levels of appetite loss, communication deficit, dyspnoea, fatigue, future uncertainty, motor dysfunction, nausea/vomiting, and very high financial difficulties	NA	Compared with HGGs, LGG patients had significantly better global HRQoL ($P = 0.04$), emotional functioning ($P = 0.05$), physical functioning ($P < 0.01$), role functioning ($P = 0.01$), and social functioning ($P < 0.01$). LGG patients also had significantly lower levels of communication deficit ($P = 0.02$), distress from hair loss ($P = 0.05$), fatigue ($P < 0.01$), nausea/vomiting ($P = 0.05$), pain ($P = 0.01$), seizures ($P = 0.01$), and suffering from headaches ($P = 0.04$), though greater financial difficulties ($P = 0.02$) than HGG patients

Table 3 (continued)

Study	Global HRQoL[a]	Specific HRQoL	HRQoL over time[a]	Findings vs comparators[a]
Okita (2015) [47]	Poor	*Symptom:* high levels of communication deficit, difficulty with bladder control, drowsiness, fatigue, financial difficulties, future uncertainty, suffering from headaches, and weakness of legs	NA	NA
Reijneveld (2001) [48]	NA	*Function:* poor general health perception, emotional and physical role functioning, mental health, and vitality *Symptom:* high levels of communication deficit, future uncertainty, seizures, and suffering from headaches	NA	Compared with NCCs, LGG patients scored significantly worse on general health perception, mental health, social functioning (all $P < 0.05$), and vitality ($P < 0.01$). LGG patients also scored significantly worse than suspected LGGs on vitality ($P < 0.05$) and had higher levels of difficulty with bladder control ($P < 0.05$) and motor dysfunction ($P < 0.01$)
Ruge (2011) [49]	NA	*Function:* poor general health perception, mental health, and vitality	NA	Compared with NCCs, LGG patients scored significantly worse on general health perception, emotional role functioning, mental health, social functioning (all $P < 0.01$), and physical role functioning ($P < 0.025$)
Salo (2002); Mainio (2006) [50, 51]	Average	NR	NR	NA
Teng (2021) [52]	Poor	*Function:* poor cognitive, emotional, and social functioning	Conclude that LGG patients sustain clinically significant impairments to global HRQoL, particularly cognitive, emotional, role, and social functioning, as well as high levels of fatigue and insomnia at 12-month intervals across 10 years	Compared with NCCs, LGG patients reported significantly worse global HRQoL, cognitive, emotional, physical, role, and social functioning (all $P < 0.01$)
Umezaki (2020) [53]	Poor	*Symptom:* high levels of communication deficit, drowsiness, fatigue, financial difficulties, future uncertainty, and weakness of legs	NA	Compared with HGGs, LGG patients reported significantly lower levels of constipation ($P = 0.04$), distress from hair loss ($P = 0.02$) and itchy skin ($P = 0.04$). No significant differences between LGG patients and HGG comparators were observed in all functioning domains assessed
Wang (2018); Li (2019a; 2019b) [54–56]	Poor	*Function:* poor brain cancer subscale scores, emotional and functional wellbeing	HRQoL was significantly better at one-year post-surgery than one-month post-surgery for emotional wellbeing, functional wellbeing, brain tumour subscale, and global HRQoL (all $P < 0.01$)	NA

Table 3 (continued)

Study	Global HRQoL[a]	Specific HRQoL	HRQoL over time[a]	Findings vs comparators[a]
Yavas (2012) [57]	Poor	*Function:* poor cognitive functioning *Symptom:* high levels of drowsiness, distress from hair loss, fatigue, financial difficulties, insomnia, and suffering from headaches	From initial assessment (*end of radiotherapy*) to 3 years since treatment, there were significant improvements in global HRQoL scores, future uncertainty, communication deficit, suffering from headaches, drowsiness, and distress from hair loss (all $P < 0.01$). More specifically, future uncertainty significantly improved from initial assessment to 2 years and 3 years (both $P < 0.01$), but not 1 year. There was progressive improvement in communication deficit across follow-up, but only significant between initial assessment and 3 years ($P = 0.016$). Compared to initial assessment, there were significant improvements to suffering from headaches at 2 and 3 years (both $P < 0.01$), but not 1 year. There were significant improvements to drowsiness from initial assessment to 1, 2, and 3 years (all $P < 0.01$). Distress from hair loss was significantly worse at 1 year, than initial assessment ($P = 0.01$), but not at 2 or 3 years. No other significant differences were observed	NA

HGG High-grade glioma, *HRQoL* Health-related quality-of-life, *LGG* Low-grade glioma; *NA* not assessed, *NCC* non-cancer controls, *NHL/CLL* non-Hodgkin's lymphoma/chronic lymphocytic leukaemia, *NR* not reported

[a] Key findings were 'not assessed' if the instrument used did not determine a global HRQoL score, a comparator/control was not included, or the study was cross-sectional and only measured a single time point

burden was evident, most notably high levels of fatigue (reported in $n=8$ of nine studies) [33, 34, 40, 41, 46, 47, 53, 57]. Other symptoms with substantial burden included: communication deficits ($n=7$ of eight) [12, 34, 41, 46–48, 53]; future uncertainty ($n=6$ of eight) [12, 41, 46–48, 53]; suffering from headaches ($n=5$ of seven) [31, 34, 47, 48, 57]; financial difficulties ($n=5$ of five) [40, 46, 47, 53, 57]; drowsiness ($n=4$ of seven) [31, 47, 53, 57]; insomnia ($n=4$ of five) [34, 39, 40, 57]; pain ($n=4$ of 12) [34, 39, 40, 42]; and motor dysfunction ($n=3$ of eight) [34, 41, 46]. The two studies that compared pain in LGG patients with NCCs were inconsistent [12, 44]. One study found motor dysfunction was significantly worse in LGG patients than those with suspected LGGs [48].

Again, compared to HGG patients, significant differences were primarily reported by Mahalakshmi et al. [46]; LGG patients had lower levels of communication deficit, distress from hair loss, fatigue, nausea/vomiting, pain, seizures, and suffering from headaches, though greater financial difficulties.

Across studies, symptoms with the worst scores were fatigue ($n=6$) [33, 34, 40, 41, 47, 57], sleep disturbances ($n=2$) [39, 50], drowsiness [53], financial difficulties [46], future uncertainty [12], and seizures [48]. This may be influenced by instrument used, as fatigue ($n=10$) was the second most assessed symptom.

Health-related quality-of-life over time

Longitudinal studies varied in the timepoints at which they measured HRQoL. Four of nine longitudinal studies (which considered different aspects of HRQoL) suggested HRQoL remains low, but stable, over time, specifically over six-months [38], one-year [37], and up to 10-[52] and 12-years since diagnosis or treatment [31] (Table 3).

Global HRQoL changes

In Wang et al. [54] and Yavas et al. [57], global HRQoL improvements were reported over one- and three-years since treatment, respectively. For Yavas et al. [57], the median improvement was consistent with the EORTC QLQ-C30 definition of a minimally important difference (i.e. 4–6 points) for global HRQoL improvement in glioma patients [58].

Specific HRQoL changes

For Wang et al., emotional and functional wellbeing, and FACT-Br brain tumour subscale scores significantly improved at one-year, compared to one-month since treatment [54]. In Yavas et al., future uncertainty, communication deficit, suffering from headaches, drowsiness, and distress from hair loss significantly improved from initial assessment (*end of radiotherapy*) to three-years since treatment [57]. For Boele et al., with longer term follow-up, SF-36 physical functioning and physical component scores worsened between a mean of 5.6 and 12 years since diagnosis [31].

Factors associated with health-related quality-of-life

Eighteen papers reporting 15 studies [12, 30, 33–35, 38, 40–42, 44, 45, 47, 49, 52, 54–57] examined 19 different factors for association with HRQoL, most often: age ($n=8$ studies) [12, 34, 35, 40, 45, 47, 49, 54], treatment ($n=8$) [12, 34, 35, 38, 45, 47, 54, 57], and tumour location ($n=7$) [12, 34, 35, 41, 45, 49, 54]. Significant associations were observed by at least one study for 17 factors (i.e. all except genetic markers and marital status) (Table 4). For eight factors—age, cognitive function, education, sex, SES, time since diagnosis/treatment, treatment, and tumour location—reported associations were not always statistically significant; the remaining nine factors – coping, depression, duration of symptoms, epilepsy/seizure burden, history of recurrence, KPS, post-traumatic growth, post-traumatic stress disorder (PTSD), and tumour type—were significantly associated with HRQoL in all studies in which they were reported.

There were 10 positively associated factors, with the most supporting evidence for KPS ($n=3$ of three). Higher KPS was positively associated with global ($n=2$) [34, 47] and specific HRQoL (e.g. less fatigue) ($n=2$) [47, 49]. There were 12 negatively associated factors, with the most supporting evidence for epilepsy/seizure burden ($n=5$ of five). Greater burden was negatively associated with global [54] and specific HRQoL (e.g. worse social functioning) ($n=4$) [12, 35, 44, 49].

Five factors, namely, age, cognitive function, time since diagnosis/treatment, treatment, and tumour location were positively and negatively associated with HRQoL. For example, older age was positively [47] and negatively [12] associated with specific symptoms (e.g. diarrhoea and visual disorder, respectively).

Discussion

Summary of main findings

This systematic review aimed to identify quantitative evidence assessing HRQoL in adult LGG patients, to establish which aspects of HRQoL were impacted; how HRQoL compared with other populations; temporal trends; and factors associated with HRQoL. The 29 papers identified relating to 22 studies were largely good quality. Thirteen studies included comparator and/or control groups, and 19 factors

Table 4 Factors associated with health-related quality-of-life

Factor	Paper	Finding
Age*	Aaronson (2011) [12]	Older age was significantly associated with worse visual disorder ($P = 0.039$)
	Budrukkar (2009) [34]	No significant associations were observed
	Campanella (2017) [35]	No significant associations were observed
	Gustafsson (2006) [40]	No significant associations were observed
	Leonetti (2021) [45]	No significant associations were observed
	Okita (2015) [47]	Older age (≥ 40) was significantly associated with lower levels of diarrhoea ($P = 0.05$)
	Ruge (2011) [49]	No significant associations were observed
	Wang (2018); Li (2019) [54, 56][a]	No significant associations were observed
Cognitive function*	Boele (2014) [30]	Greater executive functioning, processing speed, verbal memory, working memory, information processing, and attention were significantly associated with lower levels of future uncertainty (all $P < 0.01$), visual disorder (all $P < 0.01$; verbal memory $P = 0.011$), motor dysfunction (all $P < 0.01$), communication deficit ($P < 0.01$; verbal memory $P = 0.011$; executive functioning $P = 0.034$; processing speed not significant), and less seizures (all $P < 0.01$), and drowsiness (processing speed and information processing $P < 0.01$; executive functioning $P = 0.014$; verbal memory $P = 0.029$; working memory $P = 0.011$; attention not significant). Greater processing speed was significantly associated with more suffering from headaches ($P = 0.018$), while greater verbal memory ($P = 0.044$), working memory ($P = 0.036$), and information processing ($P = 0.018$) were significantly associated with less suffering from headaches
	Campanella (2017) [35]	No significant associations were observed
	Leonetti (2021) [45]	Higher levels of language deficit were significantly associated with worse mental component scores at 6-months ($P = 0.014$) and 1-year post-surgery ($P < 0.01$), and worse physical component scores at 3-months ($P = 0.025$), 6-months ($P = 0.049$), and 1-year post-surgery ($P = 0.014$)
	Ruge (2011) [49]	Better divided attention performance was significantly associated with better general health perception ($P < 0.02$) and less bodily pain ($P < 0.05$)
Coping^{-}	Gustafsson (2006) [40]	Higher levels of avoidant coping were significantly associated with worse emotional functioning ($P < 0.01$). Higher confrontive coping was significantly associated with greater financial impact ($P < 0.01$) and worse role functioning ($P < 0.01$)
	Li (2019) [56]	Higher levels of avoidant coping were significantly associated with worse global HRQoL ($P < 0.01$)
Depression^{-}	Ruge (2011) [49]	Higher levels of depression were significantly associated with worse vitality ($P < 0.01$), social functioning ($P < 0.01$), emotional functioning ($P < 0.05$) and mental health ($P < 0.01$)
	Wang (2018); Li (2019) [54, 55][a]	Higher levels of depression were significantly associated with worse global HRQoL ($P < 0.01$)
Duration of symptoms^{-}	Ruge (2011) [49]	Longer duration of symptoms (> 20 weeks) was associated with worse physical functioning ($P = 0.043$), vitality ($P = 0.023$), social functioning ($P = 0.036$), and emotional role functioning ($P = 0.014$)

Table 4 (continued)

Factor	Paper	Finding
Education$^+$	Aaronson (2011) [12]	No significant associations were observed
	Budrukkar (2009) [34]	Higher level of literacy was significantly associated with better global HRQoL ($P = 0.025$)
	Campanella (2017) [35]	No significant associations were observed
	Leonetti (2021) [45]	No significant associations were observed
Epilepsy/seizure burden$^-$	Aaronson (2011) [12]	Higher epilepsy burden was significantly associated with worse physical and mental component scores, and higher levels of future uncertainty, motor dysfunction, communication deficit, seizures (all $P < 0.01$), visual disorder ($P = 0.019$), suffering from headaches ($P = 0.046$), drowsiness ($P = 0.033$), and weakness of legs ($P = 0.021$)
	Campanella (2017) [35]	Higher epilepsy burden was significantly associated with worse psychological wellbeing ($P = 0.013$)
	Klein (2003) [44]	Higher epilepsy burden was significantly associated with worse physical health and mental component scores (both $P < 0.01$)
	Ruge (2011) [49]	Presence of seizures was significantly associated with worse social functioning ($P < 0.05$)
	Wang (2018); Li (2019) [54, 56][a]	Presence of seizures was significantly associated with worse global HRQoL ($P < 0.01$)
Genetic markers	Affronti (2018) [33]	No significant associations were observed
	Leonetti (2021) [45]	No significant associations were observed
History of recurrence$^-$	Okita (2015) [47]	A history of recurrence was significantly associated with worse cognitive functioning ($P = 0.03$) and higher levels of fatigue ($P = 0.02$), constipation ($P = 0.01$), financial difficulties ($P = 0.01$), visual disorder ($P < 0.01$), motor dysfunction ($P = 0.04$), communication deficit ($P = 0.02$), drowsiness ($P = 0.02$), weakness of legs ($P = 0.01$), and difficulty with bladder control ($P = 0.02$)
KPS$^+$	Budrukkar (2009) [34]	Higher KPS was significantly associated with better global HRQoL ($P = 0.04$)
	Okita (2015) [47]	Higher KPS was significantly associated with better global HRQoL ($P < 0.01$), physical functioning ($P < 0.01$), role functioning ($P = 0.03$), and social functioning ($P = 0.02$), as well as lower levels of fatigue ($P = 0.03$), insomnia ($P = 0.02$), constipation ($P = 0.01$), motor dysfunction ($P = 0.02$), communication deficit ($P = 0.02$), drowsiness ($P = 0.04$), weakness of legs ($P < 0.01$), and difficulty with bladder control ($P < 0.01$)
	Ruge (2011) [49]	Higher KPS was significantly associated with better physical functioning ($P < .01$) and role functioning ($P = .01$)
Marital status	Gustafsson (2006) [40]	No significant associations were observed
	Wang (2018); Li (2019) [54, 56][a]	No significant associations were observed
Post-traumatic growth (PTG)$^+$	Wang (2018); Li (2019a; 2019b) [54–56][a]	Higher PTG was significantly associated with better global HRQoL ($P < 0.01$)
Post-traumatic stress disorder (PTSD)$^-$	Jiang (2019) [42]	Those with PTSD had significantly worse HRQoL in all eight dimensions of the SF-36, than those without PTSD ($P < 0.01$; physical functioning: $P = 0.026$)
	Li (2019) [56]	Having PTSD was significantly associated with worse global HRQoL ($P < 0.01$)

Table 4 (continued)

Factor	Paper	Finding
Sex[−]	Aaronson (2011) [12]	Female sex was significantly associated with worse physical and mental component scores, and higher levels of visual disorder, motor dysfunction, suffering from headaches (all $P < 0.01$), and weakness of legs ($P = 0.028$)
	Budrukkar (2009) [34]	No significant associations were observed
	Campanella (2017) [35]	No significant associations were observed
	Gustafsson (2006) [40]	No significant associations were observed
	Leonetti (2021) [45]	No significant associations were observed
	Wang (2018); Li (2019) [54, 56][a]	No significant associations were observed
Socio-economic status (SES)[+]	Budrukkar (2009) [34]	No significant associations were observed
	Wang (2018); Li (2019a; 2019b) [54–56][a]	Having social insurance ($P < 0.01$) and higher SES ($P < 0.01$) were significantly associated with better global HRQoL
Time since diagnosis/ treatment[*]	Aaronson (2011) [12]	No significant associations were observed
	Campanella (2017) [35]	No significant associations were observed
	Gustafsson (2006) [40]	No significant associations were observed
	Okita (2015) [47]	Those 10–20 years since treatment had significantly more difficulty with bladder control than 0–4 years since treatment ($P < 0.01$)
	Teng (2021) [52]	Longer time since treatment was significantly associated with better role functioning ($P = 0.013$)
	Wang (2018); Li (2019a) [54, 55][a]	Longer time since treatment was significantly associated with better global HRQoL ($P < 0.01$)
Treatment[*]	Aaronson (2011) [12]	Surgical intervention was significantly associated with higher levels of future uncertainty ($P = 0.02$). Radiotherapy was significantly associated with worse mental component scores ($P = 0.029$)
	Budrukkar (2009) [34]	No significant associations were observed
	Campanella (2017) [35]	No significant associations were observed
	Drewes (2018) [38]	No significant associations were observed
	Leonetti (2021) [45]	Receipt of adjuvant treatments was significantly associated with worse mental component scores at 6-months post-surgery ($P < 0.01$) and worse physical component scores at 3-months ($P = 0.013$) and 6-months post-surgery ($P < 0.01$)
	Okita (2015) [47]	Radiotherapy was significantly associated with lower levels of nausea and vomiting ($P = 0.01$) and dyspnoea ($P = 0.04$), but higher levels of communication deficit ($P = 0.03$). Chemotherapy was significantly associated with worse physical functioning ($P = 0.05$) and bladder control ($P = 0.04$)
	Wang (2018); Li (2019) [54, 56][a]	No significant associations were observed
	Yavas (2012) [57]	No significant associations were observed

Table 4 (continued)

Factor	Paper	Finding
*Tumour location**	Aaronson (2011) [12]	Tumour laterality was significantly associated with higher levels of communication deficit ($P < 0.01$) (*specific laterality not given*)
	Budrukkar (2009) [34]	No significant associations were observed
	Campanella (2017) [35]	No significant associations were observed
	Jakola (2012) [41]	No significant associations were observed
	Leonetti (2021) [45]	No significant associations were observed
	Ruge (2011) [49]	Temporal, parietal, and subcortical tumour locations were significantly associated with worse physical functioning ($P = 0.014$)
	Wang (2018) [54]	Right hemisphere location was significantly associated with better global HRQoL ($P = 0.01$)
Tumour type+	Li (2019) [56]	Lower tumour grade was significantly associated with better global HRQoL ($P < 0.05$)

HRQoL Health-related quality-of-life

+Positively associated

−Negatively associated

*Both positively and negatively associated

[a] The same finding was reported by more than one paper reporting the same study

were examined. Overall, the evidence-base suggests global HRQoL in LGG patients is poor, with considerable functioning impairments and symptom burden, most notably, cognitive functioning and fatigue, respectively. Over time, HRQoL remained low, but stable, and was better than in HGG patients, but substantially worse than in NCCs. Seventeen factors, most frequently epilepsy/seizure burden, were positively ($n = 10$ factors) or negatively ($n = 12$) associated with HRQoL.

Health-related quality-of-life

Thirteen different HRQoL instruments were used. Given the variation across instruments and heterogeneity in patient samples and times at which HRQoL was assessed, we decided not to conduct a meta-analysis. We support Fountain et al.'s call, made in 2016, for a standardised set of validated HRQoL measures for future LGG studies [59]. However, since 2016, 11 studies in this review used 11 different instruments. Hence, this issue is ongoing and needs to be addressed.

Despite better HRQoL than in HGG patients, poor HRQoL in LGG patients was consistently reported, and was emphasised when compared to NCCs. Notable functioning impairments were observed for cognitive, emotional, physical role, and social functioning, general health perception, mental health, and vitality. Symptom burden was high for communication deficit, fatigue, future uncertainty, pain, and suffering from headaches. Cognitive functioning and fatigue were consistently the functioning aspect and symptom with the most impairment and burden, respectively.

Comparisons within LGG subtypes were not investigated in the eligible studies. Survival rates vary by subtype; 1–10 year survival is markedly higher in oligodendrogliomas (93.9 to 64%), than diffuse astrocytomas (72.2 to 37.6%) [3]. It is possible quality of survival also varies. Future research should compare HRQoL across LGG subtypes to distinguish whether impairments or symptoms are accentuated in particular tumour types. The EORTC QLQ-C30 reference values for brain tumours are worse than other cancers (i.e. breast and colorectal) [27]. However, research comparing HRQoL in LGG patients to other (non-brain) cancer populations is scarce. Such comparisons would be of value to help determine whether more tumour-specific, or targeted, supportive care services are required.

There was substantial heterogeneity in time since diagnosis/treatment at which HRQoL was assessed, from point of diagnosis to 20-years since treatment. In general, studies which included patients closer to diagnosis reported greater impacts on HRQoL, as sufficient time may not have elapsed to adjust. For example, in Jiang et al. [42], which included patients approximately 3-months post-diagnosis, SF-36 scores were considerably lower than in other studies. Assessing HRQoL in early stages post-diagnosis may also be problematic. Ruge et al. [49] abandoned the BN20 because LGG patients did not want to be prospectively confronted with questions about treatment effects and tumour progression.

Health-related quality-of-life over time

There was considerable heterogeneity in timepoints assessed across longitudinal studies, with follow-up from one-month to 12-years since diagnosis. Post-treatment, HRQoL typically remained stable over time. However, largely poor baseline scores mean this is not an encouraging finding; rather it suggests LGG patients experience sustained HRQoL impairments over extended periods. Observed improvements to global and specific HRQoL were largely in comparison to one-month post-treatment and probably reflect dissipation of the more acute side-effects of adjuvant therapies [45]. Time for adjustment to the diagnosis is also important, and likely influences the temporal trends; acceptance has been associated with reduced general, and cancer-related, distress [60].

The longitudinal evidence is limited by failure to account for tumour progression or recurrence. Investigators tend not to make any accommodation in their results for the fact that some people have dropped out. Drewes et al. [38] gave deceased patients at follow-up a score of zero, which drove down their mean scores. In general, within these studies, observed temporal trends may, therefore, be biased by the dropout of those whose tumours have progressed and who might plausibly have worse HRQoL. This means more clarity is needed on how long HRQoL impairments are sustained, if, and when, they alleviate, and which aspects remain impaired over time.

Factors associated with health-related quality-of-life

Eight factors were positively associated, while four factors were negatively associated, with global HRQoL. Five factors were positively associated, while 12 factors were negatively associated with specific aspects of HRQoL. Epilepsy/seizure burden was most consistently associated with worse HRQoL suggesting further seizure management, as a clinical priority, may ameliorate the impact of an LGG on patient HRQoL.

Eight factors had inconsistent findings, most notably, age, sex, treatment, and tumour location. Nonetheless, acknowledging these factors is important when considering what support may be needed. For example, PTSD was associated with worse global HRQoL [56], and worse functioning on all eight SF-36 dimensions [42]. Consequently, LGG patients with PTSD may benefit from enhanced supportive care.

Critical appraisal of evidence

Twenty of the 29 papers were judged good quality. However, an important limitation is that the available evidence for HRQoL in adult LGG patients may not represent the full LGG population. Eleven studies explicitly excluded patients with communication and/or cognitive impairments. Only Drewes et al. [38] facilitated their inclusion, but this was through proxy ratings, which may not be reliable [61]. Eight studies failed to detail how impairments were determined [12, 38, 40, 42, 44, 46, 53, 57]. Gabel et al. [39] used the Boston Diagnostic Aphasia Examination [62], and Wang et al. [54] used the Mini Mental State Exam (MMSE) [63] to assess communication and cognitive impairments, respectively. Though indicative of impairment, this should not determine someone's capacity to participate. Wang et al. [54] excluded patients with at least mild cognitive impairment (≤ 24), yet lower MMSE scores are significantly associated with worse HRQoL in brain tumour patients [64]. Therefore, the average HRQoL of LGG patients was likely overestimated.

Consistent with Brownsett et al. [65], we highlight the prevalence of poor cognitive functioning and high levels of communication deficit in adult LGG patients. However, explicit exclusion of patients with these impairments in over half of studies, means these impacts may be underestimated. For those that did not exclude such patients, if/how participation was facilitated was often unclear. Miscomprehension of a question due to such impairments could impact the reliability of results. Future research should do more to facilitate greater inclusivity. To achieve this, researchers might engage in supportive conversation training; ensure accessible formatting of study documentation; validate accessible (e.g. pictorial) rating scales (see the assessment for living with aphasia [66]); or involve/consult specialist professionals, such as speech and language therapists.

The WHO classification of tumours of the central nervous system was majorly restructured in 2016 [22], and 2021 [23]. Included studies were published 2001 to 2021, so what authors considered to be an LGG is potentially heterogeneous. Seven studies did not report tumour type [34, 35, 38, 39, 46, 48, 50], while three studies only reported tumour grade [43, 54, 57]. This may have implications for whether HRQoL findings accurately reflect LGG patients, as presently classified. Details of anti-cancer treatment(s), ethnicity and SES for study samples were also incompletely reported, which limits understanding of whether HRQoL vary by these factors. A minimum "core set" of socio-demographic, tumour, and treatment-related characteristics to be consistently reported by future study authors would be valuable.

Strengths and limitations

Our review benefitted from extensive searches, including several databases and hand searching of reference lists and citations. Our focus on HRQoL beyond the clinical trial context allowed us to examine the 'real world' experience of LGG patients, when they are not undergoing the close monitoring that may happen within a trial.

A challenge was the lack of validated cut-off values for what is considered low, high, or clinically significant for numerous HRQoL instruments. Consequently, although we attempted to be consistent across studies, interpretation of reported values was difficult for some studies.

Brain tumour patients are likely to underestimate cognitive, emotional, psychological, and social changes [67]. This highlights an issue with subjective measurement of HRQoL using patient-reported outcome measures in LGG patients, namely that, because of the tumour, patients may lack insight and not self-report issues. This could mean functioning and symptoms have been over and underestimated, respectively, in the available studies.

Future research

The international classification of functioning, disability, and health (ICF) has been used to consider 44 categories of activities and participation (e.g. walking or doing housework) that may be limited in primary brain tumour patients [68]. Future research could be conducted to understand whether, and if so, which HRQoL impairments, personal (e.g. age), clinical (e.g. tumour location), and environmental (e.g. location) factors are associated with these categories in LGG patients. This could help to further highlight specific support needs of this population overall, and subgroups within it. To do this, a useful first step would be to code the HRQoL instrument items to the ICF.

To date, one qualitative study has explored HRQoL in LGG patients [69], and this focussed largely on coping strategies used. Further qualitative research would be of value to provide a more holistic insight into patients' experiences of HRQoL impacts, functional impairments, and symptoms, and how different impacts might be interconnected. Patients could reflect on when HRQoL aspects were particularly impacted, at what point these improved or deteriorated, and valuable (in)formal support.

Conclusion

Influenced by several factors, most frequently, epilepsy/seizure burden, adult LGG patients have poor global HRQoL and experience an array of functioning impairments and symptom burden, most notably cognitive functioning and fatigue, respectively. These remain poor, but stable over time, and are markedly worse than in NCCs. Further consideration of LGG patients with speech, language, communication, and cognitive impairments is required, including steps to improve researchers' confidence in ensuring their inclusion. These findings may help clinicians recognise current supportive care needs and inform types and timings of support needed, as well as inform future interventions.

Supplementary Information The online version contains supplementary material available at https://doi.org/10.1007/s11136-022-03207-x.

Acknowledgements We thank Bogdan Metes for his assistance with the search strategy, and Tracy Finch for her contribution to the Ways Ahead project, from which this review is an output (research.ncl.ac.uk/waysahead).

Author Contributions Securing the funding: LS, JL, SW, PG, RB, VA-S Conceptualising the review: B.R, I.B, L.D and L.S. Conducting the searches: BR and IB Search screening: B.R and I.B. Data extraction, analysis, and interpretation: B.R and I.B. Drafting the manuscript: B.R. Review, revision, and approval of the final manuscript: BR, IB, LD, JL, RB, PG, SW, VA-S, FM, LS.

Funding This review was supported by funding from The Brain Tumour Charity (GN-000435).

Declarations

Conflict of interest The authors declare that they have no competing interests.

Ethical approval Not applicable.

Consent to participate Not applicable.

Consent to publish Not applicable.

References

1. Sung, H., Ferlay, J., Siegel, R. L., Laversanne, M., Soerjomataram, I., Jemal, A., & Bray, F. (2021). Global cancer statistics 2020 GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. *CA: A Cancer Journal for Clinicians, 71*(3), 209–249.
2. Miller, K. D., Ostrom, Q. T., Kruchko, C., Patil, N., Tihan, T., Cioffi, G., Fuchs, H. E., Waite, K. A., Jemal, A., & Siegel, R. L. (2021). Brain and other central nervous system tumor statistics, 2021. *CA: A Cancer Journal for Clinicians, 71*(5), 381–406.
3. Bauchet, L. (2017). Epidemiology of diffuse low grade gliomas. In *Diffuse Low-Grade Gliomas in Adults* (pp. 13–53). Springer International Publishing. https://doi.org/10.1007/978-3-319-55466-2_2

4. Dixit, K., & Raizer, J. (2017). Newer Strategies for the Management of Low-Grade Gliomas. *Oncology (Williston Park, N.Y.), 31*(9), 680–682, 684–685. https://www.scholars.northwestern.edu/en/publications/newer-strategies-for-the-management-of-low-grade-gliomas
5. Claus, E. B., Walsh, K. M., Wiencke, J. K., Molinaro, A. M., Wiemels, J. L., Schildkraut, J. M., Bondy, M. L., Berger, M., Jenkins, R., & Wrensch, M. (2015). Survival and low-grade glioma: The emergence of genetic information. *Neurosurgical Focus, 38*(1), E6. https://doi.org/10.3171/2014.10.FOCUS12367
6. Post, M. (2014). Definitions of quality of life: What has happened and how to move on. *Topics in Spinal Cord Injury Rehabilitation, 20*(3), 167–180. https://doi.org/10.1310/SCI2003-167
7. Khan, F., & Amatya, B. (2013). Factors associated with long-term functional outcomes, psychological sequelae and quality of life in persons after primary brain tumour. *Journal of Neuro-Oncology, 111*(3), 355–366. https://doi.org/10.1007/s11060-012-1024-z
8. Boele, F. W., Klein, M., Reijneveld, J. C., Verdonck-de Leeuw, I. M., & Heimans, J. J. (2014). Symptom management and quality of life in glioma patients. *In CNS oncology Future Medicine Ltd London, UK*. https://doi.org/10.2217/cns.13.65
9. Liu, R., Page, M., Solheim, K., Fox, S., & Chang, S. M. (2009). Quality of life in adults with brain tumors: Current knowledge and future directions. *Neuro-Oncology, 11*(3), 330–339. https://doi.org/10.1215/15228517-2008-093
10. *Losing myself the reality of life with a brain tumour Contents*. (n.d.)
11. Huang, M. E., Wartella, J., Kreutzer, J., Broaddus, W., & Lyckholm, L. (2001). Functional outcomes and quality of life in patients with brain tumours: A review of the literature. *Brain Injury, 15*(10), 843–856. https://doi.org/10.1080/02699050010013653
12. Aaronson, N. K., Taphoorn, M. J. B., Heimans, J. J., Postma, T. J., Gundy, C. M., Beute, G. N., Slotman, B. J., & Klein, M. (2011). Compromised health-related quality of life in patients with low-grade glioma. *Journal of Clinical Oncology, 29*(33), 4430–4435. https://doi.org/10.1200/JCO.2011.35.5750
13. Cheng, J. X., Liu, B., & lin, Zhang, X., Lin, W., Zhang, Y. qiang, Liu, W. ping, Zhang, J. N., Lin, H., Wang, R., & Yin, H. (2010). Health-related quality of life in glioma patients in China. *BMC Cancer, 10*(1), 305. https://doi.org/10.1186/1471-2407-10-305
14. Giovagnoli, A. R., Meneses, R. F., Silvani, A., Milanesi, I., Fariselli, L., Salmaggi, A., & Boiardi, A. (2014). Quality of life and brain tumors: What beyond the clinical burden? *Journal of Neurology, 261*(5), 894–904. https://doi.org/10.1007/s00415-014-7273-3
15. Farace, E., & Sheehan, J. (2014). QL-09 * Trajectory of quality of life at end of life in malignant glioma: Support for the terminal drop theory. *Neuro-Oncology, 16*(suppl 5), v180–v180. https://doi.org/10.1093/neuonc/nou269.9
16. Kennedy-Martin, T., Curtis, S., Faries, D., Robinson, S., & Johnston, J. (2015). (2015) A literature review on the representativeness of randomized controlled trial samples and implications for the external validity of trial results. *Trials, 16*(1), 1–14. https://doi.org/10.1186/S13063-015-1023-4
17. Jakola, A. S., Unsgård, G., Myrmel, K. S., Kloster, R., Torp, S. H., Sagberg, L. M., Lindal, S., & Solheim, O. (2014). Surgical strategies in low-grade gliomas and implications for long-term quality of life. *Journal of Clinical Neuroscience, 21*(8), 1304–1309. https://doi.org/10.1016/j.jocn.2013.11.027
18. Kiebert, G. M., Curran, D., Aaronson, N. K., Bolla, M., Menten, J., Rutten, E. H. J. M., Nordman, E., Silvestre, M. E., Pierart, M., & Karim, A. B. M. F. (1998). Quality of life after radiation therapy of cerebral low-grade gliomas of the adult: Results of a randomised phase III trial on dose response (EORTC trial 22844). *European Journal of Cancer, 34*(12), 1902–1909. https://doi.org/10.1016/S0959-8049(98)00268-8
19. Taphoorn, M. J. B., Van Den Bent, M. J., Mauer, M. E. L., Coens, C., Delattre, J. Y., Brandes, A. A., Sillevis Smitt, P. A. E., Bernsen, H. J. J. A., Frénay, M., Tijssen, C. C., Lacombe, D., Allgeier, A., & Bottomley, A. (2007). Health-related quality of life in patients treated for anaplastic oligodendroglioma with adjuvant chemotherapy: Results of a European Organisation for Research and Treatment of Cancer randomized clinical trial. *Journal of Clinical Oncology, 25*(36), 5723–5730. https://doi.org/10.1200/JCO.2007.12.7514
20. Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D., Shamseer, L., Tetzlaff, J. M., Akl, E. A., & Brennan, S. E. (2021). The PRISMA 2020 statement: An updated guideline for reporting systematic reviews. *BMJ, 372*, 23.
21. Bottomley, A. (2002). The cancer patient and quality of life; The cancer patient and quality of life. *The Oncologist, 7*, 120–125. https://doi.org/10.1634/theoncologist.7-2-120
22. Louis, D. N., Perry, A., Reifenberger, G., von Deimling, A., Figarella-Branger, D., Cavenee, W. K., Ohgaki, H., Wiestler, O. D., Kleihues, P., & Ellison, D. W. (2016). The 2016 world health organization classification of tumors of the central nervous system: A summary. *In Acta Neuropathologica, 131*(6), 803–820. https://doi.org/10.1007/s00401-016-1545-1
23. Louis, D. N., Perry, A., Wesseling, P., Brat, D. J., Cree, I. A., Figarella-Branger, D., Hawkins, C., Ng, H. K., Pfister, S. M., Reifenberger, G., Soffietti, R., von Deimling, A., & Ellison, D. W. (2021). The 2021 WHO classification of tumors of the central nervous system: A summary. *Neuro-Oncology, 23*(8), 1231–1251. https://doi.org/10.1093/NEUONC/NOAB106
24. Taphoorn, M. J. B. (2013). *Quality of life in low-grade gliomas*. Cham: In Diffuse Low-Grade Gliomas in Adults Springer.
25. Dunne, S., Mooney, O., Coffey, L., Sharp, L., Desmond, D., Timon, C., O'Sullivan, E., & Gallagher, P. (2017). Psychological variables associated with quality of life following primary treatment for head and neck cancer: A systematic review of the literature from 2004 to 2015. *Psycho-Oncology, 26*(2), 149–160. https://doi.org/10.1002/pon.4109
26. Popay, J., Roberts, H., Sowden, A., Petticrew, M., Arai, L., Rodgers, M., Britten, N., Roen, K., & Duffy, S. (2006). Guidance on the conduct of narrative synthesis in systematic reviews. *A Product from the ESRC Methods Programme Version, 1*, b92.
27. Scott, N. W., Fayers, P., Aaronson, N. K., Bottomley, A., de Graeff, A., Groenvold, M., Gundy, C., Koller, M., Petersen, M. A., & Sprangers, M. A. G. (2008). *EORTC QLQ-C30 reference values manual*
28. Janssen, B., & Szende, A. (2014). Population norms for the EQ-5D. *Self-Reported Population Health: An International Perspective Based on EQ-5D*, 19–30
29. Holzner, B., Kemmler, G., Cella, D., de Paoli, C., Meraner, V., Kopp, M., Greil, R., Fleischhacker, W. W., & Sperner-Unterweger, B. (2004). Normative data for functional assessment of cancer therapy general scale and its use for the interpretation of quality of life scores in cancer survivors. *Acta Oncologica, 43*(2), 153–160.
30. Boele, F. W., Zant, M., Heine, E. C. E., Aaronson, N. K., Taphoorn, M. J. B., Reijneveld, J. C., Postma, T. J., Heimans, J. J., & Klein, M. (2014). The association between cognitive functioning and health-related quality of life in low-grade glioma patients. *Neuro-Oncology Practice, 1*(2), 40–46. https://doi.org/10.1093/nop/npu007
31. Boele, F. W., Douw, L., Reijneveld, J. C., Robben, R., Taphoorn, M. J. B., Aaronson, N. K., Heimans, J. J., & Klein, M. (2015). Health-related quality of life in stable. *Long-Term Survivors of Low-Grade Glioma*. https://doi.org/10.1200/JCO.2014.56.9079
32. Ediebah, D. E., Reijneveld, J. C., & Martin, •, Taphoorn, J. B., Coens, • Corneel, Zikos, E., Aaronson, N. K., Heimans, J. J.,

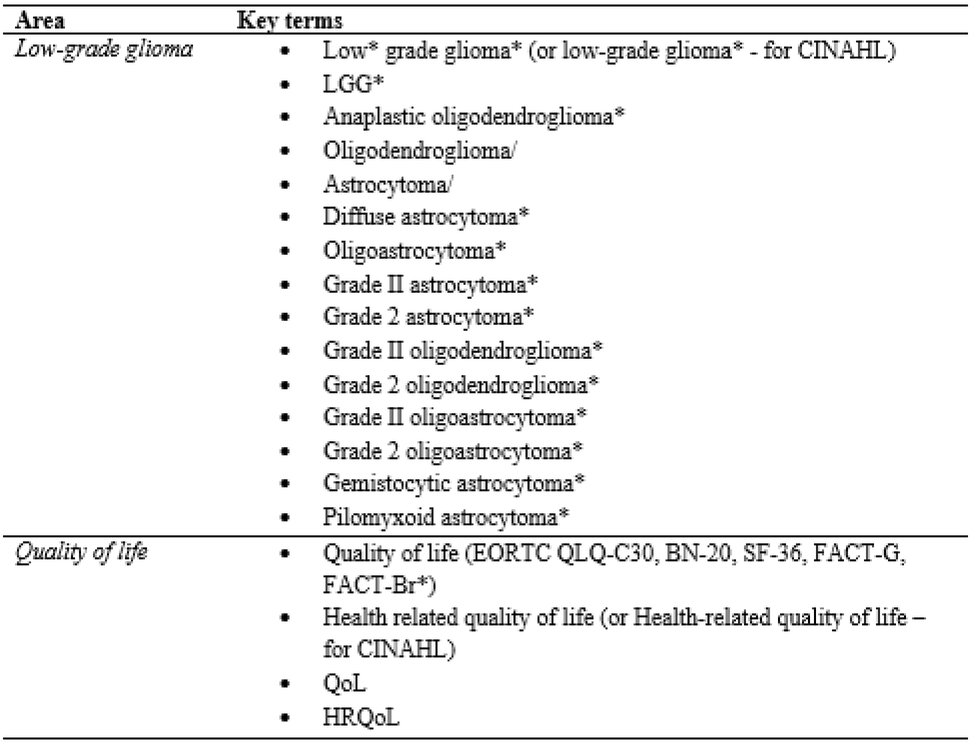
Bottomley, • Andrew, & Klein, • Martin. (2016). Impact of neurocognitive deficits on patient-proxy agreement regarding health-related quality of life in low-grade glioma patients on behalf of the EORTC. *Quality of Life Department and Patient Reported Outcome and Behavioral Evidence (PROBE)*. https://doi.org/10.1007/s11136-016-1426-z

33. Affronti, M. L., Randazzo, D., Lipp, E. S., Peters, K. B., Herndon, S. C., Woodring, S., Healy, P., Cone, C. K., Herndon, J. E., & Schneider, S. M. (2018). Pilot study to describe the trajectory of symptoms and adaptive strategies of adults living with low-grade glioma. *Seminars in Oncology Nursing, 34*(5), 472–485. https://doi.org/10.1016/j.soncn.2018.10.006
34. Budrukkar, A., Jalali, R., Dutta, D., Sarin, R., Devlekar, R., Parab, S., & Kakde, A. (2009). Prospective assessment of quality of life in adult patients with primary brain tumors in routine neurooncology practice. *Journal of Neuro-Oncology, 95*(3), 413–419. https://doi.org/10.1007/s11060-009-9939-8
35. Campanella, F., Palese, A., Del Missier, F., Moreale, R., Ius, T., Shallice, T., Fabbro, F., & Skrap, M. (2017). Long-term cognitive functioning and psychological well-being in surgically treated patients with low-grade glioma. *World Neurosurgery, 103*, 799-808.e9. https://doi.org/10.1016/J.WNEU.2017.04.006
36. Correa, D. D., DeAngelis, L. M., Shi, W., Thaler, H. T., Lin, M., & Abrey, L. E. (2007). Cognitive functions in low-grade gliomas: Disease and treatment effects. *Journal of Neuro-Oncology, 81*(2), 175–184. https://doi.org/10.1007/s11060-006-9212-3
37. Correa, D. D., Shi, W., Thaler, H. T., Cheung, A. M., DeAngelis, L. M., & Abrey, L. E. (2008). Longitudinal cognitive follow-up in low grade gliomas. *Journal of Neuro-Oncology, 86*(3), 321–327. https://doi.org/10.1007/s11060-007-9474-4
38. Drewes, C., Sagberg, L. M., Jakola, A. S., & Solheim, O. (2018). Perioperative and postoperative quality of life in patients with glioma–a longitudinal cohort study. *World Neurosurgery, 117*, e465–e474. https://doi.org/10.1016/j.wneu.2018.06.052
39. Gabel, N., Altshuler, D. B., Brezzell, A., Briceño, E. M., Boileau, N. R., Miklja, Z., Kluin, K., Ferguson, T., McMurray, K., Wang, L., Smith, S. R., Carlozzi, N. E., & Hervey-Jumper, S. L. (2019). Health related quality of life in adult low and high-grade glioma patients using the national institutes of health patient reported outcomes measurement information system (PROMIS) and Neuro-QOL assessments. *Frontiers in Neurology, 10*, 212. https://doi.org/10.3389/fneur.2019.00212
40. Gustafsson, M., Edvardsson, T., & Ahlström, G. (2006). The relationship between function, quality of life and coping in patients with low-grade gliomas. *Supportive Care in Cancer, 14*(12), 1205–1212. https://doi.org/10.1007/s00520-006-0080-3
41. Jakola, A. S., Unsgård, G., Myrmel, K. S., Kloster, R., Torp, S. H., Lindal, S., & Solheim, O. (2012). Low grade gliomas in eloquent locations – implications for surgical strategy, survival and long term quality of life. *PLoS ONE, 7*(12), e51450. https://doi.org/10.1371/journal.pone.0051450
42. Jiang, C., & Wang, J. (2019). Post-traumatic stress disorders in patients with low-grade glioma and its association with survival. *Journal of Neuro-Oncology, 142*(2), 385–392. https://doi.org/10.1007/s11060-019-03112-3
43. Kim, S. R., Kim, H. Y., Nho, J. H., Ko, E., Moon, K. S., & Jung, T. Y. (2020). Relationship among symptoms, resilience, posttraumatic growth, and quality of life in patients with glioma. *European Journal of Oncology Nursing, 48*, 101830. https://doi.org/10.1016/j.ejon.2020.101830
44. Klein, M., Engelberts, N. H. J., van der Ploeg, H. M., Kasteleijn-Nolst Trenité, D. G. A., Aaronson, N. K., Taphoorn, M. J. B., Baaijen, H., Vandertop, W. P., Muller, M., Postma, T. J., & Heimans, J. J. (2003). Epilepsy in low-grade gliomas: The impact on cognitive function and quality of life. *Annals of Neurology, 54*(4), 514–520. https://doi.org/10.1002/ana.10712
45. Leonetti, A., Puglisi, G., Rossi, M., Viganò, L., Nibali, M. C., Gay, L., Sciortino, T., Howells, H., Fornia, L., Riva, M., Cerri, G., & Bello, L. (2021). Factors influencing mood disorders and health related quality of life in adults with glioma: A longitudinal study. *Frontiers in Oncology*. https://doi.org/10.3389/FONC.2021.662039
46. Mahalakshmi, P., & Vanisree, A. (2015). Quality of life measures in glioma patients with different grades: A preliminary study. *Indian Journal of Cancer, 52*(4), 580. https://doi.org/10.4103/0019-509X.178395
47. Okita, Y., Narita, Y., Miyahara, R., Miyakita, Y., Ohno, M., & Shibui, S. (2015). Health-related quality of life in long-term survivors with Grade II gliomas: The contribution of disease recurrence and Karnofsky Performance Status. *Japanese Journal of Clinical Oncology, 45*(10), 906–913. https://doi.org/10.1093/jjco/hyv115
48. Reijneveld, J. C., Sitskoorn, M. M., Klein, M., Nuyen, J., & Taphoorn, M. J. B. (2001). Cognitive status and quality of life in patients with suspected versus proven low-grade gliomas. *Neurology, 56*(5), 618–623. https://doi.org/10.1212/WNL.56.5.618
49. Ruge, M. I., Ilmberger, J., Tonn, J. C., & Kreth, F. W. (2011). Health-related quality of life and cognitive functioning in adult patients with supratentorial WHO grade II glioma: Status prior to therapy. *Journal of Neuro-Oncology, 103*(1), 129–136. https://doi.org/10.1007/s11060-010-0364-9
50. Salo, J., Niemelä, A., Joukamaa, M., & Koivukangas, J. (2002). Effect of brain tumour laterality on patients' perceived quality of life. *Journal of Neurology Neurosurgery and Psychiatry, 72*(3), 373–377. https://doi.org/10.1136/jnnp.72.3.373
51. Mainio, A., Tuunanen, S., Hakko, H., Niemelä, A., Koivukangas, J., & Räsänen, P. (2006). Decreased quality of life and depression as predictors for shorter survival among patients with low-grade gliomas: A follow-up from 1990 to 2003. *European Archives of Psychiatry and Clinical Neuroscience, 256*(8), 516–521. https://doi.org/10.1007/s00406-006-0674-2
52. Teng, K. X., Price, B., Joshi, S., Alukaidey, L., Shehab, A., Mansour, K., Toor, G. S., Angliss, R., & Drummond, K. (2021). Life after surgical resection of a low-grade glioma: A prospective cross-sectional study evaluating health-related quality of life. *Journal of Clinical Neuroscience, 88*, 259–267. https://doi.org/10.1016/j.jocn.2021.03.038
53. Umezaki, S., Shinoda, Y., Mukasa, A., Tanaka, S., Takayanagi, S., Oka, H., Tagawa, H., Haga, N., & Yoshino, M. (2020). Factors associated with health-related quality of life in patients with glioma: Impact of symptoms and implications for rehabilitation. *Japanese Journal of Clinical Oncology, 50*(9), 990–998. https://doi.org/10.1093/jjco/hyaa068
54. Wang, X., Li, J., Chen, J., Fan, S., Chen, W., Liu, F., Chen, D., & Hu, X. (2018). Health-related quality of life and posttraumatic growth in low-grade gliomas in China: A prospective study. *World Neurosurgery, 111*, e24–e31. https://doi.org/10.1016/j.wneu.2017.11.122
55. Li, J., Wang, X., Wang, C., & Sun, L. (2019). The moderating role of depression on the association between posttraumatic growth and health-related quality of life in low-grade glioma patients in China. *Psychology, Health & Medicine, 24*(6), 643–653. https://doi.org/10.1080/13548506.2018.1557714
56. Li, J., Sun, L., Wang, X., Sun, C., Heng, S., Hu, X., Chen, W., & Liu, F. (2019). Are Posttraumatic stress symptoms and avoidant coping inhibitory factors? The association between posttraumatic growth and quality of life among low-grade gliomas patients in China. *Frontiers in Psychology, 10*, 330. https://doi.org/10.3389/fpsyg.2019.00330
57. Yavas, C., Zorlu, F., Ozyigit, G., Gurkaynak, M., Yavas, G., Yuce, D., Cengiz, M., Yildiz, F., & Akyol, F. (2012). Prospective assessment of health-related quality of life in patients with low-grade

glioma A single-center experience. *Supportive Care in Cancer, 20*(8), 1859–1868. https://doi.org/10.1007/s00520-011-1288-4

58. Dirven, L., Groups, on behalf of the E. B. T. G. and Q. of L., Musoro, J. Z., Groups, on behalf of the E. B. T. G. and Q. of L., Coens, C., Groups, on behalf of the E. B. T. G. and Q. of L., Reijneveld, J. C., Groups, on behalf of the E. B. T. G. and Q. of L., Taphoorn, M. J. B., Groups, on behalf of the E. B. T. G. and Q. of L., Boele, F. W., Groups, on behalf of the E. B. T. G. and Q. of L., Groenvold, M., Groups, on behalf of the E. B. T. G. and Q. of L., van den Bent, M. J., Groups, on behalf of the E. B. T. G. and Q. of L., Stupp, R., Groups, on behalf of the E. B. T. G. and Q. of L., Velikova, G., Groups, on behalf of the E. B. T. G. and Q. of L. (2021). Establishing anchor-based minimally important differences for the EORTC QLQ-C30 in glioma patients. *Neuro-Oncology, 23*(8), 1327–1336. https://doi.org/10.1093/NEUONC/NOAB037
59. Fountain, D. M., Allen, D., Joannides, A. J., Nandi, D., Santarius, T., & Chari, A. (2016). Reporting of patient-reported health-related quality of life in adults with diffuse low-grade glioma: A systematic review. *Neuro-Oncology, 18*(11), 1475–1486. https://doi.org/10.1093/NEUONC/NOW107
60. Secinti, E., Tometich, D. B., Johns, S. A., & Mosher, C. E. (2019). The relationship between acceptance of cancer and distress: A meta-analytic review. *Clinical Psychology Review, 71*, 27–38. https://doi.org/10.1016/J.CPR.2019.05.001
61. Hilari, K., Owen, S., & Farrelly, S. J. (2007). Proxy and self-report agreement on the stroke and aphasia quality of life scale-39. *Journal of Neurology, Neurosurgery & Psychiatry, 78*(10), 1072–1075. https://doi.org/10.1136/JNNP.2006.111476
62. Goodglass, H., Kaplan, E., & Barresi, B. (2001). *The assessment of aphasia and related disorders*. Lippincott Williams & Wilkins.
63. Cockrell, J. R., & Folstein, M. F. (2002). Mini-mental state examination. *Principles and Practice of Geriatric Psychiatry*. https://doi.org/10.1002/0470846410.ch27(ii)
64. Taphoorn, M. J. B., Claassens, L., Aaronson, N. K., Coens, C., Mauer, M., Osoba, D., Stupp, R., Mirimanoff, R. O., van den Bent, M. J., & Bottomley, A. (2010). An international validation study of the EORTC brain cancer module (EORTC QLQ-BN20) for assessing health-related quality of life and symptoms in brain cancer patients. *European Journal of Cancer, 46*(6), 1033–1040. https://doi.org/10.1016/j.ejca.2010.01.012
65. Brownsett, S. L. E., Ramajoo, K., Copland, D., McMahon, K. L., Robinson, G., Drummond, K., Jeffree, R. L., Olson, S., Ong, B., & Zubicaray, G. D. (2019). Language deficits following dominant hemisphere tumour resection are significantly underestimated by syndrome-based aphasia assessments. *Aphasiology, 33*(10), 1163–1181. https://doi.org/10.1080/02687038.2019.1614760
66. Simmons-Mackie, N., Kagan, A., Charles Victor, J., Carling-Rowland, A., Mok, A., Hoch, J. S., Huijbregts, M., & Streiner, D. L. (2014). The assessment for living with aphasia: Reliability and construct validity. *International Journal of Speech-Language Pathology, 16*(1), 82–94. https://doi.org/10.3109/17549507.2013.831484
67. Andrewes, H. E., Drummond, K. J., Rosenthal, M., Bucknill, A., & Andrewes, D. G. (2013). Awareness of psychological and relationship problems amongst brain tumour patients and its association with carer distress. *Psycho-Oncology, 22*(10), 2200–2205. https://doi.org/10.1002/PON.3274
68. Khan, F., & Amatya, B. (2013). Use of the international Classification of Functioning, Disability and Health (ICF) to describe patient -reported disability in primary brain tumour in an Australian comunity cohort. *Journal of Rehabilitation Medicine, 45*(5), 434–445. https://doi.org/10.2340/16501977-1132
69. Edvardsson, T., & Ahlström, G. (2005). Illness-related problems and coping among persons with low-grade glioma. *Psycho-Oncology, 14*(9), 728–737. https://doi.org/10.1002/PON.898

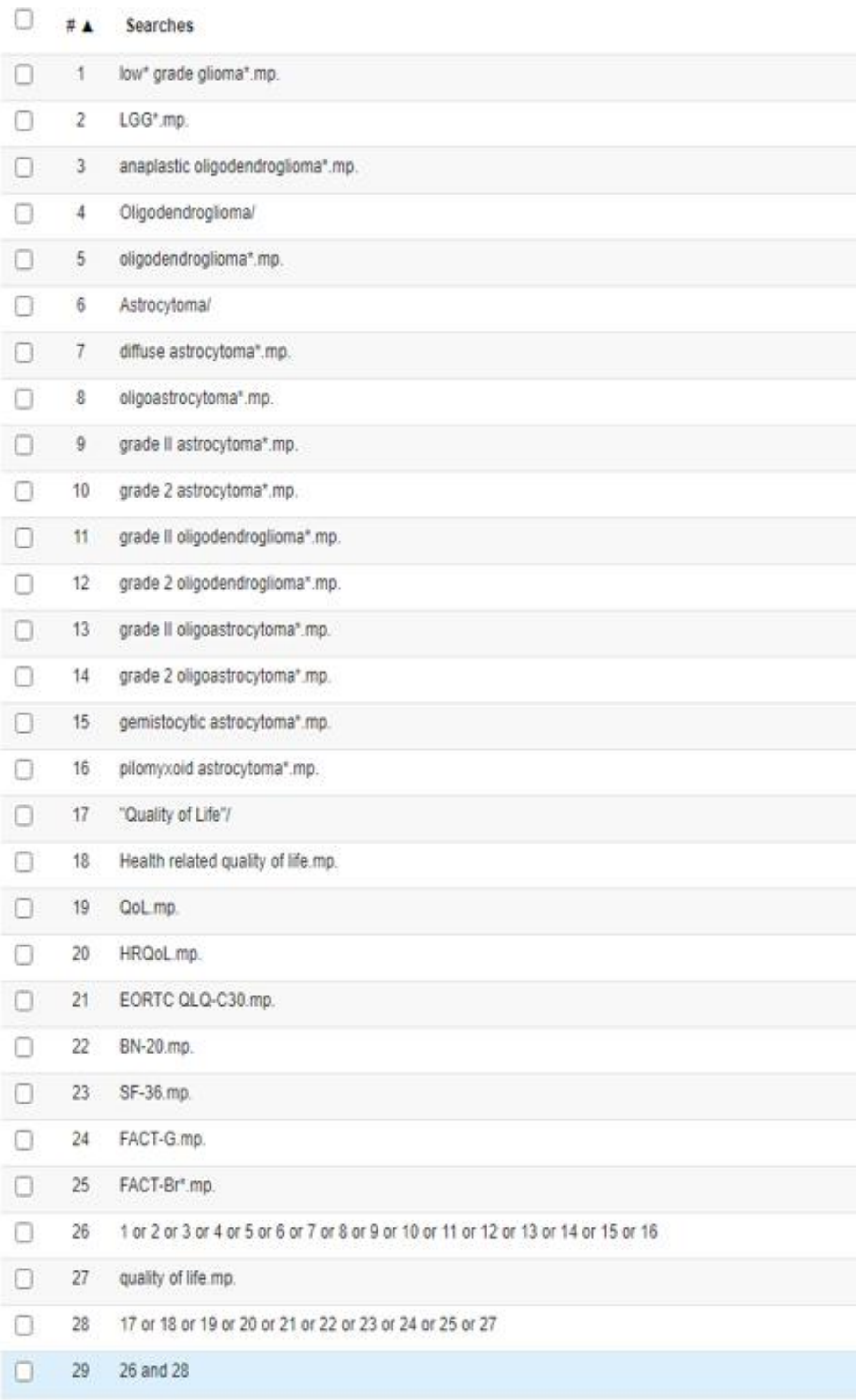
Supplementary table 1: Search strategy



Area	Key terms
Low-grade glioma	• Low* grade glioma* (or low-grade glioma* - for CINAHL) • LGG* • Anaplastic oligodendroglioma* • Oligodendroglioma/ • Astrocytoma/ • Diffuse astrocytoma* • Oligoastrocytoma* • Grade II astrocytoma* • Grade 2 astrocytoma* • Grade II oligodendroglioma* • Grade 2 oligodendroglioma* • Grade II oligoastrocytoma* • Grade 2 oligoastrocytoma* • Gemistocytic astrocytoma* • Pilomyxoid astrocytoma*
Quality of life	• Quality of life (EORTC QLQ-C30, BN-20, SF-36, FACT-G, FACT-Br*) • Health related quality of life (or Health-related quality of life – for CINAHL) • QoL • HRQoL

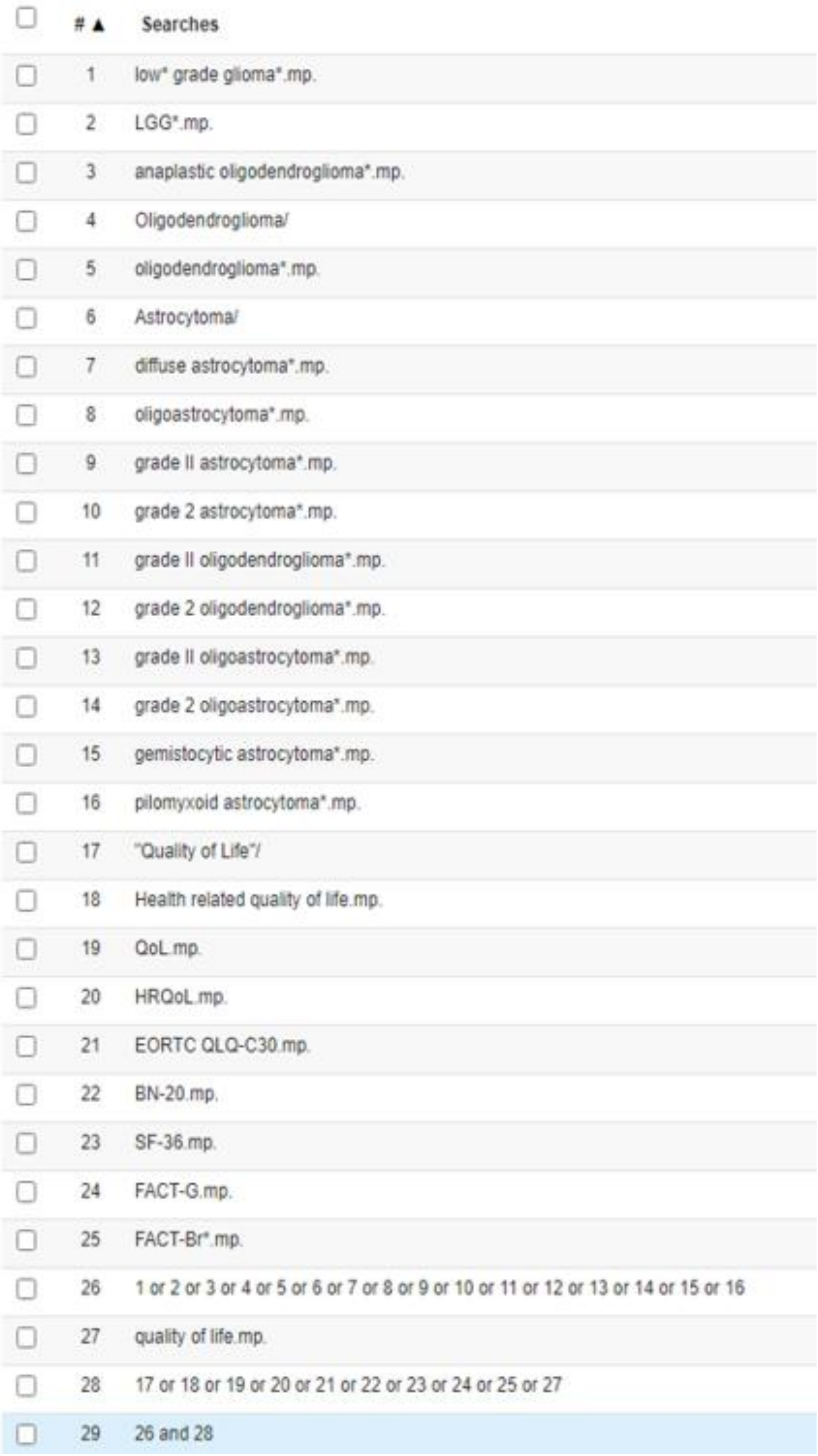
Supplementary table 2: Database searches

MEDLINE search



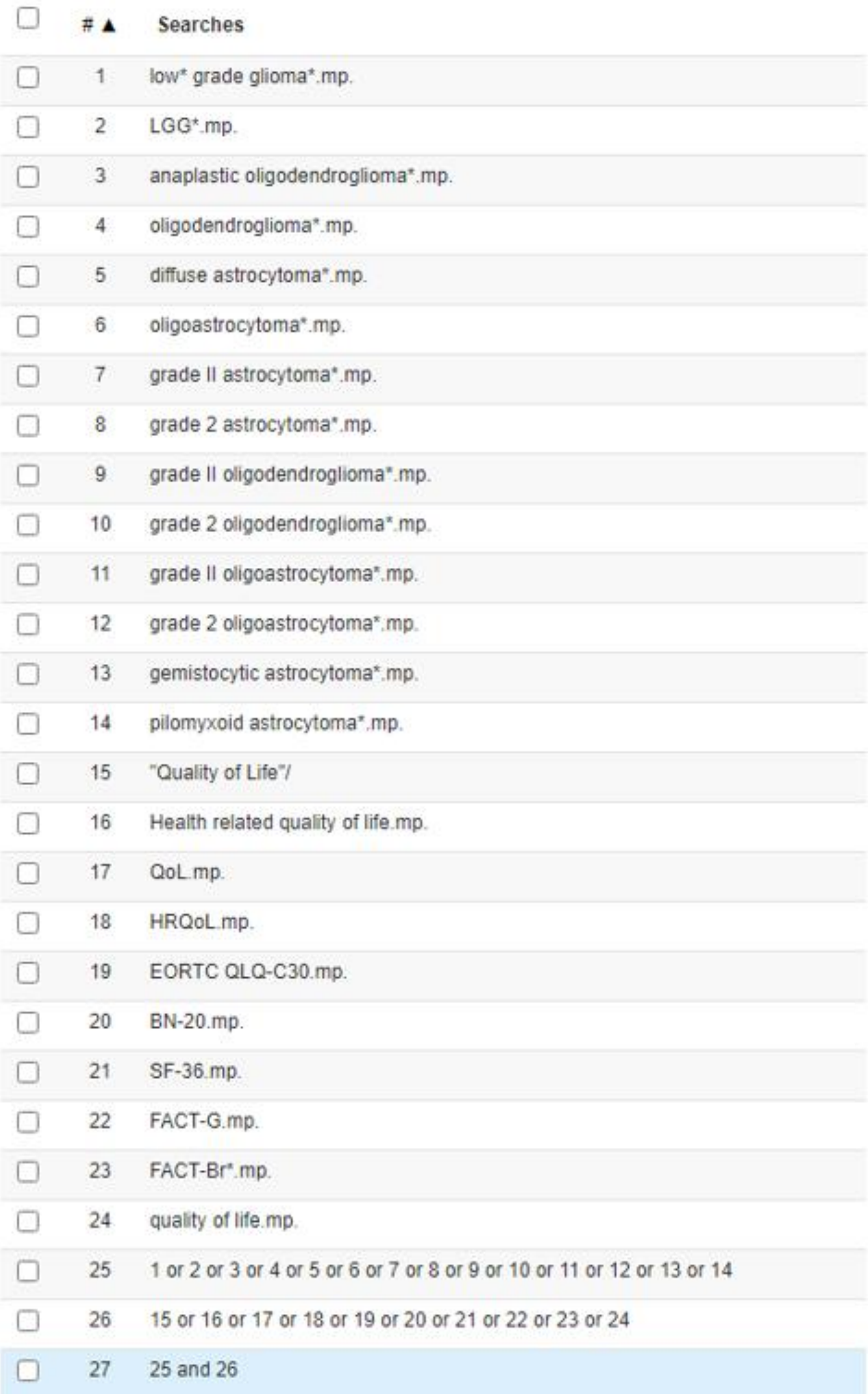
☐	# ▲	Searches
☐	1	low* grade glioma*.mp.
☐	2	LGG*.mp.
☐	3	anaplastic oligodendroglioma*.mp.
☐	4	Oligodendroglioma/
☐	5	oligodendroglioma*.mp.
☐	6	Astrocytoma/
☐	7	diffuse astrocytoma*.mp.
☐	8	oligoastrocytoma*.mp.
☐	9	grade II astrocytoma*.mp.
☐	10	grade 2 astrocytoma*.mp.
☐	11	grade II oligodendroglioma*.mp.
☐	12	grade 2 oligodendroglioma*.mp.
☐	13	grade II oligoastrocytoma*.mp.
☐	14	grade 2 oligoastrocytoma*.mp.
☐	15	gemistocytic astrocytoma*.mp.
☐	16	pilomyxoid astrocytoma*.mp.
☐	17	"Quality of Life"/
☐	18	Health related quality of life.mp.
☐	19	QoL.mp.
☐	20	HRQoL.mp.
☐	21	EORTC QLQ-C30.mp.
☐	22	BN-20.mp.
☐	23	SF-36.mp.
☐	24	FACT-G.mp.
☐	25	FACT-Br*.mp.
☐	26	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16
☐	27	quality of life.mp.
☐	28	17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 27
☐	29	26 and 28

Embase search



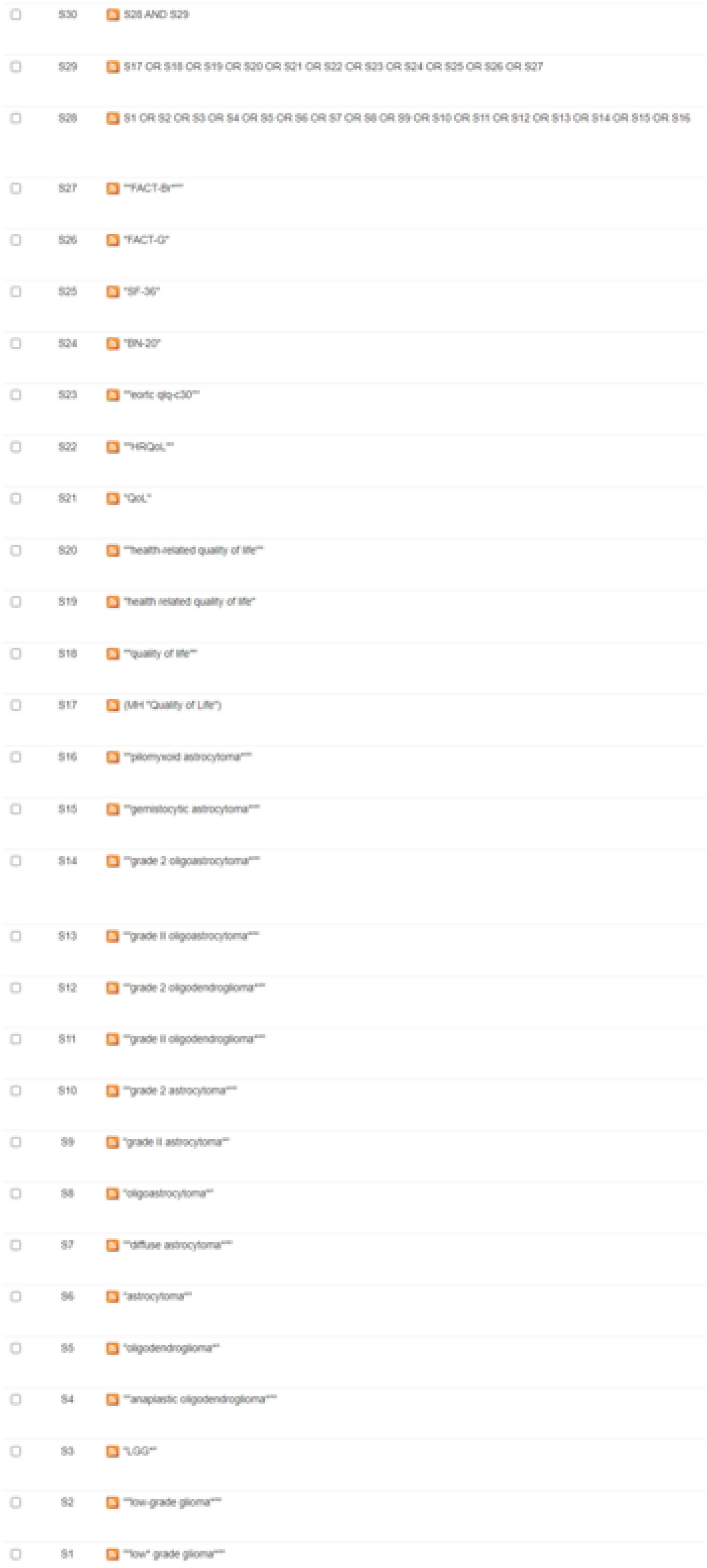
☐	# ▲	Searches
☐	1	low* grade glioma*.mp.
☐	2	LGG*.mp.
☐	3	anaplastic oligodendroglioma*.mp.
☐	4	Oligodendroglioma/
☐	5	oligodendroglioma*.mp.
☐	6	Astrocytoma/
☐	7	diffuse astrocytoma*.mp.
☐	8	oligoastrocytoma*.mp.
☐	9	grade II astrocytoma*.mp.
☐	10	grade 2 astrocytoma*.mp.
☐	11	grade II oligodendroglioma*.mp.
☐	12	grade 2 oligodendroglioma*.mp.
☐	13	grade II oligoastrocytoma*.mp.
☐	14	grade 2 oligoastrocytoma*.mp.
☐	15	gemistocytic astrocytoma*.mp.
☐	16	pilomyxoid astrocytoma*.mp.
☐	17	"Quality of Life"/
☐	18	Health related quality of life.mp.
☐	19	QoL.mp.
☐	20	HRQoL.mp.
☐	21	EORTC QLQ-C30.mp.
☐	22	BN-20.mp.
☐	23	SF-36.mp.
☐	24	FACT-G.mp.
☐	25	FACT-Br*.mp.
☐	26	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16
☐	27	quality of life.mp.
☐	28	17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 27
☐	29	26 and 28

PsycINFO search



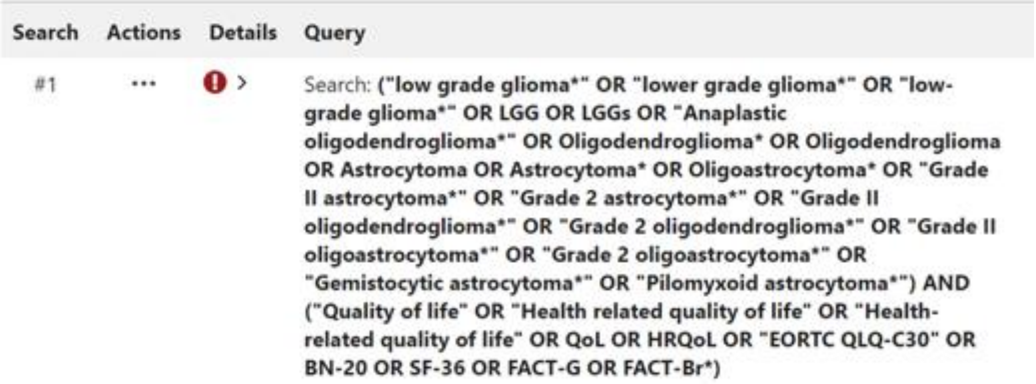
☐	# ▲	Searches
☐	1	low* grade glioma*.mp.
☐	2	LGG*.mp.
☐	3	anaplastic oligodendroglioma*.mp.
☐	4	oligodendroglioma*.mp.
☐	5	diffuse astrocytoma*.mp.
☐	6	oligoastrocytoma*.mp.
☐	7	grade II astrocytoma*.mp.
☐	8	grade 2 astrocytoma*.mp.
☐	9	grade II oligodendroglioma*.mp.
☐	10	grade 2 oligodendroglioma*.mp.
☐	11	grade II oligoastrocytoma*.mp.
☐	12	grade 2 oligoastrocytoma*.mp.
☐	13	gemistocytic astrocytoma*.mp.
☐	14	pilomyxoid astrocytoma*.mp.
☐	15	"Quality of Life"/
☐	16	Health related quality of life.mp.
☐	17	QoL.mp.
☐	18	HRQoL.mp.
☐	19	EORTC QLQ-C30.mp.
☐	20	BN-20.mp.
☐	21	SF-36.mp.
☐	22	FACT-G.mp.
☐	23	FACT-Br*.mp.
☐	24	quality of life.mp.
☐	25	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14
☐	26	15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24
☐	27	25 and 26

CINAHL search



☐	S30	S28 AND S29
☐	S29	S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27
☐	S28	S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16
☐	S27	""FACT-Br"""
☐	S26	"FACT-G"
☐	S25	"SF-36"
☐	S24	"BN-20"
☐	S23	""eortc qlq-c30""
☐	S22	""HRQoL""
☐	S21	"QoL"
☐	S20	""health-related quality of life""
☐	S19	"health related quality of life"
☐	S18	""quality of life""
☐	S17	(MH "Quality of Life")
☐	S16	""pilomyxoid astrocytoma"""
☐	S15	""gemistocytic astrocytoma"""
☐	S14	""grade 2 oligoastrocytoma"""
☐	S13	""grade II oligoastrocytoma"""
☐	S12	""grade 2 oligodendroglioma"""
☐	S11	""grade II oligodendroglioma"""
☐	S10	""grade 2 astrocytoma"""
☐	S9	"grade II astrocytoma""
☐	S8	"oligoastrocytoma""
☐	S7	""diffuse astrocytoma"""
☐	S6	"astrocytoma""
☐	S5	"oligodendroglioma""
☐	S4	""anaplastic oligodendroglioma"""
☐	S3	"LGG""
☐	S2	""low-grade glioma"""
☐	S1	""low" grade glioma"""

PubMed search



Search	Actions	Details	Query
#1	•••	❗ >	Search: **("low grade glioma*" OR "lower grade glioma*" OR "low-grade glioma*" OR LGG OR LGGs OR "Anaplastic oligodendroglioma*" OR Oligodendroglioma* OR Oligodendroglioma OR Astrocytoma OR Astrocytoma* OR Oligoastrocytoma* OR "Grade II astrocytoma*" OR "Grade 2 astrocytoma*" OR "Grade II oligodendroglioma*" OR "Grade 2 oligodendroglioma*" OR "Grade II oligoastrocytoma*" OR "Grade 2 oligoastrocytoma*" OR "Gemistocytic astrocytoma*" OR "Pilomyxoid astrocytoma*") AND ("Quality of life" OR "Health related quality of life" OR "Health-related quality of life" OR QoL OR HRQoL OR "EORTC QLQ-C30" OR BN-20 OR SF-36 OR FACT-G OR FACT-Br*)**

Supplementary table 3: Additional population characteristics of included studies that assessed HRQoL in people with LGG

Study	Eligible population	Ethnicity	Socio-economic status[a]	Karnofsky performance status	Genetic markers
Aaronson (2011); Boele (2014; 2015); Ediebah (2017)	*Inclusion:* no tumour recurrence for ≥1 year after diagnosis and primary treatment, no radiological signs of recurrence within 3 months prior to participation; *Exclusion:* corticosteroid users, non-Dutch speakers and people with severe neuropsychiatric deficits that were unable to communicate adequately. *Do not detail what determines severe neuropsychiatric deficits.*	NR	*Education:* mean level 4.2 (SD 2.1)	88.1 (SD 13.6)	NR
Affronti (2018)	*Inclusion:* adults over 18; Pathological diagnosis of LGG (WHO grade II); enrolled at first 2 months after diagnosis; *Exclusion:* KPS <70	White (93%), African American (7%)	NR	70-80 (60%), 90-100 (40%)	IDH1 mutation (60%), IDH1 wild type (27%); TERT mutation (53%), TERT wild type (27%); 1p19q codeleted (40%), 1p19q intact (40%); MGMT methylated (63%), MGMT unmethylated (13%)
Budrukkar (2009)	*Inclusion:* every consecutive adult brain tumour patients (age ≥18 years) registered in the neuro-oncology clinic, histological subtypes of high-grade glioma, low-grade glioma and benign tumours; *Exclusion:* histopathology other than these three groups.	NR	NR[b]	NR[b]	NR
Campanella (2017)	*Inclusion:* patients showing radiologically stable LGG appearance at the time of evaluation, fluent in Italian, free from treatment for preceding psychiatric conditions; *Exclusion:* LGGs who progressed toward a HGG.	NR	*Education:* mean 14.2 (8-17) years	NR	NR
Correa (2007; 2008)	*Inclusion:* not undergoing treatment or completed treatment >6 months prior to enrollment, no active disease (stable MRI); *Exclusion:* psychiatric or neurological disorders, not fluent in English.	NR	*Employment:* working (62.5%), not working (37.5%); *Education:* mean 16 years	NR	NR
Drewes (2018)	*Inclusion:* adults aged ≥18 years, undergoing first time surgery for glioma; *Exclusion:* further surgeries needed, missing forms, do not understand due to cognitive or language problems (*proxy ratings by close relatives used where possible if patient was not able to answer due to speech or cognitive impairment*).	NR	NR	≥70 (95%), <70 (5%)	NR
Gabel (2019)	*Inclusion:* Histological diagnosis of a grade I-IV glioma, aged ≥18 years; *Exclusion:* Language and/or neurocognitive dysfunction limiting patient ability to participate. *Aphasia was assessed by the Boston Diagnostic Aphasia Examination. Cognitive function was screened using the Montreal Cognitive Assessment.*	NR	*Education:* completed college (71.4%), did not complete college (28.6%); *Employment:* employed at diagnosis (57.1%), unemployed (42.9%)	NR	NR
Gustafsson (2006)	*Inclusion:* Histologically verified LGG, aged ≥18 years, capable of completing the questionnaire (independent or with help); *Exclusion:* Severe cognitive problems resulting in obvious difficulty in communicating. *Do not*	NR	NR	NR	NR

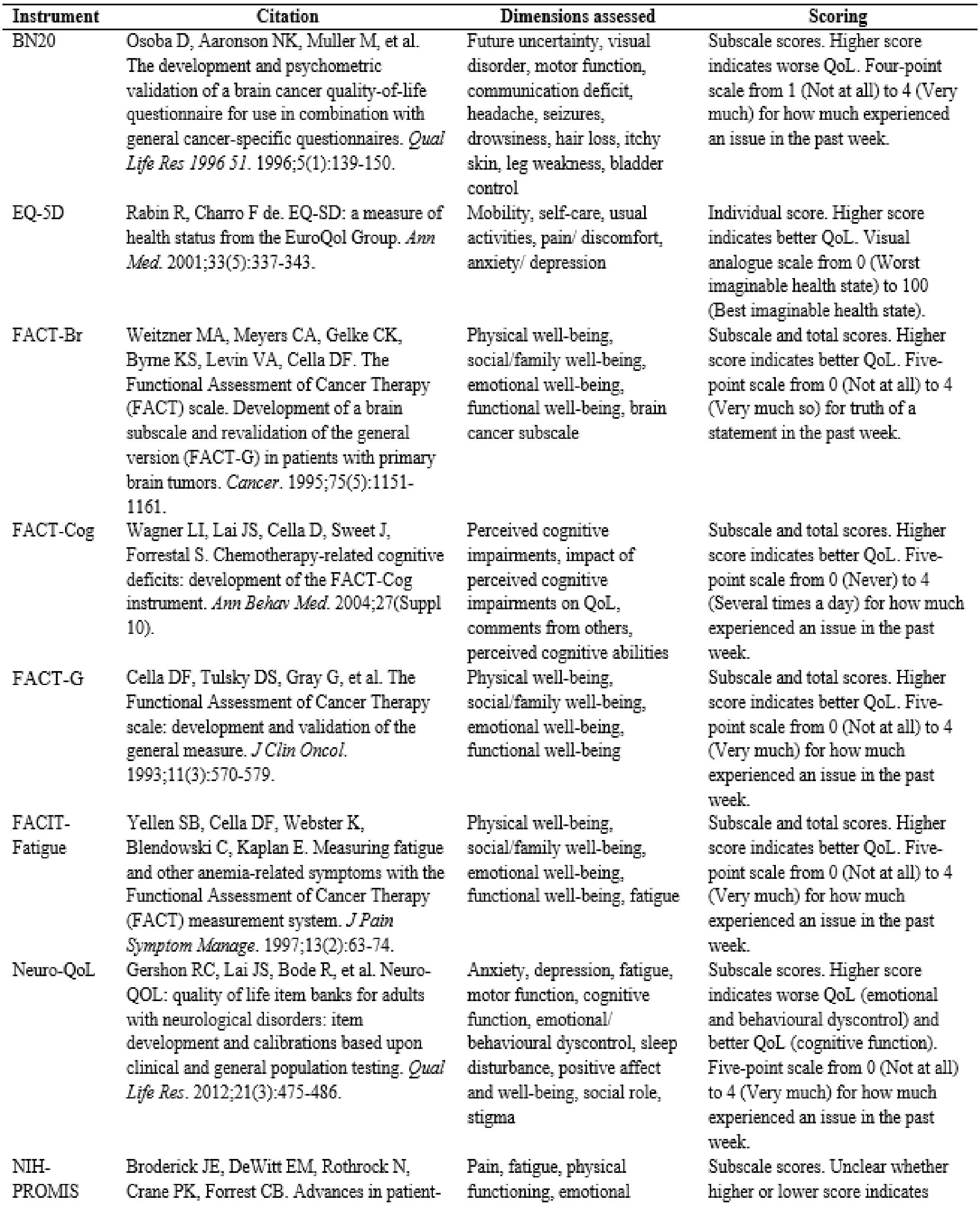
Study	Eligible population	Ethnicity	Socio-economic status[a]	Karnofsky performance status	Genetic markers
	detail what determines severe cognitive impairment.				
Jakola (2012)	*Inclusion:* Adult patients ≥18 years with histological verified supratentorial grade II glioma (diffuse astrocytomas, oligodendrogliomas and oligoastrocytomas); *Exclusion:* patients that did not receive a reliable grading	NR	NR	≥80 (91%)	NR
Jiang (2019)	*Inclusion:* histological diagnosis of LGG (WHO grade II), age ≥18 years; *Exclusion:* severe cognitive/ neurological impairment preventing communication with the patient; a history of psychiatric disorders before the diagnosis of brain tumour; time elapse from the diagnosis of brain tumour to surgery >3 month. *Do not detail what determines severe cognitive impairment.*	NR	*Employment (before surgery):* working (62%), not working (38%); *Education:* <high school (32%), high school (53%), graduate degree (15%)	NR	IDH1 mutation: mutated (85%), wild type (15%); 1p/19q codeletion: detected (28%), Not detected (72%)
Kim (2020)	*Inclusion:* age ≥20 years, diagnosis of a primary glioma for more than 3 months, receiving follow-up care for 3 months since completion of treatments following diagnosis; *Exclusion:* history of other major health issues that could influence quality of life or symptoms.	NR	NR[b]	NR	NR
Klein (2003)	*Inclusion:* patients (1) with low-grade astrocytomas, oligodendrogliomas or oligoastrocytomas, (2) without clinical signs of tumour recurrence for at least 1 year after the histological diagnosis and primary treatment, and (3) without radiological signs of recurrence within 3 months before testing; *Exclusion:* if they used corticosteroids, did not have a basic proficiency in the Dutch language, were unable to communicate adequately, or received radiotherapy as secondary treatment. *Do not detail what determines an inability to communicate adequately.*	NR	*Education:* mean level 4.2 (2.2); 4.5 (2.2); 4.1 (1.8); 4 (2.3); 3.7 (2); 4.7 (2.1)	NR	NR
Leonetti (2021)	*Inclusion:* age ≥18 years, absence of severe comprehension deficits affecting the abilities to complete the questionnaires (tested using token test), absence of previous psychiatric symptoms or disease, absence of current medications for psychiatric conditions, histomolecular diagnosis of LGGs and HGGs, newly diagnosed glioma with no history of treatments; *Exclusion:* tumour progression during the assessment period.	NR	*Education:* mean 13.9 (3.01) years	NR	IDH mutated (73.8%), IDH wildtype (26.3%)
Mahalakshmi (2015)	*Inclusion:* Patient diagnosed with a brain tumour, ≥18 years old, conscious and able to sign the consent forms; *Exclusion:* Suspected brain tumour patients before the confirmation, severe cognitive problems resulting in obvious difficulty in communicating, those who had other disease such as diabetes, neurodegeneration, and heart related problems. *Do not detail what determines severe cognitive problems.*	NR	NR[b]	NR[b]	NR
Okita (2015)	*Inclusion:* grade II glioma with no evidence of active disease, or receipt of radiotherapy and chemotherapy at the time of participation.	NR	NR	100 (16%), 90 (58%), 80 (16%), 70 (10%)	NR

Study	Eligible population	Ethnicity	Socio-economic status[a]	Karnofsky performance status	Genetic markers
Reijneveld (2001)	*Inclusion:* all patients were at least 18 years old, presented with epileptic seizures without neurologic deficits, showed non-enhancing supratenorial lesions without edema, no radiologic or clinical signs of progression for >6 months from presumed diagnosis.	NR	*Education:* mean level 3.5	88.7 (SD 9.7)	NR
Ruge (2011)	*Inclusion:* newly diagnosed, untreated supratentorial LGG; *Exclusion:* diagnosis other than WHO grade II astrocytoma, oligodendroglioma, and oligoastrocytoma.	NR	*Employment:* employed at time of diagnosis (91%)	83.6 (SD 6.5)	NR
Salo (2002); Mainio (2006)	*Inclusion:* adult >16 years old with a primary brain tumour diagnosis; *Exclusion:* those with metastases	NR	NR	NR	NR
Teng (2021)	*Inclusion:* age >18 years, undergone biopsy or resection of an intracranial LGG and were in routine follow-up; *Exclusion:* patients with other brain or spine lesions, previous malignancy, Grade III or IV gliomas, or neurofibromatosis type 1 or 2; need to complete questionnaires independently in English.	NR	NR	NR	NR
Umezaki (2020)	*Inclusion:* adult patients with WHO grade II–IV glioma according to 2016 classification; *Exclusion:* those who could not answer the questionnaire because of impaired consciousness or aphasia. *Do not detail how aphasia was determined.*	NR	NR[b]	NR[b]	IDH-mutant (n=13), IDH-wildtype (n=3), 1p19-codeleted (n=9), not otherwise specified (n=15)
Wang (2018); Li (2019a; 2019b)	*Inclusion:* histologically confirmed diagnoses of WHO grade I or II glioma, ≥18 years old; KPS >60; *Exclusion:* abnormal cognition MMSE ≤24, unable to read or understand the questionnaire. *Excludes those with at least mild cognitive impairment, determined by MMSE, despite impact to cognitive function being common in this population.*	NR	*Insurance:* yes (62.7%), no (37.3%)	>60 (100%)	NR
Yavas (2012)	*Inclusion:* >18 years of age and had a histological diagnosis of a primary low-grade brain tumour; *Exclusion:* patients who were not able to read or write the questionnaires, who had severe cognitive impairment resulting in obvious difficulty in communicating, whose KPS were <70 and/or whose expected survival time <3 months. *Do not detail what determines significant cognitive impairment; excluding these participants despite cognitive function being a primary measure.*	NR	*Education (literary status):* primary (20.93%), middle (18.6%), high (13.95%), university (46.51%)	100 (39.53%), 90 (48.84%), 80 (6.98%)	NR

[a] Socio-economic status was assessed based on education, employment, monthly income, and insurance status.

[b] This demographic was not reported separately for low-grade gliomas.

Supplementary table 4: HRQoL instruments and their scoring



Instrument	Citation	Dimensions assessed	Scoring
BN20	Osoba D, Aaronson NK, Muller M, et al. The development and psychometric validation of a brain cancer quality-of-life questionnaire for use in combination with general cancer-specific questionnaires. *Qual Life Res 1996 51*. 1996;5(1):139-150.	Future uncertainty, visual disorder, motor function, communication deficit, headache, seizures, drowsiness, hair loss, itchy skin, leg weakness, bladder control	Subscale scores. Higher score indicates worse QoL. Four-point scale from 1 (Not at all) to 4 (Very much) for how much experienced an issue in the past week.
EQ-5D	Rabin R, Charro F de. EQ-SD: a measure of health status from the EuroQol Group. *Ann Med.* 2001;33(5):337-343.	Mobility, self-care, usual activities, pain/ discomfort, anxiety/ depression	Individual score. Higher score indicates better QoL. Visual analogue scale from 0 (Worst imaginable health state) to 100 (Best imaginable health state).
FACT-Br	Weitzner MA, Meyers CA, Gelke CK, Byrne KS, Levin VA, Cella DF. The Functional Assessment of Cancer Therapy (FACT) scale. Development of a brain subscale and revalidation of the general version (FACT-G) in patients with primary brain tumors. *Cancer*. 1995;75(5):1151-1161.	Physical well-being, social/family well-being, emotional well-being, functional well-being, brain cancer subscale	Subscale and total scores. Higher score indicates better QoL. Five-point scale from 0 (Not at all) to 4 (Very much so) for truth of a statement in the past week.
FACT-Cog	Wagner LI, Lai JS, Cella D, Sweet J, Forrestal S. Chemotherapy-related cognitive deficits: development of the FACT-Cog instrument. *Ann Behav Med.* 2004;27(Suppl 10).	Perceived cognitive impairments, impact of perceived cognitive impairments on QoL, comments from others, perceived cognitive abilities	Subscale and total scores. Higher score indicates better QoL. Five-point scale from 0 (Never) to 4 (Several times a day) for how much experienced an issue in the past week.
FACT-G	Cella DF, Tulsky DS, Gray G, et al. The Functional Assessment of Cancer Therapy scale: development and validation of the general measure. *J Clin Oncol.* 1993;11(3):570-579.	Physical well-being, social/family well-being, emotional well-being, functional well-being	Subscale and total scores. Higher score indicates better QoL. Five-point scale from 0 (Not at all) to 4 (Very much) for how much experienced an issue in the past week.
FACIT-Fatigue	Yellen SB, Cella DF, Webster K, Blendowski C, Kaplan E. Measuring fatigue and other anemia-related symptoms with the Functional Assessment of Cancer Therapy (FACT) measurement system. *J Pain Symptom Manage*. 1997;13(2):63-74.	Physical well-being, social/family well-being, emotional well-being, functional well-being, fatigue	Subscale and total scores. Higher score indicates better QoL. Five-point scale from 0 (Not at all) to 4 (Very much) for how much experienced an issue in the past week.
Neuro-QoL	Gershon RC, Lai JS, Bode R, et al. Neuro-QOL: quality of life item banks for adults with neurological disorders: item development and calibrations based upon clinical and general population testing. *Qual Life Res*. 2012;21(3):475-486.	Anxiety, depression, fatigue, motor function, cognitive function, emotional/ behavioural dyscontrol, sleep disturbance, positive affect and well-being, social role, stigma	Subscale scores. Higher score indicates worse QoL (emotional and behavioural dyscontrol) and better QoL (cognitive function). Five-point scale from 0 (Not at all) to 4 (Very much) for how much experienced an issue in the past week.
NIH-PROMIS	Broderick JE, DeWitt EM, Rothrock N, Crane PK, Forrest CB. Advances in patient-	Pain, fatigue, physical functioning, emotional	Subscale scores. Unclear whether higher or lower score indicates

Instrument	Citation	Dimensions assessed	Scoring
	reported outcomes: the NIH PROMIS® measures. *Egems*. 2013;1(1).	distress, social role participation	better QoL. Five-point scale from 1 to 5 (anchors vary).
Nottingham Health Profile	Hunt SM, McKenna SP, McEwen J, Williams J, Papp E. The Nottingham Health Profile: subjective health status and medical consultations. *Soc Sci Med Part A Med Psychol Med Sociol*. 1981;15(3):221-229.	Pain, mobility, social isolation, energy, emotion, sleep	Subscale scores. Higher score indicates worse QoL. Weighted 'yes' or 'no' questions for a score 0-100 for whether something is a problem.
PWB	Ryff CD, Keyes CLM. The structure of psychological well-being revisited. *J Pers Soc Psychol*. 1995;69(4):719.	Psychological wellbeing	Subscale and total scores. Higher scores indicate better psychological wellbeing. Six-point scale from 1 (strongly disagree) to 6 (strongly agree)
QLQ-C30	Aaronson NK, Ahmedzai S, Bergman B, et al. The European Organization for Research and Treatment of Cancer QLQ-C30: a quality-of-life instrument for use in international clinical trials in oncology. *JNCI J Natl Cancer Inst*. 1993;85(5):365-376.	Physical, role, emotional, cognitive, social functioning, fatigue, nausea, pain, dyspnoea, insomnia, appetite loss, constipation, diarrhoea, financial difficulties	Subscale and total scores. Higher functioning score indicates better QoL. Higher symptom score indicates worse QoL. Four-point scale from 1 (Not at all) to 4 (Very much) for how much experienced an issue in the last week.
SF-36	Aaronson NK, Muller M, Cohen PDA, et al. Translation, validation, and norming of the Dutch language version of the SF-36 Health Survey in community and chronic disease populations. *J Clin Epidemiol*. 1998;51(11):1055-1068.	Physical functioning, role functioning - physical, bodily pain, general health, vitality, social functioning, role functioning - emotional, mental health	Subscale scores. Higher score indicates better QoL. Variety of scales and endpoints used.
Sin Tonen's 15D	Sintonen H. The 15D instrument of health-related quality of life: properties and applications. *Ann Med*. 2001;33(5):328-336.	Mobility, vision, hearing, breathing, sleeping, eating, speech, excretion, usual activities, mental function, discomfort and symptoms, depression, distress, vitality, sexual activity	Total score. Higher score indicates better QoL. Index score ranges from 0 (being dead) to 1 (no problems). Five-point scales (anchors vary) for describing present health status.

Abbreviations: *BN-20 = European Organisation for Research and Treatment of Cancer Quality of life Questionnaire Brain Neoplasm; EQ-5D = EuroQoL 5 dimension; FACT-Br = Functional Assessment of Cancer Therapy - Brain; FACT-Cog = Functional Assessment of Cancer Therapy – Cognitive function; FACT-G = Functional Assessment of Cancer Therapy – General; FACIT-Fatigue = Functional Assessment of Chronic Illness Therapy - Fatigue; NIH-PROMIS = National Institutes of Health - Patient Reported Outcomes Measurement Information System; Neuro-QoL = Quality of Life in Neurological Disorders; PWB = Psychological wellbeing scale; QLQ-C30 = European Organisation for Research and Treatment of Cancer Quality of life Questionnaire Core; SF-36 = Short Form 36 health survey questionnaire*

Supplementary table 5: Quality appraisal

Appraisal items	Aaronson (2011)[a]	Boele (2014)[a]	Boele (2015)[a]	Ediebah (2017)[a]	Affronti (2018)	Budrukkar (2009)	Campanella (2017)	Correa (2007)[b]	Correa (2008)[b]	Drewes (2018)	Gabel (2019)	Gustafsson (2006)	Jakola (2012)	Jiang (2019)	Kim (2020)
1. Clearly stated aims	2	1	2	2	2	2	2	2	2	2	1	2	2	2	2
2. Participant eligibility and recruitment strategy clearly documented	1	1	1	1	2	2	2	2	2	2	2	1	2	1	2
3. Main features of population/design described	2	2	2	2	2	1	1	2	2	2	1	2	2	2	0
4. Non-responders (and non-participants) described	2	2	2	2	1	1	1	2	2	2	0	2	1	1	1
5. Presence of a control group	2	2	2	0	0	1	1	0	0	1	1	0	0	0	1
6. Main limitations identified and acceptable	2	1	2	2	1	1	2	1	1	2	2	2	2	1	2
7. Sample size justified	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
8. No evidence of selective reporting of results	2	2	2	2	2	2	2	1	1	2	2	2	1	2	2
9. Statistical methods described	2	2	2	2	1	1	2	2	2	2	2	1	2	2	2
10. Statistical methods appropriate	2	2	2	2	1	1	2	2	2	2	2	1	2	2	2
11. Measures relevant, validated and described adequately	2	2	2	2	1	2	2	1	1	2	2	2	2	2	2
12. Results discussed adequately	2	1	2	2	2	2	1	0	0	2	2	2	1	2	1
Total score	**21**	**18**	**20**	**19**	**15**	**16**	**18**	**15**	**15**	**21**	**17**	**17**	**17**	**17**	**17**

Appraisal items	Klein (2003)	Leonetti (2021)	Mahalakshmi (2015)	Okita (2015)	Reijneveld (2001)	Ruge (2011)	Salo (2002)[c]	Mainio (2006)[c]	Teng (2021)	Umezaki (2020)	Wang (2018)[d]	Li (2019a)[d]	Li (2019b)[d]	Yavas (2012)
1. Clearly stated aims	2	2	2	2	2	2	2	2	2	2	2	2	2	2
2. Participant eligibility and recruitment strategy clearly documented	1	2	1	1	2	2	2	2	2	1	2	2	2	1
3. Main features of population/design described	2	2	1	2	1	2	1	1	1	1	2	2	2	2
4. Non-responders (and non-participants) described	2	1	2	1	1	2	2	0	0	2	2	2	2	0
5. Presence of a control group	1	1	1	0	1	1	1	0	1	1	0	0	0	0
6. Main limitations identified and acceptable	0	2	2	1	1	0	0	1	2	2	2	2	2	1
7. Sample size justified	0	0	0	0	0	0	0	0	0	0	2	0	0	0
8. No evidence of selective reporting of results	2	1	2	2	0	2	2	2	1	2	2	2	2	2
9. Statistical methods described	2	2	2	2	2	2	2	2	2	2	2	2	2	2
10. Statistical methods appropriate	2	2	2	2	2	2	2	2	2	2	2	2	2	2
11. Measures relevant, validated and described adequately	2	2	2	2	2	2	2	2	2	2	2	2	2	2
12. Results discussed adequately	2	1	2	2	1	2	0	1	1	2	1	2	2	1
Total score	**18**	**18**	**19**	**17**	**15**	**19**	**16**	**15**	**16**	**19**	**21**	**20**	**20**	**15**

Score Key: *Yes* = Score of 2; *Partial* = Score of 1; *No* = Score of 0

Scoring: *Good quality* = 17-24; *Acceptable quality* = 9-16; *Low quality* = 0-8

[a] Aaronson (2011), Boele (2014; 2015), and Ediebah (2017) report from the same study.

[b] Correa (2007; 2008) report from the same study.

[c] Salo (2002) and Mainio (2006) report from the same study.

[d] Wang (2018) and Li (2019a; 2019b) report from the same study.

3.2.1 PP1 commentary

This systematic review represents the first time quantitative studies of HRQoL in adults with LGG have been synthesised. This review was designed to examine the ‘real world’ HRQoL, outwith the context of clinical trials. The findings present several key messages: (1) people with LGG experience wide-ranging impairments which negatively impact HRQoL; (2) these problems are largely sustained over time, indicating a need for long-term management/support. While this publication was in press, Frances et al.[78] published a systematic review of the *long-term* consequences of adult grade 2/3 gliomas on HRQoL, which affirmed our finding that poor HRQoL is sustained over time; (3) numerous factors may influence HRQoL, meaning lived experiences could vary for each individual; and (4) in comparison with non-cancer controls, people with LGG have marked impairment in a range of areas (e.g. cognitive, emotional, social functioning).

These findings signify *what* the consequences are and *when* HRQoL is affected in people with LGG but do little to help understand *how* these symptoms and impairments are experienced in day-to-day life and *why* they may be important to each individual. This inspired the need for a qualitative analysis to explore and understand how people experience the impact of living with a LGG. Specifically, to contextualise the implications of these HRQoL findings on people’s lived experiences.

3.3 PP2: “It changes everything” Understanding how people experience the impact of living with a lower-grade glioma.

Rimmer, B., Balla, M., Dutton, L., Williams, S., Lewis, J., Gallagher, P., Finch, T., Burns, R., Araújo-Soares, V., Menger, F., & Sharp, L. (2024). Neuro-Oncology Practice. 11(3), 255-265.

Neuro-Oncology Practice

11(3), 255–265, 2024 | https://doi.org/10.1093/nop/npae006 | Advance Access date 29 January 2024

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

Ben Rimmer, Michelle Balla, Lizzie Dutton, Sophie Williams, Joanne Lewis, Pamela Gallagher, Tracy Finch, Richéal Burns, Vera Araújo-Soares, Fiona Menger, and Linda Sharp, on behalf of the Ways Ahead Study Team[†]

All author affiliations are listed at the end of the article

[†]The Ways Ahead study team comprises, in addition to the named authors, Sara Erridge, Pauline Sturdy, and Catherine McBain.

Corresponding Author: Ben Rimmer, MSc, Population Health Sciences Institute, Newcastle University, Ridley Building 1, Newcastle upon Tyne, NE1 7RU, UK (ben.rimmer@newcastle.ac.uk).

Abstract

Background. Quantitative studies show people living with a lower-grade glioma (LGG) often report low health-related quality of life. However, it is unclear how this impact is experienced; resulting supportive care needs are also poorly understood. We explored how people experience the impact of living long-term with an LGG, to help identify potential supportive care needs.

Methods. We conducted semi-structured interviews with a diverse group of people with LGG ($n = 28$) across the United Kingdom, who had completed primary treatment (male $n = 16$, female $n = 12$, mean age 54.6 years, mean time since diagnosis 8.7 years). Interviews were transcribed and inductive thematic analysis was conducted.

Results. Four themes relating to the impact experiences of people with LGG were generated: "*Emotional response to the diagnosis*," "*Living with the 'What ifs'*," "*Changing relationships*," and "*Faltering independence*." These reflect participants' experiences with symptoms (eg, fatigue, seizures) and impairments (eg, motor dysfunction, cognitive deficits), and how these, in turn, drive impacts on daily living (including on work, relationships, social activities, and transport). Participants spoke about their experiences with profound emotion throughout.

Conclusions. People with LGG can experience wide-ranging everyday impacts and may have extensive supportive care needs. This study highlights how this impact is experienced and what it means to people with LGG. Best practice suggestions for conducting comprehensive needs assessments tailored to those with LGG, and the development of personalized plans to meet those needs, would be a critical step to ensure that people with LGG are best supported in living with their condition.

Keywords

lower-grade glioma | qualitative | quality of life | supportive care needs

Gliomas are the most common malignant tumor of the brain.[1] Approximately 15% of all gliomas are lower-grade gliomas (LGG). These are largely diagnosed at a critical time in working and family lives in adults in their 30s and 40s.[2] They are mostly incurable and will likely progress to a high-grade glioma (HGG),[3] limiting life expectancy to 5–15 years depending on the subtype.[2,4] Hence, LGGs are distinct from other cancers in that people may live for long periods with a condition likely to be terminal.

People with LGG can experience wide-ranging, and often co-occurring, symptoms and impairments that are both more general cancer-related (eg, fatigue, pain) and quite tumor-specific (eg, seizures, cognitive deficits).[5,6] Individuals also report considerable emotional and psychological impact; largely influenced by future uncertainty surrounding their prognosis.[7] Indeed, there is a high prevalence of mental health disorders in people with glioma.[8] Quantitative studies indicate that these symptoms and impairments adversely impact health-related quality of life (HRQoL) in people with LGG.[9,10] HRQoL is markedly worse in people with LGG than people with meningiomas[11] and non-cancer controls, and remains generally poor over time[5]; in particular, fatigue and the emotional impact may persist long-term post-diagnosis with an LGG.[12]

Social decline following a brain tumor diagnosis can follow a similar trajectory to physical decline.[13] Cubis et al. outline the social trajectory of a brain tumor more generally, highlighting the loss of pre-illness networks (eg, work, peer)[14] and how physical, cognitive, and psychological factors can present a barrier to social interaction.[15] Though potentially applicable to people with LGG, these studies largely included people with HGGs, which are more aggressive,[1] so participants may have experienced a more intensified impact over a shorter duration. People with LGG may encounter social challenges, such as strained relationships, financial, or work-related problems[6]; certainly return to work rates are typically low in people with LGG.[16] However, patient-reported outcome measures may not sufficiently encompass these impacts.[17]

In terms of qualitative research, there is a paucity of data which may help us to understand how people experience the impact of living long-term with an LGG. One previous study focused on the experiences of onset and diagnosis among people with LGG.[18] Edvardsson et al.[19] highlight the broad range of illness-related problems perceived by people living with a grade 1 or 2 brain tumor; however grade 1 tumors are distinct from LGGs, as they have a more favorable prognosis.[3] Further, they focused on identifying areas of impact, rather than how the impact was experienced.

It is crucial to consider the impact experiences of people with LGG to understand what it means to them; this is important to help recognize potential supportive care needs and develop appropriate supports. For example, seizure burden is commonly associated with worse HRQoL in people with LGG[5]; we need to understand how this impact is experienced (eg, inability to drive) and why it is important to people with LGG, to fully comprehend the extent of the impact (eg, unable to transport to work).

Therefore, this study aimed to explore how people experience the long-term impact of living with an LGG. This will expand on existing knowledge to understand what is important to people with LGG and how symptoms and impairments drive the impacts on daily living.

Methods

Design

This qualitative study, part of the multi-method Ways Ahead project,[20] was descriptive in design and sought to recognize the diverse and subjective experiences of participants in an area where little is known.[21] We used semi-structured interviews to generate data on the experiences of people with LGG; the data analyzed here focused on how people experience the impact of living with an LGG. We have reported elsewhere from this dataset on the strategies used by people with LGG to self-manage this impact[22]; the 2 papers are thus complementary. Ways Ahead was reviewed and approved by the Wales Research Ethics Committee (REC ref: 20/WA/0118).

Participants and Recruitment

Individuals were eligible if they were aged ≥18 years at diagnosis, resided in the United Kingdom (UK), and had completed primary treatment, or were stable under observation, for a grade 2 astrocytoma, or a grade 2 or 3 oligodendroglioma.[23] Participants were excluded if they were non-English speaking or their clinical team judged they had severe psychological or social problems and there was a risk that an interview would cause further distress.

Potentially eligible people with LGG were identified through collaborating National Health Service (NHS) sites and the Brain Tumour Charity's networks. Purposive sampling was used to ensure we recruited a range of ages, sex, diagnoses, and time since diagnosis (<5 years, ≥5–10, >10 years).

For NHS sites, people with LGG were identified from medical records and given an information sheet by a healthcare professional. For the Brain Tumour Charity networks, BR disseminated a flyer advertising the study, with the information sheet attached. The researchers conducting the interviews were briefly introduced in the information sheet. People with LGG were asked to call or email the study team to register their interest. BR and LD subsequently called each interested person to confirm eligibility, afford the opportunity to ask questions, and, if the individual was confirmed as eligible and wanted to proceed, arrange a convenient interview date and time. Participants were recruited August 2020–May 2022.

Data Generation

One-to-one interviews were conducted by BR (Male, MSc, Research Assistant) and LD (Female, PhD, Research Associate): both trained and experienced in qualitative research. All interviews were conducted remotely, via a phone or video call (eg, Zoom or Teams), as per interviewee preference. To support participants who may have had cognitive impairments, such as memory and processing speed limitations, we offered an interview topic overview in advance and, in the interview, allowed ample time to consider and respond to each question.

Audio-recorded consent was acquired immediately prior to each interview. We also collected basic demographics (including sex, age, employment and relationship status, years of education, number of dependents) and clinical and tumor-related information (including diagnosis, date of diagnosis, tumor location and laterality, treatment, IDH1-mutation and 1p19q codeletion status). We asked participants recruited through the Brain Tumour Charity for their main treating hospital and consultant. For all participants, we asked their treating hospital to confirm clinical and tumor-related details; self-reported information is reported where confirmation could not be obtained.

Interviews were semi-structured following a topic guide (Supplementary Material), which was informed by the literature and expert knowledge, and modified following review by a brain tumor Patient and Public Involvement (PPI) panel and discussions with healthcare professionals (JL and SW). Throughout data generation, the topic guide was used flexibly; topic order varied for each interview, depending on what the participant chose to speak about. Any new issues raised were added and explored in subsequent interviews.

To begin, participants were asked to broadly reflect on life following diagnosis. Participants' experiences of what areas of their life and functioning were affected by the tumor and its treatment (eg, cognitive, physical, psychological) and the impacts on aspects of daily life (eg, work, transport, relationships, finances) were then explored. For each area, participants were asked how they were impacted, what type of support was needed and in which situations, and whether support was received. Probe questions were used to explore further, and participants could raise any additional issues of importance to them. Finally, participants were offered a £20 voucher to thank them for their time, and a post-interview sheet with details of charities and helplines, should they experience distress post-interview. Interviews were audio-recorded and lasted on average 102 min (range 54–167 min). Field notes were taken by the researchers during each interview for their own reference.

Data Analysis

Interviews were transcribed verbatim, anonymized, and checked for accuracy against the audio-recordings. The present analysis used a flexible, data-driven approach, in line with inductive thematic analysis[24]; this allowed us to develop patterns of meaning from the impact experiences described by people living with an LGG.

Following familiarization with the data, 2 trained researchers (BR and MB) independently generated initial codes, using NVivo, for a sample of transcripts ($n = 6$ of 28); similarities and differences in preliminary codes were discussed between the researchers. BR coded the remaining transcripts, adding any new codes as needed; findings and any uncertainties were discussed with the study team as analysis progressed. Potential themes at the semantic level were then constructed from these codes and discussed with the study team. Data sufficiency was determined by the perception that we had generated sufficient data to support and understand the impact experiences of people living with an LGG.[25] Final themes and subthemes were refined and defined by BR, and are reported below with illustrative quotes. Each participant was provided a summary of findings and given the opportunity to offer feedback.

Results

Participant Characteristics

Thirty-nine people with LGG registered interest; 4 were excluded for non-completion of primary treatment ($n = 2$), ineligible diagnosis ($n = 1$), and residence outside the UK ($n = 1$). Of 35 eligible people, 28 were interviewed (10 recruited through NHS sites; 18 through the Brain Tumour Charity). There were 16 male and 12 female participants; mean age at the interview was 50.4 years (median 52 years, range 22–69 years) (Table 1). Diagnoses comprised grade 2 oligodendroglioma ($n = 10$: IDH1-mutant, yes $n = 7$, no $n = 2$, unknown $n = 1$; 1p/19q codeletion, yes $n = 9$, unknown $n = 1$), grade 3 oligodendroglioma ($n = 9$: IDH1-mutant, yes $n = 6$, no $n = 1$, unknown $n = 2$; 1p/19q codeletion, yes $n = 7$, unknown $n = 2$), and grade 2 astrocytoma ($n = 9$: IDH1-mutant, yes $n = 6$, no $n = 1$, unknown $n = 2$; 1p/19q codeletion, no $n = 7$, unknown $n = 2$). Mean time since diagnosis was 8.7 years (range 1–18 years).

Overview of Findings

We constructed 4 themes to portray how people experience the impact of living with an LGG (Figure 1), namely: "*Emotional response to the diagnosis,*" "*Living with the 'What ifs',*" "*Changing relationships,*" and "*Faltering independence.*" These themes reflect participants' experiences with tumor-related symptoms (eg, fatigue, seizures) and impairments (eg, motor dysfunction, cognitive deficits), and how these impacted on multiple areas of their daily lives. Participants spoke about their experiences with profound emotion throughout, as demonstrated in the illustrative quotes; additional supporting quotes are available in Table 2.

Emotional Response to the Diagnosis

Most participants described feeling considerably 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)

Many experienced difficulties with accepting the impact the diagnosis had, or would have in the future, on their life. Despite this, several participants felt "*proud*" with how they had coped with the challenges that followed the LGG diagnosis and its treatment. Many participants were conflicted by feeling emotionally impacted, while also feeling lucky compared to others; these feelings came from observing that their diagnosis was not as aggressive as a HGG, or that they had fewer symptoms than other people with LGG, and from recognizing the strength of their support network.

Living With the "What ifs"

This theme encompassed how participants experience the impact of, and uncertainties related to, living with fatigue, cognitive impairment, seizures, and the incurable nature of an LGG diagnosis.

"What if I have a seizure?".—For several participants, the anxiety about having a seizure influenced their approach to

Table 1. Lower-Grade Glioma Participants' Characteristics at Time of Interview

Characteristic	*n*	Characteristic	Mean (range)
Diagnosis[a]		Time since diagnosis (years)[a]	8.7 (1–18)
Grade 2 oligodendroglioma	10	Time since radiotherapy (years)[a,c]	6.9 (0.7–17.8)
Grade 3 oligodendroglioma	9	Time since chemotherapy (years)[a,c]	3.4 (0.1–13.5)
Grade 2 astrocytoma	9	Full-time education (years)	15.8 (11–20)
IDH-mutation status[a]		Sex	*n*
Yes	19	Female	12
No	4	Male	16
Unknown	5	Age	
1p/19q codeletion status[a,b]		≤40	4
Yes	16	41-50	8
No	7	51-60	11
Unknown	5	>60	5
Treatment[a]		Dependents	
Surgery	28	None	18
Radiotherapy	22	One	3
Chemotherapy	17	Two	6
Tumour location[a]		Three	1
Frontal	18	Employment status	
Temporal	3	Full-time employee	8
Parietal	3	Part-time employee	4
Overlapping regions	3	Retired	4
Unknown	1	Medically retired	6
Tumour laterality[a]		Unable to work	6
Right hemisphere	13	Relationship status	
Left hemisphere	15	Married	21
Dominant hemisphere	13	In a relationship	3
Non-dominant hemisphere	15	Single	2
		Widowed	2

[a] Clinical and tumor-related details were self-reported for 8 participants.
[b] All participants with 1p/19q codeletion were people with oligodendroglioma; all participants without 1p/19q codeletion were people with astrocytoma.
[c] Time since radiotherapy and chemotherapy were not available for 2 participants.

daily life. Some avoided certain physical activities that they had enjoyed pre-diagnosis (eg, cycling, swimming), due to the anticipated negative repercussions of having a seizure while on the road or in the pool, for example. Others were unwilling to travel far from home due to possible negative reactions from other people if they had a seizure on public transport or worries about having a seizure in unfamiliar surroundings.

> *"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?"*.**—For many participants, cognitive impairments frequently impacted numerous aspects of daily life, with potentially substantial consequences. They described possible security and safety repercussions of forgetting how to cook or leaving the front door open, for example. Several participants stressed how important and how challenging it was to remember their medication and health appointments. Some felt confined because they were losing familiarity with their local surroundings, often getting lost in places they once knew; this had implications for willingness to use public transport and travel alone.

> *"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)

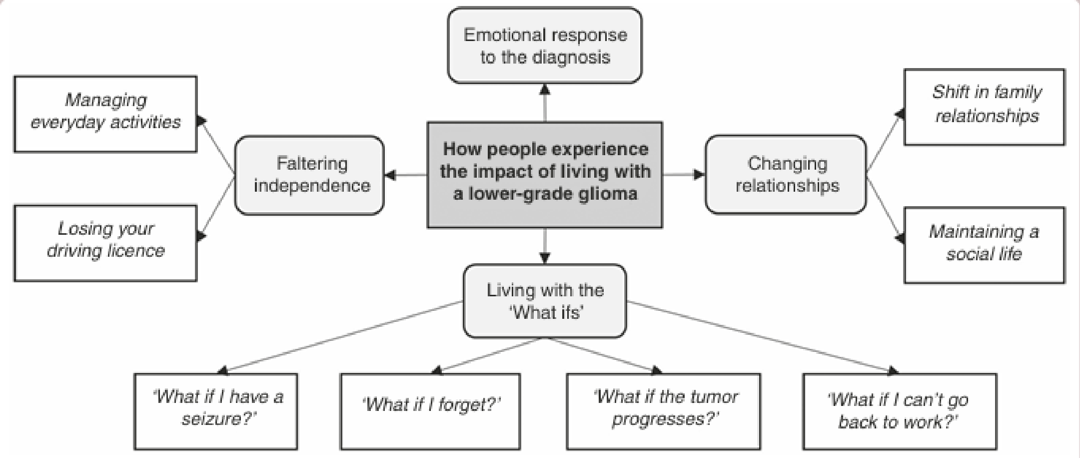


Figure 1. An overview of the themes and subthemes reflecting how people experience the impact of living with an LGG.

"What if the tumour progresses?".**—**All participants spoke emotively about their worry surrounding future uncertainty due to the incurable nature of the diagnosis and potential for tumor progression; some feared they were '*a ticking time bomb*' or "*waiting to be even more disabled*." Several expressed how anxiety worsened around scan appointments. Many found it challenging to remain positive: they found the uncertainty "*mentally draining*" and felt guilty about the prospect of "*leaving your family behind*" when they died. Participants described having to "*learn to live*" with how this uncertainty negatively impacted their ability to make decisions, both about smaller (eg, booking a holiday) and larger (eg, 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?".**—**This subtheme encompassed how people experience the uncertainties around returning to, and sustaining, work. Many participants highlighted the pressure of the financial consequences of employment changes (eg, going part-time). For some participants, work was a substantial source of social support, with time away from work resulting in feelings of loneliness. Those unable to work post-diagnosis (eg, due to fatigue and cognitive impairments) talked about how that "*kicks your confidence*," with several feeling "*stripped*" of their identity, direction, purpose, and control over their life.

> *"Because I wasn't working and getting any positive feedback, I was sitting at home thinking that I was useless, pointless."*
> (Pa29, aged 51, female, grade 3 oligodendroglioma)

Changing Relationships

This theme encompassed how participants experience the impact of living with an LGG on their relationships with partners and family, and their ability to engage in social activities with friends.

Shift in family relationships.**—**All participants spoke emotively about how their diagnosis has influenced their relationships with family; largely acknowledging how emotional it had been for close family, particularly children. Some participants found new value in their relationships; though others recognized that family members were worrying about them more following their diagnosis. Some participants described no longer feeling equal in the relationship with their partner, because they could not contribute as much as they used to. Family relationships were further strained for several participants, by the impact of cognitive impairments (eg, forgetting plans) and personality changes (eg, short-temper).

> *"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)

Maintaining a social life.**—**Most participants stressed the challenges with maintaining their social life and the consequent loneliness they felt. Many felt their relationships had changed with friends, attributing feelings of isolation mainly to a lack of willingness from others to "*get on board with*" the diagnosis and accept that things had changed. Fatigue had a substantial impact on several participants' ability to go out with friends and engage in social activities. Those that mentioned attempts to socialize spoke about how they now lacked confidence due to difficulties with

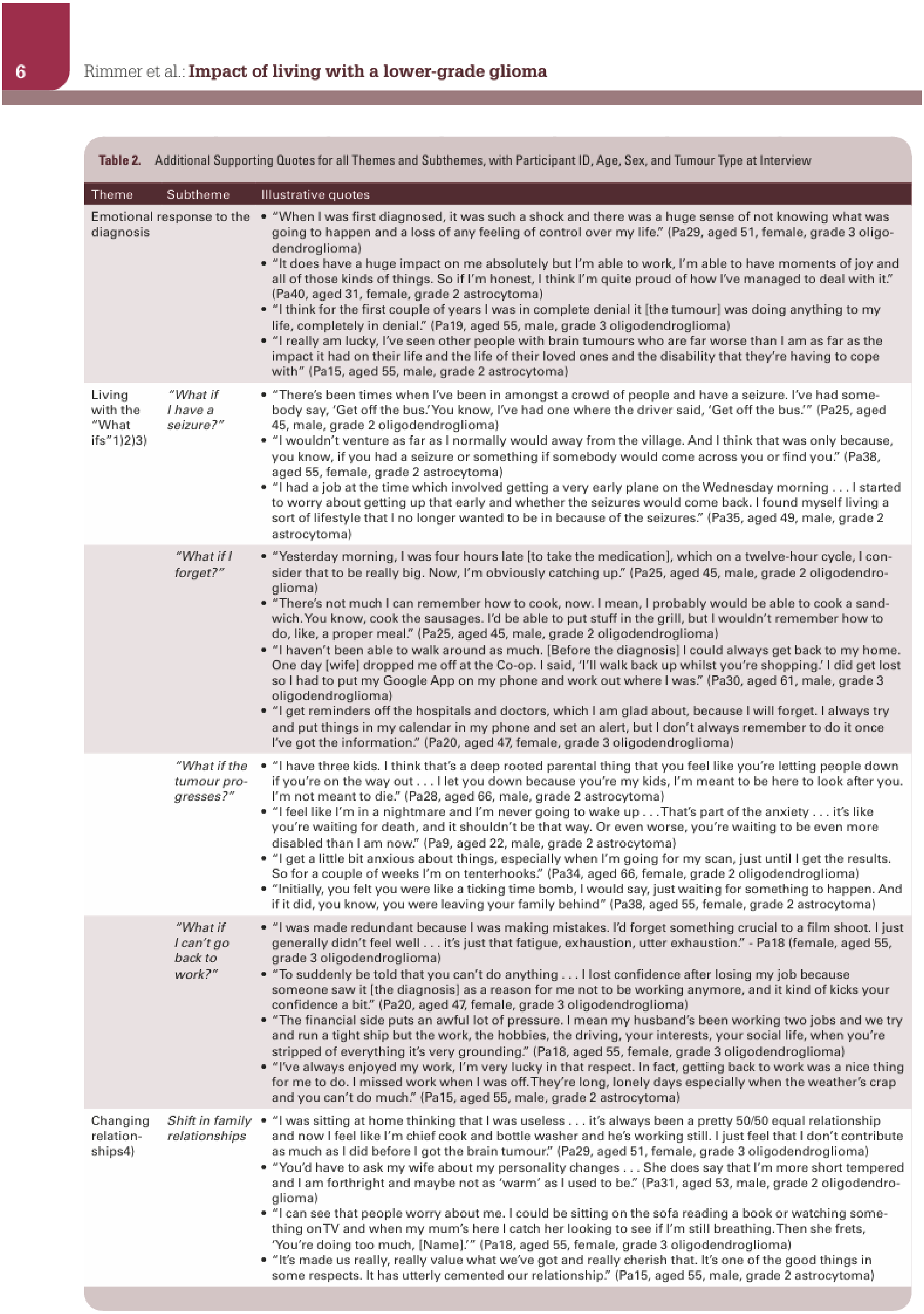


Table 2. Additional Supporting Quotes for all Themes and Subthemes, with Participant ID, Age, Sex, and Tumour Type at Interview

Theme	Subtheme	Illustrative quotes
Emotional response to the diagnosis		• "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) • "It does have a huge impact on me absolutely but I'm able to work, I'm able to have moments of joy and all of those kinds of things. So if I'm honest, I think I'm quite proud of how I've managed to deal with it." (Pa40, aged 31, female, grade 2 astrocytoma) • "I think for the first couple of years I was in complete denial it [the tumour] was doing anything to my life, completely in denial." (Pa19, aged 55, male, grade 3 oligodendroglioma) • "I really am lucky, I've seen other people with brain tumours who are far worse than I am as far as the impact it had on their life and the life of their loved ones and the disability that they're having to cope with" (Pa15, aged 55, male, grade 2 astrocytoma)
Living with the "What ifs"1)2)3)	*"What if I have a seizure?"*	• "There's been times when I've been in amongst a crowd of people and have a seizure. I've had somebody say, 'Get off the bus.' You know, I've had one where the driver said, 'Get off the bus.'" (Pa25, aged 45, male, grade 2 oligodendroglioma) • "I wouldn't venture as far as I normally would away from the village. And I think that was only because, you know, if you had a seizure or something if somebody would come across you or find you." (Pa38, aged 55, female, grade 2 astrocytoma) • "I had a job at the time which involved getting a very early plane on the Wednesday morning . . . I started to worry about getting up that early and whether the seizures would come back. I found myself living a sort of lifestyle that I no longer wanted to be in because of the seizures." (Pa35, aged 49, male, grade 2 astrocytoma)
	"What if I forget?"	• "Yesterday morning, I was four hours late [to take the medication], which on a twelve-hour cycle, I consider that to be really big. Now, I'm obviously catching up." (Pa25, aged 45, male, grade 2 oligodendroglioma) • "There's not much I can remember how to cook, now. I mean, I probably would be able to cook a sandwich. You know, cook the sausages. I'd be able to put stuff in the grill, but I wouldn't remember how to do, like, a proper meal." (Pa25, aged 45, male, grade 2 oligodendroglioma) • "I haven't been able to walk around as much. [Before the diagnosis] I could always get back to my home. One day [wife] dropped me off at the Co-op. I said, 'I'll walk back up whilst you're shopping.' I did get lost so I had to put my Google App on my phone and work out where I was." (Pa30, aged 61, male, grade 3 oligodendroglioma) • "I get reminders off the hospitals and doctors, which I am glad about, because I will forget. I always try and put things in my calendar in my phone and set an alert, but I don't always remember to do it once I've got the information." (Pa20, aged 47, female, grade 3 oligodendroglioma)
	"What if the tumour progresses?"	• "I have three kids. I think that's a deep rooted parental thing that you feel like you're letting people down if you're on the way out . . . I let you down because you're my kids, I'm meant to be here to look after you. I'm not meant to die." (Pa28, aged 66, male, grade 2 astrocytoma) • "I feel like I'm in a nightmare and I'm never going to wake up . . . That's part of the anxiety . . . it's like you're waiting for death, and it shouldn't be that way. Or even worse, you're waiting to be even more disabled than I am now." (Pa9, aged 22, male, grade 2 astrocytoma) • "I get a little bit anxious about things, especially when I'm going for my scan, just until I get the results. So for a couple of weeks I'm on tenterhooks." (Pa34, aged 66, female, grade 2 oligodendroglioma) • "Initially, you felt you were like a ticking time bomb, I would say, just waiting for something to happen. And if it did, you know, you were leaving your family behind" (Pa38, aged 55, female, grade 2 astrocytoma)
	"What if I can't go back to work?"	• "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, grade 3 oligodendroglioma) • "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 financial side puts an awful lot of pressure. I mean my husband's been working two jobs and we try and run a tight ship but the work, the hobbies, the driving, your interests, your social life, when you're stripped of everything it's very grounding." (Pa18, aged 55, female, grade 3 oligodendroglioma) • "I've always enjoyed my work, I'm very lucky in that respect. In fact, getting back to work was a nice thing for me to do. I missed work when I was off. They're long, lonely days especially when the weather's crap and you can't do much." (Pa15, aged 55, male, grade 2 astrocytoma)
Changing relationships4)	*Shift in family relationships*	• "I was sitting at home thinking that I was useless . . . it's always been a pretty 50/50 equal relationship and now I feel like I'm chief cook and bottle washer and he's working still. I just feel that I don't contribute as much as I did before I got the brain tumour." (Pa29, aged 51, female, grade 3 oligodendroglioma) • "You'd have to ask my wife about my personality changes . . . She does say that I'm more short tempered and I am forthright and maybe not as 'warm' as I used to be." (Pa31, aged 53, male, grade 2 oligodendroglioma) • "I can see that people worry about me. I could be sitting on the sofa reading a book or watching something on TV and when my mum's here I catch her looking to see if I'm still breathing. Then she frets, 'You're doing too much, [Name].'" (Pa18, aged 55, female, grade 3 oligodendroglioma) • "It's made us really, really value what we've got and really cherish that. It's one of the good things in some respects. It has utterly cemented our relationship." (Pa15, aged 55, male, grade 2 astrocytoma)

Table 2. Continued

Theme	Subtheme	Illustrative quotes
	Maintaining a social life	• "I wasn't able to go out and visit friends or anything really because I just didn't have the energy, just no energy at all." (Pa35, aged 49, male, grade 2 astrocytoma) • "I constantly feel as though I'm on the outside, looking in. I've said that to the family, because I feel as though I have to invite myself to things." (Pa20, aged 47, female, grade 3 oligodendroglioma) • "Some people, it's [the diagnosis] just not something they're willing or able to get on board with . . . maybe they'll reappear when things are easier for a period of time, so they'll be there for the fun times so to speak." (Pa40, aged 31, female, grade 2 astrocytoma) • "My speech sometimes goes a bit slurry . . . I don't think I would put my point across and join in the conversation as much as I used because of that." (Pa38, aged 55, female, grade 2 astrocytoma)
Faltering independence	*Managing everyday activities*	• "I have to think what I'm ordering off the menu if we do go out for a meal because I feel embarrassed because I can't cut up the meal because I can't put pressure down with my right hand. I like steaks and whatever but I can't cut them up." (Pa22, aged 43, female, grade 2 astrocytoma) • "I'm going for the [job role] instead so I can catch some bad guys but it's the fitness side I fail. I failed on the bleep test because I couldn't turn around quick enough." (Pa26, aged 37, female, grade 2 oligodendroglioma) • "I wouldn't get on a bike. My balance isn't . . . you know, there are certain things that would be dumb." (Pa13, aged 52, male, grade 3 oligodendroglioma) • "If I washed my own pots, I was then too tired to go for a walk and get some fresh air and walk my dog." (Pa17, aged 51, female, grade 3 oligodendroglioma)
	Losing your driving license	• "The only downside was I couldn't drive, because once you have a seizure, you have to have a minimum year off. Being in sales, it's not ideal." (Pa11, aged 57, male, grade 2 oligodendroglioma) • "You feel like you're, not a liability, but you feel like everybody has to almost give you something, that type of thing. I don't want to be like that. I want to be the person who could give people lifts and that type of thing." (Pa32, aged 46, female, grade 3 oligodendroglioma) • "The physical side, and losing my driving licence. It's the independent side of me that gets the kick in the teeth." (Pa26, aged 37, female, grade 2 oligodendroglioma) • "You don't realize when you've driven all your life and I used to do crazy journeys and to have that taken away, that's the biggest loss." (Pa16, aged 69, male, grade 3 oligodendroglioma)

communication impairments, and sometimes felt overwhelmed by too many things going on around them in social situations.

> *"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

This theme encompassed how participants experience the impact of living with an LGG on their independence, particularly concerning their engagement with practical activities (eg, physical activity, transport).

Managing everyday activities.—Several participants spoke emotively about how fatigue impacted their ability to do things for themselves in their daily life both generally, and specifically; the impacts were felt both on activities of daily living such as housework and on leisure activities like exercise. For some, completing one task or activity would leave them "*too tired*" to attempt another. For many participants, motor dysfunctions and issues with balance had wide-ranging consequences on their independence, from lacking the confidence to ride a bike, to feeling unable to cut up a meal. The combined effects of trying to deal with the side-effects of the tumor and its treatment while also managing everyday activities could feel overwhelming.

> *"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)

Losing your driving license.—The majority of participants reported losing their driving license following diagnosis and treatment; how long their license was revoked for was influenced by the presence of seizures. In those no longer able to drive, reactions were centered around the substantial impact this had on their independence, with some participants expressing that it was their "biggest loss." This loss of independence had implications for participants' work and hobbies. Some described feeling reluctant to be dependent on others (eg, take lifts because they could not drive), which limited their ability to engage with activities and interests outside of the home.

> *"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)

Discussion

Quantitative studies show that people with LGG have low HRQoL and can face wide-ranging symptoms (eg, fatigue, seizures) and impairments (eg, poor motor dysfunction, cognitive deficits).[5] To shed light on supportive care needs, our study aimed to explore how people experience the impact of living with an LGG. The four themes constructed from the data revealed how people with LGG experience wide-ranging impacts on activities of daily living, work, relationships, social and leisure activities, alongside emotional challenges in response to the diagnosis and the uncertainty of the prognosis.

Overall, our findings are coherent with the aspects of HRQoL evidenced to be impacted in people with LGG.[5,6] The areas of impact reported were largely synonymous with the problems identified by Edvardsson et al. for grade 1 and 2 brain tumors[19]; an important addition from this study is that we stress the impact of seizures in people with LGG. In addition, by illuminating *how* people experience these impacts, our findings provide a more holistic insight, and suggest how different impacts might be interconnected. Moreover, our data relates to impact experiences after "active" (interventional) treatment; this means it complements Hayhurst et al.'s qualitative study of experiences of people with LGG being managed by the "wait and see" approach.[26] Of note, the majority of our sample had received radiotherapy, which might have influenced the cognitive issues reported by participants.[27]

Our study participants reported considerable emotional and psychological burden following the initial shock of diagnosis, and ongoing fear of tumor progression and future uncertainty. Living long-term with this burden may be what contributes to persistent feelings of low mood[12] and risk of mental health disorders,[8] which have been reported in other studies. Our findings also underline the need for support with psychological adjustment in people with LGG.[28]

Some participants felt lucky to have a good support network, which is important because readily available emotional support can relieve the psychological burden.[13] What the present study adds is how living with an LGG can hinder the maintenance of social connections both within the family and beyond. Participants particularly acknowledged the emotional burden their diagnosis had on their family, and spoke about how personality changes (eg, short-temper) and cognitive impairments strained their close relationships; this is similar to findings reported by people with HGG,[29] though the data here shows these impacts are sustained longer-term in people with LGG. This is echoed in findings we have reported elsewhere from interviews with informal caregivers of people with LGG[30]; it also emphasizes that the support network of someone diagnosed with a LGG can have supportive care needs of their own.

Our findings are in line with the social trajectory of people with grade 1 to 4 brain tumors proposed in a qualitative metasynthesis.[14] Specifically, participants in this study reported losing pre-illness support networks of colleagues and peers, with the decision or need to take time off work, or changes in employment contributing to feelings of loneliness, loss of direction and purpose. Losing their driving license could exacerbate isolation; communication impairments and fatigue further influenced participants' confidence, and perceived ability, to engage in social activities. This supports findings on experiences of communication difficulties after glioma surgery.[31] These examples of how functional impairments may drive the everyday impact of living with an LGG demonstrate the need to find ways to preserve social involvement and supportive relationships. As others have argued, this would likely help people to sustain their social identity and get the greatest benefit from their support network.[32,33]

An important challenge for participants was their ability to manage daily activities. Our findings are congruent with past work on the consequences of seizures in this population (eg, inability to drive)[5,34]; yet the present study goes further by highlighting how anxiety about the possibility of having a seizure also has ramifications, which further limit people's lives. For example, such worries sometimes prompted the avoidance of certain physical activities (eg, swimming, cycling). Further, cognitive deficits, fatigue, and motor dysfunction presented difficulties with activities of daily living (eg, housework, using public transport). Overall, these impairments had implications for participants' independence, leading to (further) changes in relationship dynamics with their partner and feelings of a loss of control over their lives. Hence, people with LGG may need several different types of support to manage individual impairments; for example, with seizures, there may be a primary need for these to be medically controlled, but also a need for psychological support to manage the unpredictability of, and anxiety about the consequences of having, potential seizures.

Implications

Summary of practical insights from this study

- Need to develop best practice suggestions for needs assessments in clinical practice for people with LGG, capturing and contextualizing symptoms and impairments.
- Need to co-develop supportive care plans to meet identified needs for each individual.
- There is scope to develop self-management interventions for people with LGG, with adjustment- and problem-focused elements.

The box summarizes several practical insights from the study with implications for clinicians. The wide-ranging, and sometimes distinct, challenges and impacts faced by people with LGG demonstrate the importance of identifying what is important to each person and what support might be beneficial to them. There is a need to develop best practice suggestions for the conduct of needs assessments in clinical practice. Such needs assessments should be comprehensive in terms of the symptoms and concerns they capture and contextualize these by also assessing impact. For example, we showed here that fatigue can impact numerous aspects of life (eg, work, social activities, housework), hence, it is important to consider the context of the impact for the individual, so that support can be both tailored to the experience of having an LGG (as opposed to a different form of cancer) and personalized to the individual.[35] Moreover, the assessment should be followed by working with the person with LGG to develop a supportive care plan for how best to meet identified needs. As part of that, it is important to acknowledge how people use support (eg, with assistance from family) and whether there are any barriers to engagement (access to support) that need to be overcome. Still, people with brain tumors may underestimate psychological, emotional, cognitive, and social changes[36]; thus, this needs to be dealt with sensitively, due to the risk of causing distress by getting people to realize that they are more impacted than they thought.

We have previously reported that people with LGG use many strategies to help them self-manage their illness.[22] This indicates a willingness to engage in self-management, suggesting there is scope for more formal or structured self-management support to help people with LGG manage the consequences of their illness. Health professionals have a key role to play in encouraging, facilitating and supporting self-management.[37] The present study outlines the areas of support that might be appropriate for the development of a self-management intervention targeted at people with LGG[20,38]; this could include adjustment-focused (eg, learning to live with future uncertainty) or problem-focused elements (eg, managing anxiety surrounding seizures; exploring strategies to compensate for cognitive impairments).[39] This aligns with the goal of existing guidelines to provide the support that helps people to maintain independence and participate in valued activities.[40] Still, future research should consider what may help or hinder an individual's ability, capacity or willingness to engage with self-management (eg, strength of support network, executive functioning deficits hampering the ability to follow instructions), to ensure that the potential benefits of such support can be fully realized. Finally, routine monitoring of patient experiences of care and patient-reported outcomes would be of value to understand the impact of services and service changes (including needs assessments and supportive care plans), rehabilitation strategies, and self-management support, among people with LGG.

Strengths and Limitations

Our study provides a novel understanding of the diverse and multi-faceted ways people experience the impact of living long-term with, and post-treatment for, an LGG. There was extensive data to support and understand the everyday impact of living with an LGG and the findings here are supported by multiple quotes; hence we are confident that reasonable data sufficiency was achieved. The relatively wide age range of participants means that people were likely at different stages of their lives; while this means that we captured diverse experiences, it also means we were unable to fully unpack how experiences might vary for people of different ages. For example, while issues around relationships, marriage, and children were evident within two themes, these may have been more strongly represented had participation been restricted to people in their 30s.

Due to corona virus disease 2019, all interviews were conducted remotely; however, this facilitated widespread recruitment across the UK,[41] and may have helped people feel more comfortable to disclose sensitive information.[42] It is possible that those recruited through the Brain Tumour Charity may have been self-selected, having more time, interest, and capacity to take part. Further, they may not represent those carrying on "as normal," meaning the perspective of people who are managing well, with lesser impact, might have been missed. It is also possible that health professionals in collaborating sites may have been thoughtful in terms of who they approached to take part.

It has recently been noted that the exclusion of people with cognitive and communication impairments is not uncommon in LGG literature[5] and that this has implications for the generalizability of findings. Although participants were given ample time in the interview to consider and respond to each question, we cannot discount the possibility people with more limited capacity were discouraged by the expected interview length (approx. 90 min) and chose not to take part. Future research might consider offering multiple, shorter interviews to mitigate the risk of fatigue and further support participation. Finally, participants did not undergo assessments of their abilities; such information (eg, in relation to cognition) may have been useful to set the findings in a clinical context.

Conclusions

This study explored how people experience the impact of living long-term with an LGG. Our findings point to extensive supportive care needs, pertaining to psychological wellbeing, independence, and social identity among this population; these are driven largely by challenges with fatigue, seizures, cognitive deficits, and the emotional impact of living with an incurable condition. In the short-term, the findings will be of value to health professionals involved in the follow-up care of people with LGG. Longer-term, best practice suggestions for the conduct of comprehensive needs assessments tailored to those with LGG, and the development of personalized plans to meet those needs should be considered. This would be a critical step to ensure that people with LGG are best supported in living with their condition.

Supplementary material

Supplementary material is available online at *Neuro-Oncology* (https://academic.oup.com/neuro-oncology).

Funding

This work was supported by funding from The Brain Tumour Charity (GN-000435).

Acknowledgments

This is an output for the Ways Ahead project (research.ncl.ac.uk/waysahead/). We would like to thank all of the people with lower-grade gliomas that took the time to participate in this study. We would also like to thank our collaborating NHS sites, Newcastle upon Tyne Hospitals NHS Foundation Trust, NHS Lothian, South Tees Hospitals NHS Foundation Trust, and The Christie NHS Foundation Trust, for their assistance with recruitment to the project. We extend this thanks to colleagues at the Brain Tumour Charity.

Conflict of interest statement

None declared.

Authorship statement

L.S., P.G., R.B., J.L., S.W., V.A.S., and T.F. secured the funding and developed the idea for the study. S.E., P.S., and C.M. facilitated recruitment in N.H.S. sites. B.R. acquired ethical approval and conducted recruitment. B.R. and L.D. conducted the interviews. B.R. and M.B. conducted the analysis and interpreted the findings. B.R. drafted the manuscript. All authors reviewed, revised, and approved the final manuscript.

Affiliations

Population Health Sciences Institute, Newcastle University Centre for Cancer, Newcastle University, Newcastle upon Tyne, UK (B.R., L.D., V.A.-S., L.S.); Faculty of Medical Sciences, Newcastle University, Newcastle upon Tyne, UK (M.B.); Newcastle upon Tyne Hospitals NHS Foundation Trust, Newcastle upon Tyne, UK (S.W., J.L.); School of Psychology, Dublin City University, Dublin, Ireland (P.G.); Department of Nursing, Midwifery and Health, Northumbria University, Newcastle upon Tyne, UK (T.F.); Faculty of Science, Atlantic Technological University, Sligo, Ireland (R.B.); Health and Biomedical Strategic Research Centre, Atlantic Technological University, Sligo, Ireland (R.B.); Centre for Preventive Medicine and Digital Health, Department for Prevention, Medical Faculty Mannheim, Heidelberg University, Heidelberg, Germany (V.A.-S.); School of Education, Communication and Language Sciences, Newcastle University, Newcastle upon Tyne, UK (F.M.)

References

1. Miller KD, Ostrom QT, Kruchko C, et al. Brain and other central nervous system tumor statistics, 2021. *CA Cancer J Clin.* 2021;71(5):381–406.
2. Bauchet L. Epidemiology of diffuse low grade gliomas. In: *Diffuse Low-Grade Gliomas in Adults.* Springer International Publishing; 2017:13–53. doi:10.1007/978-3-319-55466-2_2
3. Claus EB, Walsh KM, Wiencke JK, et al. Survival and low-grade glioma: The emergence of genetic information. *Neurosurg Focus.* 2015;38(1):E6.
4. Dixit K, Raizer J. Newer strategies for the management of low-grade gliomas. *Oncology (Williston Park).* 2017;31(9):680684–682685.
5. Rimmer B, Bolnykh I, Dutton L, et al. Health-related quality of life in adults with low-grade gliomas: a systematic review. *Qual Life Res: Int J Qual Life Aspects Treatment, Care Rehab.* 2023;32(3):625–651.
6. Frances SM, Velikova G, Klein M, et al. Long-term impact of adult WHO grade II or III gliomas on health-related quality of life: a systematic review. *Neurooncol Pract.* 2022;9(1):3–17.
7. Ley A, Kamp M, von Sass C, et al. Psychooncological distress in low-grade glioma patients—a monocentric study. *Acta Neurochirurg.* 2021;164(3):713–722.
8. Young JS, Al-Adli N, Sibih YE, et al. Recognizing the psychological impact of a glioma diagnosis on mental and behavioral health: a systematic review of what neurosurgeons need to know. *J Neurosurg.* 2022;1(aop):1–9.
9. Aaronson NK, Taphoorn MJB, Heimans JJ, et al. Compromised health-related quality of life in patients with low-grade glioma. *J Clin Oncol: Offic J Ame Soc Clin Oncol.* 2011;29(33):4430–4435.
10. Teng KX, Price B, Joshi S, et al. Life after surgical resection of a low-grade glioma: A prospective cross-sectional study evaluating health-related quality of life. *J Clin Neurosci: Off J Neurosurg Soc Australasia.* 2021;88(1):259–267.
11. Heffernan AE, Wu Y, Benz LS, et al. Quality of life after surgery for lower grade gliomas. *Cancer.* 2023;129(23):3761–3771.
12. Boele FW, Den Otter PWM, Reijneveld JC, et al. Long-term wellbeing and neurocognitive functioning of diffuse low-grade glioma patients and their caregivers: a longitudinal study spanning two decades. *Neuro-Oncol.* 2022;25(2):351–364.
13. Cavers D, Hacking B, Erridge SE, et al. Social, psychological and existential well-being in patients with glioma and their caregivers: a qualitative study. *CMAJ.* 2012;184(7):E373–E382.
14. Cubis L, Ownsworth T, Pinkham MB, Chambers S. The social trajectory of brain tumor: a qualitative metasynthesis. *Disabil Rehabil.* 2018;40(16):1857–1869.
15. Cubis L, Ownsworth T, Pinkham MB, et al. "Hey, I'm still here!": Maintaining, managing and rebuilding social connections after brain tumour. *Neuropsychol Rehabil.* 2023;33(3):454–479.
16. Pascual JSG, Duffau H. The need to consider return to work as a main outcome in patients undergoing surgery for diffuse low-grade glioma: a systematic review. *Acta Neurochir (Wien).* 2022;164(10):2789–2809.
17. Dirven L. Importance of evaluating health-related quality of life issues in survivors of WHO grade II or III gliomas. *Neurooncol Pract.* 2022;9(1):1–2.
18. Edvardsson T, Påhlson A, Ahlstrom G. Experiences of onset and diagnosis of low-grade glioma from the patient's perspective. *Cancer Nurs.* 2006;29(5):415–422.
19. Edvardsson T, Ahlström G. Illness-related problems and coping among persons with low-grade glioma. *Psychooncology.* 2005;14(9):728–737.
20. Rimmer B, Dutton L, Lewis J, et al. 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.
21. Doyle L, McCabe C, Keogh B, Brady A, McCann M. An overview of the qualitative descriptive design within nursing research. *J Res Nurs.* 2020;25(5):443–455.
22. Rimmer B, Balla M, Dutton L, et al. Identifying and understanding how people living with a lower-grade glioma engage in self-management. *J Cancer Survivorship.* 2023:1–14.
23. Louis DN, Perry A, Wesseling P, et al. The 2021 WHO classification of tumors of the central nervous system: a summary. *Neuro-Oncol.* 2021;23(8):1231–1251.
24. Clarke V, Braun V. *Thematic Analysis: A Practical Guide.* Sage; 2021.
25. Low J. A pragmatic definition of the concept of theoretical saturation. *Sociol Focus.* 2019;52(2):131–139.

26. Hayhurst C, Mendelsohn D, Bernstein M. Low grade glioma: a qualitative study of the wait and see approach. *Can J Neurol Sci.* 2011;38(2):256–261.

27. Douw L, Klein M, Fagel SS, et al. Cognitive and radiological effects of radiotherapy in patients with low-grade glioma: long-term follow-up. *Lancet Neurol.* 2009;8(9):810–818.

28. Cavers D, Hacking B, Erridge SC, et al. Adjustment and support needs of glioma patients and their relatives: serial interviews. *Psychooncology.* 2013;22(6):1299–1305.

29. Piil K, Laegaard Skovhus S, Tolver A, Jarden M. Neuro-oncological symptoms: a longitudinal quantitative study of family function, perceived support, and caregiver burden. *J Fam Nurs.* 2022;28(1):43–56.

30. Rimmer B, Balla M, Dutton L, et al. 'A constant black cloud': the emotional impact of informal caregiving for someone with a lower-grade glioma. *Qual Health Res.* 2023;34(3):227–238.

31. Åke S, Hartelius L, Jakola AS, Antonsson M. Experiences of language and communication after brain-tumour treatment: A long-term follow-up after glioma surgery. *Neuropsychol Rehabil.* 2023;33(7):1225–1261.

32. Cubis L, Ownsworth T, Pinkham MB, et al. The importance of staying connected: mediating and moderating effects of social group memberships on psychological well-being after brain tumor. *Psychooncology.* 2019;28(7):1537–1543.

33. Dahlberg M, Bylund A, Gustavsson P, Calero TH, Wannheden C. What matters to persons living with brain tumors and their informal caregivers? An interview study of qualities in interpersonal relations. *Soc Sci Med.* 2022;292(1):114575.

34. Shin JY, Kizilbash SH, Robinson SI, et al. Seizures in patients with primary brain tumors: what is their psychosocial impact? *J Neurooncol.* 2016;128(2):285–291.

35. Sainsbury K, Walburn J, Foster L, et al. Improving photoprotection in adults with xeroderma pigmentosum: personalisation and tailoring in the 'XPAND' intervention. *Health Psychol Behav Med.* 2020;8(1):543–572.

36. Andrewes HE, Drummond KJ, Rosenthal M, Bucknill A, Andrewes DG. Awareness of psychological and relationship problems amongst brain tumour patients and its association with carer distress. *Psychooncology.* 2013;22(10):2200–2205.

37. Dwarswaard J, Bakker EJM, van Staa A, Boeije HR. Self-management support from the perspective of patients with a chronic condition: a thematic synthesis of qualitative studies. *Health Expect.* 2016;19(2):194–208.

38. Araújo-Soares V, Hankonen N, Presseau J, Rodrigues A, Sniehotta FF. Developing behavior change interventions for self-management in chronic illness. *Eur Psychol.* 2018;24(1):7–25. doi:10.1027/1016-9040/a000330.

39. Rimmer B, Sharp L; Ways Ahead study team. Implementation of self-management interventions in cancer survivors: why are we not there yet? *J Cancer Educ.* 2021;36(6):1355–1358.

40. Recommendations | Brain tumours (primary) and brain metastases in over 16s | Guidance | NICE. https://www.nice.org.uk/guidance/ng99/chapter/Recommendations#care-needs-of-people-with-brain-tumours. Accessed October 10, 2023.

41. Gray LM, Wong-Wylie G, Rempel GR, Cook K. Expanding qualitative research interviewing strategies: zoom video communications. *Qualit Report.* 2020;25(5):1292–1301.

42. Drabble L, Trocki KF, Salcedo B, Walker PC, Korcha RA. Conducting qualitative interviews by telephone: lessons learned from a study of alcohol use among sexual minority and heterosexual women. *Qual Soc Work.* 2016;15(1):118–133.

3.3.1 PP2 commentary

This descriptive qualitative study builds on the findings of the systematic review (PP1[47]) to elicit how the symptoms and impairments can drive impacts on day-to-day life for people with LGG (e.g. seizures influence transport, which limits social opportunities). An inductive thematic analysis[79] was considered appropriate here, as it facilitated the development of patterns of meaning from the participants' lived experiences. This work represents one of the first qualitative studies to provide context for what the impact means to people with LGG and identify where priorities for support may vary for each individual. For example, one person may wish for support with returning to work, while another may deem it more important to access support with physical exercise. This has future research implications for the development and tailored delivery of a self-management intervention, as discussed further in chapter 7.3.1.

This paper stimulated the publication of an editorial by Darlix et al.[80], which suggested ways to guide neuro-oncologists to advance the understanding and management of life with a LGG. This included reflections on the pitfalls of existing needs assessments and ways to afford people sufficient opportunity to report their support needs; this is discussed further in chapter 7.4.1. The authors also called for more qualitative studies to generate a comprehensive understanding of the experiences of, and challenges faced by, people with LGG, across different contexts (e.g. self-management, return to work). Overall, in accordance with a recent call for guiding patient-centred care in neuro-oncology[81], these findings signify positive progress in the desire and attempts to understand the patient perspective. Specifically, this helps ensure that the *quality* of support is a central focus in the development of neuro-oncological interventions.

3.4 Chapter summary

The work presented in this chapter highlights the wide-ranging impact of life with a LGG and outlines the need and scope for interventions that seek to improve the QoL of this population. The lived experiences of day-to-day life presented in the qualitative findings provide important context for the substantial symptom burden identified in the reviewed quantitative studies. This emphasises the value of a mixed-methods approach to recognising the impact of living with a LGG. Quantitative findings more broadly indicate the types and timings of support required for this population, while qualitative findings help to capture and contextualise what is important to each individual. Overall, this has implications for the challenges that people with LGG may need to self-manage, while also indicating that symptoms and impairments might influence an individual's ability to self-manage.

Chapter 4: Engagement in self-management for people with lower-grade gliomas

In chapter 3, one of the key findings was that the wide-ranging impacts experienced by people with LGG can persist for several years following treatment, indicating a need for effective, long-term self-management and more 'formal' support. This chapter introduces how people living with and beyond cancer engage in self-management and considers what might influence someone's ability to engage in self-management. The two publications included in this chapter focus on providing a complete insight into engagement in self-management for people with LGG. The first publication (PP3[49]) presents additional qualitative findings from the interviews with people with LGG and aimed to identify and understand how people with LGG engage in the self-management of their condition. The second publication (PP4[50]) presents further qualitative findings from the interviews with people with LGG and aimed to identify and understand the barriers and facilitators to self-management in people with LGG.

The chapter is organised as follows: introduction to engagement in self-management for people living with and beyond cancer; PP3; PP3 commentary; PP4; PP4 commentary; chapter summary.

4.1 Engagement in self-management for people living with and beyond cancer

4.1.1 Approaches to self-management across different cancers

The evidence base on self-management in cancer is largely focused on the effectiveness of self-management interventions (e.g.[20,24,27]), with a relative paucity of evidence available to understand people's self-management attitudes or behaviours. Where such data has been reported, cancer survivors generally had a positive attitude towards self-management, conveying a motivation to maintain control over their health and well-being[82]. Yun et al.[83] developed a taxonomy of the strategies people living with cancer might use to self-manage; this has since been extended in studies with head and neck cancer survivors[84] and childhood cancer survivors[85] to now encompass 118 specific self-management strategies across 20 self-management strategy types. Having such a taxonomy allows studies to explore self-management in a more systematic way and understand what strategies people use. A self-management strategy concerns the specific behaviour used by the individual to manage their health and well-being, while a self-management strategy type concerns a group of similar self-management strategies to represent an approach to self-management. To exemplify this, the self-management strategy type of 'adopting a healthy lifestyle' encompasses specific strategies such as 'exercising' or 'adopting a healthy diet'.

The self-management strategy types presented in the taxonomy may be commonly used across different cancers; still, the changes made in each iteration of the taxonomy indicate the nuances in how different cancer populations engage in self-management. For example, in head and neck cancer survivors, Dunne et al.[84] stressed the importance of including a new 'meaning making' strategy type, due to a diminished sense of self from possible facial disfigurement and communication difficulties. In childhood cancer survivors, Brown et al.[85] reported the inclusion of specific strategies used to help survivors try to live 'normal' lives through adolescence (e.g. 'balancing life with health needs' and 'recognising one's own limits'). Jung et al.[86] suggests that engagement in self-management could also vary by cancer stage; early-stage cancer patients favour goal and action setting strategies, compared to advanced cancer patients' preference for more pro-active problem solving, in response to enhanced physical and mental difficulties.

The potential need for long-term management of an incurable condition, which can be accompanied by tumour-specific symptoms and impairments (highlighted in chapter 3), suggests it is likely that self-management could look different still for people with LGG. In PP3[49], I present the need to understand how people with LGG engage in self-management, and the value of applying the latest iteration of the existing taxonomy of self-management strategies[85] to develop this understanding.

4.1.2 Factors influencing engagement in self-management

While section 4.1.1 outlines potential approaches to self-management across different cancers, it is crucial to recognise what helps and hinders people to effectively engage in self-management. Indeed, self-efficacy is a key factor influencing self-management in cancer survivors[87].

In 2016, Schulman-Green et al.[88] published a framework of 18 factors (across five categories) influencing self-management, developed in chronic (non-cancer) illness, for example, ‘motivation’, ‘symptoms/side effects’, ‘psychosocial resources’. These factors are common across several patient populations; however, the experiences of these factors can be distinctive for each population, for example: (1) in chronic illness, the role of smoking in chronic obstructive pulmonary disease patients was reported to adversely impact motivation for self-care, due to feelings of guilt and self-blame[89]; (2) in neurological populations, the unpredictable presentation of wide-ranging symptoms (e.g. fatigue, speech problems) in people with multiple sclerosis, disrupted valued activities and daily routines[90]; and (3) in other cancers, lower levels of physical functioning, resigned acceptance and low mood, presented difficulties with physical exercise for advanced cancer patients[91]. Overall, this demonstrates the complexity of self-management and shows how influencing factors may interact and be nuanced by the challenges faced by the patient population. Hence, the impact of life with a LGG (highlighted in chapter 3), suggests that people with LGG’s ability to engage in self-management may be influenced by those experiences. In PP4[50], I present the rationale for improving understanding of factors influencing self-management in people with LGG, including the benefits of using the aforementioned framework[88] to organise and present the findings.

4.2 PP3: Identifying and understanding how people living with a lower-grade glioma engage in self-management.

Rimmer, B., Balla, M., Dutton, L., Lewis, J., Brown, M. C., Burns, R., Gallagher, P., Williams, S., Araújo-Soares, V., Finch, T., Menger, F., & Sharp, L. (2024). Journal of Cancer Survivorship, 18(1), 1837–1850.

Journal of Cancer Survivorship
https://doi.org/10.1007/s11764-023-01425-x

Identifying and understanding how people living with a lower-grade glioma engage in self-management

Ben Rimmer[1] · **Michelle Balla**[2] · **Lizzie Dutton**[1] · **Joanne Lewis**[3] · **Morven C. Brown**[1] · **Richéal Burns**[4,5] · **Pamela Gallagher**[6] · **Sophie Williams**[3] · **Vera Araújo-Soares**[1,7] · **Tracy Finch**[8] · **Fiona Menger**[9] · **Linda Sharp**[1] · **on behalf of the Ways Ahead study team**

Received: 28 March 2023 / Accepted: 23 June 2023

Abstract

Purpose Lower-grade gliomas (LGG) are mostly diagnosed in working-aged adults and rarely cured. LGG patients may face chronic impairments (e.g. fatigue, cognitive deficits). Self-management can improve clinical and psychosocial outcomes, yet how LGG patients self-manage the consequences of their tumour and its treatment is not fully understood. This study, therefore, aimed to identify and understand how LGG patients engage in the self-management of their condition.

Methods A diverse group of 28 LGG patients (age range 22–69 years; male $n=16$, female $n=12$; mean time since diagnosis = 8.7 years) who had completed primary treatment, were recruited from across the United Kingdom. Semi-structured interviews were conducted. Informed by a self-management strategy framework developed in cancer, directed content analysis identified and categorised self-management types and strategies used by patients.

Results Overall, 20 self-management strategy types, comprising 123 self-management strategies were reported; each participant detailed extensive engagement in self-management. The most used strategy types were 'using support' ($n=28$), 'creating a healthy environment' ($n=28$), 'meaning making' ($n=27$), and 'self-monitoring' ($n=27$). The most used strategies were 'accepting the tumour and its consequences' ($n=26$), 'receiving support from friends ($n=24$) and family' ($n=24$), and 'reinterpreting negative consequences' ($n=24$).

Conclusions This study provides a comprehensive understanding of the strategies used by LGG patients to self-manage their health and wellbeing, with a diverse, and substantial number of self-management strategies reported.

Implications for Cancer Survivors The findings will inform the development of a supported self-management intervention for LGG patients, which will be novel for this patient group.

Keywords Lower-grade glioma · Self-management · Wellbeing · Qualitative

---

✉ Ben Rimmer
ben.rimmer@newcastle.ac.uk

[1] Population Health Sciences Institute, Newcastle University Centre for Cancer, Newcastle University, Newcastle Upon Tyne, England

[2] Faculty of Medical Sciences, Newcastle University, Newcastle Upon Tyne, England

[3] Newcastle Upon Tyne Hospitals NHS Foundation Trust, Newcastle Upon Tyne, England

[4] Faculty of Science, Atlantic Technological University, Sligo, Ireland

[5] Health and Biomedical Strategic Research Centre, Atlantic Technological University, Sligo, Ireland

[6] School of Psychology, Dublin City University, Dublin, Ireland

[7] Centre for Preventive Medicine and Digital Health, Department for Prevention of Cardiovascular and Metabolic Disease, Medical Faculty Mannheim, Heidelberg University, Heidelberg, Germany

[8] Department of Nursing, Midwifery and Health, Northumbria University, Newcastle Upon Tyne, England

[9] School of Education, Communication and Language Sciences, Newcastle University, Newcastle Upon Tyne, England

Introduction

Lower-grade gliomas (LGG) are a subgroup of brain tumours, most commonly diagnosed in working-aged adults [1]. LGGs are rarely cured and typically recur or progress to a high-grade glioma [2]; life expectancy is limited to approximately 5–15 years, depending on the subtype [1, 3]. LGG patients can experience a diverse, often co-occurring, range of tumour-specific (e.g. cognitive impairment, seizures, personality changes, and mobility issues) and more general cancer-related symptoms (e.g. fatigue, pain) [4]. These, in turn, can contribute to changes in social roles, daily functioning, and loss of independence [5, 6].

There is a large and growing evidence base in cancer to suggest that self-management can improve clinical, psychosocial, and health economic outcomes [7]. Self-management in cancer is defined as 'awareness and active participation by the person in their recovery, recuperation, and rehabilitation to minimise the consequences of treatment, promote survival, health, and wellbeing'. [8] For successful self-management, individuals require a set of behavioural and emotional regulatory skills (e.g. problem solving, decision making), supported by mechanisms of action driven by motivation and confidence [9].

Yun et al. developed a self-management framework [10] that has been extended to head and neck [11] and childhood cancer survivors [12], which identified and categorised the numerous strategy types (i.e. an individual's approach to self-management) and strategies (i.e. how an individual implements their approach to self-management) used by people living with and beyond cancer. However, little is known about how LGG patients self-manage their condition. It is important that elements of self-management interventions are designed to meet the specific needs of the target population. Existing interventions have typically been developed for specific cancers (e.g. breast) and, consequently, lack adaptability [13]. For LGG patients, living long-term with the emotional impact of an incurable condition, and tumour-specific impairments (e.g. cognitive deficits), may influence both what, and how, self-management strategies are used.

Only two qualitative studies have explored self-management in LGG patients; both reporting few self-management strategies due to these studies narrow focus on coping and adapting [14, 15]. Affronti et al.'s [14] limited inclusion of patients up to 6-months post-diagnosis is restrictive, as people may need more time to accept and adapt to their condition [16], and the strategies needed to self-manage are likely to change over time. Self-management in the longer-term is likely especially important, as people attempt to return to a perceived 'normality', beyond support from their care team (e.g. return to work, regaining independence). Though Edvardsson et al.'s [15] participants were, on average, 16 years since diagnosis, most were grades 1–2; grade 1 tumours are distinct from LGGs and have a more favourable prognosis [2]. Consequently, further research is needed to investigate the strategies used to self-manage living with an LGG.

Online self-management resources for adult brain tumour patients largely encompass the active treatment period [17]; hence, a comprehensive understanding of self-management in LGG patients post-treatment would be beneficial to outline the areas where targeted information and advice is required. This study, therefore, aimed to identify and understand how LGG patients engage in the self-management of their condition, post-treatment.

Method

Design

This cross-sectional, qualitative study, part of the wider Ways Ahead project [18] was reviewed and approved by the Wales Research Ethics Committee (REC ref: 20/WA/0118). The present analysis focused on identifying and understanding the self-management strategies used by LGG patients.

Participants and recruitment

Participants were adult LGG patients who lived in the United Kingdom (UK). Individuals were eligible if they were aged ≥ 18 years at diagnosis and were in remission following completion of primary treatment, or stable under observation, following an LGG diagnosis, specifically a grade 2 astrocytoma, or a grade 2 or 3 oligodendroglioma [19]. Participants were ineligible if they were non-English speaking or perceived by a health professional at collaborating National Health Service (NHS) sites to have severe psychological or social problems where participation could risk causing further distress.

Potentially eligible patients were identified through collaborating NHS sites and networks of the Brain Tumour Charity, a leading brain tumour charity based in the UK. Purposive sampling ensured a range of age, sex, diagnoses, and time since diagnosis (< 5, 5–10, > 10 years). At NHS sites, patients were identified from their medical records and provided with a study information sheet by a health professional during a clinic visit. For recruitment via the Brain Tumour Charity, a study flyer and participant information sheet was circulated through newsletters. People were asked to call or email the study team to register their interest. BR and LD called interested patients to confirm eligibility, afford the opportunity for questions, and if the individual was eligible and willing to take part, arrange a convenient interview date and time. Recruitment was conducted between August 2020 and May 2022.

Data collection

Interviews were conducted by BR and LD, who are trained and experienced in qualitative research. All interviews were conducted remotely using video-conferencing software (e.g. Zoom or Microsoft Teams) or telephone, as per participant preference. Cognitive or communication impairments might impact a patient's ability to retain or understand questions or provide responses. To facilitate this, we provided a topic overview prior to the interview and allowed ample time for the participant to consider and respond to each question.

Immediately prior to each interview, audio-recorded consent was obtained, and patient-related (including sex, age, employment and relationship status, years of education, number of dependents) and clinical and tumour-related (including diagnosis, date of diagnosis, tumour location and laterality, treatment, IDH1-mutation and 1p19q codeletion status) information was collected. For participants recruited through the Brain Tumour Charity, we asked for their main treating hospital and managing clinician. For all participants, we contacted the treating hospital to confirm the clinical and tumour-related details; where confirmation could not be obtained, the patient-reported information is reported.

Interviews were semi-structured following a topic guide (Online resource 1), which was developed with input from a patient and public involvement panel of brain tumour patients, and clinical colleagues with experience in managing LGG patients (JL & SW). Throughout data collection, any new issues raised were added to the guide, to be explored in subsequent interviews.

Participants were first asked to broadly reflect on life following their LGG diagnosis. How they were impacted by the tumour and its treatment (e.g. cognitive, physical, psychological) and the social and role implications of this impact (e.g. work, transport, relationships, and finances) were then explored. For each area, the interviewer asked probing questions around how the participant managed this impact, and what, and when, support was received or needed. Throughout, participants could raise any additional issues of importance to them.

To thank participants for their time, £20 vouchers were offered. They were also provided with a post-interview sheet with details of charities and helplines, should they have questions at a later date or experience distress. Interviews were audio-recorded and lasted 102 min on average (range 54 to 167 min).

Data analysis

Interviews were transcribed verbatim and anonymised by an external transcription service, with each participant allocated a unique ID. For accuracy, transcripts were checked against the audio-recordings. Coding and analysis primarily used a deductive, framework-driven approach in line with directed content analysis [20].

The initial categorisation matrix was informed by Brown et al.'s extension of the self-management framework [12], as this was the most recent update and had the most extensive number of strategies. This included 20 self-management strategy types (i.e. an individual's approach to self-management, such as 'self-monitoring'), encompassing 133 self-management strategies (i.e. how an individual implements their approach to self-management, such as 'monitoring emotions'). Concurrent inductive content analysis enabled the identification of new self-management strategies used by LGG patients that were not included in the initial categorisation matrix. Data saturation was determined by the perception that there was sufficient data to support and expand upon the analysis framework [21].

Two trained qualitative researchers (MiB and BR) independently read and coded a random sample of the same six transcripts to the framework. Text that did not map to an existing category was coded as a new category and labelled appropriately. Similarities, differences, and new strategies were discussed, with reference to concrete examples to help distinguish between categories. Remaining transcripts were analysed by MiB, who discussed findings and uncertainties with BR as analysis progressed. The frequency of each strategy type and individual strategy across the interview set is reported in Table 2; illustrative quotes are provided in Online resource 2 to outline LGG patients' engagement in self-management. To provide greater understanding and illustration of how LGG patients are distinct in their use of self-management, we also report how participants described using and experiencing the most common self-management strategy types.

Results

Participant characteristics

Thirty-nine LGG patients registered an interest in taking part. Of these, 35 were eligible and 28 were subsequently interviewed (10 recruited through NHS sites and 18 through the Brain Tumour Charity). Reasons for exclusion included: non-completion of primary treatment ($n=2$); ineligible diagnosis ($n=1$); and not a UK resident ($n=1$). The mean age at interview was 50.4 years (range 22–69 years), and 16 participants were male (Table 1). Diagnoses were grade 2 oligodendroglioma ($n=10$: IDH1-mutant, yes $n=7$, no $n=2$, unknown $n=1$; 1p/19q codeletion, yes $n=9$, not known $n=1$), grade 3 oligodendroglioma ($n=9$: IDH1-mutant, yes $n=6$, no $n=1$, unknown $n=2$; 1p/19q codeletion, yes $n=7$, not known $n=2$), and grade 2 astrocytoma ($n=9$: IDH1-mutant, yes $n=6$, no $n=1$, unknown $n=2$; 1p/19q codeletion, no $n=7$, not known $n=2$). Participants had a mean time since diagnosis of 8.7 years (range 1–18 years).

Table 1 Lower-grade glioma sample characteristics at time of interview

Characteristic	*n*	Characteristic	Mean (range)
Diagnosis[a]		*Time since diagnosis (years)*[a]	8.7 (1–18)
Grade 2 oligodendroglioma	10	*Full-time education (years)*	15.8 (11–20)
Grade 3 oligodendroglioma	9	*Sex*	***n***
Grade 2 astrocytoma	9	Female	12
IDH1-mutation status[a]		Male	16
Yes	19	*Age*	
No	4	≤ 40	4
Unknown	5	41–50	8
1p/19q codeletion status[a,b]		51–60	11
Yes	16	> 60	5
No	7	*Dependents*	
Unknown	5	None	18
Treatment[a]		One	3
Surgery	28	Two	6
Radiotherapy	22	Three	1
Chemotherapy	17	*Employment status*	
Tumour location[a]		Full-time employee	8
Frontal	18	Part-time employee	4
Temporal	3	Retired	4
Parietal	3	Medically retired	6
Overlapping regions	3	Unable to work	6
Unknown	1	*Relationship status*	
Tumour laterality[a]		Married	21
Right hemisphere	13	In a relationship	3
Left hemisphere	15	Single	2
Dominant hemisphere	13	Widowed	2
Non-dominant hemisphere	15		

[a] Clinical and tumour-related details were patient-reported for eight participants

[b] All participants with 1p/19q codeletion were oligodendroglioma patients; all participants without 1p/19q codeletion were astrocytoma patients

Engagement in self-management

We found evidence for all 20 self-management strategy types in the initial categorisation matrix and did not identify any new strategy types. In total, 123 different self-management strategies were reported by participants. To manage, protect, and improve their health and wellbeing, each LGG patient reported using a wide range of self-management strategies (median 39; range 19–54) within multiple self-management strategy types (median 16; range 9–18) (Table 2; Online resource 2).

Framework revisions

LGG patients reported 117 of the 133 self-management strategies detailed in the initial categorisation matrix [11, 12], meaning evidence for 16 strategies was not found (e.g. *avoiding negative health behaviours*). Labels for self-management strategy types were left intact to facilitate future use of the framework. For several of the interviewees, the term ‘cancer’ did not resonate with them; therefore, labels for 12 strategies were altered to remove or replace ‘cancer’ with ‘the tumour’ or ‘illness’ (e.g. *seeking support from cancer care team* became *seeking support from care team*; *accepting cancer and its consequences* became *accepting the tumour and its consequences*; and *appreciating the severity of one’s cancer history* became *appreciating the severity of one’s illness history*, respectively). Due to the depth of data reported, we separated ‘having someone to talk to’ into two individual strategies, ‘having family and friends to talk to’ and ‘having health professionals to talk to’.

New self-management strategies reported by LGG patients

Five novel self-management strategies were identified, within three of the strategy types (meaning the updated framework now includes 139 strategies). Within ‘creating a healthy environment’, 16 participants reported ‘using external aids to overcome cognitive difficulties’ (e.g. using a calendar to

Table 2 Self-management strategy types and individual strategies used by LGG patients

Self-management strategy types	Self-management strategies[a]	*n*
Acceptance		**26**
Accepting functional, lifestyle, and social changes following the tumour and its treatment	Accepting new health behaviours	6
	Accepting support[+]	3
	Accepting the tumour and its consequences	26
Activity-based coping		**19**
Use or uptake of hobbies or activities to manage one's wellbeing	Pursuing an existing hobby/activity	19
	Taking up a new hobby/activity	8
Adopting a healthy lifestyle		**26**
Adopting generic health behaviours to boost one's general physical and/or emotional wellbeing	Adopting a healthy diet	4
	Being physically active in everyday life	19
	Drinking more water	1
	Exercising	16
	Meditating	4
	Sleeping well	1
	Taking medication	18
	Taking vitamins and minerals	1
Behavioural avoidance		**8**
Behavioural strategies which minimise one's contact with threats to one's physical and/or emotional wellbeing	Avoiding activities that may cause harm	4
	Avoiding situations that may cause harm	2
	Avoiding uncomfortable social encounters	5
Cognitive avoidance		**20**
Strategies involving the avoidance of thoughts concerning the negative consequences of the tumour and its treatment	Avoiding finding out too much	9
	Avoiding thoughts about the tumour and its consequences	18
	Distracting oneself by keeping busy	2
Conserving emotional energy		**13**
Strategies which enable one to conserve emotional energy in order to better self-manage one's condition	Having time to yourself	3
	Letting emotions out	4
	Minimising stress	5
	Switching off	1
	Using sleep	5
Conserving physical energy		**18**
Strategies which enable one to conserve physical energy in order to better self-manage one's condition	Reducing activities	3
	Reducing workload	14
	Taking a break	13
Creating a healthy environment		**28**
Attempts to create an environment which enables effective self-management	Acquiring knowledge about the tumour, treatment and late-effects and available support	19
	Attending follow-up and screening appointments	21
	Collecting materials to aid self-management	9
	Ensuring reliability of health information on the internet	6
	Learning self-management skills	4
	Obtaining resources to aid self-management	16
	Relationship-building with health practitioner	3
	Using external aids to overcome cognitive difficulties[+]	16
	Utilising skills for independent living	3
	Valuing and respecting relationship with care team	3
Goal and action setting		**25**

Table 2 (continued)

Self-management strategy types	Self-management strategies[a]	*n*
Use of planning or goal-setting self-management strategies	Coping planning	3
	Planning daily activities	8
	Priority-based planning	7
	Setting future goals	18
	Setting up facilitating conditions	18
Managing others		**22**
Active attempts to effectively manage one's social relationships following treatment	Being assertive in social encounters	1
	Being open with others about the tumour and its consequences	18
	Keeping others happy	5
	Protecting others from harm	18
Meaning-making		**27**
Interpreting the tumour and its consequences in the broader context of life as a whole	Appreciating health more	4
	Appreciating life more	10
	Appreciating support	15
	Appreciating the importance of family	5
	Appreciating the severity of one's illness history	7
	Changing one's image	1
	Finding meaning in work	4
	Giving back	10
	Taking every day as it comes	12
	Wanting to give something back	12
Positive appraisal		**26**
Focusing on positive aspects of one's immediate situation	Benefit finding	13
	Downward comparison	18
	Reinterpreting negative consequences	24
Proactive problem solving		**18**
Active attempts to solve problems in-the-moment arising from the consequences of the tumour and its treatment	Acting to prevent further complications	7
	Adaptive approaches to ongoing physical consequences of the tumour and its treatment	17
Reasoned decision-making		**23**
Objective decision-making strategies relating to survivor self-management	Considering the benefits of positive health behaviours	9
	Considering pros and cons of self-management	9
	Evaluating effectiveness of self-management	10
	Thinking objectively about negative health behaviours	1
	Thinking objectively about negative thoughts and emotions	9
Seeking normality		**23**
Active attempts to return to normal living following treatment	Carrying out tasks to the best of one's ability	5
	Choosing when and to whom to disclose illness history	2
	Focusing on doing normal activities	8
	Focusing on getting back to work	13
	Gaining independence	4
	Maintaining independence	3
	Regaining strength	6
	Returning to normal	10
	Testing oneself	1
Self-monitoring		**27**

Table 2 (continued)

Self-management strategy types	Self-management strategies[a]	*n*
Active self-monitoring of one's health, wellbeing and ongoing care	Knowing your body	7
	Monitoring emotions	23
	Monitoring for symptoms of the tumour and late effects	15
	Monitoring general health	4
	Monitoring health behaviours	1
	Monitoring relationship with health professionals	1
	Recognising one's own limits	21
Self-motivating		**25**
Strategies which help to motivate oneself to effectively self-manage	Being healthy for sake of one's family	2
	Challenging yourself	2
	Developing confidence and self-efficacy	1
	Drawing on spiritual resources	1
	Drawing strength from past experiences	2
	Employing a determined attitude	14
	Encouraging oneself	6
	Focusing on milestones of survivorship	3
	Interacting with others	1
	Maintaining a positive outlook	20
	Not dwelling on the past	2
	Persevering with healthy behaviours	3
	Recognising the need for motivation and discipline	1
	Taking responsibility for own health	11
	Wanting to stay in good health	1
Self-sustaining		**12**
Strategies which enable one to consistently implement self-management strategies in one's daily life	Customising dietary practises	2
	Following health practitioner's advice	4
	Incorporating self-management behaviours into daily routine	8
	Keeping busy to avoid negative behaviours	2
	Maintaining medical equipment	1
Using sense of humour		**6**
Use of humour to manage emotions associated with the negative consequences of the tumour and its treatment	Finding humour in others' reactions	1
	Laughing about the tumour and its consequences	5
	Using humour to hide insecurities	1
Using support		**28**

Table 2 (continued)

Self-management strategy types	Self-management strategies[a]	*n*
Use of appropriate supports to assist in one's recovery and recuperation following treatment	Companionship from pet	2
	Drawing support from similar other	15
	Giving advice to similar others$^+$	7
	Having family and friends to talk to†	7
	Having health professionals to talk to†	16
	Receiving formal support	20
	Receiving support from charities and organisations	19
	Receiving support from care team	17
	Receiving support from family	24
	Receiving support from friends	24
	Receiving support from partner	20
	Receiving support from the workplace	21
	Seeking formal help	17
	Seeking support from care team	13
	Seeking support from charities and organisations$^+$	14
	Seeking support from family	1
	Seeking support from friends	2
	Seeking support from the workplace$^+$	1

$^+$New strategy identified in interviews with LGG patients

†Original strategy has been sub-divided into new categories: 'having family and friends to talk to' and 'having health professionals to talk to' adapted from 'having someone to talk to'

[a] Strategies in the framework not identified in interviews with LGG patients: accepting social difficulties, avoiding contact with others for possible infection, avoiding negative health behaviours, avoidance of negative relationships, balancing life with health needs, becoming more altruistic, caring less about what others think, dealing with (in)fertility at the right time, ensuring personal hygiene, receiving support from educational provider, reducing negative health behaviours, rewarding oneself, seeking support from partner, treating illness as a project, trying to fit in, wanting to look good

Bold values indicate the number of people that reported at least one of the individual self-management strategieswithin each strategy type

remember health appointments). Within 'acceptance', three participants reported 'accepting support' (i.e. accepting help with something they could manage previously). Three new strategies were identified within 'using support', namely 'giving advice to similar others' (i.e. sharing tips from their experiences with other patients), 'seeking support from charities and organisations', both reported by several participants, and 'seeking support from the workplace', reported by one participant.

Most common self-management strategy types and strategies

Four self-management strategy types were reported by all (or all bar one) participants: 'using support' ($n=28$), 'creating a healthy environment' ($n=28$), 'meaning making' ($n=27$), and 'self-monitoring' ($n=27$); we expand on how LGG patients implemented these strategy types in detail below. A further five strategy types were reported by the majority of participants: 'acceptance', 'adopting a healthy lifestyle', 'positive appraisal' ($n=26$ each), 'goal and action setting', and 'self-motivating' ($n=25$ each).

The most frequently reported self-management strategies were 'accepting the tumour and its consequences' ($n=26$; within strategy type 'acceptance'), 'receiving support from friends' ($n=24$; within 'using support'), 'receiving support from family' ($n=24$; within 'using support'), 'reinterpreting negative consequences' ($n=24$; within 'positive appraisal'), and 'monitoring emotions' ($n=23$; within 'self-monitoring').

Strategy type: using support

Many participants reported seeking support from formal sources/networks (e.g. care team, charities, and organisations) to acquire information and assistance with managing the consequences of their illness; only a few reported seeking support from informal networks like family and friends. Several participants noted the benefit of having family/friends or health professionals available to talk to, should they need their support.

> I made an appointment speaking to [the Consultant] about all aspects of [the diagnosis] and what would happen maybe further down the line, so I'm a little bit more informed. (Pa37, aged 54, Male, grade 2 astrocytoma, 3 years since diagnosis).

Most participants reported receiving formal support; for example, physiotherapy or counselling to help manage the physical or psychological impact, respectively. Charities (e.g. the Brain Tumour Charity, Maggie's, Macmillan Cancer Support), were frequently cited as sources of self-management support via their helplines, websites, and centres.

> A lot of information I get from the website of the Brain Tumour Charity itself…We've been to a couple of the workshop sessions that they held in the early days. There is a supportive community out there. (Pa15, aged 55, Male, grade 2 astrocytoma, 7 years since diagnosis).

The majority of participants described receiving support from friends, family, partners, and their workplace; for example, practical (e.g. housework, transport) and emotional support, with close contacts often adopting caring roles. Partners and spouses played a major role in providing support.

> Like I say, you still get lifts to work and stuff like that and driving, yes, and my wife did a lot of it just to keep basically the pressure off [me]. (Pa31, aged 53, Male, grade 2 oligodendroglioma, 14 years since diagnosis).

Several participants reported drawing support from similar others through support groups and forums, alleviating feelings of isolation and promoting camaraderie. This provided some with a welcome opportunity to give advice and share acquired knowledge of available resources as well as to receive support.

> We all had our feelings for each other, that we all had the illness in the same place. There was all the people who had helped, or were still helping…their family. That was really nice…I appreciated it. (Pa19, aged 55, Male, grade 3 oligodendroglioma, 5 years since diagnosis).

Strategy type: creating a healthy environment

Most participants reported attending follow-up appointments for routine scans and results to maintain contact with their care team and monitor their condition. Many participants detailed acquiring knowledge about the tumour, treatment, available support, and ways to manage health and wellbeing, by accessing reputable charity websites, webinars, and scientific journals. Participants were mindful of ensuring online information was reliable; where questions were raised, a few participants sought clarity from their care team.

> That's a good thing I learnt from that [fatigue] webinar [run by Brainstrust], when you have energy, spend it on things that you want to do… I think I spend far too much energy on doing things that I don't, necessarily, want to do. (Pa9, aged 22, Male, grade 2 astrocytoma 1 year since diagnosis).

Most participants actively obtained resources to aid self-management; for example, bus passes and rail cards to manage transport while their driving licence was revoked due to the illness. Several participants reported collecting materials, such as books or charity information packs from their hospital to, for example, improve understanding of symptom management, or find out how to arrange financial support.

> There's actually a book I know, written for people with the same low-grade glioma as mine, which has been quite helpful as it covers a lot of similarities with how I feel. (Pa3, aged 45, Male, grade 2 oligodendroglioma, 18 years since diagnosis).

Many participants detailed using external aids to facilitate memory; for example, using dosette boxes, or setting phone reminders and alarms, to manage medication or remember social engagements. A few participants recounted learning new physical and cognitive skills to maintain hobbies and interests.

> I've got a big calendar that I write everything on in the kitchen. I just keep on top of things that way. (Pa29, aged 51, Female, grade 3 oligodendroglioma, 9 years since diagnosis).

Strategy type: meaning-making

Most participants acknowledged the importance of, and appreciation towards, the availability of a support network; some specifically credited family, feeling lucky to have their support.

> My wife's very supportive, she's very good at seeing when I'm tired and saying. "Go and sit down." So, that's how I manage it…it's been very good to have that support. (Pa5, aged 56, Male, grade 2 oligodendroglioma, 2 years since diagnosis).

Many participants reported a desire to give something back; for example, through research participation or emotional support to newly diagnosed patients. Several had already attempted to give back, describing charity fundraising efforts and volunteering at hospitals and the resulting benefits of this.

> 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, aged 69, Male, grade 3 oligodendroglioma, 2 years since diagnosis).

Several participants detailed taking every day as it comes, approaching challenges of their illness gradually, without becoming overwhelmed. To affirm this, some acknowledged the severity of their illness history, expressing a new appreciation for life, their health, and the positive progress they have made.

> You've got to be thankful…I look back and see where I was and where I am now. (Pa22, aged 43, Female, grade 2 astrocytoma, 16 years since diagnosis).

Strategy type: self-monitoring

Most participants reported self-monitoring their health and emotions to identify any issues with, and in some cases, feel control over, their health and wellbeing. Many described strong emotions in relation to their condition, including fear of tumour progression and anxiety, and/or emotional consequences such as being short-tempered; some participants implemented strategies (e.g. taking a break) to control their emotions.

> I can feel myself snapping, not being aggressive or anything but just being a bit snappy. I'll be like, "You're right". I need to lie down. (Pa33, aged 45, Male, grade 2 oligodendroglioma, 9 years since diagnosis).

Several participants reported active monitoring for symptoms: for example, being aware of, and acknowledging, how it feels when they are fatigued, or about to have a seizure. Many detailed an awareness of environments or situations that may exacerbate the risk of a seizure; this awareness allowed them to plan accordingly. For some, this extended to monitoring of general health and taking remedial actions.

> My speech was slurred. I sat down and I thought, breathe deeply, keep calm, let's see what happens, this might resolve itself…The discomfort or the lack of control in the jaw and the tingling in the hand, that subsided. (Pa14, aged 66, Male, grade 2 oligodendroglioma, 4 years since diagnosis).

Through self-monitoring, most participants acknowledged that, largely due to fatigue or the chance of having a seizure, they could not manage the same activity levels as before diagnosis.

> There are always going to be times when you can't do things as fully or as well as you would like to because of your condition and it's just recognising that fact. (Pa36, aged 42, Female, grade 2 astrocytoma, 8 years since diagnosis).

Recognising these limits impacted participants' perceived capacity to work and maintain hobbies (e.g. gardening). Consequently, many participants reported only engaging in activities they felt were manageable; these fatigue management approaches link with the strategy type 'conserving physical energy'. Some suggested this was assisted by the feeling that they knew their body.

Discussion

LGG patients often live long-term with an incurable condition and its wide-ranging consequences; however, little is known about how they manage their health and wellbeing. Understanding whether, and which, self-management strategies are used is important to inform the need for, and development of, self-management interventions. This study aimed to comprehensively identify and understand the self-management strategies used by LGG patients to manage the consequences of their tumour and its treatment.

To classify and categorise reported self-management strategies, we built upon an established self-management framework for cancer survivors [11, 12]. Through this approach, we recognised 20 strategy types and 123 individual strategies used by LGG patients; this encompassed psychological, social, and behavioural approaches to self-management, comprehensively expanding on existing evidence in LGG patients [14, 15]. We found a similar frequency of 'self-motivating' and 'meaning making' strategy types in LGG patients, compared to head and neck cancer survivors [11], and 'creating a healthy environment' and 'adopting a healthy lifestyle', compared to young adult survivors of childhood cancer [12]. 'Using support' was one of the most common strategy types used by all three patient groups. However, a 'healthy environment' for childhood cancer survivors meant acquiring resources to facilitate physical activity (i.e. gym membership), whereas LGG patients favoured resources to facilitate memory and manage fatigue. This underlines the importance of understanding how different strategies are used by different patient populations, as this likely varies with the consequences of each condition (and, perhaps, where the patient group are in their life course).

Encouraging and facilitating self-management in LGG patients is crucial to ensure they can effectively engage in managing their health and wellbeing. People living with a brain tumour may underestimate cognitive, emotional, psychological, and social changes [22]. This could have implications for patient self-management; for example, 'monitoring emotions' and 'recognising one's own limits' were amongst the most commonly reported self-management strategies, but patients would need to be aware of their limitations and changes in emotion to effectively engage with these strategies.

It has been noted previously that self-management should not be a solitary activity but rather one that an individual is supported to engage with [23]. The frequency with which patients in this study spoke about support received from (in)formal support networks underlines the influential role of health professionals, family, and friends in self-management [23, 24]. The practical (e.g. help with housework), emotional (e.g. having someone to talk to), and information (e.g. symptom management leaflet) support provided could facilitate the implementation of numerous self-management strategies, such as 'reducing workload', 'letting emotions out', and 'setting up facilitating conditions', respectively. Still, to expedite the benefits of supported self-management, we need to understand whether there are reasons why LGG patients may not seek help from their support networks [25].

Despite the limited life expectancy following an LGG diagnosis, there was a common refrain of optimism, appreciation, and planning for the future amongst many of the most frequently reported self-management strategy types, such as 'acceptance' (particularly 'accepting the tumour and its consequences'), 'goal and action setting', 'meaning making', 'positive appraisal' (particularly 'reinterpreting negative consequences'), and 'self-motivating'. These approaches appear to form a substantial part of self-management in LGG patients; if maintained, acceptance in particular, has been associated with reduced levels of distress [26]. Further, consistent with past work on other cancers [27], the data here indicates that LGG patients may experience post-traumatic growth (PTG), as several frequently reported strategies resembled PTG dimensions (e.g. 'taking every day as it comes' resonates with 'appreciation of life'; 'reinterpreting negative consequences' resonates with 'personal strength').

While engagement in self-management was consistently high, the importance of, and need for, self-management varied for each participant, with a range of strategies used. We do not know whether participants used these strategies before diagnosis, or if they were approaches that they initiated post-diagnosis or had been taught in rehabilitation. We focused on the most common strategy types as people largely reported, and talked about, what has been helpful to them; yet it is important to acknowledge that less common strategy types, such as 'activity-based coping' and 'conserving physical energy' were sometimes highly valued by those who reported them. It is important to note that, as others have reported, which strategies are most important for an individual may be influenced by wide-ranging clinical (e.g. tumour type) [28], environmental (e.g. strength of support network), or personal (e.g. employment ambitions) factors [29].

Seizure burden is consistently associated with worse quality-of-life in people living with an LGG [4]. It was interesting, therefore, that seizures were not often mentioned in a self-management context; only a few participants spoke about self-monitoring in relation to minimising the chance of having a seizure. It is possible that this is a result of our participants being, on average, 8.7 years from diagnosis; by this time, seizures may have stabilised for many and be well managed with antiepileptic drugs. Indeed, in a study reporting long-term follow-up of LGG patients, mean symptom scores for seizures were low [30]; and 43% of participants reported a decrease in seizure activity from 6 to 12 years since diagnosis [31].

Implications

Our findings demonstrate that LGG patients use wide-ranging strategies in the long-term self-management of their condition; thus this patient group may be open to interventions to support them to self-manage. Our data highlights the value of self-monitoring and using support, which may aid the general transition to living with a brain tumour [32]. We also identified the importance of strategies used to manage tumour-specific impairments, such as cognitive function and personality changes. Future intervention development might consider education, information, and signposting, supplemented with appropriate behavioural change techniques, to ensure and maintain awareness of what support is available, what can be done to self-manage different symptoms and impairments, and how this might be achieved. An example would be an interactive session with different strategies to self-manage medication adherence, including making a medication intake plan with anchoring to other activities, setting reminders, and suggestions of using tools like dosette boxes in order to, in time, establish a habit.

Strengths and limitations

Our study benefitted from recruitment across the UK, covering several regions where available support and resources may differ; the availability of formal support may influence the importance of, need for, and ability to implement, different self-management strategies. Semi-structured interviews, and the wide range of topics covered, gave participants the freedom to report their self-management across various contexts, thus capturing what was important to each individual. Since interviews were conducted remotely, participants may have perceived greater anonymity, thus feeling more comfortable and encouraging more disclosure [33].

Efforts were made to facilitate the inclusion of patients with cognitive, speech, language, and communication impairments, following expert advice from a Speech and Language Therapist. However, the demands of an interview may have prevented patients with fatigue or poor cognitive function from registering an interest, or being approached by health professionals. Consequently, the self-management strategies of LGG patients with these symptoms or impairments may be underrepresented. Ways to facilitate their participation (e.g. multiple, shorter interviews to mitigate fatigue, strategies to support communication) should be considered in future research [34]. Due to COVID-19, the need for partial recruitment through the Brain Tumour Charity means we cannot discount the possibility that participants were somewhat self-selected, and were people who more actively engaged in self-management, had higher levels of self-efficacy, and/or particularly valued support groups/networks. Although we did not formally seek to compare participants recruited through different routes; post-hoc analysis suggested there is little difference in the strategy types or experiences reported. Despite repeated attempts to contact the clinical care teams of participants recruited through the Brain Tumour Charity for confirmation of clinical and tumour-related details, this information was patient-reported for eight participants and IDH1 mutation and 1p19q codeletion status were unknown for five participants.

Conclusions

This study provides, for the first time, a comprehensive understanding of the strategies used by LGG patients to self-manage their health and wellbeing, post-treatment. LGG patients reported using an extensive and diverse range of self-management strategies, indicating a willingness to engage in self-management. The most common approaches to self-management included the use of support from (in)formal networks, and creating an environment that facilitates effective self-management. How LGG patients implemented their approach to self-management was distinct from other cancer survivors, favouring strategies that facilitated tumour-specific symptoms and impairments (e.g. memory deficits). These findings are valuable to inform the development of supported self-management interventions for this largely neglected patient group [35].

Supplementary information The online version contains supplementary material available at https://doi.org/10.1007/s11764-023-01425-x.

Acknowledgements This is an output for the Ways Ahead project (research.ncl.ac.uk/waysahead). We would like to thank all of the patients that took the time to participate in this study. We would also like to thank our collaborating NHS sites, Newcastle upon Tyne Hospitals NHS Foundation Trust, NHS Lothian, The Christie NHS Foundation Trust, and South Tees Hospitals NHS Foundation Trust, for their assistance with recruitment to the project. We extend this thanks to colleagues at the Brain Tumour Charity. The Ways Ahead study team comprises, in addition to the named authors, Sara Erridge, Pauline Sturdy, and Catherine McBain.

Author contribution LS, JL, SW, PG, RB, VAS, and TF secured the funding and developed the idea for the study. SE, PS, and CM facilitated recruitment in NHS sites. BR acquired ethical approval and conducted recruitment. BR and LD conducted the interviews. MiB and BR conducted the analysis and interpreted the findings. BR drafted the manuscript. All authors reviewed, revised, and approved the final manuscript.

Funding This work was supported by funding from the Brain Tumour Charity (GN-000435).

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.

Declarations

Ethics approval The study has been reviewed and approved by a National Health Service Research Ethics Committee (REC ref: 20/WA/0118).

Consent to participate Informed consent was obtained from all individual participants included in the study.

Consent for publication Not applicable.

Competing interests The authors declare no competing interests.

References

1. Bauchet L. Epidemiology of diffuse low grade gliomas. Diffuse Low-Grade Gliomas in Adults, 2017;13–53. https://doi.org/10.1007/978-3-319-55466-2_2
2. Claus EB, Walsh KM, Wiencke JK, Molinaro AM, Wiemels JL, Schildkraut JM, Bondy ML, Berger M, Jenkins R, Wrensch M. Survival and low-grade glioma: the emergence of genetic information. Neurosurg Focus. 2015;38(1):E6. https://doi.org/10.3171/2014.10.FOCUS12367.

3. Dixit K, Raizer J. Newer strategies for the management of low-grade gliomas. Oncology (Williston Park, N.Y.) 2017; 31(9), 680–682, 684. https://europepmc.org/article/med/29071695
4. Rimmer B, Bolnykh I, Dutton L, Lewis J, Burns R, Gallagher P, Williams S, Araújo-Soares V, Menger F, Sharp L. Health-related quality of life in adults with low-grade gliomas: a systematic review. Qual Life Res. 2022;2022(1):1–27. https://doi.org/10.1007/S11136-022-03207-X.
5. The Brain Tumour Charity. Losing myself: the reality of life with a brain tumour. 2015. http://publications.cancerresearchuk.org/publicationformat/formatfactsheet/keyfactsbrain.html
6. Huang ME, Wartella J, Kreutzer J, Broaddus W, Lyckholm L. Functional outcomes and quality of life in patients with brain tumours: a review of the literature. Brain Inj. 2001;15(10):843–56. https://doi.org/10.1080/02699050010013653.
7. Howell D, Harth T, Brown J, Bennett C, Boyko S. Self-management education interventions for patients with cancer: a systematic review. Support Care Cancer. 2017;25(4):1323–55. https://doi.org/10.1007/S00520-016-3500-Z/FIGURES/2.
8. Foster C, Brown J, Killen M, Brearley S. The NCRI cancer experiences collaborative: defining self management. Eur J Oncol Nurs. 2007;11(4):295–7. https://doi.org/10.1016/J.EJON.2007.08.002.
9. Lorig KR, Holman HR. Self-management education: history, definition, outcomes, and mechanisms. Ann Behav Med. 2003;26(1):1–7. https://doi.org/10.1207/S15324796ABM2601_01.
10. Yun YH, Jung JY, Sim JA, Choi H, Lee JM, Noh DY, Han W, Park KJ, Jeong SY, Park JW, Wu HG, Chie EK, Kim HJ, Lee JH, Zo ZI, Kim S, Lee JE, Nam SJ, Lee ES., … Shim YM. Patient-reported assessment of self-management strategies of health in cancer patients: development and validation of the Smart Management Strategy for Health Assessment Tool (SAT). Psycho-Oncol, 2015;24(12), 1723–1730. https://doi.org/10.1002/PON.3839
11. Dunne S, Mooney O, Coffey L, Sharp L, Timmons A, Desmond D, Gooberman-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. Psychooncology. 2017;26(12):2194–200. https://doi.org/10.1002/pon.4447.
12. Brown MC, Haste A, Araújo-Soares V, Skinner R, Sharp L. Identifying and exploring the self-management strategies used by childhood cancer survivors. J Cancer Surviv. 2021;15(2):344–57. https://doi.org/10.1007/s11764-020-00935-2.
13. Rimmer B, Sharp L. Implementation of self-management interventions in cancer survivors: why are we not there yet? J Cancer Educ. 2021;36(6):1355–8. https://doi.org/10.1007/s13187-021-02021-2.
14. Affronti ML, Randazzo D, Lipp ES, Peters KB, Herndon SC, Woodring S, Healy P, Cone CK, Herndon 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, Issue 5, pp. 472–485). W.B. Saunders. https://doi.org/10.1016/j.soncn.2018.10.006
15. Edvardsson T, Ahlström G. Illness-related problems and coping among persons with low-grade glioma. Psychooncology. 2005;14(9):728–37. https://doi.org/10.1002/PON.898.
16. Keeling M, Bambrough J, Simpson J. Depression, anxiety and positive affect in people diagnosed with low-grade tumours: the role of illness perceptions. Psychooncology. 2013;22(6):1421–7. https://doi.org/10.1002/PON.3158.
17. Schaefer I, Heneka N, Luckett T, Agar MR, Chambers SK, Currow DC, Halkett G, Disalvo D, Amgarth-Duff I, Anderiesz C, Phillips JL. Quality of online self-management resources for adults living with primary brain cancer, and their carers: a systematic environmental scan. BMC Palliat Care. 2021;20:1–11. https://doi.org/10.1186/s12904-021-00715-4.
18. 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. https://doi.org/10.1136/bmjopen-2020-041465.
19. Louis DN, Perry A, Wesseling P, Brat DJ, Cree IA, Figarella-Branger D, Hawkins C, Ng HK, Pfister SM, Reifenberger G, Soffietti R, von Deimling A, Ellison DW. The 2021 WHO classification of tumors of the central nervous system: a summary. Neuro Oncol. 2021;23(8):1231–51. https://doi.org/10.1093/neuonc/noab106.
20. Assarroudi A, Heshmati Nabavi F, Armat MR, Ebadi A, Vaismoradi M. Directed qualitative content analysis: the description and elaboration of its underpinning methods and data analysis process. J Res Nurs. 2018;23(1):42–55. https://doi.org/10.1177/1744987117741667.
21. Low J. A pragmatic definition of the concept of theoretical saturation. Sociol Focus. 2019;52(2):131–9.
22. Andrewes HE, Drummond KJ, Rosenthal M, Bucknill A, Andrewes DG. Awareness of psychological and relationship problems amongst brain tumour patients and its association with carer distress. Psychooncology. 2013;22(10):2200–5. https://doi.org/10.1002/PON.3274.
23. Dwarswaard J, Bakker EJM, van Staa A, Boeije HR. Self-management support from the perspective of patients with a chronic condition: a thematic synthesis of qualitative studies. Health Expect. 2016;19(2):194–208. https://doi.org/10.1111/HEX.12346.
24. Cornwell P, Dicks B, Fleming J, Haines TP, Olson S. Care and support needs of patients and carers early post-discharge following treatment for non-malignant brain tumour: establishing a new reality. Support Care Cancer. 2012;20(10):2595–610. https://doi.org/10.1007/S00520-012-1383-1/TABLES/3.
25. Langbecker D, Ekberg S, Yates P. Don't need help, don't want help, can't get help: how patients with brain tumors account for not using rehabilitation, psychosocial and community services. Patient Educ Couns. 2017;100(9):1744–50. https://doi.org/10.1016/J.PEC.2017.04.004.
26. Secinti E, Tometich DB, Johns SA, Mosher CE. The relationship between acceptance of cancer and distress: a meta-analytic review. Clin Psychol Rev. 2019;71:27–38. https://doi.org/10.1016/J.CPR.2019.05.001.
27. Menger F, Mohammed Halim NA, Rimmer B, Sharp L. Post-traumatic growth after cancer: a scoping review of qualitative research. Support Care Cancer. 2021;29(11):7013–27. https://doi.org/10.1007/S00520-021-06253-2/TABLES/3.
28. Ruge MI, Ilmberger J, Tonn JC, Kreth FW. Health-related quality of life and cognitive functioning in adult patients with supratentorial WHO grade II glioma: status prior to therapy. J Neurooncol. 2011;103(1):129–36. https://doi.org/10.1007/s11060-010-0364-9.
29. Khan F, Amatya B. Use of the international classification of functioning, disability and health (ICF) to describe patient -reported disability in primary brain tumour in an Australian comunity cohort. J Rehabil Med. 2013;45(5):434–45. https://doi.org/10.2340/16501977-1132.
30. Boele FW, Den Otter PWM, Reijneveld JC, De PC, Hamer W, Van Thuijl HF, Lorenz LMC, Wesseling P, Lagerwaard FJ, Taphoorn MJ, Kouwenhoven MC, Snijders TJ, Douw L, Klein M. Long-term wellbeing and neurocognitive functioning of diffuse low-grade glioma patients and their caregivers: a longitudinal study spanning two decades. Neuro Oncol. 2022. https://doi.org/10.1093/NEUONC/NOAC185.
31. Boele FW, Douw L, Reijneveld JC, Robben R, Taphoorn MJB, Aaronson NK, Heimans JJ, Klein M. Health-related quality of life in stable, long-term survivors of low-grade glioma. J Clin Oncol. 2015. https://doi.org/10.1200/JCO.2014.56.9079.

32 McCorkle R, Ercolano E, Lazenby M, Schulman-Green D, Schilling LS, Lorig K, Wagner EH. Self-management: enabling and empowering patients living with cancer as a chronic illness. CA: Cancer J Clin. 2011;61(1):50–62. https://doi.org/10.3322/CAAC.20093.

33. Drabble L, Trocki KF, Salcedo B, Walker PC, Korcha RA. Conducting qualitative interviews by telephone: lessons learned from a study of alcohol use among sexual minority and heterosexual women. Qual Soc Work : QSW : Res Pract. 2016;15(1):118–33. https://doi.org/10.1177/1473325015585613.

34. Menger F, Cresswell H, Lewis J, Volkmer A, Sharp L. Speaking up for the lost voices: representation and inclusion of people with communication impairment in brain tumour research. Support Care Cancer. 2023;31(6):355.

35. Araújo-Soares V, Hankonen N, Presseau J, Rodrigues A, Sniehotta FF. Developing behavior change interventions for self-management in chronic illness. Eur Psychol. 2018;24(1):7–25. https://doi.org/10.1027/1016-9040/A000330.

Online resource. Content codes, definitions and examples for self-management strategy types and strategies

Strategy types	Specific strategies	N	%	Illustrative quotes
1. Acceptance		**26**	**92.9**	
Accepting functional, lifestyle and social changes following the tumour and its treatment.	*Accepting new health behaviours*	6	21.4	**Pa32:** I mean I'm on about 400mg. It's something called Carbamazepine. I think I'll always have to have it for the rest of my life. (aged 46, F, grade 3 oligodendroglioma, 14 years since diagnosis)
	Accepting social difficulties§	0	0	
	*Accepting support**	3	10.7	**Pa17:** I had to accept practical help, emotional help. And I struggled with that for a long time. And I kept wanting to be… I wasn't a very good patient at the beginning, you know, because that losing of independence is massive. (aged 51, F, grade 3 oligodendroglioma, 8 years since diagnosis)
	Accepting the tumour and its consequences	26	92.9	**Pa9:** There's nothing that you can do. It is just that it is what it is, and you've just got to make the best of it. (aged 22, M, grade 2 astrocytoma, 1 year since diagnosis) **Pa26:** If you've got a brain tumour you know your life expectancy is going to be shot a little bit, so don't focus on that. (aged 37, F, grade 2 oligodendroglioma, 15 years since diagnosis)
2. Activity-based coping		**19**	**67.9**	
Use or uptake of hobbies or activities to manage one's wellbeing.	*Pursuing an existing hobby/activity*	19	67.9	**Pa18:** Yes, so music, cooking. I love cooking. Been decorating the house. Some people say I have a good eye. I think I've got a very good eye. (aged 55, F, grade 3 oligodendroglioma, 1 year since diagnosis) **Pa33:** I mean I love my reading. I read a lot and I've got no problem with that. I watch quite a lot of films. (aged 45, M, grade 2 oligodendroglioma, 9 years since diagnosis)
	Taking up a new hobby/activity	8	28.6	**Pa35:** I had bought myself lots of pieces and started building myself an aeroplane. I'm finally finishing it right now which is exciting. (aged 49, M, grade 2 astrocytoma, 18 years since diagnosis)
3. Adopting a healthy lifestyle		**26**	**92.9**	
Adopting generic health behaviours to boost one's general physical and/or emotional wellbeing.	*Adopting a healthy diet*	4	14.3	**Pa13:** keep the iron up, a lot of kale, a lot of spinach… so I researched diet and I decided to…take control. (aged 52, M, grade 3 oligodendroglioma, 13 years since diagnosis)
	Avoiding negative health behaviours§	0	0	
	Being physically active in everyday life	19	67.9	**Pa9:** Yeah. So, I mean, I used to walk and still try to walk every, like, all the time, every day. (aged 22, M, grade 2 astrocytoma, 1 year since diagnosis) **Pa36:** My husband and I play tennis. We play squash. What else do we do? We swim. (aged 42, F, grade 2 astrocytoma, 8 years since diagnosis)
	Drinking more water	1	3.6	**Pa34:** So I make sure I drink plenty now. All of the time I'm drinking and it seems to help. (aged 66, F, grade 2 oligodendroglioma, 11 years since diagnosis)
	Ensuring personal hygiene§	0	0	
	Exercising	16	57.1	**Pa11:** I've always been relatively fit and I used my exercise as my stress buster and whatever. (aged 57, M, grade 2 oligodendroglioma, 14 years since diagnosis) **Pa17:** I do yoga. I actually do more since because I now do it almost daily from the TV, whereas when I went to a class it was once a week. (aged 51, F, grade 3 oligodendroglioma, 8 years since diagnosis)
	Meditating	4	14.3	**Pa36:** Mindfulness is a huge thing which my therapist introduced me to about five years ago. I've done lots of mindfulness in various guises. (aged 42, F, grade 2 astrocytoma, 8 years since diagnosis)

Strategy types	Specific strategies	N	%	Illustrative quotes
	Reducing negative health behaviours§	0	0	
	Sleeping well	1	3.6	**Pa18:** Eat well, sleep well, take some gentle exercise, walk the dog, get on the bike. (aged 55, F, grade 3 oligodendroglioma, 1 year since diagnosis)
	Taking medication	18	64.3	**Pa26:** Just the epilepsy pills. I take four in the morning and four in the evening. (aged 37, F, grade 2 oligodendroglioma, 15 years since diagnosis) **Pa37:** I take two tablets of one drug twice a day and another two tablets of another drug twice a day. (aged 54, M, grade 2 astrocytoma, 3 years since diagnosis)
	Taking vitamins and minerals	1	3.6	**Pa17:** I've got to take all sorts of supplements. (aged 51, F, grade 3 oligodendroglioma, 8 years since diagnosis)
4. Behavioural avoidance		**8**	**28.6**	
Behavioural strategies which minimise one's contact with threats to one's physical and/or emotional wellbeing.	*Avoiding activities that may cause harm*	4	14.3	**Pa31:** Don't read the internet. That is a nightmare. If you read that, you're on deaths door and it's not like that for all of them. (aged 53, M, grade 2 oligodendroglioma, 14 years since diagnosis)
	Avoiding contact with others for possible infection§	0	0	
	Avoiding situations that may cause harm	2	7.1	**Pa5:** It's just this sort of brain flooding. If we have a lot of people over for a meal or something like that. I do sometimes take myself off because it gets a bit, there's too much going on, the brain has taken too much. (aged 56, M, grade 2 oligodendroglioma, 2 years since diagnosis)
	Avoiding uncomfortable social encounters	5	17.9	**Pa3:** I suppose, because I've been so lucky with having such a minimal impact, and I've got a very low-grade diagnosis, and I've had a lot of healthy years, there is also part of me that is quite afraid of being in an environment where you meet other people who are suffering much more or have a much worse diagnosis. (aged 45, M, grade 2 oligodendroglioma, 18 years since diagnosis)
5. Cognitive avoidance		**20**	**71.4**	
Strategies involving the avoidance of thoughts concerning the negative consequences of the tumour and its treatment.	*Avoiding finding out too much*	9	32.1	**Pa38:** No. I'm one of these people that probably prefers not to know what's coming, to be honest with you. (aged 55, F, grade 2 astrocytoma, 1 year since diagnosis)
	Avoiding thoughts about the tumour and its consequences	18	64.3	**Pa3:** I am happy, normally, to talk about it quite openly, if someone asks, but it is, there is an emotional effort in not letting it take over, you know, your life and how you think about things. (aged 45, M, grade 2 oligodendroglioma, 18 years since diagnosis) **Pa18:** I forget. I forget because what's the point in walking around with a sticker on your forehead saying I've got a brain tumour? (aged 55, F, grade 3 oligodendroglioma, 1 year since diagnosis)
	Dealing with (in)fertility at the right time§	0	0	
	Distracting oneself by keeping busy	2	7.1	**Pa10:** I think I've often used work as a distraction. (aged 37, F, grade 2 oligodendroglioma, 14 years since diagnosis)
6. Conserving emotional energy		**13**	**46.4**	
Strategies which enable one to conserve emotional energy in order to better self-manage one's condition.	*Caring less about what others think§*	0	0	
	Having time to yourself	3	10.7	**Pa18:** I dedicate more time to myself. I give myself time to get ready and whatever. (aged 55, F, grade 3 oligodendroglioma, 1 year since diagnosis)

Strategy types	Specific strategies	N	%	Illustrative quotes
	Letting emotions out	4	14.3	**Pa26:** There was lots of swearing and literally I just spoke to my dad and partner, leave me alone for about three hours. I need to vent. (aged 37, F, grade 2 oligodendroglioma, 15 years since diagnosis)
	Minimising stress	5	17.9	**Pa36:** A very big piece I think for me and I'm sure other brain tumour sufferers is stress and just trying to manage your stress…don't put too much stress or pressure on yourself. (aged 42, F, grade 2 astrocytoma, 8 years since diagnosis)
	Switching off	1	3.6	**Pa28:** Other things are piled on you, you really do think, well yeah, I've had enough. It does sometimes get to that point, yes. I've had enough of all this yes and the best thing at that time is to blast out some music or go for a walk down the seafront. (aged 66, M, grade 2 astrocytoma, 7 years since diagnosis)
	Using sleep	5	17.9	**Pa35:** I'm trying to spend more time sleeping, resting, being less tired. (aged 49, M, grade 2 astrocytoma, 18 years since diagnosis)
7. Conserving physical energy		**18**	**64.3**	
Strategies which enable one to conserve physical energy in order to better self-manage one's condition.	*Reducing activities*	3	10.7	**Pa40:** I just try and agree to do a little bit less than I would have done before to try and stop myself getting worn out (aged 31, F, grade 2 astrocytoma, 1 year since diagnosis)
	Reducing workload	14	50	**Pa3:** "Well, actually, I'd quite like to go part-time, just to…" you know, just to give myself a bit more breathing space in my work week, kind of thing. (aged 45, M, grade 2 oligodendroglioma, 18 years since diagnosis) **Pa30:** Starting with half days originally, five half days. Then it would be two full days and gradually build it up until you felt like you could do your seven. If at any time I felt like I couldn't do it, I could just say, "I need to stop." (aged 61, M, grade 3 oligodendroglioma, 12 years since diagnosis)
	Taking a break	13	46.4	**Pa26:** There's a pond round the corner, I say just round corner but there were times it took me nearly two hours to get there and back, I didn't complete it every time, I'd have two days rest and then go again and go a bit further each time. (aged 37, F, grade 2 oligodendroglioma, 15 years since diagnosis) **Pa36:** If I have a quick nap for half an hour, that usually rejuvenates me. (aged 42, F, grade 2 astrocytoma, 8 years since diagnosis)
8. Creating a healthy environment		**28**	**100**	
Attempts to create an environment which enables effective self-management.	*Acquiring knowledge about the tumour, treatment and late effects and available support*	19	67.9	**Pa5:** The brain tumour charity website's really good for the particular… You know if you put in oligo grade 2, diffuse, you get a lot of information about that actually. (aged 56, M, grade 2 oligodendroglioma, 2 years since diagnosis) **Pa10:** I just looked for health anxiety therapist or something like that in Google, like, local to [City] and I found her that way. (aged 37, F, grade 2 oligodendroglioma, 14 years since diagnosis)
	Attending follow-up and screening appointments	21	75	**Pa13:** We have routine… yeah, there are scans built-in, you know, sort of, every three months. And every time we see the oncologist, we usually book in the next scan at the same time. (aged 52, M, grade 3 oligodendroglioma, 13 years since diagnosis) **Pa22:** I was going for regular scans. (aged 43, F, grade 2 astrocytoma, 16 years since diagnosis)
	Collecting materials to aid self-management	9	32.1	**Pa18:** PIP I was given a Macmillan pack at the hospital. I brought that home, read through it. (aged 55, F, grade 3 oligodendroglioma, 1 year since diagnosis)
	Ensuring reliability of health information on the internet	6	21.4	**Pa5:** You get to know actually which are the websites and which are the people you want to take information from and those which you think, no, you don't really know what you're talking about. (aged 56, M, grade 2 oligodendroglioma, 2 years since diagnosis)
	Learning self-management skills	4	14.3	**Pa30:** Because it affects my left hand side, the tumour, I was always right handed anyhow, I've started using my left hand as much as I can to do things.

Strategy types	Specific strategies	N	%	Illustrative quotes
				I don't know whether it helps or not but it helps me. (aged 61, M, grade 3 oligodendroglioma, 12 years since diagnosis)
	Obtaining resources to aid self-management	16	57.1	**Pa15:** I've got my disabled person's rail pass, I've got the local bus pass. (aged 55, M, grade 2 astrocytoma, 7 years since diagnosis) **Pa36:** For relaxation, when I rest I have the Calm app. I'll put that music or meditation on and listen to that. (aged 42, F, grade 2 astrocytoma, 8 years since diagnosis)
	Relationship-building with health practitioner	3	10.7	**Pa18:** I found right from the start is that develop good relationships with these people. They're working with you. They have their expertise. My expertise is elsewhere. But develop really good relationships. (aged 55, F, grade 3 oligodendroglioma, 1 year since diagnosis)
	Using external aids to overcome cognitive difficulties	16	57.1	**Pa29:** I've got a big calendar that I write everything on in the kitchen. I just keep on top of things that way. (aged 51, F, grade 3 oligodendroglioma, 9 years since diagnosis) **Pa38:** I thought, "Oh, God, I forgot to take that medicine." So, my tablet. So, we've actually set the Alexa down the stairs in the living room. So, she's got an alarm at both times, just in case. (aged 55, F, grade 2 astrocytoma, 1 year since diagnosis)
	Utilising skills for independent living	3	10.7	**Pa3:** I'll tap my back pocket, and I should be able to hear my pills rattling. And if I can't feel the pill box in there, then something is wrong, and I've got to go back home and get my pills… sort of like a habit. (aged 45, M, grade 2 oligodendroglioma, 18 years since diagnosis)
	Valuing and respecting relationship with care team	3	10.7	**Pa28:** [Consultant]'s team, the nurses, you can ring them anytime. I've got their times and their numbers pinned up in the kitchen there, so, that is like a little support team in itself so that's useful. (aged 66, M, grade 2 astrocytoma, 7 years since diagnosis)
9. Goal and action setting		**25**	**89.3**	
Use of planning or goal-setting self-management strategies.	*Coping planning*	3	10.7	**Pa36:** I think it's just the approach of taking one step at a time. (aged 42, F, grade 2 astrocytoma, 8 years since diagnosis)
	Planning daily activities	8	28.6	**Pa30:** I've just been pottering round as it was trying to achieve something every day, no matter what it is or how small. (aged 61, M, grade 3 oligodendroglioma, 12 years since diagnosis)
	Priority-based planning	7	25	**Pa18:** Well I've got things to look forward to and the first thing is rebuilding myself inside out. (aged 55, F, grade 3 oligodendroglioma, 1 year since diagnosis)
	Setting future goals	18	64.3	**Pa13:** The swimming is… the aim is to try and get good enough to do a sponsored swim. (aged 52, M, grade 3 oligodendroglioma, 13 years since diagnosis) **Pa31:** If you have three, well three and a bit, medical licences, you get your ten-year licence back. It's something to look forward to in my eyes. Well, it was for me. (aged 53, M, grade 2 oligodendroglioma, 14 years since diagnosis)
	Setting up facilitating conditions	18	64.3	**Pa16:** I've got lists coming out of my ears. I've got Google Keep lists, I've got a daybook, I've got a little notebook. (aged 69, M, grade 3 oligodendroglioma, 2 years since diagnosis) **Pa33:** I said to my wife, I said, "I want another box so I can keep two weeks' worth of medication going just to give me a bit more notice of when I'm getting low." (aged 45, M, grade 2 oligodendroglioma, 9 years since diagnosis)
10. Managing others		**22**	**78.6**	
Active attempts to effectively manage one's social relationships following treatment.	*Avoidance of negative relationships§*	0	0	
	Being assertive in social encounters	1	3.6	**Pa31:** Some things, I would never say things once upon a time, but now I will if I need to. (aged 53, M, grade 2 oligodendroglioma, 14 years since diagnosis)

Strategy types	Specific strategies	N	%	Illustrative quotes
	Being open with others about the tumour and its consequences	18	64.3	**Pa15:** I'm really open with everybody about it, everybody knows it, everybody knows I suffer from epilepsy. It's not a secret. (aged 55, M, grade 2 astrocytoma, 7 years since diagnosis) **Pa29:** With friends and that kind of thing, there are certain ones that I know that I could talk to about it and that would be fine. (aged 51, F, grade 3 oligodendroglioma, 9 years since diagnosis)
	Keeping others happy	5	17.9	**Pa25:** There was other things I used to be a part of, but I get a little bit sort of wary about making life difficult for them. You know, these people don't know anything or don't want to deal with somebody who's got cancer. (aged 45, M, grade 2 oligodendroglioma, 11 years since diagnosis)
	Protecting others from harm	18	64.3	**Pa11:** I suppose when she realised, obviously, when she was a bit younger, we didn't say it was a brain tumour or whatever, just said daddy's got a wee, funny spells and whatever, and that was good enough for her. (aged 57, M, grade 2 oligodendroglioma, 14 years since diagnosis) **Pa17:** I still feel the need to protect others by being positive even when I don't feel it. (aged 51, F, grade 3 oligodendroglioma, 8 years since diagnosis)
11. Meaning-making		**27**	**96.4**	
Interpreting the tumour and its consequences in the broader context of life as a whole.	*Appreciating health more*	4	14.3	**Pa30:** That is what well for me is. As long as I can keep my mobility and things like that I'll be quite happy. (aged 61, M, grade 3 oligodendroglioma, 12 years since diagnosis)
	Appreciating life more	10	35.7	**Pa17:** Your appreciation suddenly becomes, you know… you stop taking things for granted. You don't waste time as you can probably tell, I don't. And I put live again. Don't waste time. (aged 51, F, grade 3 oligodendroglioma, 8 years since diagnosis)
	Appreciating support	15	53.6	**Pa9:** I don't know what I'd do if it weren't for my mum. She always rings up the hospital, and I probably wouldn't even of had the operation. (aged 22, M, grade 2 astrocytoma, 1 year since diagnosis) **Pa15:** I'm lucky to have such supportive family and friends, and such a brilliant medical team looking after me. I'm really lucky. (aged 55, M, grade 2 astrocytoma, 7 years since diagnosis)
	Appreciating the importance of family	5	17.9	**Pa33:** My kids, they are my prime… any time I have when I'm feeling good, I want to spend it with my kids. (aged 45, M, grade 2 oligodendroglioma, 9 years since diagnosis)
	Appreciating the severity of one's illness history	7	25	**Pa13:** You know, it's thirteen years, and the amount of treatments… all the chemo, all the radiation… and, you know, having my brain chopped open three times… Yeah, I'm still quite impressed with my physical robustness. (aged 52, M, grade 3 oligodendroglioma, 13 years since diagnosis)
	Becoming more altruistic§	0	0	
	Changing one's image	1	3.6	**Pa34:** I was more empathetic with patients who had other conditions as well as kidney stones because it made me think, "Well if I had this and kidney stones which would be the more dominant thing to think about?"... I think I was probably a better nurse because I'd had this experience myself. (aged 66, F, grade 2 oligodendroglioma, 11 years since diagnosis)
	Finding meaning in work	4	14.3	**Pa15:** I missed work when I was off. They're long, lonely days especially when the weather's crap and you can't do much. So, getting back to work with colleagues that I value and trust and enjoy working with, was a real kind of boost for me. (aged 55, M, grade 2 astrocytoma, 7 years since diagnosis)
	Giving back	10	35.7	**Pa11:** I set up, with the help of a few friends, we did a couple of running events, and we raised about £25,000 for charity. (aged 57, M, grade 2 oligodendroglioma, 14 years since diagnosis) **Pa16:** 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. (aged 69, M, grade 3 oligodendroglioma, 2 years since diagnosis)

Strategy types	Specific strategies	N	%	Illustrative quotes
	Taking every day as it comes	12	42.9	**Pa29:** I think we're quite practical and so things like that, we deal with it as and when it comes. (aged 51, F, grade 3 oligodendroglioma, 9 years since diagnosis) **Pa37:** I just try to take each day as it comes and that's the way I cope with it. (aged 54, M, grade 2 astrocytoma, 3 years since diagnosis)
	Wanting to give something back	12	42.9	**Pa18:** I said, "When I come back, I'd really like to talk to people in the company who are either supporting, caring for somebody who's unwell or somebody who is going through a really crappy time through either health or whatever." (aged 55, F, grade 3 oligodendroglioma, 1 year since diagnosis) **Pa26:** I'd love to sit and help someone or just listen to their problems rather than it being mine. (aged 37, F, grade 2 oligodendroglioma, 15 years since diagnosis)
12. Positive appraisal		**26**	**92.9**	
Focusing on positive aspects of one's immediate situation.	*Benefit finding*	13	46.4	**Pa5:** In some ways the tumour's been a good thing. It's given me an excuse to rest. Before I probably would have got a bit het up and frustrated I wasn't doing all the stuff on this list. (aged 56, M, grade 2 oligodendroglioma, 2 years since diagnosis) **Pa17:** None of my good friends abandoned me. And I've actually gained a lot more friendships since, you know. (aged 51, F, grade 3 oligodendroglioma, 8 years since diagnosis)
	Downward comparison	18	64.3	**Pa10:** Some patients have horrible side effects from their surgery or from their chemo or whatever whereas I've never had that, luckily. (aged 37, F, grade 2 oligodendroglioma, 14 years since diagnosis) **Pa19:** I've got to make decisions and I imagine because most people are dead within ten years with what I've got, 80% of people are dead within ten years. I'm now coming to my eleventh year. (aged 55, M, grade 3 oligodendroglioma, 5 years since diagnosis)
	Reinterpreting negative consequences	24	85.7	**Pa13:** When I came out, I thought, "You know, a wheelchair is not too bad. Wheelchair guys are pretty buff. And wheelchair rugby looks like a good sport." So I had these visions of becoming a Paralympian. (aged 52, M, grade 3 oligodendroglioma, 13 years since diagnosis) **Pa33:** I retired medically, got all the stuff done with occ health and all the rest of it. It's the best thing I've ever done, retiring. It's the best thing I've ever done because at least now I can have some life with my kids and my wife. (aged 45, M, grade 2 oligodendroglioma, 9 years since diagnosis)
13. Proactive problem solving		**18**	**64.3**	
Active attempts to solve problems in-the-moment arising from the consequences of the tumour and its treatment.	*Acting to prevent further complications*	7	25	**Pa14:** I was prompt to complete the six-page form to reapply for the reinstatement of my licence and I submitted that in good time along with supporting documentation. (aged 66, M, grade 2 oligodendroglioma, 4 years since diagnosis)
	Adaptive approaches to ongoing physical consequences of the tumour and its treatment	17	60.7	**Pa29:** I can walk to the supermarket at the end of our street. I could live without driving the car. (aged 51, F, grade 3 oligodendroglioma, 9 years since diagnosis) **Pa33:** Even just coming up and down the stairs, I try and bring everything down that I need for the day so I don't have to go back up and down the stairs. (aged 45, M, grade 2 oligodendroglioma, 9 years since diagnosis)
14. Reasoned decision-making		**23**	**82.1**	
Objective decision-making strategies relating to survivor self-management.	*Considering benefits of positive health behaviours*	9	32.1	**Pa22:** I was going to the exercise class at the leisure centre. That was just once a week. I did feel that did me good just to get out the house. (aged 43, F, grade 2 astrocytoma, 16 years since diagnosis)
	Considering pros and cons of self-management	9	32.1	**Pa19:** I'm writing and I 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. (aged 55, M, grade 3 oligodendroglioma, 5 years since diagnosis)

Strategy types	Specific strategies	N	%	Illustrative quotes
	Evaluating effectiveness of self-management	10	35.7	**Pa11:** I think maybe that's the whole process of basically speaking through things over the years. And now, I just feel completely comfortable with the whole situation. So, no, it's good. (aged 57, M, grade 2 oligodendroglioma, 14 years since diagnosis) **Pa30:** I've been doing things on my own, word searches, brain tests…sometimes helps. (aged 61, M, grade 3 oligodendroglioma, 12 years since diagnosis)
	Thinking objectively about negative health behaviours	1	3.6	**Pa35:** I definitely work too hard and I've got to try and reduce that by my partner's right. (aged 49, M, grade 2 astrocytoma, 18 years since diagnosis)
	Thinking objectively about negative thoughts and emotions	9	32.1	**Pa26:** If I get too upset and I over think things and I get too down that can then trigger my seizures and then that means I lose my license. (aged 37, F, grade 2 oligodendroglioma, 15 years since diagnosis)
15. Seeking normality		**23**	**82.1**	
Active attempts to return to normal living following treatment.	*Balancing life with health needs§*	0	0	
	Carrying out tasks to the best of one's ability	5	17.9	**Pa19:** I try to do as much as I can, but I have to be realistic about my energy, having so much energy. (aged 55, M, grade 3 oligodendroglioma, 5 years since diagnosis)
	Choosing when and to whom to disclose illness history	2	7.1	**Pa28:** I think the best friends don't really ask for much about what's going on. I think they don't really say, oh, how's your tumour today and I think probably our best friends have never really asked about it which I think that's quite a good thing. (aged 66, M, grade 2 astrocytoma, 7 years since diagnosis)
	Focusing on doing normal activities	8	28.6	**Pa18:** I'll cook dinner because I choose to. I'll make sure the washing has been done. (aged 55, F, grade 3 oligodendroglioma, 1 year since diagnosis)
	Focusing on getting back to work	13	46.4	**Pa11:** I'm one of these stubborn people that, the one constant, because I worked since I was 17 and the one constant is work for me. So, I basically got back to work as quickly as I could. (aged 57, M, grade 2 oligodendroglioma, 14 years since diagnosis) **Pa32:** I wanted to be at work because I wanted my life to be normal. I needed that normality to get through stuff as well. (aged 46, F, grade 3 oligodendroglioma, 14 years since diagnosis)
	Gaining independence	4	14.3	**Pa34:** I think I'm fiercely independent, more independent now because of the diagnosis. I like to be able to do things myself. (aged 66, F, grade 2 oligodendroglioma, 11 years since diagnosis)
	Maintaining independence	3	10.7	**Pa29:** I'm still competent enough that I can read the website and the letters that they sent me and understand what I need to do. (aged 51, F, grade 3 oligodendroglioma, 9 years since diagnosis)
	Regaining strength	6	21.4	**Pa15:** I've also continued my physiotherapy for the best part of a year, for the remainder of 2014, which effectively got my fitness back and my strength back. (aged 55, M, grade 2 astrocytoma, 7 years since diagnosis)
	Returning to normal	10	35.7	**Pa3:** Before you know it, you're sitting in front of the TV and watching box sets again, like you always were. (aged 45, M, grade 2 oligodendroglioma, 18 years since diagnosis) **Pa18:** I don't think you need to change everything. It's about keeping a sense of normality, yes, mum's got this but listen, hey, see, I'm doing really well. (aged 55, F, grade 3 oligodendroglioma, 1 year since diagnosis)
	Testing oneself	1	3.6	**Pa26:** The lady who was doing the physio, she left and it wasn't really continued at the hospital or it was a hospital fairly near, so I started making my own with a ball, walking little bits and seeing if I can get up the stairs. (aged 37, F, grade 2 oligodendroglioma, 15 years since diagnosis)
	Trying to fit in§	0	0	
16. Self-monitoring		**27**	**96.4**	

Strategy types	Specific strategies	N	%	Illustrative quotes
Active self-monitoring of one's health, wellbeing and ongoing care.	*Knowing your body*	7	25	**Pa19:** I'm in charge of my own body. I'm not going to ignore what you say but I know my body. I know my body. (aged 55, M, grade 3 oligodendroglioma, 5 years since diagnosis)
	Monitoring emotions	23	82.1	**Pa18:** I think it's about managing your emotions, being able to talk myself down if I'm panicking. (aged 55, F, grade 3 oligodendroglioma, 1 year since diagnosis) **Pa35:** I suppose there's a small amount of anxiety but it's definitely manageable. It's not something I'm going to lose sleep about. (aged 49, M, grade 2 astrocytoma, 18 years since diagnosis)
	Monitoring for symptoms of the tumour and late-effects	15	53.6	**Pa5:** The brain flooding thing, if we have a lot of people over as I said earlier or if I was in an open plan office that was really problematic. I really felt myself just going downhill quite quickly and feeling like I couldn't speak properly. (aged 56, M, grade 2 oligodendroglioma, 2 years since diagnosis) **Pa14:** The other day I was sat just quietly reading something and I was aware that [pause] I was having tinnitus and I thought: "Oh dear, I hope this isn't something sinister coming back." (aged 66, M, grade 2 oligodendroglioma, 4 years since diagnosis)
	Monitoring general health	4	14.3	**Pa36:** So I think when you have a tumour, you're always like, "Is this a bit sore today? Am I not quite right or a little bit tired?" (aged 42, F, grade 2 astrocytoma, 8 years since diagnosis)
	Monitoring health behaviours	1	3.6	**Pa17:** I need something creative, I need something for exercise, I need somethings for my mind, you know, you need to think of everything and make sure you've got things in all your boxes. (aged 51, F, grade 3 oligodendroglioma, 8 years since diagnosis)
	Monitoring relationship with health professionals	1	3.6	**Pa28:** If I had a closer relationship… yes, that's the right word, closer links with the GP surgery I'd probably feel a bit better, but I can't say there's any specific reason why I would need that. (aged 66, M, grade 2 astrocytoma, 7 years since diagnosis)
	Recognising one's own limits	21	75	**Pa13:** I wouldn't get on a bike, you know. My balance isn't… you know, there are certain things that would be dumb. (aged 52, M, grade 3 oligodendroglioma, 13 years since diagnosis) **Pa16:** I wouldn't take on anything I wouldn't… I couldn't manage, if there was an opportunity, I would investigate what was involved and see whether I felt I could do it well enough. (aged 69, M, grade 3 oligodendroglioma, 2 years since diagnosis)
17. Self-motivating		**25**	**89.3**	
Strategies which help to motivate oneself to effectively self-manage.	*Being healthy for sake of one's family*	2	7.1	**Pa15:** So, my biggest challenge is to make sure that I keep giving her support and try to look after myself so I don't put her in a position whereby she's got to pick up the pieces again. (aged 55, M, grade 2 astrocytoma, 7 years since diagnosis)
	Challenging yourself	2	7.1	**Pa11:** I set myself my own personal challenge which was doing one 10k a week for a year. And that doesn't sound like a lot, because I used to run 10ks every day. And I thought that will be easy. But I didn't take into account that I started it when I was just starting my chemotherapy. So, it was hard. (aged 57, M, grade 2 oligodendroglioma, 14 years since diagnosis)
	Developing confidence and self-efficacy	1	3.6	**Pa31:** I was quite shy and quite introverted at the time, before, but now it kind of gave me a bit more confidence. (aged 53, M, grade 2 oligodendroglioma, 14 years since diagnosis)
	Drawing on spiritual resources	1	3.6	**Pa14:** There have been some kind of spiritual and interpersonal aspects to the experience that have been an important boost and support to me. (aged 66, M, grade 2 oligodendroglioma, 4 years since diagnosis)
	Drawing strength from past experiences	2	7.1	**Pa34:** I'm more in control now than I think I was earlier and it's because of my experience of the tumour I think. (aged 66, F, grade 27 oligodendroglioma, 11 years since diagnosis)

Strategy types	Specific strategies	N	%	Illustrative quotes
	Employing a determined attitude	14	50	**Pa13:** I managed to get myself to bed every time without using the stair-lift. It was a personal sense of achievement…I'm a stubborn bugger. (aged 52, M, grade 3 oligodendroglioma, 13 years since diagnosis) **Pa32:** You just have to think, "No, I'm not going to die. I'm going to get through this. It's not easy but at the same time I'm not going to let it beat me." (aged 46, F, grade 3 oligodendroglioma, 14 years since diagnosis)
	Encouraging oneself	6	21.4	**Pa17:** You know, you really find your zest for life. As long as you don't let it beat you. I know some people sink into depression and they just can't rise above that. And I'm just glad I'm not in that position. (aged 51, F, grade 3 oligodendroglioma, 8 years since diagnosis)
	Focusing on milestones of survivorship	3	10.7	**Pa14:** I feel very satisfied with it. I'm waiting to hear further… I think I would be due for a scan, they were scanning me…every four months and now I think since then I've had nearly a year of being clear since surgery. (aged 66, M, grade 2 oligodendroglioma, 4 years since diagnosis)
	Interacting with others	1	3.6	**Pa19:** It was quiet. I thought well let's kick off with starting something about how it started. I spoke for about 30 seconds or something. Then these two other people said that they'd got it. I thought brilliant that's three of us, but some people didn't speak at all. (aged 55, M, grade 3 oligodendroglioma, 5 years since diagnosis)
	Maintaining a positive outlook	20	71.4	**Pa18:** If I have a good night and the power of positive thinking and a general air of positivity and hopefulness, I'll start the next day. (aged 55, F, grade 3 oligodendroglioma, 1 year since diagnosis) **Pa33:** Emotionally, I try and look at things just as positively as I can. I have two small kids. I've got my wife. I can't just go on moping about stuff so I just try and stay positive emotionally. I just try and stay positive. (aged 45, M, grade 2 oligodendroglioma, 9 years since diagnosis)
	Not dwelling on the past	2	7.1	**Pa26:** I don't really want to look back and see how tough it's been. I like to look forward. (aged 37, F, grade 2 oligodendroglioma, 15 years since diagnosis)
	Persevering with healthy behaviours	3	10.7	**Pa30:** At the moment I don't know whether it's my walking that's got worse or my energy level, I don't know. I'm just not getting there at the moment but I keep trying. (aged 61, M, grade 3 oligodendroglioma, 12 years since diagnosis)
	Recognising the need for motivation and discipline	1	3.6	**Pa31:** I should really get on the bike but it's finding the time and the inclination to do that. (aged 53, M, grade 2 oligodendroglioma, 14 years since diagnosis)
	Rewarding oneself§	0	0	
	Taking responsibility for own health	11	39.3	**Pa9:** In the end, only you can make the end decision. And that's a responsibility that I'm going to have to bear. (aged 22, M, grade 2 astrocytoma, 1 year since diagnosis) **Pa17:** Because of my previous job as a social worker, I was quite proactive in my own, you know, finding answers and not accepting, you know, nothing. (aged 51, F, grade 3 oligodendroglioma, 8 years since diagnosis)
	Treating illness as a project§	0	0	
	Wanting to look good§	0	0	
	Wanting to stay in good health	1	3.6	**Pa14:** Given the age at which I am, it's made me be more reflective, shall we say, or contemplating what I need to care for myself, to keep optimum health and activity. (aged 66, M, grade 2 oligodendroglioma, 4 years since diagnosis)
18. Self-sustaining		**12**	**42.9**	
Strategies which enable one to consistently implement self-	*Customizing dietary practices*	2	7.1	**Pa30:** I only spoke to a dietician about foods to eat for fatigue. My go to food was, to try and keep my energy levels up was peanut butter when I couldn't eat anything else. (aged 61, M, grade 3 oligodendroglioma, 12 years since diagnosis)

Strategy types	Specific strategies	N	%	Illustrative quotes
management strategies in one's daily life.	*Following health practitioner's advice*	4	14.3	**Pa30:** I couldn't steady my hip so she gave me some exercises to do which I carried on doing. (aged 61, M, grade 3 oligodendroglioma, 12 years since diagnosis)
	Incorporating self-management behaviours into daily routine	8	28.6	**Pa33:** I just make sure I put anything important in my phone calendar and every morning I look at my calendar in my phone. That is a habit now. (aged 45, M, grade 2 oligodendroglioma, 9 years since diagnosis)
	Keeping busy to avoid negative behaviours	2	7.1	**Pa11:** I suppose work as well, it's kept me going as well. Because you're not sort of dwelling on things if you're keeping yourself busy. And that's one of the things I've tried not to do. (aged 57, M, grade 2 oligodendroglioma, 14 years since diagnosis)
	Maintaining medical equipment	1	3.6	**Pa13:** I had a port fitted for the chemotherapy. So I have to manage to… you have to get that flushed every month. (aged 52, M, grade 3 oligodendroglioma, 13 years since diagnosis)
19. Using sense of humour		**6**	**21.4**	
Use of humour to manage emotions associated with the negative consequences of the tumour and its treatment.	*Finding humour in others' reactions*	1	3.6	**Pa15:** I've said a number of times that if I had a pound for everybody who says, "Oh, you have got a brain then?" I say, "Yes, I have. I've seen it, I've seen scans, I have got a brain. I might have a bit of a hole in it [laughs]. A bit might be missing but I have got a brain." It's a joke and that's how we deal with it. (aged 55, M, grade 2 astrocytoma, 7 years since diagnosis)
	Laughing about the tumour and its consequences	5	17.9	**Pa29:** I keep saying to him, "I don't want you wiping my bum. Get me on a plane to Dignitas as soon as possible once I realise I'm past it." I joke about that kind of thing. (aged 51, F, grade 3 oligodendroglioma, 9 years since diagnosis)
	Using humour to hide insecurities	1	3.6	**Pa20:** I've said that about the personality changes. I said, "If I ever get really bad, just stick me in a home, walk away and forget about me." And he said, "Well, that was the plan anyway, but alright." (aged 47, F, grade 3 oligodendroglioma, 6 years since diagnosis)
20. Using support		**28**	**100**	
Use of appropriate supports to assist in one's recovery and recuperation following treatment.	*Companionship from pet*	2	7.1	**Pa26:** In the field he was a spaniel, but he came with me when I was working. I worked for four children under the age of 10 and he would come with me everywhere. When I had my seizures he would be with me. At my mum and dad's he would be next to me. (aged 37, F, grade 2 oligodendroglioma, 15 years since diagnosis)
	Drawing support from similar other	15	53.6	**Pa13:** That's why Maggie's is so good. You are dealing with people that, you know… everyone is in the same boat. So, you know, we're all dealing with it the best we can, so everyone trades tips. (aged 52, M, grade 3 oligodendroglioma, 13 years since diagnosis) **Pa40:** I find it most useful in terms of gleaning information that might be helpful or prior to my surgery for instance, hearing people say, "Yes, I've had a craniotomy and it was fine". (aged 31, F, grade 2 astrocytoma, 1 year since diagnosis)
	*Giving advice to similar others**	7	25	**Pa22:** Somebody was saying they'd had to surrender their driving licence. I think I suggested, "Well you can get a free bus pass," and things like that. (aged 43, F, grade 2 astrocytoma, 16 years since diagnosis)
	Having family and friends to talk to† (split from having someone to talk to)	7	25	**Pa31:** Her parents are still alive. My mother's still alive. I've got brothers, her sister-in-law who lives up in the Borders, then there's my wife's sister lives in Australia. The people on this side of the world, they're always available to talk to if you want them. (aged 53, M, grade 2 oligodendroglioma, 14 years since diagnosis)
	Having health professionals to talk to† (split from having someone to talk to)	16	57.1	**Pa5:** Obviously there is care going on and they're there if I need them. The clinical nurse specialists are there and I've got a number I can call if there's any problems. (aged 56, M, grade 2 oligodendroglioma, 2 years since diagnosis) **Pa36:** They're the neuro nurses for the whole department. There are two or three of them and they are brilliant. I email them a lot and they always get

Strategy types	Specific strategies	N	%	Illustrative quotes
				back to me or phone me or email me. (aged 42, F, grade 2 astrocytoma, 8 years since diagnosis)
	Receiving formal support	20	71.4	**Pa14:** The neuro-physiotherapist sent me some exercises to be getting on with. I related to her, so my postural and mobility issues that are limited by symptoms. She sent me a programme. (aged 66, M, grade 2 oligodendroglioma, 4 years since diagnosis) **Pa25:** I see a psychiatrist…in the cancer centre. And he's absolutely fantastic. And he's always really, really good at being able to give me advice about what I can do if I've got a problem. (aged 45, M, grade 2 oligodendroglioma, 11 years since diagnosis)
	Receiving support from care team	19	67.9	**Pa10:** I could speak to the neuro-oncology nurses and say, "Look, this is what's happening, what do you think?" And they were like, "Well, we think it's probably okay. We doubt it's anything to do with your brain tumour." So that was reassuring really because nobody else knew what was going on. (aged 37, F, grade 2 oligodendroglioma, 14 years since diagnosis) **Pa18:** I think definitely my brain care nurse has been amazing but having one person that can say, "Oh yes, you need to go here," that's great. (aged 55, F, grade 3 oligodendroglioma, 1 year since diagnosis)
	Receiving support from charities and organisations	17	60.7	**Pa9:** I did, like, this webinar, actually, last week and it was about fatigue. So, that was, like, a helpful thing. It was through The Brain Tumour People, I think it's called. Well, Brain Cancer People. (aged 22, M, grade 2 astrocytoma, 1 year since diagnosis) **Pa26:** Macmillan nurses are gold dust. Without them, they gave me a grant when I first had my brain surgery. It wasn't masses but it was something. (aged 37, F, grade 2 oligodendroglioma, 15 year since diagnosis)
	Receiving support from educational provider§	0	0	
	Receiving support from family	24	85.7	**Pa16:** If I'm running out of energy, strength then I can call upon brothers-in-law to come and give me a lift. My two sisters-in-law have been really supportive of my wife, that's been rather lovely, yeah, been very lovely, yes. (aged 69, M, grade 3 oligodendroglioma, 2 years since diagnosis) **Pa17:** When I was poorlier, people cooked for me, they took me out, they drove me. You know, I couldn't drive, they took me shopping. (aged 51, F, grade 3 oligodendroglioma, 8 years since diagnosis)
	Receiving support from friends	24	85.7	**Pa32:** I used to go to work in the morning. My friends were just incredible. They set up a little rota to take me there and then I'd do it like that. (aged 46, F, grade 3 oligodendroglioma, 14 years since diagnosis) **Pa37:** We have a close relationship with a couple of families if you like or certainly they're friends of ours shall we say. They're very, very supportive. Very, very supportive. (aged 54, M, grade 2 astrocytoma, 3 years since diagnosis)
	Receiving support from partner	20	71.4	**Pa3:** It was kind of fortunate, because my dad and my partner could, kind of, work as, sort of, like, a caring team together, if you like, to sort through it. (aged 45, M, grade 2 oligodendroglioma, 18 years since diagnosis) **Pa33:** My wife is brilliant. She supports me fantastically well…I don't know where I'd be without my wife. (aged 45, M, grade 2 oligodendroglioma, 9 years since diagnosis)
	Receiving support from the workplace	21	75	**Pa10:** They kept a TA, a teaching assistant in the room with me for the first few days just in case I was unwell or anything like that. (aged 37, F, grade 2 oligodendroglioma, 14 years since diagnosis) **Pa14:** Well, I didn't suffer any penalty financially, my employer continued to pay me my monthly salary as normal. (aged 66, M, grade 2 oligodendroglioma, 4 years since diagnosis)
	Seeking formal help	17	60.7	**Pa18:** I found out about the EESA because I had a query about child benefit. I thought, "Oh okay," so it just led me on to seeing if there was anything I

Strategy types	Specific strategies	N	%	Illustrative quotes
				was entitled to as somebody with a longstanding illness and that was it. (aged 55, F, grade 3 oligodendroglioma, 1 year since diagnosis) **Pa31:** I went in because obviously it was brand new. I didn't know where I stood financially and all the rest of it. I went in to get some information from there at… the [hospital]. (aged 53, M, grade 2 oligodendroglioma, 14 years since diagnosis)
	Seeking support from care team	13	46.4	**Pa14:** I rang the clinical nurse specialist to tell them about it. They said thank you for letting us know and we'll speak with our colleagues, and they came back to me and said: "We would like you to come in," and I went into clinic and saw them. (aged 66, M, grade 2 oligodendroglioma, 4 years since diagnosis) **Pa20:** We've also got a hospice in town, and it's actually not far from here. I've been before for acupuncture, and they said that they do counselling and stuff, so I might have to go to them. (aged 47, F, grade 3 oligodendroglioma, 6 years since diagnosis)
	*Seeking support from charities and organisations**	14	50	**Pa17:** Brain Trust, if you contact them, they will send you a brain box, which is a shoebox full of useful books, leaflets, contact numbers, stress balls, tea bags. You know, they're all sponsored by, you know, people donating. (aged 51, F, grade 3 oligodendroglioma, 8 years since diagnosis) **Pa29:** I knew there was a Maggie's Centre there and I think I'd just gone across after one of my scans probably to have a look and had a wander round. (aged 51, F, grade 3 oligodendroglioma, 9 years since diagnosis)
	Seeking support from family	1	3.6	**Pa22:** I had to ask friends or family and it was that reliance on other people. (aged 43, F, grade 2 astrocytoma, 16 years since diagnosis)
	Seeking support from friends	2	7.1	**Pa32:** That first night I found out, I did think, "Oh my God. Am I going to die?" It says it all, I probably didn't like to call mum but I called my friend [name] really early because she gets into work stupid early. I was in tears with her. (aged 46, F, grade 3 oligodendroglioma, 14 years since diagnosis)
	Seeking support from partner§	0	0	
	*Seeking support from the workplace**	1	3.6	**Pa29:** "Get back in touch with [employer]…and see if there's any way they can retire you on ill health grounds." So I got in touch with them. (aged 51, F, grade 3 oligodendroglioma, 9 years since diagnosis)

M = Male; F = Female

* New strategy identified in the LGG data

† Original strategy has been sub-divided into new categories

§ Original strategy not identified in the LGG data

4.2.1 PP3 commentary

The findings presented here show support for the use of 123 different self-management strategies, categorised within 20 self-management strategy types among people with LGG. This qualitative study, therefore, represents the most comprehensive understanding of how people with LGG engage in the self-management of their condition in the literature. A directed content analysis[92] was considered appropriate here to examine the extent to which people with LGG engage in self-management across an extensive taxonomy of self-management strategies that has been iteratively developed across different cancers[83–85]. This helped to identify and compare how approaches to self-management differ across people with LGG and other cancer populations. It also provided some insight into *how* people engage with the most used strategies.

The diverse range of self-management strategies used corroborates the wide-ranging impact of life with a LGG, outlined in chapter 3, from acceptance of their incurable condition, to using external aids to overcome cognitive difficulties. This presents possible target areas for a self-management intervention, which could look to facilitate the use of commonly used self-management strategies (e.g. increasing awareness of appropriate external aids); this future research implication is discussed further in chapter 7.3.1. Still, the number of self-management strategies reported by each participant ranged from 19 to 54, indicating substantial variation in the level of engagement in self-management. This identified a need to understand whether people with LGG face any challenges that present a barrier to engagement in self-management, inspiring the qualitative analysis presented below in PP4[50].

4.3 PP4: Barriers and facilitators to self-management in people living with a lower-grade glioma.

Rimmer, B., Balla, M., Dutton, L., Williams, S., Araújo-Soares, V., Gallagher, P., Finch, T., Lewis, J., Burns, R., Menger, F., & Sharp, L. (2024). Journal of Cancer Survivorship.

Journal of Cancer Survivorship
https://doi.org/10.1007/s11764-024-01572-9

Barriers and facilitators to self-management in people living with a lower-grade glioma

Ben Rimmer[1] · Michelle Balla[2] · Lizzie Dutton[1] · Sophie Williams[3] · Vera Araújo-Soares[1,4] · Pamela Gallagher[5] · Tracy Finch[6] · Joanne Lewis[3] · Richéal Burns[7,8] · Fiona Menger[9] · Linda Sharp[1] on behalf of the Ways Ahead study team

Received: 21 February 2024 / Accepted: 16 March 2024

Abstract

Purpose Self-management can have clinical and quality-of-life benefits. However, people with lower-grade gliomas (LGG) may face chronic tumour- and/or treatment-related symptoms and impairments (e.g. cognitive deficits, seizures), which could influence their ability to self-manage. Our study aimed to identify and understand the barriers and facilitators to self-management in people with LGG.

Methods We conducted semi-structured interviews with 28 people with LGG across the United Kingdom, who had completed primary treatment. Sixteen participants were male, mean age was 50.4 years, and mean time since diagnosis was 8.7 years. Interviews were audio-recorded and transcribed. Following inductive open coding, we deductively mapped codes to Schulman-Green et al.'s framework of factors influencing self-management, developed in chronic illness.

Results Data suggested extensive support for all five framework categories ('Personal/lifestyle characteristics', 'Health status', 'Resources', 'Environmental characteristics', 'Healthcare system'), encompassing all 18 factors influencing self-management. How people with LGG experience many of these factors appears somewhat distinct from other cancers; participants described multiple, often co-occurring, challenges, primarily with knowledge and acceptance of their incurable condition, the impact of seizures and cognitive deficits, transport difficulties, and access to (in)formal support. Several factors were on a continuum, for example, sufficient knowledge was a facilitator, whereas lack thereof, was a barrier to self-management.

Conclusions People with LGG described distinctive experiences with wide-ranging factors influencing their ability to self-manage.

Implications for cancer survivors These findings will improve awareness of the potential challenges faced by people with LGG around self-management and inform development of self-management interventions for this population.

Keywords Barriers · Facilitators · Self-management · Lower-grade glioma

---

+The Ways Ahead study team comprises, in addition to the named authors, Sara Erridge, Pauline Sturdy, and Catherine McBain.

✉ Ben Rimmer
ben.rimmer@newcastle.ac.uk

[1] Population Health Sciences Institute, Newcastle University, Newcastle University Centre for Cancer, Ridley Building 1, Newcastle Upon Tyne NE1 7RU, England

[2] Faculty of Medical Sciences, Newcastle University, Newcastle Upon Tyne, England

[3] Newcastle Upon Tyne Hospitals NHS Foundation Trust, Newcastle Upon Tyne, England

[4] Centre for Preventive Medicine and Digital Health, Department for Prevention, Medical Faculty Mannheim, Heidelberg University, Heidelberg, Germany

[5] School of Psychology, Dublin City University, Dublin, Ireland

[6] Department of Nursing, Midwifery and Health, Northumbria University, Newcastle Upon Tyne, England

[7] Faculty of Science, Atlantic Technological University, Sligo, Ireland

[8] Health and Biomedical Strategic Research Centre, Atlantic Technological University, Sligo, Ireland

[9] School of Education, Communication and Language Sciences, Newcastle University, Newcastle Upon Tyne, England

Introduction

In living with and beyond a cancer diagnosis, many people can face challenges with healthcare interactions, managing emotional distress, adjusting to a new normal, and re-establishing routine and social roles; engagement in self-management may help people meet and overcome these challenges [1]. Self-management in cancer is defined as "*awareness and active participation by the person in their recovery, recuperation, and rehabilitation to minimise the consequences of treatment, promote survival, health and well-being*" [2]. A growing evidence-base in people living with and beyond cancer suggests that quality-of-life, clinical (e.g. physical fitness), and health economic (e.g. reduction in healthcare utilisation) outcomes may be improved through self-management [3, 4]. It is, therefore, important to understand what factors influence whether someone can or does engage in self-management.

In people living with a chronic (non-cancer) illness, Schulman-Green et al. [5] identified five categories of wide-ranging factors that may present a barrier or facilitator to effective engagement in self-management, namely: 'Personal/lifestyle characteristics' (e.g. '*Motivation*'), 'Health status' (e.g. '*Symptoms/side-effects*'), 'Resources' (e.g. '*Financial*'), 'Environmental characteristics' (e.g. '*Community*'), and 'Healthcare system' (e.g. '*Relationship with providers*'). These factors are extensively supported by literature across chronic illnesses [6–10], neurological populations (e.g. multiple sclerosis (MS)) [11, 12], and some forms of cancer (e.g. breast, head and neck) [13–17].

Lower-grade gliomas (LGG) (e.g. grade 2 astrocytoma and oligodendroglioma) account for approximately 15% of gliomas, one of the most common types of brain tumour [18]. Unlike most common cancers (which tend to affect older adults), these tumours are typically diagnosed in adults in their 30 s and 40 s [19], are largely incurable, and often progress to a high-grade glioma [20], with a limited life expectancy of 5–15 years, depending on the subtype [19, 21]. People with LGG can experience substantial impacts on their daily lives (e.g. work, relationships, transport) [22], as a consequence of diverse, often co-occurring, symptoms and impairments. These can be both general cancer-related (e.g. fatigue, pain) and more tumour- and/or treatment-related (e.g. cognitive deficits, seizures) and can persist long-term [23].

The specific challenges faced by people with LGG may nuance the factors evidenced to influence self-management. For example, the psychological burden of living with an incurable condition [24] may influence one's motivation to self-manage. Only one study appears to have explored barriers to self-management in people with brain tumours, finding that knowledge of their condition and available support were barriers to support service utilisation [25]. However, this study included all types of primary brain tumours with varying prognoses and focused specifically on access to support services. We have previously reported that people with LGG engage with a wide range of self-management strategies, such as self-monitoring and acquiring information [26]. To understand how best to encourage and support people with LGG to self-manage, it is important to have a comprehensive understanding of the factors that influence their engagement with self-management across a range of contexts in day-to-day life [27].

This analysis, therefore, aimed to identify and understand the barriers and facilitators to self-management in people with LGG, with the intention of helping to inform the development of self-management interventions for this population.

Method

Design

This qualitative study, part of the multi-method Ways Ahead project [28], used semi-structured interviews to generate data on experiences of self-management in people with LGG across a range of contexts in day-to-day life. The analysis reported here highlights the factors that may influence the self-management strategies used by people with LGG that we have reported elsewhere from this dataset [26]; the two papers are thus complementary. Ways Ahead was reviewed and approved by the Wales Research Ethics Committee (REC ref: 20/WA/0118).

Participants and recruitment

Potentially eligible people with LGG were identified through collaborating National Health Service (NHS) sites and the Brain Tumour Charity's networks. Participants were aged ≥ 18 years when diagnosed with a grade 2 astrocytoma or a grade 2 or 3 oligodendroglioma [29]. Individuals resided in the United Kingdom (UK), and were stable under observation, or had completed primary treatment. Non-English speakers or those with severe psychosocial problems – determined by healthcare professionals at collaborating NHS sites – who were at risk of further distress by participating, were excluded. Purposive sampling was used to ensure a range of ages, both sexes, diagnoses, and times since diagnosis.

Healthcare professionals at collaborating NHS sites identified people with LGG from their medical records and provided them with an information sheet by post or during a clinic visit. A researcher (BR) advertised the study on the

Brain Tumour Charity's networks with the information sheet attached. The information sheet included a brief introduction to the researchers conducting the interviews. People with LGG were asked to register their interest by contacting the study team; BR and LD subsequently called to confirm eligibility, afford the opportunity to ask questions, and, if willing, arrange a convenient interview date and time. A follow-up call could be requested if the individual needed more time to process the information. Recruitment was carried out between August 2020 and May 2022.

Data collection

Trained and experienced in qualitative research, BR (male, MSc) and LD (female, PhD) conducted all interviews remotely, using video-conferencing software (e.g. Zoom or Microsoft Teams) or telephone. Cognitive or communication impairments can influence people with LGGs' ability to retain, process, and respond to questions. To support the participation of people who may have had these impairments, we provided a topic overview in advance, and allowed ample time to consider and respond to each question during interviews.

Immediately prior to each interview, audio-recorded consent was acquired. Basic demographics (e.g. sex, age, employment and relationship status) and clinical and tumour-related information (e.g. diagnosis, tumour location, and treatment) were also collected. Participants recruited through the Brain Tumour Charity were asked for their main treating hospital and consultant. The treating hospital of every participant was contacted to confirm clinical and tumour-related information; where confirmation could not be obtained, this information was self-reported.

Interviews were semi-structured following a topic guide (*Online resource 1*), which comprised open questions informed by the literature. Appropriate modifications were made following discussions with a patient and public involvement panel of people affected by brain tumours, and the study team healthcare professionals (JL, SW). Throughout data collection, the topic order varied, influenced by what the participant chose to speak about.

Interviews commenced with a broad reflection on life following the LGG diagnosis. Participants' experiences of how they were impacted by the tumour and its treatment (e.g. cognitive, physical, psychological) and how this affected daily life (e.g. work, relationships, and finances) were then explored. We asked probing questions across each area for what people did to self-manage living with the tumour, and what helped and hindered them to do this. Throughout the interview, participants could raise any additional issues they perceived as important; new issues raised were explored in subsequent interviews. Following each interview, a post-interview sheet detailing available charities and helplines was provided, alongside offer of a £20 voucher to thank them for their time. Interviews were audio-recorded, averaging 102 min in length (range 54 to 167 min).

Data analysis

Each interview was transcribed verbatim and anonymised. We applied the framework method [30] to identify and understand the barriers and facilitators to self-management in people with LGG.

Analysis commenced with inductive open coding in accordance with the initial steps of an inductive thematic analysis [31]. Following independent familiarisation, BR and MB, both trained in qualitative analysis, generated initial codes for a sample of transcripts (n = 6 of 28). BR and MB discussed similarities and resolved differences to refine the coding frame. BR coded the remaining transcripts and discussed codes and uncertainties with MB and LS, as coding progressed. This stage of analysis occurred in parallel with data collection. Recruitment ceased when reasonable data sufficiency was reached; this was determined by the judgement of the research team that sufficient data had been generated to support and understand the barriers and facilitators to self-management in people with LGG [32].

These codes were then deductively mapped to Schulman-Green et al.'s pre-existing framework of 18 factors across five categories influencing self-management [5], namely: 'Personal/lifestyle characteristics' (e.g. '*Motivation*'), 'Health status' (e.g. '*Symptoms/side-effects*'), 'Resources' (e.g. '*Financial*'), 'Environmental characteristics' (e.g. '*Work*'), and 'Healthcare system' (e.g. '*Access*'). This charting was conducted by BR and, to enhance trustworthiness, checked by MB; any disagreements were discussed to reach consensus. During this stage, we remained alert to any new factors influencing engagement with self-management that were not included within the existing framework, though all the data fit, so no new factors were added. Below, we report how our participants' experiences related to Schulman-Green et al.'s framework [5], with illustrative quotes throughout.

Results

Participant characteristics

Thirty-five of 39 people with LGG that registered their interest were eligible; exclusion reasons included: non-completion of primary treatment (n = 2), ineligible diagnosis (n = 1), resided outside the UK (n = 1). We purposively selected 28 people with LGG for interview (recruitment routes: The Brain Tumour Charity, n = 18; NHS sites, n = 10). Sixteen participants were male (Table 1). At interview, mean age

Table 1 Lower-grade glioma participants' characteristics at time of interview

Characteristic	n	Characteristic	Mean (range)
Diagnosis[a]		***Time since diagnosis (years)***[a]	8.7 (1–18)
Grade 2 oligodendroglioma	10	***Time since radiotherapy (years)***[a,c]	6.9 (0.7–17.8)
Grade 3 oligodendroglioma	9	***Time since chemotherapy (years)***[a,c]	3.4 (0.1–13.5)
Grade 2 astrocytoma	9	***Full-time education (years)***	15.8 (11–20)
IDH-mutation status[a]		***Sex***	**n**
Yes	19	Female	12
No	4	Male	16
Unknown	5	***Age***	
1p/19q codeletion status[a,b]		≤ 40	4
Yes	16	41–50	8
No	7	51–60	11
Unknown	5	> 60	5
Treatment[a]		***Dependents***	
Surgery	28	None	18
Radiotherapy	22	One	3
Chemotherapy	17	Two	6
Tumour location[a]		Three	1
Frontal	18	***Employment status***	
Temporal	3	Full-time employee	8
Parietal	3	Part-time employee	4
Overlapping regions	3	Retired	4
Unknown	1	Medically retired	6
Tumour laterality[a]		Unable to work	6
Right hemisphere	13	***Relationship status***	
Left hemisphere	15	Married	21
Dominant hemisphere	13	In a relationship	3
Non-dominant hemisphere	15	Single	2
		Widowed	2

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

[b] All participants with 1p/19q codeletion were people with oligodendroglioma; all participants without 1p/19q codeletion were people with astrocytoma

[c] Time since radiotherapy and chemotherapy was not available for two participants

was 50.4 years (median 52 years, range 22–69 years) and mean time since diagnosis was 8.7 years (range 1–18 years). Diagnoses were: grade 2 astrocytoma (n = 9: IDH1-mutant, yes n = 6, no n = 1, unknown n = 2; 1p/19q codeletion, no n = 7, unknown n = 2), grade 2 oligodendroglioma (n = 10: IDH1-mutant, yes n = 7, no n = 2, unknown n = 1; 1p/19q codeletion, yes n = 9, unknown n = 1), and grade 3 oligodendroglioma (n = 9: IDH1-mutant, yes n = 6, no n = 1, unknown n = 2; 1p/19q codeletion, yes n = 7, unknown n = 2).

Factors influencing self-management

Our data suggested extensive support for all five categories and all 18 factors influencing self-management in Schulman-Green et al.'s framework [5] (Fig. 1); additional supporting quotes can be found in Table 2. Individual factors that were spoken about most extensively across most participants were: '*Symptoms/side-effects*' (within 'Health status'), '*Psychosocial*' (within 'Resources'), '*Community*' (within 'Environmental characteristics'), '*Navigating system/continuity of care*', and '*Relationship with provider*' (both within 'Healthcare system').

Several factors influenced self-management on a continuum; whether a factor was a barrier or facilitator to self-management was determined by where the individual fell on the continuum. For example, sufficient financial resources was a facilitator, whereas a lack thereof, was a barrier to self-management. Within each category, this applied most prominently to the following individual factors: '*Knowledge*' (within 'Personal/lifestyle characteristics'), '*Symptoms/side-effects*' (within 'Health status'), '*Psychosocial*' (within 'Resources'), '*Community*' (within 'Environmental characteristics'), and '*Relationship with provider*' (within 'Healthcare system').

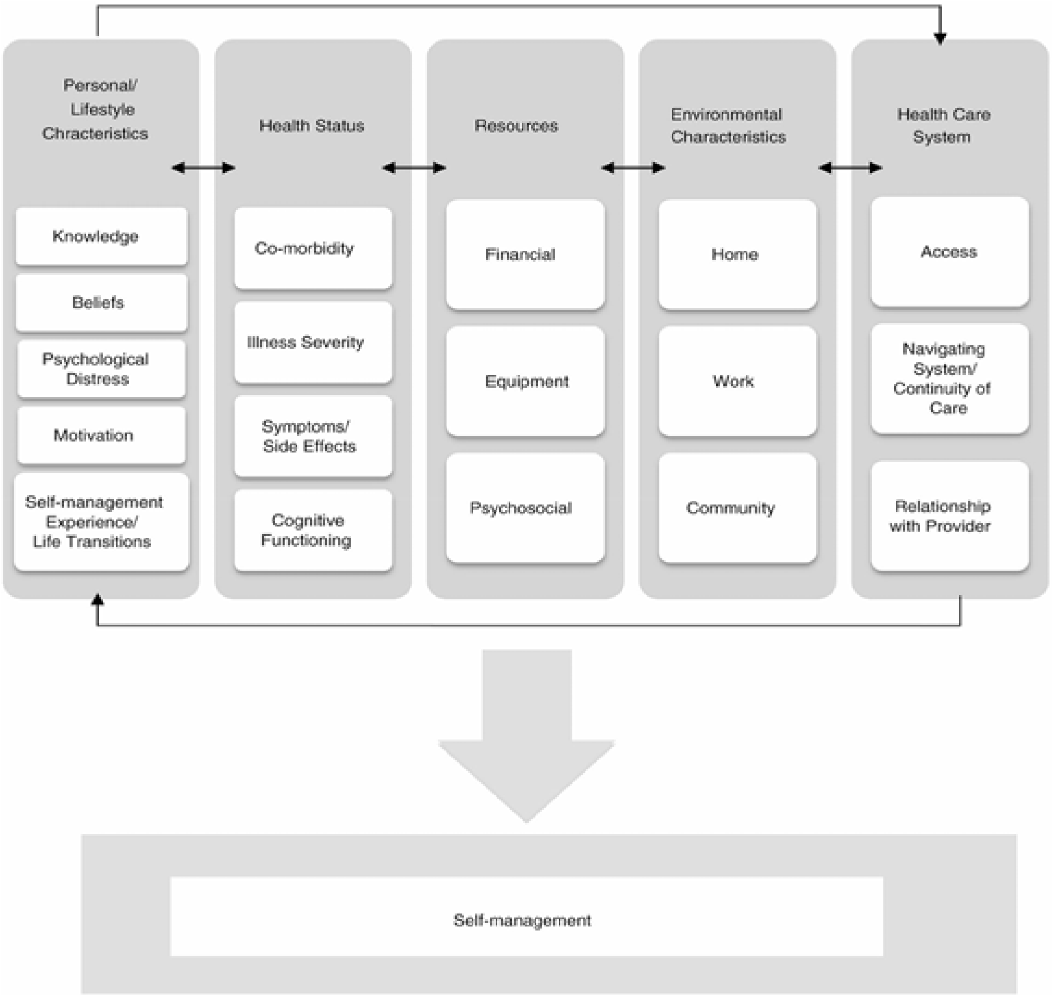


Fig. 1 Factors influencing self-management. "Re-used with permission from the Copyright Clearance Center: Wiley, Journal of Advanced Nursing, [5]. A metasynthesis of factors affecting self-management of chronic illness

Personal/lifestyle characteristics

The five factors that participants spoke about within 'Personal/lifestyle characteristics' were '*Knowledge*', '*Beliefs*', '*Psychological distress*', '*Motivation*', and '*Self-management experience/life transitions*'.

Several participants highlighted the importance of knowledge for understanding how to self-manage their condition. For some, knowledge and awareness of potential treatment pathways provided reassurance that consequences of their condition could be managed. Alternatively, not knowing what symptoms and impairments they might experience meant that some participants either did not seek the necessary information and support or found themselves distressed when a symptom (e.g. seizure) spontaneously occurred.

> "If you don't know what to ask for, you don't know… if you don't know that people can get fatigued, you're not going to ask about fatigue." – Pa33 (aged 41–50, male, grade 2 oligodendroglioma).

Many participants detailed how their beliefs about the extent to which they had accepted their diagnosis influenced their engagement in self-management. Acceptance was hindered by feeling a lack of direction, purpose, or control over one's life, with '*slow progress*' deterring their motivation to engage in self-management.

Most participants recounted the adverse effect of psychological distress on their ability to maintain a positive outlook. Some participants drew from positive aspects of their life (e.g. family) to maintain a positive attitude. However, the incurable nature of the condition, and the possibility of

Table 2 Additional supporting quotes for all categories and factors influencing self-management, with participant ID, age group at interview, sex, and tumour type

Categories and factors	Illustrative quotes
Personal/lifestyle characteristics	
Knowledge	• "It's an oligodendroglioma and that that can potentially be dealt with again, you know, if it got more severe, that there are other treatments that it should respond to. So, yeah. So, I think that is the good thing about having that extra information" – Pa10 (aged < 40, female, grade 2 oligodendroglioma) • "I thought I was having a seizure, so we were panicking because I hadn't had a seizure since before my operation. Then it transpired that it was actually an aura before a migraine and I had no idea, clue that you could have auras before migraines because I'd always had migraines without auras." – Pa36 (aged 41–50, female, grade 2 astrocytoma)
Beliefs	• "I'm still not convinced I've necessarily fully accepted my diagnosis because some days I'm just, "I don't have a brain tumour. I'm sure I don't have a brain tumour." I know I do but sometimes it's hard just to be forced into living a different life as such." – Pa36 (aged 41–50, female, grade 2 astrocytoma) • "There was a huge sense of not knowing what was going to happen and a loss of any kind of feeling of control over my life." – Pa29 (aged 51–60, female, grade 3 oligodendroglioma) • "I'm not like the same as what I was before. I was struggling with that because I've got mobility problems and the right sided weakness. Obviously, I am working on that but it's just slow progress. I feel that I've reached a plateau, but I don't want to [pause] give up if you like." – Pa22 (aged 41–50, female, grade 2 astrocytoma)
Psychological distress	• "Sometimes the fear of death and the fear of what's going to happen next and brain surgery for a second time potentially, it gets on top of you and not being able to life your life as fully as you hoped you would." – Pa36 (aged 41–50, female, grade 2 astrocytoma) • "You wouldn't be totally comfortable planning anything beyond three months down the line or whenever the next scan is I guess and that obviously longer term, you just don't know what it's going to look like. I think anything beyond a three-month time period really." – Pa40 (aged < 40, female, grade 2 astrocytoma) • "I just felt I was getting squeezed and squeezed and squeezed and I was going to break to a point but slowly but surely the layers are coming off." – Pa37 (aged 51–60, male, grade 2 astrocytoma)
Motivation	• "Talking from a man's perspective, going to a counsellor feels like defeat…it feels like you've accepted defeat, and it shouldn't feel like that. Like, it's taken me a year to get a counsellor. But that's because I've only just now got the courage to talk about it, whereas I feel like if it was easier then I would talk about it sooner." – Pa9 (aged < 40, male, grade 2 astrocytoma) • "Emotionally, I try and look at things just as positively as I can. I have two small kids. I've got my wife. I can't just go on moping about stuff, so I just try and stay positive emotionally. I just try and stay positive." – Pa33 (aged 41–50, male, grade 2 oligodendroglioma) • "I've always felt quite well supported by the health professionals and also brave enough that I can ring them and say I needed a bit of information on that." – Pa29 (aged 51–60, female, grade 3 oligodendroglioma)
Self-management experience/ life transitions	• "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." – Pa17 (aged 51–60, female, grade 3 oligodendroglioma) • "One of the lessons that I need to learn and to remind myself of, is the importance of self-care which can be done in a way that is not selfish in orientation but needful to make the most of. You can't give to the world if you're not giving to yourself in a way" – Pa14 (aged > 60, male, grade 2 oligodendroglioma) • "One 10 k a week for a year. And that doesn't sound like a lot because I used to run 10ks every day. And I thought that will be easy. But I didn't take into account that I started it when I was just starting my chemotherapy. So, it was hard. I thought I was indestructible, but I realised I wasn't." – Pa11 (aged 51–60, male, grade 2 oligodendroglioma)
Health status	
Co-morbidity	• "There is apparently a school of thought that the thyroid medication I'm on [for thyroid cancer] can be bad for brain tumours." – Pa40 (aged < 40, female, grade 2 astrocytoma) • "Yesterday, I could hardly walk, and some people say it could be your age, you could be arthritis and it could be this and it could be that. I don't want to overthink it or be a burden to anybody or on the other hand I'm stabbing in the dark for an answer." – Pa14 (aged > 60, male, grade 2 oligodendroglioma) • "I feel that my memory isn't what it was. That might be tumour removal. It might be something else. It might be age. It might be self-abuse, who knows. But certainly, my memory isn't what it was." – Pa35 (aged 41–50, male, grade 2 astrocytoma)
Illness severity	• "To be honest, in terms of what it actually means we can and can't do, it has very… it's very hard for me to actually point to anything I can't do. Driving is probably the one thing that I, you know… that is unusual that I can't do." – Pa3 (aged 41–50, male, grade 2 oligodendroglioma) • "I am lucky. I really am lucky, I've seen other people with brain tumours who are far worse than I am as far as the impact it had on their life and the life of their loved ones and the disability that they're having to cope with" – Pa15 (aged 51–60, male, grade 2 astrocytoma)

Table 2 (continued)

Categories and factors	Illustrative quotes
Symptoms/side-effects	• "It's a bit worse for me now because I like to walk and I can't walk now whereas before I'd walk as far, I'd walk on my frame and still got as far as I could before because then you get all the fresh air and the trees." – Pa30 (aged > 60, male, grade 3 oligodendroglioma) • "Seizures. I'm not allowed to go swimming, and I used to be an avid swimmer. I used to love it. So, that's something else that I can't do now." – Pa9 (aged < 40, male, grade 2 astrocytoma) • "I went through a few boxes just to check and I was absolutely done in. I went to bed at 2 o'clock in the afternoon, yesterday because I'd sorted through four boxes." – Pa19 (aged 51–60, male, grade 3 oligodendroglioma)
Cognitive functioning	• "[medication] goes in the medicine pot and it sits on the kitchen bench so I can see it all the time because if I didn't see it, I would probably forget to take it." – Pa34 (aged > 60, female, grade 2 oligodendroglioma) • "This has gone on for so long that there's not much I can remember how to cook, now. I mean, I probably would be able to cook a sandwich. You know, cook the sausages. I'd be able to put stuff in the grill, but I wouldn't remember how to do, like, a proper meal." – Pa25 (aged 41–50, male, grade 2 oligodendroglioma)
Resources	
Financial	• "I saw my naturopath… and again, I was paying, like, £60 a session. So, I saw him for a while, but I couldn't… and then in between there was always things to buy and it just got too expensive." – Pa17 (aged 51–60, female, grade 3 oligodendroglioma) • "I knew I needed to get the mortgage away from me to give me a chance to survive on half a wage. So we managed that with savings and things like that. So the house we live in now, we own. We don't have a mortgage and that's a big help." – Pa30 (aged > 60, male, grade 3 oligodendroglioma)
Equipment	• "This shoulder bracelet I've got on has already… it makes me walk straighter, and it… and I think, if I can get my shoulder right, I'll probably get my elbow right, and then I'll probably get my wrist right. If I get my wrist right, I stand a chance of getting my fingers back." – Pa13 (aged 51–60, male, grade 3 oligodendroglioma) • "I've got a little plastic box thing in the kitchen where I put out the medicines for about the next week or the next five days or something, morning and evening." – Pa28 (aged > 60, male, grade 2 astrocytoma)
Psychosocial	• "I only go to the pub, for example, if I'm going with a friend, I could not go on my own to somewhere like that [because of the seizures]." – Pa25 (aged 41–50, male, grade 2 oligodendroglioma) • "I know she'd [my daughter] be supportive if I said I couldn't do something. As she lives nearby she will be supportive as indeed with my son, that's good." – Pa5 (aged 51–60, male, grade 2 oligodendroglioma)
Environmental characteristics	
Home	• "We were in a larger house before, so we basically downsized a bit. And so, as we moved in, we thought… we worked out that walk-in showers were essential, so we got a walk-in shower." – Pa13 (aged 51–60, male, grade 3 oligodendroglioma)
Work	• "They said they'll never push me. They'll never well yes, push me to, "When will you go full time?" No, they won't do that. At some point they probably will but at this precarious time at the minute, no, they've been more than supportive." – Pa18 (aged 51–60, female, grade 3 oligodendroglioma) • "At times it's very, very, very stressful, to the point, with the condition I have and the drugs I take, my bosses have said, "Just go into the yard, have a walk round, then come back." I'll come back settled and I'll just fly into it again." – Pa37 (aged 51–60, male, grade 2 astrocytoma)
Community	• "I don't see a lot, where I am. Because when I'm on this information group, there are a lot of people going to meet-ups and things, and I did tell The Brain Tumour Charity that there is nothing round here. The last time I looked, the closest one to me was on the other side of [place], and I can't travel very well." – Pa20 (aged 41–50, female, grade 3 oligodendroglioma) • "We live near major bus links really so it just wasn't a problem. The only places I used to go were [City] to do some shopping or go for a drink or whatever, my parents' house and the nursery and primary school. The nursery and primary school are right next to each other and they're on a bus route where the bus is literally outside our house" – Pa33 (aged 41–50, male, grade 2 oligodendroglioma) • "There's been times when I've been in amongst a crowd of people and have a seizure. I've had somebody say, "Get off the bus." You know, I've had one where the driver said, "Get off the bus."" – Pa25 (aged 41–50, male, grade 2 oligodendroglioma)

Table 2 (continued)

Categories and factors	Illustrative quotes
Healthcare system	
Access	• "In an ideal world you'd have all of this information at your fingertips because anybody with a brain tumour doesn't want to receive a plethora of post with loads of paper because you're still getting to grips with the fact that you have a debilitating, longstanding illness." – Pa18 (aged 51–60, female, grade 3 oligodendroglioma) • "I've had to seek it out. There's nothing upfront that says, "This is what you've been diagnosed with. This is what you can expect. This is what we can do for you." … I've had to go and look for it." – Pa20 (aged 41–50, female, grade 3 oligodendroglioma) • "I had to pay for it because nothing was available apart from the counselling through Macmillan and a few treatments like Reiki through Macmillan. everything else was paid for that I did." – Pa17 (aged 51–60, female, grade 3 oligodendroglioma)
Navigating system/ Continuity of care	• "I understand it's the patient's responsibility to negotiate. But they should at least be given the tools to allow them a fighting chance…I think they should point you in the right direction." – Pa9 (aged < 40, male, grade 2 astrocytoma) • "What constitutes primary treatment? Brain tumour charity talk about adjuvant or primary. I've got a letter from [consultant] describing my radiotherapy and chemotherapy as adjuvant. So I thought, aha, two years from the surgery. So, I applied, I got back a large envelope from the DVLA saying: "No, no, it's two years from the end of primary treatment." – Pa16 (aged > 60, male, grade 3 oligodendroglioma)
Relationship with provider	• "I remember one of these was very, kind of, stand-offy – he didn't even make eye contact with me. Another person, I kind of talked about having a lot of migraines and I was worried about the migraines, and was that something. And they said, "Well, you know, you've had brain surgery. You're sure to have headaches, aren't you?"…I thought, "That's not a particularly helpful thing to say." – Pa3 (aged 41–50, male, grade 2 oligodendroglioma) • "As soon as we went in there she was almost like, "I want to put your mind at rest about this," kind of thing. Even though it's become more serious… I think she even said, "The treatment for this we can get for you is better." So, it's worse but we can do more for you for it kind of thing. Whatever she said was really reassuring." – Pa32 (aged 41–50, female, grade 3 oligodendroglioma)

tumour progression, was '*mentally draining*' and elicited anxiety and low mood in several participants. For many, this future uncertainty limited their perceived control, decision making, and engagement in goal and action planning, with some no longer comfortable thinking more than a few months ahead.

> "When I am feeling down, I worry more about the impact [the tumour] has had, and the medication, the possible progression, and the impact it will have on my life in the future. And it is, kind of, mentally draining." – Pa3 (aged 41–50, male, grade 2 oligodendroglioma).

Though most participants acknowledged the need for support, their self-confidence influenced whether they were motivated to seek support in a timely manner. Some perceived a stigma in asking for emotional support, saying that doing so '*feels like defeat*'. Others noted that the consequences of the tumour (e.g. cognitive deficits) impacted their ability to determine what support was needed.

> "It's hard for me to tell [what issues I'm having] because the very thing I've been measuring any side-effects with is the very thing that's damaged." – Pa35 (aged 41–50, male, grade 2 astrocytoma).

A few participants described how certain life events, and the success (or lack thereof) of previous attempts to self-manage, both influenced their continued engagement in self-management. For example, one participant recounted how a major life event (divorce) influenced by their diagnosis, was a considerable set-back to engaging with self-management. The importance of self-care was acknowledged by a few participants, though they also described low self-efficacy and unsuccessful attempts to engage in activities (e.g. exercise) at the desired level.

Health status

The four factors that participants spoke about within 'Health status' were '*Co-morbidity*', '*Illness severity*', '*Symptoms/ side-effects*', and '*Cognitive functioning*'.

One participant was concerned that medication for a separate cancer diagnosis would be detrimental for their brain tumour. Further, though not explicitly a co-morbidity, some were unsure whether cognitive or mobility issues were a consequence of their condition or ageing, more generally. This led to uncertainty with whether, and how, to seek relevant information or support to facilitate self-management.

Some participants described conflicting feelings of luck when interpreting the consequences of their condition, comparing their experience to other people with brain tumours that were more impacted. Some reported feeling '*pretty much normal*', citing an inability to drive as the main consequence of their condition. Others noted that symptom severity is unpredictable and variable, day-to-day, creating challenges for their active participation in self-management.

> "Each day is completely different. Like today, I had a good night's sleep it's like, yeah, crack on with this. Yesterday I was like, "Ugh…" It's just variable, pretty variable" – Pa19 (aged 51–60, male, grade 3 oligodendroglioma).

Many detailed the implications of the presence of, or anxiety about having, seizures, on social and occupational roles. Participants also outlined the influence of fatigue on self-management, describing how they required frequent breaks and rest to complete what they perceived as a simple task (e.g. sorting boxes). Some alluded to feeling inhibited by physical impairments, particularly those affecting mobility. Across each symptom, participants generally felt unable to do what they once could, hindering attempts to return to 'normal' living.

> "I started to worry about getting up that early [for work] and whether the seizures would come back and all the rest of it. I found myself living a sort of lifestyle that I no longer wanted to be in because of the seizures." – Pa35 (aged 41–50, male, grade 2 astrocytoma).

Most participants detailed an awareness that cognitive deficits had implications for their ability to self-manage, particularly concerning medication management (e.g. due to attention deficits) and activities of daily living (e.g. cooking due to memory deficits). Some reported the influence of communication deficits on their confidence to engage in social activities, reducing their opportunities for social engagement and connection.

> "I don't think I would put my point across and join in the conversation as much as I used to because of [slurred speech]." – Pa38 (aged 51–60, female, grade 2 astrocytoma).

Resources

The three factors that participants spoke about within 'Resources' were '*Financial*', '*Equipment*', and '*Psychosocial*'.

Almost all participants acknowledged the financial implications of their condition. For some, challenges with maintaining employment and accessing benefits resulted in considerable financial uncertainty.

> "The housing or council benefit I can't use that as one of my incomes. I can only work 16 h a week whereas I'd love to work more. If I did that, I'd have to lose the other benefits. If I lose those benefits and then [the tumour] does something I'd have to start right back at the beginning." – Pa26 (aged < 40, female, grade 2 oligodendroglioma).

Others noted that for '*a chance to survive*' substantial financial adjustments were needed to create an environment that enabled them to self-manage with a change in financial resources. A few participants described attempts to finance additional support (e.g. naturopath) themselves, but these were often unsustainable.

Some participants detailed how certain equipment and resources were helpful, for example: dosette boxes improved medication management; shoulder braces improved mobility impairments; and railcards and bus passes alleviated financial pressures concerning public transport.

> "If you're on anti-epileptic medication you can get the 20% disabled rail card for £20 a year or whatever it is. I've got a bus pass as well." – Pa5 (aged 51–60, male, grade 2 oligodendroglioma).

Most participants emphasised the value of knowing that support was available from family and friends, should it be needed. Some participants highlighted that informal support networks were specifically important for maintaining social and occupational roles (e.g. transport to work). These participants spoke about how self-management would be more difficult if these support networks were not available.

> "I have to travel to work, and it was just lucky I had friends around me that would give me a lift to work and giving me a lift back and stuff." – Pa31 (aged 51–60, male, grade 2 oligodendroglioma).

However, sometimes participants experienced excessive or unsolicited support from others and this, when it occurred, limited their independence and opportunities to self-manage.

> "People want to wrap you up in cotton wool and it's like, "No. I just can't walk as far as I used to."." – Pa18 (aged 51–60, female, grade 3 oligodendroglioma).

Environmental characteristics

The three factors that participants spoke about within 'Environmental characteristics' were '*Home*', '*Work*', and '*Community*'.

A few participants mentioned the need for appropriate adjustments at home to accommodate for symptoms and impairments (e.g. walk-in shower for impaired mobility). One participant set up home gym equipment to provide a means of exercising.

> "My bike is set up in the garage. I've worked a way of getting my leg over the top of it so I can pedal on it." – Pa30 (aged > 60, male, grade 3 oligodendroglioma).

Several participants reported the effect of their work environment; for most, this concerned whether their employer was understanding and supportive, and made reasonable accommodations (e.g. allowing reduced working hours or additional breaks). Where understanding/support was lacking, work became a stressful, unpleasant environment for some; these participants felt that employers were scrutinising, rather than accommodating, changes in their capabilities. This created challenges for peoples' ability to use support from employers in attempts to return to work.

> "One of my managers wasn't particularly supportive of [a part-time arrangement] and started capability proceedings against me, which is very, very pleasant indeed – not." – Pa15 (aged 51–60, Male, grade 2 astrocytoma).

Most participants detailed the influence of their community – essentially, where they lived – on their self-management. The (lack of) availability, and access to community support services (e.g. support groups) shaped access to information and skills to facilitate self-management. For some, this was exacerbated by an inability to drive to where support was available.

> "I would have thought there would be [a support group] in my part of the country, the centres. This must be volunteers who are running it near to where it happened to them. If I could drive, I'd go every month, I definitely would." – Pa19 (aged 51–60, male, grade 3 oligodendroglioma).

Several participants cited how good public transport links facilitated access to support and activities of daily living (e.g. grocery shopping); however, due to risk of seizures or cognitive difficulties with planning, public transport was not seen as a viable option for some.

Healthcare system

The three factors that participants spoke about within 'Healthcare system' were '*Access*', '*Navigating system/Continuity of care*', and '*Relationship with provider*'.

Many participants described how access to support and information from healthcare professionals and the healthcare system influenced their ability to self-manage. Some spoke about how being able to easily access their clinical care team provided opportunities to acquire knowledge and support.

> "The nurses, you can ring them anytime. I've got their times and their numbers pinned up in the kitchen there, so, that is like a little support team in itself so that's useful." – Pa28 (aged > 60, male, grade 2 astrocytoma).

However, several participants reported the need to seek information elsewhere because '*there's nothing (provided) upfront*', or they had received too much information at a time when it was not useful. For some, a lack of knowledge about, or access to, available support within the public healthcare system meant they sought private alternatives.

The majority of participants reported unsuccessful attempts to navigate the healthcare system; markedly several participants noted the absence of advice and signposting to available support. Some suggested they needed and wanted to be '*given the tools*' to self-manage but support received was insufficient; sometimes care ceased when it was still needed.

> "They put me on some physio, but I only had, maybe, six sessions and then the physiotherapist left, and it wasn't really continued…if there had been a handover to someone else, I think that would have been much more productive for myself. I had maybe two years where I wasn't really doing anything." – Pa26 (aged < 40, female, grade 2 oligodendroglioma).

When navigating non-healthcare services (e.g. social welfare system, vehicle licencing authorities), many participants expressed challenges with understanding the health-related information required (e.g. what treatment(s) for the tumour they had received), creating setbacks when attempting to arrange additional support and self-manage.

Most participants recounted the influence of their relationship with healthcare providers, reporting that the strength of the relationship depended on the provider's social skills. Several participants detailed feeling trust in, and reassurance from, healthcare providers, which provided them with the knowledge and belief that they could self-manage.

> "I see a psychiatrist who's in the cancer centre. And he's absolutely fantastic. And he's always really, really good at being able to give me advice about what I can do if I've got a problem." – Pa25 (aged 41–50, male, grade 2 oligodendroglioma).

Conversely, where participants reported negative interactions, this often exacerbated health-related concerns, as they were unable to acquire the appropriate knowledge to facilitate self-management.

Discussion

Self-management can have numerous quality-of-life, clinical, and health economic benefits [3, 4], but various factors can influence engagement in self-management [5]. Our study aimed to identify and understand the barriers and facilitators to self-management in people with LGG, a group who may experience a wide-range of chronic, tumour-related, symptoms and impairments.

In accordance with Schulman-Green et al.'s framework of factors influencing self-management [5], our data extensively supported all five categories, encompassing all 18 factors, and highlights how these factors distinctively influence self-management in people with LGG. What was also evident from our findings was that numerous factors may interact to influence an individual's ability to self-manage. For example, with support group attendance, the individual may need self-confidence to seek support ('*Motivation*' within 'Personal/lifestyle characteristics') to then receive appropriate signposting to available support ('*Navigating system*' within 'Healthcare system'). Should a support group be available in their location ('*Community*' within 'Environmental characteristics'), transport issues or risk of seizures may mean they feel unable to attend alone ('*Psychosocial*' within 'Resources'). Moreover, communication impairments might inhibit self-confidence to contribute to the support group ('*Cognitive functioning*' within 'Health status'), which may precede the initial motivation to seek support. Hence, challenges with self-management can be complex and multi-dimensional, and this must be considered in the development of self-management support.

Our findings also highlight the adverse influence of beliefs (e.g. lack of control) and psychological distress on self-management. Though we draw similarities to studies in other cancers [16, 33], we would argue that people with LGG may be somewhat distinct in living with an incurable, life-limiting illness; indeed, future uncertainty concerning possible tumour progression was described as the main source of psychological distress in our participants, congruent with Ley et al. [24]. Further, challenges with acceptance and future uncertainty led to difficulties with maintaining a positive outlook and feeling motivated to self-manage. This could have implications for whether an individual seeks support for, and engages in, self-management; hence, this is an important consideration for healthcare professionals, when implementing self-management support for people with LGG.

Quantitative studies of people with LGG have indicated that poor cognitive function and seizure burden are consistently associated with worse health-related quality-of-life [23]. We expand on this to highlight how such symptoms and impairments can create specific challenges for self-management engagement (e.g. the often-significant cognitive deficits can hinder medication management). These support needs are somewhat distinct from the influence of symptoms on self-management found in studies of other cancers [14, 17] and have more in common with neurological populations such as MS or stroke [11, 34]. Therefore, when encouraging people with LGG to self-manage, consideration of their cognitive function and seizure burden will help determine whether certain self-management activities (e.g. cooking, physical activity, use of public transport) are achievable, or require an adapted approach. Implementation of needs assessments in clinical practice could be of value to identify issues or problems that people with LGG would like more support with; in this way, support could be tailored to the needs of the individual. For example, identifying that an individual would like help with managing cognitive deficits could prompt the co-development of self-management strategies (e.g. use of external aids) to overcome these challenges. Existing reviews show that many such needs assessment instruments are available for people with cancer [35, 36], though none of these seem to be specific to people with LGG or brain tumours more generally.

Since LGGs are typically diagnosed in working-aged adults [19], those affected may want or need to return to work [37]. Our data highlights the importance of understanding and support from employers for work-related self-management. Still, several factors may interact (including '*Symptoms/side-effects*' and '*Psychosocial resources*') to influence people with LGGs' work experiences [38]. For example, transport assistance facilitated engagement in occupational roles; one of numerous ways that psychosocial resources aided self-management. This is consistent with the wide-ranging role and responsibilities of family and friends (e.g. cognitive, emotional, practical support) that we have observed in a parallel set of interviews with informal caregivers of people with LGG. Informal caregivers also have a critical role in supporting and facilitating self-management [39]; however, care needs to be taken – as we highlight here, and as reported by others – to ensure such support does not tip over into limiting the independence of people with LGG [40], as this could create a barrier to self-management.

Participants in our study reported difficulty with accessing appropriate support; as with Langbecker et al.'s study of people with brain tumours [25], this barrier was exacerbated by whether support was available and accessible within a person's community. Studies of people with chronic illness detail the impact of transport challenges on self-management [10, 41]. However, people with LGGs' experiences are distinct, at least in cancer terms, because their driving licence is typically revoked, often due to ongoing seizure activity, presenting consequent challenges (e.g. time and uncertainty) with reobtaining their licence. Hence, this barrier to self-management may be sustained longer-term for people with LGG, meaning greater support with transport challenges may be necessary, particularly for those with weaker support networks.

Our participants described the need to actively engage in help-seeking to ensure awareness of available support, as insufficient or inappropriate information, advice, and signposting from healthcare providers, was a key barrier to self-management. However, help-seeking may be hindered by poor knowledge [7], as not knowing what to expect (e.g. symptoms) meant our participants often did not seek appropriate, timely support. Further, our data supports the suggestion that people with brain tumours can underestimate cognitive, emotional, psychological, and social changes [42]. Nonetheless, with sufficient knowledge, self-confidence to seek help is also important for self-management [9], and – as our data suggests – this may be influenced by the person with LGG's relationship with their healthcare provider. We indicate the benefits (e.g. reassurance) of strong relationships, and detriments (e.g. distrust) of poor relationships between people with LGG and their healthcare provider. Consideration of how others might facilitate or encourage autonomy within supportive relationships could have fundamental importance for improving peoples' confidence to self-manage.

Implications

Internationally, there is a call to action for health systems to improve integration of self-management support in cancer care [43]. In a recent systematic review of self-management interventions in cancer, it was noteworthy that none were targeted to people affected by brain tumours [3]. The present analysis comprehensively complements and expands on data we have reported elsewhere from this study (e.g. [26].), filling the evidence gap around self-management and its determinants among people with LGG; this is a fundamental first step towards developing and/or implementing effective self-management support for this population [44]. Overall, our findings serve to improve awareness of the challenges faced by people with LGG that may influence whether they are able to self-manage in day-to-day life, while emphasising how these challenges can co-occur and vary for each individual. For healthcare professionals, who are increasingly encouraged to engage patients with self-management, and researchers interested in developing self-management interventions for those affected by cancer, such an understanding is invaluable.

Strengths and limitations

A key strength of our study is the novel understanding of factors influencing self-management in people with LGG; semi-structured interviews provided the freedom to explore these factors across a diverse range of contexts (e.g. domestic and social roles). We are confident that reasonable data sufficiency was achieved, as there was extensive data, supported by multiple quotes, to understand the factors influencing self-management in people with LGG.

Due to Covid-19, all interviews were conducted remotely; this facilitated recruitment across the UK [45], and may have encouraged more disclosure, through less discomfort and a perception of greater anonymity [46]. However, despite attempts to support participation of people with LGG with cognitive and communication impairments, remote interviews and expected interview length (approx. 90 min) may have made it more difficult for them to take part. It is not uncommon in LGG literature for people with these impairments to be excluded [23], therefore, further consideration of how to support participation is required (e.g. multiple, shorter interviews to mitigate the risk of fatigue).

We sought a wide range of times since diagnosis in our sample to generate an understanding of the factors influencing self-management in people living short- and long-term with an LGG. The challenges perceived by someone more than 10 years post-diagnosis are likely different to the challenges perceived in the early stages following primary treatment. However, the cross-sectional design means we cannot be certain whether or how these factors may be experienced differently over time. Future longitudinal studies could be beneficial to explore how barriers and facilitators to self-management in people with LGG may change over time.

Conclusions

This study explored the barriers and facilitators to self-management in people with LGG, highlighting the distinctive experiences within the wide-ranging factors influencing self-management in this population. These findings may improve awareness of the challenges faced by people with LGG in self-management following completion of initial treatment. Notably, we emphasise potential supportive care needs, and how multiple factors may interact, and influence each individual differently. Our findings could be useful to inform the development of self-management interventions for people with LGG, ensuring, where possible, that potential barriers are addressed to facilitate effective engagement in self-management.

Supplementary Information The online version contains supplementary material available at https://doi.org/10.1007/s11764-024-01572-9.

Acknowledgements This is an output for the Ways Ahead project (research.ncl.ac.uk/waysahead). We would like to thank our collaborating NHS sites, Newcastle upon Tyne Hospitals NHS Foundation Trust, NHS Lothian, The Christie NHS Foundation Trust, and South Tees Hospitals NHS Foundation Trust, as well as colleagues at the Brain Tumour Charity, for their assistance with recruitment to the project.

Author contributions LS, JL, SW, PG, RB, VAS, and TF secured the funding and developed the idea for the study. JL, SW, SE, PS, and CM facilitated recruitment in NHS sites. BR acquired ethical approval and conducted recruitment. BR and LD conducted the interviews. BR and MB conducted the analysis and interpreted the findings. BR

drafted the manuscript. FM and LS provided critical input into the initial manuscript draft. All authors reviewed, revised, and approved the final manuscript.

Funding This work was supported by funding from The Brain Tumour Charity (GN-000435).

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.

Declarations

Ethics approval The study has been reviewed and approved by a National Health Service Research Ethics Committee (REC ref: 20/WA/0118).

Consent to participate Informed consent was obtained from all individual participants included in the study.

Consent to publish Not applicable.

Competing interests The authors declare no competing interests.

References

1. McCorkle R, Ercolano E, Lazenby M, Schulman-Green D, Schilling LS, Lorig K, Wagner EH. Self-management: Enabling and empowering patients living with cancer as a chronic illness. CA: A Cancer J Clin. 2011;61(1):50–62. https://doi.org/10.3322/caac.20093.
2. Foster C, Brown J, Killen M, Brearley S. The NCRI Cancer Experiences Collaborative: Defining self management. Eur J Oncol Nurs. 2007;11(4):295–7. https://doi.org/10.1016/J.EJON.2007.08.002.
3. Rimmer B, Brown MC, Sotire T, Beyer F, Bolnykh I, Balla M, Richmond C, Dutton L, Williams S, Araújo-Soares V, Finch T, Gallagher P, Lewis J, Burns R, Sharp L. Characteristics and Components of Self-Management Interventions for Improving Quality of Life in Cancer Survivors: A Systematic Review. Cancers. 2023;16(1):14. https://doi.org/10.3390/CANCERS16010014.
4. Cuthbert CA, Farragher JF, Hemmelgarn BR, Ding Q, McKinnon GP, Cheung WY. Self-management interventions for cancer survivors: a systematic review and evaluation of intervention content and theories. Psychooncology. 2019;28(11):2119–40. https://doi.org/10.1002/pon.5215.
5. Schulman-Green D, Jaser SS, Park C, Whittemore R. A meta-synthesis of factors affecting self-management of chronic illness. J Adv Nurs. 2016;72(7):1469–89. https://doi.org/10.1111/JAN.12902.
6. Memory KE, Wilkinson TJ, Smith AC, Lightfoot CJ. A qualitative exploration of the facilitators and barriers to self-management in kidney transplant recipients. J Nephrol. 2022;1:1–10. https://doi.org/10.1007/S40620-022-01325-W/TABLES/4.
7. Nguyen TNM, Whitehead L, Saunders R, Dermody G. Systematic review of perception of barriers and facilitators to chronic disease self-management among older adults: Implications for evidence-based practice. Worldviews Evid-Based Nurs. 2022;19(3):191–200. https://doi.org/10.1111/WVN.12563.
8. Russell S, Ogunbayo OJ, Newham JJ, Heslop-Marshall K, Netts P, Hanratty B, Beyer F, Kaner E. Qualitative systematic review of barriers and facilitators to self-management of chronic obstructive pulmonary disease: views of patients and healthcare professionals. Npj Prim Care Respir Med. 2018;28(1):1–13. https://doi.org/10.1038/s41533-017-0069-z.
9. Hwang SJ, Tan NC, Yoon S, Ramakrishnan C, Paulpandi M, Gun S, Lee JY, Chang ZY, Jafar TH. Perceived barriers and facilitators to chronic kidney disease care among patients in Singapore: a qualitative study. BMJ Open. 2020;10(10):e041788. https://doi.org/10.1136/BMJOPEN-2020-041788.
10. Balogun-Katung A, Carswell C, Brown JVE, Coventry P, Ajjan R, Alderson S, Bellass S, Boehnke JR, Holt R, Jacobs R, Kellar I, Kitchen C, Lister J, Peckham E, Shiers D, Siddiqi N, Wright J, Young B, Taylor J. Exploring the facilitators, barriers, and strategies for self-management in adults living with severe mental illness, with and without long-term conditions: A qualitative evidence synthesis. PLoS ONE. 2021;16(10):e0258937. https://doi.org/10.1371/JOURNAL.PONE.0258937.
11. Desborough J, Brunoro C, Parkinson A, Chisholm K, Elisha M, Drew J, Fanning V, Lueck C, Bruestle A, Cook M, Suominen H, Tricoli A, Henschke A, Phillips C. 'It struck at the heart of who I thought I was': A meta-synthesis of the qualitative literature examining the experiences of people with multiple sclerosis. Health Expect. 2020;23(5):1007–27. https://doi.org/10.1111/HEX.13093.
12. Barnard E, Brown CR, Weiland TJ, Jelinek GA, Marck CH. Understanding barriers, enablers, and long-term adherence to a health behavior intervention in people with multiple sclerosis. Disabil Rehabil. 2018;42(6):822–32. https://doi.org/10.1080/09638288.2018.1510550.
13. Loh SY, Packer T, Yip CH, Low WY. Perceived barriers to self-management in Malaysian women with breast cancer. Asia Pac J Public Health. 2007;19(3):52–7. https://doi.org/10.1177/101053950701900309.
14. Beghean R, Coffey L. "You either sink or you swim, and you're better off swimming": A qualitative study exploring the self-management experiences of soft tissue sarcoma survivors. Eur J Oncol Nurs. 2021;55:102062. https://doi.org/10.1016/J.EJON.2021.102062.
15. Ostby PL, Armer JM, Smith K, Stewart BR. Patient Perceptions of Barriers to Self-Management of Breast Cancer-Related Lymphedema. West J Nurs Res. 2018;40(12):1800–17. https://doi.org/10.1177/0193945917744351.
16. Dunne S, Coffey L, Sharp L, Timmons A, Desmond D, Gooberman-Hill R, O'Sullivan E, Keogh I, Timon C, Gallagher P. Barriers to active self-management following treatment for head and neck cancer: Survivors' perspectives. Psychooncology. 2018;27(10):2382–8. https://doi.org/10.1002/PON.4835.
17. Noorlandt H, Stoevelaar R, van Dongen S, Arslan M, Luu N, Kranenburg L, Witkamp E, van der Rijt C, Lorig K, van der Heide A, Rietjens J. Challenges in self-management of persons living with advanced cancer: An exploratory, in-depth interview study. Eur J Cancer Care. 2022;e13638. https://doi.org/10.1111/ECC.13638.
18. Miller KD, Ostrom QT, Kruchko C, Patil N, Tihan T, Cioffi G, Fuchs HE, Waite KA, Jemal A, Siegel RL. Brain and other central

nervous system tumor statistics, 2021. CA: A Cancer J Clin. 2021;71(5):381–406. https://doi.org/10.3322/caac.21693.

19. Bauchet L. Epidemiology of Diffuse Low Grade Gliomas. Diffuse Low-Grade Gliomas Adults. 2017;13–53. https://doi.org/10.1007/978-3-319-55466-2_2.
20. Claus EB, Walsh KM, Wiencke JK, Molinaro AM, Wiemels JL, Schildkraut JM, Bondy ML, Berger M, Jenkins R, Wrensch M. Survival and low-grade glioma: The emergence of genetic information. Neurosurg Focus. 2015;38(1):E6. https://doi.org/10.3171/2014.10.FOCUS12367.
21. Dixit K, Raizer J. Newer strategies for the management of low-grade gliomas. Oncology (Williston Park, N.Y.). 2017;31(9):680–5. https://europepmc.org/article/med/29071695.
22. Rimmer B, Balla M, Dutton L, Williams S, Lewis J, Gallagher P, Finch T, Burns R, Araujo-Soares V, Menger F, Sharp L, team, W A study. "It changes everything" Understanding how people experience the impact of living with a lower-grade glioma. Neuro-Oncol Pract. 2024. https://doi.org/10.1093/NOP/NPAE006.
23. Rimmer B, Bolnykh I, Dutton L, Lewis J, Burns R, Gallagher P, Williams S, Araújo-Soares V, Menger F, Sharp L. Health-related quality of life in adults with low-grade gliomas: a systematic review. Qual Life Res. 2023;32:625–51. https://doi.org/10.1007/S11136-022-03207-X.
24. Ley A, Kamp M, von Sass C, Hänggi D, Sabel M, Rapp M. Psychooncological distress in low-grade glioma patients—a monocentric study. Acta Neurochir. 2021;1:1–10. https://doi.org/10.1007/S00701-021-04863-7.
25. Langbecker D, Ekberg S, Yates P. Don't need help, don't want help, can't get help: How patients with brain tumors account for not using rehabilitation, psychosocial and community services. Patient Educ Couns. 2017;100(9):1744–50. https://doi.org/10.1016/J.PEC.2017.04.004.
26. Rimmer B, Balla M, Dutton L, Lewis J, Brown MC, Burns R, Gallagher P, Williams S, Araújo-Soares V, Finch T, Menger F, Sharp L. Identifying and understanding how people living with a lower-grade glioma engage in self-management. J Cancer Survivorship. 2023;1–14. https://doi.org/10.1007/S11764-023-01425-X.
27. Rimmer B, Sharp L. Implementation of Self-Management Interventions in Cancer Survivors: Why Are We Not There Yet? J Cancer Educ. 2021;36(6):1355–8. https://doi.org/10.1007/s13187-021-02021-2.
28. 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 multimethod study. BMJ Open.2020;10(7). https://doi.org/10.1136/bmjopen-2020-041465.
29. Louis DN, Perry A, Wesseling P, Brat DJ, Cree IA, Figarella-Branger D, Hawkins C, Ng HK, Pfister SM, Reifenberger G, Soffietti R, von Deimling A, Ellison DW. The 2021 WHO classification of tumors of the central nervous system: A summary. Neuro Oncol. 2021;23(8):1231–51. https://doi.org/10.1093/neuonc/noab106.
30. Gale NK, Heath G, Cameron E, Rashid S, Redwood S. Using the framework method for the analysis of qualitative data in multi-disciplinary health research. BMC Med Res Methodol. 2013;13(1):1–8. https://doi.org/10.1186/1471-2288-13-117/METRICS.
31. Clarke V, Braun V. Thematic analysis: a practical guide. Sage. 2021:1–100.
32. Low J. A pragmatic definition of the concept of theoretical saturation. Sociol Focus. 2019;52(2):131–9.
33. Kidd LA. Consequences, control and appraisal: cues and barriers to engaging in self-management among people affected by colorectal cancer – a secondary analysis of qualitative data. Health Expect. 2014;17(4):565–78. https://doi.org/10.1111/J.1369-7625.2012.00785.X.
34. Tang EYH, Price C, Stephan BCM, Robinson L, Exley C. Impact of Memory Problems Post-stroke on Patients and Their Family Carers: A Qualitative Study. Front Med. 2020;7:531413. https://doi.org/10.3389/FMED.2020.00267/BIBTEX.
35. Rimmer B, Crowe L, Todd A, Sharp L. Assessing unmet needs in advanced cancer patients: a systematic review of the development, content, and quality of available instruments. J Cancer Survivorship. 2021. https://doi.org/10.1007/s11764-021-01088-6.(Springer)
36. Tian L, Cao X, Feng X. Evaluation of psychometric properties of needs assessment tools in cancer patients: A systematic literature review. PLoS ONE. 2019;14(1):e0210242. https://doi.org/10.1371/JOURNAL.PONE.0210242.
37. Silvestre J, Pascual G, Duffau H. The need to consider return to work as a main outcome in patients undergoing surgery for diffuse low-grade glioma: a systematic review. Acta Neurochir. 2022;1:1–21. https://doi.org/10.1007/S00701-022-05339-Y.
38. Walker H, Rimmer B, Dutton L, Finch T, Gallagher P, Lewis J, Burns R, Araújo-Soares V, Williams S, Sharp L. Experiences of work for people living with a grade 2/3 oligodendroglioma: a qualitative analysis within the Ways Ahead study. BMJ Open. 2023;13(9):e074151. https://doi.org/10.1136/BMJOPEN-2023-074151.
39. Dwarswaard J, Bakker EJM, van Staa A, Boeije HR. Self-management support from the perspective of patients with a chronic condition: a thematic synthesis of qualitative studies. Health Expect. 2016;19(2):194–208. https://doi.org/10.1111/HEX.12346.
40. Zanotto A, Goodall K, Ellison M, McVittie C. Perceptions of social support and relationships while living with a brain tumour: a qualitative study. Psychol Health. 2023. https://doi.org/10.1080/08870446.2023.2237995.
41. Bustillos BD, Sharkey JR. "I Try to Keep That Sugar Down." Experiences of Homebound Older Adults With Type 2 Diabetes: Barriers to Self-Management. J Nutr Gerontol Geriatr. 2019;39(1):69–87. https://doi.org/10.1080/21551197.2019.1695037.
42. Andrewes HE, Drummond KJ, Rosenthal M, Bucknill A, Andrewes DG. Awareness of psychological and relationship problems amongst brain tumour patients and its association with carer distress. Psychooncology. 2013;22(10):2200–5. https://doi.org/10.1002/pon.3274.
43. Howell D, Mayer DK, Fielding R, Eicher M, Verdonck-De Leeuw IM, Johansen C, Soto-Perez-De-Celis E, Foster C, Chan R, Alfano CM, Hudson SV, Jefford M, Lam WWT, Loerzel V, Pravettoni G, Rammant E, Schapira L, Stein KD, Koczwara B. Management of cancer and health after the clinic visit: A call to action for self-management in cancer care. J National Cancer Inst. 2021;113(5):523–31. https://doi.org/10.1093/jnci/djaa083. (**Oxford University Press**).
44. Araújo-Soares V, Hankonen N, Presseau J, Rodrigues A, Sniehotta FF. Developing Behavior Change Interventions for Self-Management in Chronic Illness. 2018;24(1):7–25. https://doi.org/10.1027/1016-9040/A000330
45. Gray LM, Wong-Wylie G, Rempel GR, Cook K. Expanding Qualitative Research Interviewing Strategies: Zoom Video Communications. Qual Rep. 2020;25(5):1292–301.
46. Drabble L, Trocki KF, Salcedo B, Walker PC, Korcha RA. Conducting qualitative interviews by telephone: Lessons learned from a study of alcohol use among sexual minority and heterosexual women. Qual Soc Work: QSW: Res Pract. 2016;15(1):118–33. https://doi.org/10.1177/1473325015585613.

4.3.1 PP4 commentary

This qualitative study represents the most comprehensive understanding of the barriers and facilitators to self-management in people with brain tumours in the literature to date; it is also the first to focus specifically on the experiences of people with LGG. Applying the framework method[93] was considered appropriate here, combining inductive and deductive coding approaches to examine how the lived experiences of people with LGG mapped to a comprehensive framework of 18 factors (across five categories) influencing self-management[88]. The findings showed that the tumour-specific symptoms and impairments outlined in chapter 3, particularly seizures and cognitive impairment, present distinctive challenges around self-management for people with LGG.

The key message from PP4[50] is the clear demonstration that there are wide-ranging, often interacting, factors influencing self-management in people with LGG. This has crucial implications for whether people with LGG feel able to self-manage and the support they may need to effectively engage in self-management. Referring to the call to action for enhancing self-management in cancer care[18] (introduced in chapter 1.1.3), this speaks to priority action one, around preparing patients for active involvement in care. Improving HCPs' understanding of the challenges around self-management may help give direction to where people with LGG require assistance with preparation for engagement in self-management. Acknowledging where and how these challenges may vary will aid the personalisation of support to meet the needs of each individual. For researchers, these findings provide valuable understanding of what might facilitate self-management for people with LGG, which is informative for the design of self-management interventions.

4.4 Chapter summary

Together, the two papers presented in this chapter provide a comprehensive understanding of how people with LGG engage in self-management. The directed content analysis (PP3[49]) identified that people with LGG use a substantial number of self-management strategies, indicating a possible willingness to engage in the self-management of their health and well-being. It was crucial here to also understand how people with LGG experience (often distinct) challenges around self-management (PP4[50]). This identifies areas where support may be required to facilitate effective and independent engagement in self-management. For example, the impact of seizures and cognitive impairment on self-management may have influenced the infrequent reporting of 'self-sustaining' and 'independence' related self-management strategies, and the more frequent reports of 'using support'. Overall, this has future research and clinical implications for the development and implementation of self-management support, particularly concerning the encouragement of autonomy and independence; these implications are discussed further in chapters 7.3.1 and 7.4.2.

Chapter 5: The role of informal caregivers in supporting people with lower-grade gliomas

In chapter 4, one of the key findings from PP3[49] was that 'receiving support from family' and 'receiving support from friends' were amongst the most used self-management strategies. Further, PP4[50] emphasised the value of 'psychosocial resources' (e.g. strong informal support networks) for facilitating self-management in people with LGG. However, these findings also suggested that excessive or unsolicited support could limit the care recipient's independence and opportunities to self-manage. Therefore, there is a need to improve understanding of how ICs perceive their role in supporting people with LGG; this is the focus of this chapter.

The chapter presents a broad overview of what it means to be an IC and how ICs can have a role in providing self-management support. The chapter starts with the types of support that have been evidenced in IC literature across different cancers, before considering the challenges that ICs may experience with providing support for the care recipient. The publication introduced in this chapter (PP5[51]) presents findings from Ways Ahead interviews with ICs of people with LGG and aimed to understand how ICs experience the role and responsibilities of supporting someone living with a LGG. The overarching aim of this chapter was to understand the potential for ICs to be involved in supporting the care recipient to self-manage.

The chapter is organised as follows: introduction to the role of ICs in providing self-management support; PP5; PP5 commentary; chapter summary.

5.1 The role of informal caregivers in providing self-management support

5.1.1 Types of support provided by informal caregivers

Family-members, partners, and close friends often assume the role of IC when an individual is diagnosed with cancer; this pertains to the unpaid provision of ongoing care and assistance. A systematic review of studies in other cancers suggests that ICs have an integral role in supporting the day-to-day self-management of the care recipient[94]. In ICs of people with chronic illness, Schulman-Green et al.[95] outlined three processes of care to emphasise the multidimensional nature of an IC's role in supporting self-management: (1) 'Focusing on the patient's illness needs', which concerns learning (e.g. about the health condition), activating healthcare resources (e.g. obtaining information and support), and supporting the patient (e.g. supporting physical and emotional health, performing everyday tasks); (2) 'Activating resources to support oneself as the family caregiver', which concerns identifying and benefitting from psychological and social resources (e.g. emotional support from other ICs) to sustain their role. In other published work from interviews with ICs in Ways Ahead (*Appendix B.6*) the analysis described how ICs of people with LGG sought and received multiple forms of support (e.g. opportunities to talk, opportunities for relief, information on available support) from their own informal networks to help protect their well-being[96]; and (3) 'Supporting a patient living with a chronic, life-limiting illness', which concerns managing their own physical and emotional health, adjusting to the diagnosis and potential prognosis, and meaning-making (e.g. accepting the caregiving situation, increasing empathy). Further published work from Ways Ahead interviews with ICs highlighted the wide-ranging emotional responses to and impacts of the illness, uncertain prognosis, care recipient changes, and the toll of caregiving reported by ICs of people with LGG[97] (*Appendix B.5*). This indicates the emotional health adjustments that ICs of people with LGG may need to manage. Overall, there is still a need to better understand the first process of care (i.e. support role and responsibilities) in ICs of people with LGG; this is the focus of the work presented in this chapter.

Across different cancers, ICs typically provide practical (e.g. medication management, transportation) and psychosocial support (e.g. alleviating stress, providing hope and motivation), with responsibilities increasing in line with the care recipient's level of symptom distress[94]. Furthermore, focus groups with ICs of cancer survivors found that ICs fulfil House's four dimensions of social support[98], including emotional (e.g. offering empathy), informational (e.g. giving advice), appraisal (e.g. aiding self-evaluation), and instrumental support (e.g. direct physical assistance)[99]. Frambes et al.[100] classified the care activities performed by ICs of cancer survivors into four categories: (1) 'Managing cancer and comorbidities', which encompasses the physical and emotional support; (2) 'Communication', for example, interactions with HCPs about the care recipient's symptoms, or discussing the diagnosis with children; (3) 'Decision making/problem solving' around medical treatment decisions and symptom management; and (4) 'Accessing community resources', including access to web-based information and support about the condition and its treatment.

The support provided by ICs may be influenced by the challenges faced by the care recipient because of the specific form of cancer and its treatment. For example, ICs of head and neck cancer survivors report responsibilities with managing nutritional issues and adapting to changed eating and mealtimes, due to impairments related to eating and swallowing[101]. Indeed, a mixed methods systematic review of 14 studies found that cognitive impairments and the uncertainty of disease progression influenced the perceived caregiving responsibilities of ICs of people with brain tumours, and their approach to providing support (e.g. desire to work from home to be there for the care recipient)[102]. However, existing evidence on the role of ICs of people with brain tumours is limited and largely concerns the support of people with HGG, who have higher dependency and a shorter prognosis than those diagnosed with a LGG[102,103]. In PP5[51], I develop the rationale for understanding the types of support provided by ICs of people with LGG (i.e. what the 'role' of an IC encompasses), and how these responsibilities are experienced.

5.1.2 The challenges of informal caregiving

To understand what might influence informal caregiving in cancer, Molassiotis et al.[104] presented five levels of factors, in accordance with a social-ecological model[105]: (1) 'Intrapersonal', such as age, occupation, income, and resilience; (2) 'Interpersonal', such as quality of relationship with, and functional status of, the care recipient; (3) 'Institutional', such as timing of healthcare appointments and communication between ICs and HCPs; (4) 'Community', such as transportation, informal support networks (e.g. family and friends), and support from non-governmental organisations; and (5) 'Policy/environmental', such as financial compensation from the government. ICs are often thrust into a role that they are not prepared for[106] and have substantial information support needs around the condition and its treatment, knowing what to expect (e.g. symptoms and side-effects), and caregiving expectations (i.e. role and responsibilities)[107,108]. Qualitative evidence suggests this can be influenced by the quality of IC-HCP communication and available resources; where this is poor or lacking, it has been described as 'disempowering'[95] and leading to ICs of people with glioma feeling 'left in the dark'[109]. Evidence suggests that ICs of people with glioma benefit from information and advice on managing daily challenges[110]. Thus, identifying and meeting information support needs may be important for ensuring an IC feels empowered to provide appropriate support to the care recipient.

It is well documented in the cancer literature that ICs may also experience substantial personal consequences following the care recipient's diagnosis, particularly related to fatigue and emotional issues[107,111]. A systematic review of quantitative studies found that caregiving burden (i.e. the stress of caregiving) and psychological challenges have been shown to negatively affect QoL in ICs of people with brain tumours[108]. Using the caregiver needs screening tool, Pointon et al.[112] suggest that the most distress for ICs of people with brain tumours stems from care recipients' changes in memory and fatigue, and the uncertainty of disease progression. Indeed, other published work from the Ways Ahead interviews with ICs has discussed the substantial emotional impact experienced by ICs of people with LGG[97] (*Appendix B.5*). While an IC's physical and emotional health status may influence their ability to support the care recipient[95], for the context of this thesis, the focus is on understanding how ICs experience the *provision* of support. The intention here is to comprehend the feasibility of ICs' role in supporting self-management. Hence, there is a separate need for future research to further explore the physical and emotional health of ICs of people with LGG.

Across different cancers, ICs commonly report challenges with maintaining (full-time) employment[113]. This is due to balancing the need to work to overcome the financial strain, where the care recipient is unable to work[111], and adjusting to a relationship dynamic that requires the IC to be more active in caregiving, childcare, and domestic roles[114]. Systematic reviews of qualitative research have found that such challenges can be exacerbated by the IC's general desire to put the needs of the care recipient before their own, to reduce the risk of distress for the care recipient[109,115]. This informs the rationale for a qualitative approach in PP5[51], to understand how ICs experience their role in supporting people with LGG, and identify any challenges faced.

5.2 PP5: "It's a delicate dance" How informal caregivers experience the role and responsibilities of supporting someone living with a lower-grade glioma

Rimmer, B., Balla, M., Dutton, L., Burns, R., Araújo-Soares, V., Finch, T., Lewis, J., Gallagher, P., Williams, S., Menger, F., & Sharp, L. (2024) "It's a delicate dance" How informal caregivers experience the role and responsibilities of supporting someone living with a lower-grade glioma. Neuro-Oncology Practice, *12*(2), 340–350.

Neuro-Oncology Practice

12(2), 340–350, 2025 | https://doi.org/10.1093/nop/npae096 | Advance Access date 14 October 2024

“It’s a delicate dance”: How informal caregivers experience the role and responsibilities of supporting someone living with a lower-grade glioma

Ben Rimmer, Michelle Balla, Lizzie Dutton, Richéal Burns, Vera Araújo-Soares, Tracy Finch, Joanne Lewis, Pamela Gallagher, Sophie Williams, Fiona Menger, and Linda Sharp

All author affiliations are listed at the end of the article

Corresponding Author: Ben Rimmer, Population Health Sciences Institute, Newcastle University, Ridley Building 1, Newcastle upon Tyne, NE1 7RU, England (ben.rimmer@newcastle.ac.uk).

Abstract

Background: People with lower-grade gliomas (LGG) often require long-term support with a condition that causes substantial symptom burden and is likely to progress. Partners, family, and friends often become informal caregivers (IC), but the types of support they provide, and their experiences of this, have not been well investigated. We aimed to understand how ICs experience the role and responsibilities of supporting people with LGG.

Methods: This descriptive qualitative study used semistructured interviews to explore the role and responsibilities of a purposive sample of ICs across the United Kingdom, who currently, or in the past 5 years, support(ed) someone with an LGG. Interviews were audio-recorded and transcribed, and an inductive thematic analysis was conducted.

Results: Nineteen ICs were interviewed (mean age 54.6 years; 5 males/14 females). While most participants spoke about “Being a ‘carer’,” the level of care provided varied. Participants conveyed their experiences with “Adjusting for cognitive difficulties,” “Emotional protection,” “Supporting participation in daily life,” and “Healthcare advocacy.” ICs often felt “abandoned” by healthcare services to provide required care themselves, and reported experiences with “Balancing the challenges of caregiving,” including conflict with work/childcare. Issues around “Maintaining the care recipient’s independence” were interwoven throughout.

Conclusions: ICs of people with LGG provide wide-ranging support to help manage the consequences of the illness. Consideration of ways to help ICs with the challenges of fulfilling this role, particularly, balancing support provision without inhibiting the care recipient’s independence, could help improve outcomes for ICs and people with LGG.

Keywords

informal caregiving | role | responsibilities | lower-grade glioma | qualitative

Lower-grade gliomas (LGG; eg, grade 2 astrocytoma and grade 2 or 3 oligodendroglioma[1]) are largely diagnosed in adults in their 30s and 40s,[2] and account for approximately 15% of all gliomas, which are the most common group of malignant brain tumors.[3] LGGs are incurable and will progress to high-grade glioma (HGG), limiting life expectancy to 5-15 years following diagnosis, with shorter progression-free survival in people with grade 2 astrocytomas, compared to oligodendrogliomas.[3,4] People with LGG often experience changes in social roles, functions of everyday living, and loss of independence,[5] as a result of numerous, often co-occurring, symptoms and impairments (eg, fatigue, seizures, cognitive deficits, personality changes, and mobility issues)[6] arising from/consequent to the tumor and its treatment. This can have a profound impact on both the individuals, and their family, with the impact exacerbated by the relatively long-term prognosis.

Family members and friends, particularly partners of people living with and beyond cancer, often adopt the role of informal caregiver (IC), which pertains to the provision of ongoing support and care, without pay.[7] ICs have an integral role in helping the care recipient to manage the consequences of their illness[8]; in studies in other cancers, the support provided typically encompassed emotional (eg, maintaining positivity)[7,9] and practical support (eg, housework, transport, and finances),[10,11] as well as assisting with healthcare decision-making.[9,12,13] The weight of responsibility of fulfilling the role and responsibilities of being an IC is often unrecognized.[14,15]

There is a growing evidence base of studies that have investigated the experiences of ICs who support someone with a brain tumor.[16,17] While these studies suggest some similarities with the support provided by ICs of other cancers,[18,19] people with LGG may also have similar caregiving needs to people with acquired brain injuries (eg, cognitive support).[20] Indeed, the brain tumor literature highlights the importance of, and need for, cognitive support (eg, strategies to facilitate memory),[21,22] due to potential cognitive impairments.[23] However, existing studies largely include samples of ICs in support of people with HGG who, typically, have a much shorter prognosis and higher physical dependency than those diagnosed with an LGG.[19,21] Only one study appears to have reported any data on the support role of ICs for people with LGG,[24] though their focus concerned the impact of being an IC, rather than ICs' experiences of providing different types of support. A better understanding of these experiences is important for considering whether ICs feel able to provide the support required by people with LGG and what support ICs themselves might need to fulfill this role. Consequently, this study aimed to understand how ICs experience the role and responsibilities of supporting someone with an LGG.

Methods

Design

This qualitative study, part of the wider multi-method Ways Ahead project,[25] used semistructured interviews to generate data on the lived experiences of being an IC for someone with an LGG, primarily to understand how ICs experience the role and responsibilities of supporting people with LGG. As this is an area where little is known, this study was descriptive in design to recognize, and facilitate exploration of, the subjective and diverse nature of participants' experiences.[26] Due to the richness of the collected data, we have reported elsewhere on the emotional impact of being an IC for someone with an LGG[27]; the 2 papers are thus complementary. Ways Ahead was reviewed and approved by the Wales Research Ethics Committee (REC ref: 20/WA/0118).

Participants and Recruitment

Individuals were eligible if they lived in the United Kingdom, were aged 18 years or older, and were family members or friends who identified themselves as currently supporting, or having supported in the past 5 years, someone with an LGG (defined, in this study, as someone with a grade 2 astrocytoma or grade 2 or 3 oligodendroglioma).[1] Individuals who were bereaved at the time of recruitment, but were a caregiver in the past 5 years, were considered eligible. Purposive sampling was used to recruit a range of ages, sex, and relationships to the care recipient.

Recruitment occurred through one of 2 avenues: (1) healthcare professionals at collaborating National Health Service (NHS) sites provided potentially eligible individuals with an information sheet; (2) the study was advertised through the Brain Tumour Charity, with the information sheet attached. Individuals were approached, using the terms "family-member or friend" (rather than "carer"). The information sheet provided a brief introduction to the study and the researchers conducting the interviews. To register interest, individuals were asked to call or email the study team. The researchers (B.R. and L.D.) subsequently telephoned each individual to confirm eligibility and afford the opportunity to ask questions; if they were eligible and willing to take part, a convenient date and time for the interview was arranged. Participants were recruited between August 2020 and March 2022. Twenty-two of the 24 ICs that registered an interest in taking part were eligible; for the other 2, the care recipients did not have an LGG. Three people did not respond to attempts to schedule an interview.

Data Collection

Trained and experienced in qualitative research, B.R. (male, MSc, Research Assistant) and L.D. (female, PhD, Research Associate) conducted the interviews. As per interviewee preference, remote interviews were conducted using video-conferencing software (eg, Zoom) or telephone. Immediately prior to the interview, we acquired audio-recorded consent from all participants and collected basic demographics (eg, age, sex, employment, and relationship status).

Semistructured interviews followed a topic guide (Supplementary File 1) that was initially informed by the brain tumor caregiving literature, and modified following discussion with a patient and public involvement (PPI) panel, which included people with brain tumors ($n = 3$) and ICs of people with brain tumors ($n = 3$); members of the PPI panel did not take part in the study. The guide comprised open questions and was used flexibly, depending on what the participant spoke about and the order in which they discussed the issues. Any new issues raised throughout data collection were added to the topic guide to be explored in subsequent interviews.

We asked participants to broadly reflect on their experiences of supporting someone with an LGG. We also explored the interviewee's perceptions of how they and their care recipient had been impacted by the illness and consequent support needs across various areas (eg, emotions, relationships, and transport). We asked about the responsibilities and challenges involved in supporting the care recipient, as well as what, and when, (in)formal support was received or needed by the IC to help them fulfill their caring responsibilities. We used probing questions, where appropriate, to explore areas further. Throughout each interview, participants were encouraged to think beyond the period immediately following the initial diagnosis. There were opportunities during the interview for participants to raise any additional issues they wished to discuss. To finish, a postinterview sheet with details of charities and helplines was provided, and as a thank you, we offered participants a £20 voucher. Each interview was audio-recorded and lasted on average 85 minutes (range 54-110 minutes). During each interview, the researcher took field notes for their own reference.

Data Analysis

Interviews were transcribed verbatim and anonymized. We conducted an inductive thematic analysis[28] on the entire dataset, and report here data *specifically* related to the role and responsibilities of ICs. This approach to analysis was chosen for its ability to develop data-driven patterns of meaning, and therefore, help understand how ICs might experience their role and responsibilities in different ways.

We took several steps to ensure rigor (eg, credibility, dependability, and confirmability)[29] throughout data analysis: (1) We conducted data collection and analysis in parallel to ensure that any new issues raised were explored in subsequent interviews. (2) Following familiarization with the data, B.R. and M.B. (both trained in qualitative research) independently generated initial codes, using NVivo, for a sample of transcripts ($n = 5$ of 19). (3) B.R. and M.B. discussed preliminary codes to create a combined code list; B.R. applied this to the remaining transcripts, adding any new codes as the analysis progressed (and also returning to annotate earlier transcripts with these new codes). Codes and uncertainties were regularly discussed within the research team as this process progressed. (4) B.R. organized these codes to construct preliminary themes at the semantic level; these themes were modified and refined following discussion with the wider analysis team (M..B and L.S.). (5) We ceased recruitment once data sufficiency occurred; this was determined by the researchers' judgment that there was sufficient data to understand ICs' lived experiences of supporting people with LGG, and specifically for this paper, how ICs experience the role and responsibilities of supporting someone with an LGG.[30] Each participant was given a summary of findings and afforded the opportunity to provide feedback. The finalized themes are reported below.

Results

Participant Characteristics

Nineteen ICs were interviewed (7 recruited through NHS sites; 12 through the Brain Tumour Charity). Fourteen participants were female; at the interview, mean age of all participants was 54.6 years (range 36-78 years), and 13 were employed (Table 1). All except one participant was married. Fifteen participants were spouses, 2 were sisters, and 2 mothers of people with LGG. Fifteen participants lived in the same household as the care recipient. Six participants (all spouses) had children aged <18 years. None of the participants were bereaved.

Overview of Findings

We constructed 7 themes, shown in Figure 1 with supporting quotes in Table 2, accompanied by the IC's age at the interview and relationship to the care recipient. While most participants perceived themselves as having assumed a caring role, the level of care provided varied (overarching theme "Being a 'carer'"). Participants reported their experiences with specific responsibilities, which encompassed "Adjusting for cognitive difficulties," "Emotional protection," "Supporting participation in daily life" and "Healthcare advocacy." Underpinning the support themes, participants described experiences with "Balancing the challenges of caregiving," which influenced their ability to fulfill their caring role and responsibilities. Participants' attempts to find a balance between providing care and "Maintaining the care recipient's independence" were interwoven across all themes.

Being a "Carer"

In this theme, participants outlined their role as a "carer" and the level of care they provide to help the care recipient to manage their illness. Many participants reported a shift in their relationship dynamic with the care recipient; this involved a change from being in a partnership with the care recipient to taking on a greater weight of responsibility as a "carer." However, this shift did not necessarily mean the care recipient needed direct care or lacked independence, rather the IC began to feel a greater general concern for their well-being.

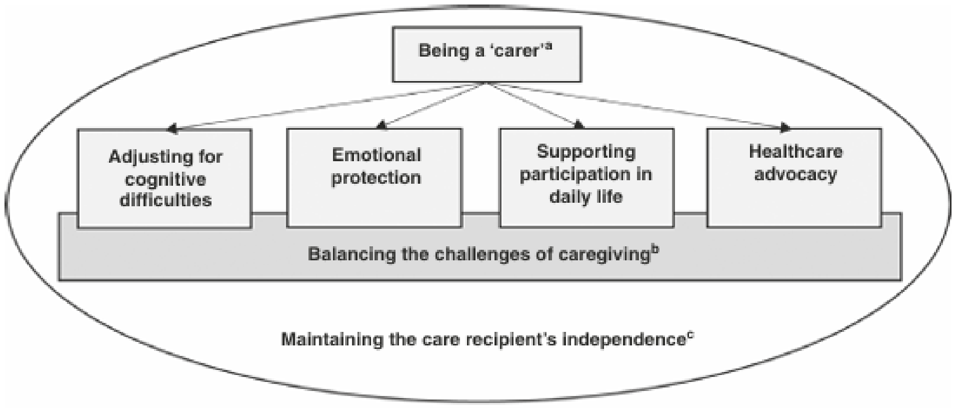
The level of care required by the person with LGG, and what was needed to facilitate that, varied across participants. For some ICs, it was important that they were physically close to the care recipient as often as possible to feel that they could be there for them. Other participants described the need to adjust their expectations of what was their responsibility, and what was the care recipient's responsibility (eg, them doing more of the housework). A few participants reported changes in their occupational roles (eg, going part-time) to allow them to maintain employment while feeling able to provide the care required.

Adjusting for Cognitive Difficulties

This theme encompassed the reported (need for) adjustment for impairments in the care recipient's memory, communication, and executive function. Most participants reported implementing strategies to facilitate the care recipient's memory; in relation to some things to be remembered (eg, social events, safety when cooking), participants were mindful to encourage or maintain the independence of the care recipient, by using prompts and reminders (eg, index cards, diary). However, for medication management, some ICs described how they felt the need to take more control (eg, setting their own alarms) to minimize the risk of missed medication and ensure, for example, the management of the care recipient's seizures. Several participants reported feeling the need to take a greater role in decision-making. How ICs aided decision-making varied;

Table 1. Informal caregiver participant characteristics (*n* = 19)

Characteristic	*n*	Characteristic	Mean (range)
Sex		*Full-time education (years)*	14.9 (10-18)
Female	14	*Relationship to care recipient*	*n*
Male	5	Wife	10
Age		Husband	5
≤ 40	3	Mother	2
41-50	3	Sister	2
51-60	8	*Relationship status*	
> 60	5	Married	18
Employment status		Single	1
Full-time employee	10	*Dependents*	
Part-time employee	3	None	13
Retired	4	One	3
Caring for family	2	Two	3
Co-habiting with the care recipient?			
Yes	15		
No	4		



[a] 'Being a 'carer'' is an overarching theme for the four support themes.
[b] 'Balancing the challenges of caregiving' underpins the carer and support themes.
[c] 'Maintaining the care recipient's independence' is a cross-cutting theme that is interwoven across all other themes.

Figure 1. Overview of themes for the role and responsibilities of being an IC for someone with an LGG

some ICs provided the care recipient with reassurance that a decision they (the care recipient) had made was reasonable or could be put into action. Others reported making larger decisions (eg, moving house) on the care recipient's behalf. A few participants detailed how the care recipient could struggle to communicate, especially when experiencing fatigue. In those instances, ICs described being patient and understanding with word-finding difficulties, giving the care recipient time to find the words.

Emotional Protection

In this theme, most participants reported efforts to protect the care recipient's emotional well-being, particularly related to managing the psychological consequences of living with an incurable illness. Most participants detailed the ways they provided companionship to the care recipient; this included simply "being there" for the care recipient, but also maintaining modified engagement in

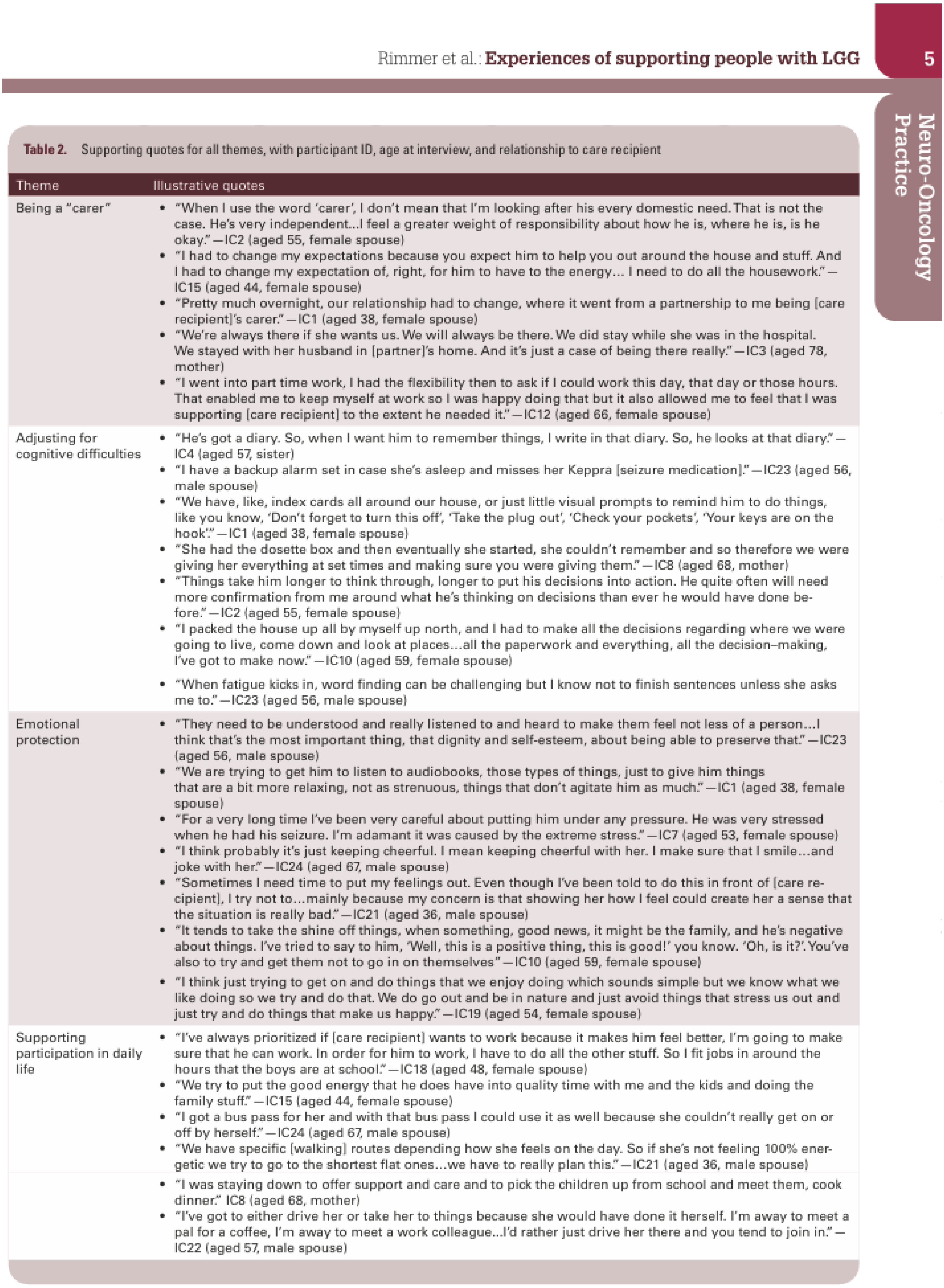


Table 2. Supporting quotes for all themes, with participant ID, age at interview, and relationship to care recipient

Theme	Illustrative quotes
Being a "carer"	• "When I use the word 'carer', I don't mean that I'm looking after his every domestic need. That is not the case. He's very independent...I feel a greater weight of responsibility about how he is, where he is, is he okay."—IC2 (aged 55, female spouse) • "I had to change my expectations because you expect him to help you out around the house and stuff. And I had to change my expectation of, right, for him to have to the energy… I need to do all the housework."—IC15 (aged 44, female spouse) • "Pretty much overnight, our relationship had to change, where it went from a partnership to me being [care recipient]'s carer."—IC1 (aged 38, female spouse) • "We're always there if she wants us. We will always be there. We did stay while she was in the hospital. We stayed with her husband in [partner]'s home. And it's just a case of being there really."—IC3 (aged 78, mother) • "I went into part time work, I had the flexibility then to ask if I could work this day, that day or those hours. That enabled me to keep myself at work so I was happy doing that but it also allowed me to feel that I was supporting [care recipient] to the extent he needed it."—IC12 (aged 66, female spouse)
Adjusting for cognitive difficulties	• "He's got a diary. So, when I want him to remember things, I write in that diary. So, he looks at that diary."—IC4 (aged 57, sister) • "I have a backup alarm set in case she's asleep and misses her Keppra [seizure medication]."—IC23 (aged 56, male spouse) • "We have, like, index cards all around our house, or just little visual prompts to remind him to do things, like you know, 'Don't forget to turn this off', 'Take the plug out', 'Check your pockets', 'Your keys are on the hook'."—IC1 (aged 38, female spouse) • "She had the dosette box and then eventually she started, she couldn't remember and so therefore we were giving her everything at set times and making sure you were giving them."—IC8 (aged 68, mother) • "Things take him longer to think through, longer to put his decisions into action. He quite often will need more confirmation from me around what he's thinking on decisions than ever he would have done before."—IC2 (aged 55, female spouse) • "I packed the house up all by myself up north, and I had to make all the decisions regarding where we were going to live, come down and look at places…all the paperwork and everything, all the decision–making, I've got to make now."—IC10 (aged 59, female spouse) • "When fatigue kicks in, word finding can be challenging but I know not to finish sentences unless she asks me to."—IC23 (aged 56, male spouse)
Emotional protection	• "They need to be understood and really listened to and heard to make them feel not less of a person…I think that's the most important thing, that dignity and self-esteem, about being able to preserve that."—IC23 (aged 56, male spouse) • "We are trying to get him to listen to audiobooks, those types of things, just to give him things that are a bit more relaxing, not as strenuous, things that don't agitate him as much."—IC1 (aged 38, female spouse) • "For a very long time I've been very careful about putting him under any pressure. He was very stressed when he had his seizure. I'm adamant it was caused by the extreme stress."—IC7 (aged 53, female spouse) • "I think probably it's just keeping cheerful. I mean keeping cheerful with her. I make sure that I smile…and joke with her."—IC24 (aged 67, male spouse) • "Sometimes I need time to put my feelings out. Even though I've been told to do this in front of [care recipient], I try not to…mainly because my concern is that showing her how I feel could create her a sense that the situation is really bad."—IC21 (aged 36, male spouse) • "It tends to take the shine off things, when something, good news, it might be the family, and he's negative about things. I've tried to say to him, 'Well, this is a positive thing, this is good!' you know. 'Oh, is it?'. You've also to try and get them not to go in on themselves"—IC10 (aged 59, female spouse) • "I think just trying to get on and do things that we enjoy doing which sounds simple but we know what we like doing so we try and do that. We do go out and be in nature and just avoid things that stress us out and just try and do things that make us happy."—IC19 (aged 54, female spouse)
Supporting participation in daily life	• "I've always prioritized if [care recipient] wants to work because it makes him feel better, I'm going to make sure that he can work. In order for him to work, I have to do all the other stuff. So I fit jobs in around the hours that the boys are at school."—IC18 (aged 48, female spouse) • "We try to put the good energy that he does have into quality time with me and the kids and doing the family stuff."—IC15 (aged 44, female spouse) • "I got a bus pass for her and with that bus pass I could use it as well because she couldn't really get on or off by herself."—IC24 (aged 67, male spouse) • "We have specific [walking] routes depending how she feels on the day. So if she's not feeling 100% energetic we try to go to the shortest flat ones…we have to really plan this."—IC21 (aged 36, male spouse)
	• "I was staying down to offer support and care and to pick the children up from school and meet them, cook dinner." IC8 (aged 68, mother) • "I've got to either drive her or take her to things because she would have done it herself. I'm away to meet a pal for a coffee, I'm away to meet a work colleague...I'd rather just drive her there and you tend to join in."—IC22 (aged 57, male spouse)

Table 2. Continued

Theme	Illustrative quotes
	• "We had to fight for the critical illness insurance because part of his symptom was that he wasn't opening any mail and he didn't pay the bills."—IC18 (aged 48, female spouse) • "There's spare cash if you want to either put some in the savings or do you want to buy a pair of trainers?"...it's just really trying to help him to think this money needs to be used for something before you buy something else. I think if he was on his own, he would be in a dire situation right now."—IC14 (aged 37, female spouse) • "I feel like we've been very lucky because partly my job is sufficiently well paid that it was never going to be an impossible situation if [care recipient] couldn't carry on working."—IC13 (aged 51, male spouse)
Healthcare advocacy	• "I find I have to kind of go along, so I can [tell them what's wrong]... because [care recipient] would just tell them everything's fine."—IC15 (aged 44, female spouse) • "I try and watch her, I pay a lot of attention to her, just to see, because I get asked these questions with [doctor's name] and the like, if there's change a lot. So, I do try and pay attention."—IC22 (aged 57, male spouse) • "I looked up things a little bit and familiarized myself with things... a little bit of knowledge has helped us to think, 'Well that's okay. It's probably this,' or, 'When we go and see such and such person, it might be helpful if you ask them about that,' only doing that as a way to try and reassure him."—IC12 (aged 66, female spouse) • "I try to do a lot of learning about how his brain might be working. I would say my role is definitely patient advocate for [care recipient]."—IC18 (aged 48, female spouse) • "I did everything. I went on courses. I read about organic food. I went on brain tumor conferences. I just wanted to know everything."—IC7 (aged 53, female spouse) • "We also go to a specialist day center for brain injury...It took us a lot of working to get him into it. But when they met [person with LGG] and listened to me, there really was no question [about whether he should be there]."—IC1 (aged 38, female spouse) • "I also have to ensure that I've got them [appointment dates] because I suppose that's my control bit, isn't it? That's not to do with [care recipient] or the hospital, that's me. I need to know when it is so I've got it and I can work my work around it. But yes, I feel I need to know it so that we don't forget."—IC2 (aged 55, female spouse) • "I actually pushed, from day one, he did get some physio but, obviously, you only get so much physio, then it ends. But she got him a wheelchair, but then I said that it was too heavy for me to pick it up and put it in the car. So she got a lightweight one, and that was a very quick phone call."—IC10 (aged 59, female spouse)
Balancing the challenges of caregiving	• "A lot of the time it was quite difficult to have the conversations that you needed to have with even the medical staff because the children were there when they came home from school and you'd have a late afternoon phone call or something like that. It was quite difficult to have those conversations."—IC8 (aged 68, mother) • "You're just being led by them. I feel like if they're okay, I'm okay. If she's happy with what's going on, then I'm happy with what's going on. You sort of have to put them at the forefront"—IC6 (aged 50, sister) • "I needed to balance... I needed to put back what I wanted. I wanted to be there, to stay there, and to be the one taking her a cup of tea up, or whatever. But I had to accept that husbands come first."—IC3 (aged 78, mother) • "There isn't really that support there. Because who is going to take a 40-year-old man or a 12-year-old off your hands who has these medical needs or these disabilities?... it's having that understanding that...there are disabilities in my house. But you do feel like you are certainly abandoned just to care by yourself."—IC1 (aged 38, female spouse) • "I've had to do a lot of Googling myself to find out the dynamics of the tumor, what's going to happen, how it grows. I just don't think there's information out there even for... if a family member wanted to look up information, there's nothing."—IC14 (aged 37, female spouse) • "I had no idea what to expect as a consequence of the treatment. I just think, 'Gosh, what if we hadn't have said about that?' because it was only in passing."—IC2 (aged 55, female spouse) • "I've tried other things to help him remember but he doesn't really want to do it, like having a little diary with things written down for him but he doesn't really want to get involved."—IC19 (aged 54, female spouse)
Maintaining the care recipient's independence	• "It's a delicate dance, it's about me not doing too much for her. It's about communicating and saying, 'I'm going to put the laundry in unless you would like to do that today?'"—IC23 (aged 56, male spouse) • "The condition isn't physically yours it belongs to them, so you have to be led by them. As hard as that is sometimes, you have to be led by them and put yourself in their shoes... if they don't want all the fussing, you have to respect that."—IC6 (aged 50, sister) • "Even though she knew that things [her functioning] were going, she still wanted that independence and that movement and I didn't want to take that away from her. I wanted to try and help her more but she was determined."—IC8 (aged 68, mother) • "I feel like we've tried to carry on as normal, I think because [care recipient] has not been massively affected in terms of her personality and physical capability, that seems to have been manageable."—IC13 (aged 51, male spouse) • "I've had to try and be really strict and not remind him of things and just say, 'Look at your calendar,' but it's very hard to communicate."—IC7 (aged 53, female spouse) • "That is a hard thing because when you've been someone's carer and used to making all the decisions, when they get back to strength and they start making their own decisions, it's like, "Oh okay. I have to take a back seat now."—IC7 (aged 53, female spouse) • "I try and give him independence. He does small routes with the dog. He's got little routes that he does... I just want to care for him as best I can but still allow him that degree of independence."—IC14 (aged 37, female spouse)

enjoyable activities (eg, nature walks). Several participants reported the need to acknowledge and respect the care recipient's desired level of emotional support. They explained how they perceived that it was important to ensure that the care recipient felt listened to, and were not considered "less of a person" because of their limitations, or placed in a position where they felt overwhelmed from too much "fussing."

Some participants reported attempts to help the care recipient maintain a positive outlook, through open communication and reassurance to "try and get them to not go in on themselves." Some ICs reported the importance of affording the care recipient time and space to de-stress and relax when needed; sometimes they also arranged relaxing activities (eg, organizing audio books). A few ICs spoke about how they actively tried to avoid expressing negative emotions, or putting any pressure on the care recipient, to minimize the possibility of the care recipient becoming distressed; high-stress levels were believed by some ICs to be linked to seizure activity.

Supporting Participation in Daily Life

This theme encompassed the ways that participants described supporting the care recipient's participation in daily life, such as helping them to maintain social and occupational roles. Several participants reported how they sought to relieve the care recipient's responsibilities by assuming a greater role with, or arranging support for, childcare and housework (eg, cooking and cleaning). ICs detailed the importance of this for enabling the care recipient to channel their energy into work or "quality time."

Most participants reported providing support with transport; many described doing more driving to facilitate attendance to health appointments, work, or social activities, particularly while the care recipient's driving license was revoked due to the risk of seizures. Some participants acquired resources for the care recipient (eg, bus pass) to make it easier for them to use public transport; these ICs reported often still accompanying the care recipient, as cognitive impairments impacted journey planning. Many participants reported implementing a variety of practical strategies to manage the care recipient's challenges with fatigue and mobility (eg, risk of falls). This included adjustments to facilitate physical activity or continued engagement with hobbies (eg, taking breaks; planning shorter, manageable walking routes; and glamping instead of camping).

Several participants reported taking on more responsibility for household financial management, for example, ensuring prompt bill payments. In order to alleviate financial pressure, some ICs described a desire or pressure to earn sufficient income so that the care recipient did not need to work. Other participants encouraged the care recipient to budget and supported the maintenance of autonomy with financial management. A few participants described the challenges they experienced with convincing decision-makers that the care recipient's symptoms and impairments were severe enough to warrant financial support (eg, critical illness insurance, personal independence payments through the social welfare system).

Healthcare Advocacy

Most participants reported being an advocate for the care recipient's healthcare; this theme encompassed how this was approached. This included accompanying the care recipient to health appointments; a few suggested that this ensured well-being concerns (eg, fatigue and medication side-effects) were mentioned to the care team, as otherwise, the care recipient may "tell [the healthcare professional] everything's fine." Some ICs described collaborating with healthcare professionals and informing them when they noticed any changes in the care recipient's symptoms and functioning.

To equip themselves with the knowledge required to better advocate for the care recipient, the majority of ICs reported asking questions at health appointments, attending information events, or searching online. This included obtaining information about the care recipient's diagnosis, potential prognosis, symptoms and impairments, and strategies that could help the care recipient manage life with an LGG. For some ICs, this helped them feel able to reassure the care recipient about what is "normal" and inform what questions might be useful to ask the healthcare professionals in an appointment.

Due to the perceived importance of health appointments, particularly scan appointments, some participants described taking control to ensure follow-up appointments were scheduled and, once scheduled, were not forgotten. Many participants reported seeking and arranging support, particularly from allied health professionals or support services (eg, counseling and physiotherapy) on the care recipient's behalf; some highlighted that accessing support sometimes took a lot of perseverance.

Balancing the Challenges of Caregiving

In this theme, most participants described wide-ranging challenges that impacted their ability to fulfill their caregiving role and responsibilities; this theme, therefore, underpinned the other support themes. Several ICs reported balancing the conflict between providing support and maintaining childcare or employment, particularly in relation to healthcare involvement (eg, due to the timing of healthcare appointments). For some participants, this extended to a perceived need to put others' (eg, care recipient and children) needs before their own. Non-spousal ICs reported how not living with the care recipient impacted their ability to provide support. A few ICs spoke about feeling "abandoned" by the health services and a lack of formal support to provide respite for them, and described how this exacerbated the challenges they faced. Some participants perceived a lack of sufficient or appropriate information from healthcare professionals, often feeling they were left to look online themselves. For many ICs, this was compounded by challenges with health literacy, as not knowing what to expect often meant they did not know what knowledge was required to effectively advocate for the care recipient's healthcare. Some participants detailed instances of frustration where the care recipient did not welcome the support they provided, or where support was (or would be) resisted (eg, not wanting to use memory strategies).

Maintaining the Care Recipient's Independence

Most ICs spoke about the challenge of finding the balance between providing enough support, while trying not to do too much, to avoid limiting the care recipient's independence. This was interwoven across all other themes; when providing different types of support, ICs reported the planning and strategies they used to maintain the care recipient's autonomy (eg, communicating desired support, and using a calendar). Most ICs acknowledged the need to be led by the care recipient, and respect their desired level of support, without too much "fussing." Still, some participants reported that facilitating independence conflicted with the desire to "care for him as best I can." This was especially difficult in situations where it would be easier for the IC to just do something themselves for the care recipient (eg, housework). In instances where the care recipient's support needs decreased over time, many participants reported attempts to cede some responsibilities to the care recipient (eg, walking the dog and housework) and return to "normal," being mindful not to cause unnecessary stress for the care recipient. Some ICs described challenges with having to "take a back seat" when symptoms improved, after providing support for an extended period.

Discussion

Partners, family members, and friends, often assume the role of IC to help people with LGG to manage their illness. The supportive role and responsibilities of ICs for people with LGG have not been well investigated, with available literature largely focused on ICs of people with HGG. Our study, therefore, explored how ICs experience the role and responsibilities of supporting someone with an LGG, a group who have (sometimes much) longer prognoses and who can live with multiple, often co-occurring, symptoms and impairments.

ICs in our study reported their experiences with providing cognitive, emotional, and practical support, and being a healthcare advocate; the level of care provided varied across participants. The themes in our findings reflect several aspects of the social support and stress buffer hypothesis,[31] indicating that there are different types of social support that people provide. The breadth of support provided emphasizes the importance of ICs in helping people with LGG to manage their illness. Echoing this, in another part of the Ways Ahead project, which involved interviews with people with LGG, "receiving support from family and friends" was the most common self-management strategy reported.[32] The types of support reported in the present study largely reflect what is known about ICs' responsibilities from other brain tumor studies[18]; still, the paucity of evidence specifically focused on ICs of people with LGG means this study brings value in highlighting that the caregiving responsibilities known for ICs of people with HGG are also applicable to this population. The importance of this study is, therefore, in ensuring that the responsibilities and potential support needs of ICs of people with LGG are not overlooked.

Where this study provides unique insight is with the cross-cutting theme related to "Maintaining the care recipient's independence," which was interwoven across all other themes. Specifically, it was noteworthy that ICs often described challenges around trying not to do too much, particularly with the management of medication, health appointments, and finances. While these were perceived as important issues to "manage," ICs were often conscious of maintaining the care recipient's autonomy, acknowledging that taking too much control over these matters could have consequences for the independence of the care recipient. This appears to be a distinct challenge for ICs of people with LGG, compared to people with HGG, who have higher physical dependency and require more direct care.[19,21] Still, our findings suggest that ICs may sometimes lack confidence in the care recipient's ability to make important decisions. Healthcare providers can assess an individual's mental capacity to make a specific decision, if concerns are raised about their decision-making ability.[33] This is important because we have reported elsewhere from the interviews with people with LGG, that excessive or unsolicited support limited care recipients' independence and created a barrier to self-management.[34]

In terms of supporting participation in daily life, our findings go beyond previous caregiving studies in other cancers[10,35] and neurological conditions[36,37] to highlight how ICs may prioritize the needs of the care recipient over their own; for example, assuming increased household/childcare responsibilities to ensure the care recipient could preserve their energy for social activities. Moreover, ICs outlined the strategies they implemented to mitigate risk and distress for the care recipient, such as introducing index cards to adjust for cognitive difficulties. However, we also show that the care recipient needs to be willing to engage with the strategy, which could be influenced by tumor-related behavioral and personality changes (eg, lack of motivation or initiative).[38] This has further implications for whether a collaborative relationship dynamic can be achieved, that does not restrict the independence of the care recipient.[8] It may be valuable for healthcare providers to support, as part of rehabilitation, the *co-development* of acceptable self-management strategies with people with LGG and their ICs; these could be goal focused and work towards greater independence for the person with LGG, in turn potentially reducing carer load for the IC. We would endorse the calls from others for research into the effectiveness of cognitive rehabilitation in supporting the autonomy of people with brain tumors[39]; interventions in other contexts (eg, primary progressive aphasia) show the value of this, for example, rehabilitation to support ICs as communication partners.[40]

The provision of "emotional protection" was a strong theme in this analysis and is consistent with the wider caregiving literature in other cancers[7,9,35] and neurological conditions.[36,37] However, the incurable nature of LGGs may present a distinct challenge. For example, it was striking that our participants spoke about avoiding expressing negative emotions; while this may be done with the intention of "protecting" the care recipient, it might also reflect ICs' attempts to "protect" themselves, with avoidance of communication around "difficult" issues associated with anticipatory grief.[41,42] ICs in our study focused on ensuring the care recipient felt supported, through desired levels of companionship; this was, however, underpinned by the fact that it was sometimes difficult to "be there" for the care recipient, either due to not living with them or conflict with work responsibilities. While some participants described moving from full-time to part-time working to facilitate caregiving, we also found that ICs often felt responsible for alleviating financial pressures, where the care recipient was unable to work. This echoes how family resources adapt in families of people with brain tumors,[43] and suggests that the financial impact of LGG on families is worthy of further exploration.

The role transition to "Being a 'carer'" in our findings is consistent with other qualitative studies in ICs of people with brain tumors.[18] Still, the potential for a long-term prognosis in people with LGG means that the assumed role and responsibilities need to be sustainable. Here, we acknowledge that one-off interviews capture only a "snapshot" of experiences at a single timepoint; we also did not explicitly capture the time since the care recipient's diagnosis. Therefore, this study does not shed light on the trajectory of the caring role and responsibilities over time, whether or how this varies, and what might impact that trajectory. This is important because the breadth of support reported by our participants outlines where people with LGG may struggle if they do not have that support available within their informal networks. This warrants further investigation to highlight both, the experiences of people with LGG with weaker support networks, and timepoints across the illness trajectory when additional support may be required.

In earlier analyses of this dataset, we reported the constellation of emotional impacts experienced by these ICs,[27] and highlighted how ICs themselves benefit from a broad range of support (eg, opportunities for relief and opportunities to talk) to help them manage and adapt to their caregiving role.[44] To add to this, here, participants emotively described feeling "abandoned" by the healthcare system and reported that this was compounded by a lack of respite once they had made the shift to become carers. Moreover, our participants frequently reported challenges with a lack of, or difficulty finding, sufficient and appropriate information. Research in other cancers shows that ICs' unmet healthcare service needs could be related with decreased quality-of-life in ICs[45] and negatively impact the well-being of the care recipient.[46] Given that ICs of people with brain tumors report poor quality-of-life,[47] our findings and the issue of long-term sustainability accentuate the importance of finding ways to meet ICs' support needs. For example, ICs may benefit from stronger connections with healthcare professionals,[48] including integration, where possible, in the dissemination of advice and signposting to support.[49] Nonetheless, to ensure that care remains person-centered for people with LGG, such integration of ICs needs to be appropriately managed and align with the desires and priorities of the care recipient.

The practical insights from this study which could help better meet the needs of ICs are summarized in the box. Of course, it is important not to divorce the perspective of the care recipients from that of the ICs; while there was no data in our interviews with people with LGG that indicate they would not be open to these suggestions,[32,34] the care recipient's needs must be paramount. Therefore, careful consideration is needed of how to ensure their autonomy is maintained in implementing strategies to better support ICs.

Summary of practical insights from this study

- During the care recipient's rehabilitation, there is a need to co-develop acceptable, goal-focused self-management strategies that support the autonomy of people with LGG.
- There is a need for appropriately managed integration of ICs in the dissemination of information and support to facilitate the sustainable fulfillment of their caregiving role and responsibilities.
- When developing supportive care plans, there is a need to acknowledge how the support needs of each person with LGG may be influenced by the strength of their informal network.

Strengths and Limitations

Our findings are supported by multiple quotes; hence, we are confident that we generated sufficient data to understand how ICs experience the role and responsibilities of supporting someone with an LGG, who, to date, are an under-investigated study population. Our sample largely included spousal ICs, with the few non-spousal ICs often not living with the care recipient; the specific challenges experienced by this group would be worthy of further exploration. Although this analysis focused entirely on the responsibilities of the IC, we acknowledge that caregiving may not be one directional, and that the care recipient may also provide support to the so-called IC; this dynamic should be explored in future research. Due to Covid-19, most of our recruitment was via the Brain Tumour Charity, which may mean that we recruited ICs that have adopted a more "active" support role and a particular perspective on some issues. While we asked each participant for some information about the care recipient (eg, tumor type), we did not formally record this, so cannot report this here. Finally, some of the reported challenges (eg, regarding financial support and healthcare advocacy) may not be entirely transferable, as they may be somewhat dependent on the UK's healthcare, social welfare, and legal systems. For example, NHS healthcare is free at the point of delivery; in settings where this is different (eg, privatized healthcare in the United States), ICs may encounter different challenges, for example, with healthcare insurance. Nonetheless, the breadth of our findings means we still add substantial value to the limited evidence base.

Conclusions

This study explored how ICs experience the role and responsibilities of supporting people with LGG. ICs in our study offered wide-ranging support to help manage the consequences of the illness, emphasizing the value of their supportive role. However, the provision of care was underpinned by several challenges, particularly related to balancing support provision without inhibiting the care recipient's independence, and the need for information and support from healthcare services. Consideration of ways to help ICs manage the challenges faced is needed to facilitate the fulfillment of their supportive role, which could, in turn, help improve outcomes for ICs and people with LGG.

Supplementary material

Supplementary material is available online at *Neuro-Oncology Practice* (https://academic.oup.com/nop/).

Funding

The Ways Ahead study, of which this is part, was supported by funding from the Brain Tumour Charity (GN-000435).

Acknowledgments

This is an output for the Ways Ahead project (research.ncl.ac.uk/waysahead). We would like to thank our collaborating NHS sites, Newcastle upon Tyne Hospitals NHS Foundation Trust, NHS Lothian, The Christie NHS Foundation Trust, and South Tees Hospitals NHS Foundation Trust, as well as colleagues at the Brain Tumour Charity, for their assistance with recruitment to the project.

Conflict of interest statement

None declared.

Authorship statement

LS, PG, RB, JL, SW, VAS, TF: conceived the Ways Ahead study and secured funding; LS, BR, LD: designed study; BR, LD: data collection; BR, MB: data coding and analysis; BR: wrote initial draft; All authors: critically reviewed paper and approved final version for submission.

Affiliations

Population Health Sciences Institute, Newcastle University, Newcastle University Centre for Cancer, Newcastle upon Tyne, England (B.R., L.D., V.A.-S., L.S.); Faculty of Medical Sciences, Newcastle University, Newcastle upon Tyne, England (M.B.); Faculty of Science, Atlantic Technological University, Sligo, Ireland (R.B.); Health and Biomedical Strategic Research Centre, Atlantic Technological University, Sligo, Ireland (R.B.); Centre for Preventive Medicine and Digital Health, Department for Prevention of Cardiovascular and Metabolic Disease, Medical Faculty Mannheim, Heidelberg University, Heidelberg, Germany (V.A.-S.); Department of Nursing, Midwifery and Health, Northumbria University, Newcastle upon Tyne, England (T.F.); Newcastle upon Tyne Hospitals NHS Foundation Trust, Newcastle upon Tyne, England (J.L., S.W.); School of Psychology, Dublin City University, Dublin, Ireland (P.G.); School of Education, Communication and Language Sciences, Newcastle University, Newcastle upon Tyne, England (F.M.)

References

1. Louis DN, Perry A, Wesseling P, et al. The 2021 WHO classification of tumors of the central nervous system: a summary. *Neuro Oncol.* 2021; 23(8):1231–1251.
2. Bauchet L. Epidemiology of diffuse low grade gliomas. In: *Diffuse Low-Grade Gliomas in Adults*. Cham: Springer International Publishing; 2017:13–53.
3. Miller KD, Ostrom QT, Kruchko C, et al. Brain and other central nervous system tumor statistics, 2021. *CA Cancer J Clin.* 2021; 71(5):381–406.
4. Dixit K, Raizer J. Newer strategies for the management of low-grade gliomas. *Oncology (Williston Park).* 2017; 31(9):680–2, 684. https://europepmc.org/article/med/29071695. Accessed December 9, 2021.
5. Rimmer B, Balla M, Dutton L, et al.; Ways Ahead Study Team. "It changes everything" Understanding how people experience the impact of living with a lower-grade glioma. *Neurooncol Pract.* 2024; 11(3):255–265.
6. Rimmer B, Bolnykh I, Dutton L, et al. Health-related quality of life in adults with low-grade gliomas: a systematic review. *Qual Life Res.* 2023; 32(3):625–651.
7. Ullgren H, Tsitsi T, Papastavrou E, Charalambous A. How family caregivers of cancer patients manage symptoms at home: a systematic review. *Int J Nurs Stud.* 2018; 85(1):68–79.
8. Schulman-Green D, Feder SL, Dionne-Odom JN, et al. Family caregiver support of patient self-management during chronic, life-limiting illness: a qualitative metasynthesis. *J Fam Nurs.* 2021; 27(1):55–72.
9. Zeng Q, Ling D, Chen W, et al. Family caregivers' experiences of caring for patients with head and neck cancer: a systematic review and metasynthesis of qualitative studies. *Cancer Nurs.* 2022; 46(1):E41–E61.
10. Adashek JJ, Subbiah IM. Caring for the caregiver: a systematic review characterising the experience of caregivers of older adults with advanced cancers. *ESMO Open.* 2020; 5(5):e000862.
11. Palmer Kelly E, Meara A, Hyer M, Payne N, Pawlik TM. Understanding the type of support offered within the caregiver, family, and spiritual/religious contexts of cancer patients. *J Pain Symptom Manage.* 2019; 58(1):56–64.
12. Shaw J, Harrison J, Young J, et al. Coping with newly diagnosed upper gastrointestinal cancer: a longitudinal qualitative study of family caregivers' role perception and supportive care needs. *Support Care Cancer.* 2013; 21(3):749–756.
13. Dionne-Odom JN, Ejem D, Wells R, et al. How family caregivers of persons with advanced cancer assist with upstream healthcare decision-making: a qualitative study. *PLoS One.* 2019; 14(3):e0212967.
14. Mohammed S, Swami N, Pope A, et al. "I didn't want to be in charge and yet I was": bereaved caregivers' accounts of providing home care for family members with advanced cancer. *Psychooncology.* 2018; 27(4):1229–1236.
15. Taylor J, Fradgley E, Clinton-McHarg T, Byrnes E, Paul C. What are the sources of distress in a range of cancer caregivers? a qualitative study. *Support Care Cancer.* 2021; 29(5):2443–2453.

16. Ownsworth T, Goadby E, Chambers SK. Support after brain tumor means different things: family caregivers' experiences of support and relationship changes. *Front Oncol.* 2015; 5(1):33.
17. Boele FW, van Uden-Kraan CF, Hilverda K, et al. Attitudes and preferences toward monitoring symptoms, distress, and quality of life in glioma patients and their informal caregivers. *Support Care Cancer.* 2016; 24(7):3011–3022.
18. Chen D, Zhu J, Xu Q, et al. The role of informal caregivers for patients with glioma: a systematic review and meta-synthesis of qualitative studies. *Ann Transl Med.* 2021; 9(12):1020–1020.
19. Au TH, Willis C, Reblin M, et al. Caregiver burden by treatment and clinical characteristics of patients with glioblastoma. *Support Care Cancer.* 2022; 30(2):1365–1375.
20. Kivunja S, River J, Gullick J. Experiences of giving and receiving care in traumatic brain injury: an integrative review. *J Clin Nurs.* 2018; 27(7-8):1304–1328.
21. McConigley R, Halkett G, Lobb E, Nowak A. Caring for someone with high-grade glioma: a time of rapid change for caregivers. *Palliat Med.* 2010; 24(5):473–479.
22. Madsen K, Poulsen HS. Needs for everyday life support for brain tumour patients' relatives: systematic literature review. *Eur J Cancer Care (Engl).* 2011; 20(1):33–43.
23. Ford E, Catt S, Chalmers A, Fallowfield L. Systematic review of supportive care needs in patients with primary malignant brain tumors. *Neuro Oncol.* 2012; 14(4):392–404.
24. Edvardsson T, Ahlström G. Being the next of kin of a person with a low-grade glioma. *Psychooncology.* 2008; 17(6):584–591.
25. Rimmer B, Dutton L, Lewis J, et al. 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.
26. Doyle L, McCabe C, Keogh B, Brady A, McCann M. An overview of the qualitative descriptive design within nursing research. *J Res Nurs.* 2020; 25(5):443–455.
27. Rimmer B, Balla M, Dutton L, et al. 'A Constant Black Cloud': the emotional impact of informal caregiving for someone with a lower-grade glioma. *Qual Health Res.* 2024; 34(3):227–238.
28. Clarke V, Braun V. *Thematic analysis: a practical guide.* London: Sage; 2021.
29. Korstjens I, Moser A. Series: Practical guidance to qualitative research. Part 4: trustworthiness and publishing. *Eur J Gen Pract.* 2018; 24(1):120–124.
30. Low JA. Pragmatic definition of the concept of theoretical saturation. *Sociol Focus.* 2019; 52(2):131–139.
31. Cohen S, Wills TA. Stress, social support, and the buffering hypothesis. *Psychol Bull.* 1985; 98(2):310–357.
32. Rimmer B, Balla M, Dutton L, et al.; on behalf of the Ways Ahead study team. Identifying and understanding how people living with a lower-grade glioma engage in self-management. *J Cancer Surviv.* 2023:1–14.
33. Johnston C, Liddle J. The Mental Capacity Act 2005: a new framework for healthcare decision making. *J Med Ethics.* 2007; 33(2):94–97.
34. Rimmer B, Balla M, Dutton L, et al.; on behalf of the Ways Ahead study team. Barriers and facilitators to self-management in people living with a lower-grade glioma. *J Cancer Surviv.* 2024:1–14.
35. Mosher CE, Adams RN, Helft PR, et al. Family caregiving challenges in advanced colorectal cancer: patient and caregiver perspectives. *Support Care Cancer.* 2016; 24(5):2017–2024.
36. Hand A, Oates LL, Gray WK, Walker RW. The role and profile of the informal carer in meeting the needs of people with advancing Parkinson's disease. *Aging Ment Health.* 2019; 23(3):337–344.
37. Rajachandrakumar R, Finlayson M. Multiple sclerosis caregiving: a systematic scoping review to map current state of knowledge. *Health Soc Care Community.* 2022; 30(4):e874–e897.
38. Zwinkels H, Dirven L, Bulbeck HJ, et al. Identification of characteristics that determine behavioral and personality changes in adult glioma patients. *Neurooncol Pract.* 2021; 8(5):550–558.
39. Weyer-Jamora C, Brie MS, Luks TL, et al. Postacute cognitive rehabilitation for adult brain tumor patients. *Neurosurgery.* 2021; 89(6):945–953.
40. Volkmer A, Walton H, Swinburn K, et al. Results from a randomised controlled pilot study of the Better Conversations with Primary Progressive Aphasia (BCPPA) communication partner training program for people with PPA and their communication partners. *Pilot Feasibility Stud.* 2023; 9(1):1–21.
41. Zhang AY, Siminoff LA. Silence and cancer: why do families and patients fail to communicate? *Health Commun.* 2003; 15(4):415–429.
42. Yu W, Lu Q, Lu Y, et al. Relationship between anticipatory grief and communication avoidance in Chinese caregivers of patients with advanced cancer. *Cancer Nurs.* 2022; 45(4):E728–E735.
43. Jung M, Jeong Y, Park BJ. Adaptation of families of adult patients with brain tumor: partial least squares structural equation modeling. *PLoS One.* 2023; 18(5):e0285677.
44. Murrell AJ, Rimmer B, Dutton L, et al. The nature and quality of support from informal networks for informal caregivers of low-grade glioma patients: a qualitative analysis within the ways ahead study. Weller D, ed. *Eur J Cancer Care (Engl).* 2023;2023(1):1–12.
45. Hanly P, Maguire R, Balfe M, et al. Burden and happiness in head and neck cancer carers: the role of supportive care needs. *Support Care Cancer.* 2016; 24(10):4283–4291.
46. Hodgkinson K, Butow P, Hunt GE, et al. Life after cancer: couples' and partners' psychological adjustment and supportive care needs. *Support Care Cancer.* 2007; 15(4):405–415.
47. Tallant J, Pakzad-Shahabi L, Lambert SD, Williams M, Wells M. Quality of life in caregivers of patients with brain tumours: a systematic review and thematic analysis. *Eur J Cancer Care (Engl).* 2023;2023(1):1–12.
48. Guldager R, Nordentoft S, Poulsen I, Aadal L, Loft MI. Wants and needs for involvement reported by relatives of patients with a malignant brain tumour: a scoping review. *JBI Evid Synth.* 2023;21(11):2188–2210.
49. Kent EE, Rowland JH, Northouse L, et al. Caring for caregivers and patients: research and clinical priorities for informal cancer caregiving. *Cancer.* 2016; 122(13):1987–1995.

5.2.1 PP5 commentary

This descriptive qualitative study represents the most comprehensive understanding to date of how ICs experience the role and responsibilities of supporting someone with a LGG. An inductive thematic analysis[79] was considered appropriate here to develop data-driven insights into how ICs support people with LGG in day-to-day life. It was valuable here to go beyond the care activities classified in existing frameworks (introduced in section 5.1.1)[100] to ensure that the findings in PP5[51] also encapsulated ICs' general perceptions of caregiving and the key challenges they faced. The caregiving responsibilities reported by ICs mirror the areas identified in PP2[48] where people with LGG may require support (e.g. with cognitive impairment), and the support received from family and friends in PP3[49] (e.g. emotional, practical). Since people with LGG and IC participants were largely not 'linked' (see chapter 2.1), this mirroring is not due to participants being dyads. The key message in PP5[51] is that ICs can be very influential in the care of people with LGG; the implication of this is that there could be areas where support may be deficient for people with LGG with 'weaker' support networks. Still, it must be stressed that there is a fine balance with ensuring that ICs support people with LGG without inhibiting their independence. This goes beyond recognising the types of support provided by ICs, to comprehend how the actions of the IC can both create, and help overcome, barriers to self-management. The implications of these concerns are summarised in section 5.3 below.

5.3 Chapter summary

The work presented in this chapter recognises the wide-ranging supportive role and caregiving responsibilities that may be assumed by those closest to people with LGG. The findings from PP5[51] outline how ICs may be influential in realising the potential for supported self-management in people with LGG. Still, the support provided by ICs can only be supplemental to the formal healthcare support required by people with LGG. This is due to concerns around maintaining the care recipient's independence, ICs' access to support and information, and potential resistance to support from the care recipient. This has important clinical and future research implications for the development and implementation of supported self-management interventions. Specifically, these findings demonstrate a need to appropriately manage the integration of ICs, to ensure support remains person-centred and encourages independence; this is discussed further in chapters 7.3.1 and 7.4.2.

Chapter 6: The implementation potential of self-management support for people with lower-grade gliomas

The previous chapters (3 and 4) recognise the importance of, and challenges impeding, engagement in self-management for people with LGG. Chapter 5 adds an understanding of the support provided by ICs and how that can help and hinder self-management. Combined, this work identifies a need for self-management support from formal networks (e.g. HCPs, third sector organisations), to empower support recipients and their ICs with the tools and information they need to overcome the evidenced challenges. Therefore, this chapter presents a broad overview of the considerations required to implement self-management support in follow-up care for people living with and beyond cancer. This includes: (1) understanding the support role of HCPs and whether HCPs feel prepared to provide self-management support; (2) the implementation and potential shortcomings of existing self-management interventions for cancer survivors; and (3) the implications of the widely used NPT[116] on the implementation of complex interventions. The presented publication (PP6[52]) aimed to use the lens of NPT to identify and understand the implementation considerations for providing self-management support to people with LGG. This included the perspectives of the support providers (i.e. HCPs involved in the care of those with brain tumours) and potential support recipients (i.e. people with LGG).

The chapter is organised as follows: introduction to the key considerations for self-management support from healthcare settings; PP6; PP6 commentary; chapter summary.

6.1 Key considerations for self-management support from healthcare settings

6.1.1 Healthcare professional views on supporting self-management

In cancer care, HCPs have a key role in enabling and empowering their patients to feel able to engage in self-management[14]. Evidence from palliative cancer care HCPs suggest that they typically view self-management to be desirable and achievable[117], though acknowledge that the support required by each individual can be diverse and dynamic, requiring the HCP to adopt different supportive roles. A qualitative study of HCPs' views of self-management for advanced cancer patients suggest these roles may include being instructive (i.e. HCP leads in directing patient self-management), collaborative (i.e. integration of patient- and professional-directed strategies, with clear delineation of tasks) and advisory (i.e. HCP follows patient-directed strategies, with a holistic approach)[118]. However, the authors of this study also found that determining the appropriate supportive role to adopt for each patient is challenging and can be influenced by the HCP's own preferences and expectations (e.g. perceived urgency of required support)[118].

HCPs' knowledge and self-efficacy have been identified as important characteristics that influence their preparedness to support self-management in ambulatory cancer care (i.e. medical care provided on an outpatient basis)[119]. There is evidence to support the effectiveness of a self-management support training programme for oncology nurses and cancer coaches with improving confidence in 15 support skills (e.g. goal setting, tailoring strategies, developing action plans)[120]. While such training may be a beneficial consideration, studies have reported that HCPs may experience challenges with patient attitudes and behaviours (e.g. resistance to support/advice) and finding a balance with providing support while promoting autonomy[117]. A literature review of self-management in cancer noted the importance of developing strong patient-provider relationships to co-create an action plan for supported self-management[14]. This could help HCPs have a clear understanding of what their support role and responsibilities are and determine in which circumstances the care recipient should take responsibility for their own self-management.

Barriers to providing self-management support in cancer care also exist at the organisation level, with varying levels of organisation readiness (e.g. staffing levels, workflow, budget), and variations in staff and leadership cultures that influence whether self-management support can be systematised in routine practice[119]. In a realist review of self-management support in survivors with a variety of different cancers, Kantilal et al.[121] summarised that HCPs will engage in supported self-management if they have: (1) appropriate knowledge and consultation skills; (2) a clear understanding of their role and responsibilities; and (3) the priorities and configuration of their organisation facilitates ease of delivery. Overall, HCPs may be willing to support self-management, but several factors could influence their perceived ability to deliver this support. For people with brain tumours, there is no evidence of the factors that need to be understood and overcome at the individual, HCP, or organisation level, to facilitate self-management support. Addressing this gap is critical for underpinning the implementation of self-management support for people with LGG.

6.1.2 Current implementation of self-management interventions for cancer survivors

There is a growing evidence base to support the effectiveness of self-management interventions for improving outcomes in cancer survivors[19–21], and increasing demand for supported self-management to become part of routine practice[18]. Despite this, there is little evidence of successful implementation of self-management interventions in cancer care. For example, under a third of eligible hospitals agreed to implement ‘Oncokompas’ (a web-based self-management application for cancer survivors), when researchers conducted a national implementation pilot study in the Netherlands[122]. A commentary from Ways Ahead (*Appendix B.2*) on the implementation of self-management interventions for cancer survivors[123], questions “Why are we not there yet?”. This presented five key areas as essential prerequisites for translation of self-management interventions from research into practice: (1) ensuring interventions are *adaptable* to different patient populations; (2) ensuring interventions are *acceptable* and *feasible* to support providers and recipients; (3) ensuring *transparency* in the description of intervention components and characteristics; (4) conducting *process evaluations* to understand what did or did not work; and (5) examining *cost-effectiveness* to help policy-makers determine the cost-benefit of implementation.

Online self-management resources have been found to be acceptable and useful for cancer survivors[124], indicating that their incorporation in routine care could be beneficial. However, there are few online resources to provide self-management advice that is applicable to people with brain tumours[125]. Chapter 3 highlighted the distinctive lived experiences of people with LGG, emphasising the need for adaptability of self-management resources to different cancer populations. This includes ensuring that resources are accessible to all, so that health inequalities are not exacerbated, for example, because of digital exclusion (e.g. lack of appropriate devices or data) or in those with technology literacy or cognitive difficulties[126,127].

In a systematic review of self-management interventions for cancer survivors, Cuthbert et al.[24] found substantial heterogeneity in the design and components of interventions, with variability of effects across outcomes. As introduced in chapter 1.1.3, this makes it difficult to understand what makes an intervention effective, hindering translation into clinical practice. To address these issues with systematic description of interventions, a systematic review from Ways Ahead[27] (*Appendix B.4*) identified 32 interventions for cancer survivors that were explicitly described as being about self-management and measured QoL as an outcome. To improve transparency and advance understanding of what works, we mapped intervention characteristics (e.g. provider, location) and components (e.g. training for psychological strategies) to the Template for Intervention Description and Replication (TIDieR) checklist[128] and PRISMS taxonomy[16], respectively. We then examined associations of each characteristic and component with QoL, finding that improvements were most consistently associated with combined individual and group delivery (characteristic), information about condition and its management, and training for practical strategies (components). Understanding what is worth adapting from existing interventions may increase the likelihood of effectiveness in subsequent intervention development for people with cancer. This could also help organisations recognise where to target training efforts with developing self-management support skills. Overall, developing evidence for approaches to supporting self-management that are widely acceptable (by support providers and recipients), replicable and adaptable, as appropriate, is crucial for stimulating the necessary culture shifts at the HCP and organisation levels[119,129].

6.1.3 Normalisation process theory and its implications

With the identified need to improve the translation of self-management interventions from research into routine care, more needs to be done to understand implementation processes and required changes to care pathways[123]. Following an identified gap in the theoretical space, NPT was developed to offer a consistent, and generalisable framework of generative mechanisms of social action for the implementation of complex interventions in everyday practice[116]. This theory encompasses four core constructs: (1) ‘Coherence’, which concerns individual and collective sense making of the importance, aims, responsibilities, and benefits of a set of practices; (2) ‘Cognitive participation’, which concerns the relational work needed to initiate, drive forward, and sustain involvement in a new set of practices; (3) ‘Collective action’, which concerns the operational work, including the interaction, skills, and resources required to enact and maintain confidence in a set of practices; and (4) ‘Reflexive monitoring’, which concerns the appraisal of a new set of practices to assess and understand its worth and effectiveness at an individual and communal level.

The value of NPT has been demonstrated across a wide range of healthcare settings, for example: in a complex intervention aimed at reducing risk in primary care prescribing[130]; the implementation of a new group therapy for people with mental health problems[131]; or normalising provider-initiated testing and counselling for HIV[132]. In a systematic review of 108 studies of complex healthcare interventions and related implementation processes, May et al.[133] found that NPT was a useful aid for intervention development and implementation planning, offering a framework to evaluate and understand the required implementation processes. NPT may, therefore, be useful in the implementation process of self-management interventions for cancer survivors generally and people with LGG specifically. For example, understanding the ‘collective action’ of supporting self-management could provide clarity on the delineation of responsibilities between support providers and recipients. Indeed, section 6.1.1 indicated that clarity on individual responsibilities was influential for whether HCPs would engage cancer survivors in discussions about self-management[121].

The future implementation of an intervention should be considered from the outset of intervention development. It may be valuable to consider NPT in formative research to shape and improve implementation processes in the design and evaluation of an intervention, *before* implementation. This could help inform the development of healthcare interventions that are feasible and compatible with clinical practice[134]. In turn, this may increase the likelihood that policy makers and support providers will feel willing and able to support and embed self-management interventions in routine practice. This informed the decision to look at implementation considerations through the lens of NPT in PP6[52], to offer an understanding of how to operationalise, sustain and appraise self-management support for people with LGG.

6.2 PP6: Understanding supported self-management for people living with a lower-grade glioma: implementation considerations through the lens of normalisation process theory

Rimmer, B., Finch, T., Balla, M., Dutton, L., Williams, S., Lewis, J., Gallagher, P., Burns, R., Araújo-Soares, V., Menger, F., & Sharp, L. (2024). Health Expectations, 27(3), e14073.

Received: 22 December 2023 | Revised: 16 February 2024 | Accepted: 2 May 2024
DOI: 10.1111/hex.14073

ORIGINAL ARTICLE

WILEY

Understanding supported self-management for people living with a lower-grade glioma: Implementation considerations through the lens of normalisation process theory

Ben Rimmer MSc, Research Assistant[1] | **Tracy Finch PhD, Professor[2]** |
Michelle Balla MSc, Research Assistant[3] | **Lizzie Dutton PhD, Research Associate[1]** |
Sophie Williams QiCN, Clinical Neuropsychologist[4] |
Joanne Lewis FRCR, MRCP, Consultant Clinical Oncologist[4] |
Pamela Gallagher PhD, Professor[5] | **Richéal Burns PhD, Lecturer[6,7]** |
Vera Araújo-Soares PhD, Professor[1,8] | **Fiona Menger PhD, Lecturer[9]** |
Linda Sharp PhD, Professor[1] | **Ways Ahead study team**

[1]Population Health Sciences Institute, Newcastle University Centre for Cancer, Newcastle University, Newcastle upon Tyne, UK

[2]Department of Nursing, Midwifery and Health, Northumbria University, Newcastle upon Tyne, UK

[3]Faculty of Medical Sciences, Newcastle University, Newcastle upon Tyne, UK

[4]Newcastle upon Tyne Hospitals NHS Foundation Trust, Newcastle upon Tyne, UK

[5]School of Psychology, Dublin City University, Dublin, Ireland

[6]Faculty of Science, Atlantic Technological University, Sligo, Ireland

[7]Health and Biomedical Strategic Research Centre, Atlantic Technological University, Sligo, Ireland

[8]Department for Prevention of Cardiovascular and Metabolic Disease, Centre for Preventive Medicine and Digital Health, Medical Faculty Mannheim, Heidelberg University, Heidelberg, Germany

[9]School of Education, Communication and Language Sciences, Newcastle University, Newcastle upon Tyne, UK

Abstract

Background: Supported self-management can improve clinical and psychosocial outcomes in people with cancer; the considerations required to implement self-management support (SMS) for people living with a lower-grade glioma (LGG)—who often have complex support needs—are not known. We aimed to identify and understand these implementation considerations through the lens of normalisation process theory (NPT), from the perspectives of healthcare professionals (HCP) and people with LGG.

Methods: We conducted semistructured interviews with HCPs who support adults with brain tumours ($n = 25$; 12 different healthcare professions), and people with LGG who had completed primary treatment ($n = 28$; male $n = 16$, mean age 54.6 years, mean time since diagnosis 8.7 years), from across the United Kingdom. Interviews were transcribed and inductive open coding conducted, before deductively mapping to constructs of NPT. We first mapped HCP data, then integrated data from people with LGG to explore alignment in experiences and perspectives.

Results: We generated supporting evidence for all four NPT constructs and related subconstructs, namely: 'Coherence', 'Cognitive participation', 'Collective action' and 'Reflexive monitoring'. Data from HCPs and people with LGG clearly demonstrated that effective SMS constitutes a collective activity.

The Ways Ahead study team comprises, in addition to the named authors, Sara Erridge, Pauline Sturdy and Catherine McBain.

Correspondence
Ben Rimmer, Population Health Sciences Institute, Newcastle University, Ridley Bldg 1, Newcastle upon Tyne NE1 7RU, UK.
Email: ben.rimmer@newcastle.ac.uk

Funding information
Brain Tumour Charity, Grant/Award Number: GN-000435

Key implementation considerations included: ensuring awareness of, and access to, support; building strong HCP-support recipient relationships; and careful inclusion of close family and friends. We identified pertinent challenges, such as identifying support needs (influenced by the extent to which those with LGG engage in help-seeking), resistance to support (e.g., technology literacy), training for HCPs and HCP cooperation.

Conclusions: This study demonstrates the collective nature of, and provides insight into the individual roles within, supported self-management. We outline considerations to operationalise, sustain and appraise the implementation of SMS for people with LGG.

Patient or Public Contribution: People with brain tumours, and informal caregivers, were involved in the development of information materials and topic guides to ensure accessibility and pertinence. They also had opportunities to comment on interview findings.

KEYWORDS
healthcare professionals, lower-grade gliomas, normalisation process theory, self-management support

1 | INTRODUCTION

With rising survival rates and growing numbers of people living with and beyond the disease, cancer is increasingly considered a chronic condition. Self-management in the context of cancer is defined as the 'awareness and active participation by the person in their recovery, recuperation, and rehabilitation to minimise the consequences of treatment, and promote survival, health, and wellbeing'.[1] There is an expanding evidence base to support the potential effectiveness of self-management interventions for improving clinical, psychosocial, and economic outcomes in people with cancer.[2,3] However, self-management is not one individual's responsibility; healthcare professionals (HCPs), family and friends have a crucial role in ensuring the person can effectively engage in self-management.[4] Indeed, self-management strategies are more likely to be effective when planned together with support from HCPs.[5]

In 2020, there were an estimated 300,000 new diagnoses, worldwide, of primary brain and central nervous system tumours[6]; amongst the most common of these were gliomas, which can be high- or low-grade.[7] People with lower-grade gliomas (LGG) have a life expectancy of 5–15 years following diagnosis,[8,9] and can experience wide-ranging symptoms and impairments (e.g., fatigue, seizures, cognitive deficits) that adversely affect health-related quality of life.[10,11] These impacts may persist long-term, particularly concerning fatigue and emotional impact.[12] Consequently, people with LGG may have prolonged, multifaceted supportive care needs; it is, therefore, important to identify how they can be supported and empowered to self-manage their condition.

People with LGG have shown a willingness to engage in self-management, reporting the use of a diverse and extensive number of self-management strategies; the most common strategy type was 'using support' (e.g., receiving support from family).[13] This complements the finding that people with brain tumours desire timely access to information and support from HCPs to help them self-manage (e.g., development of shared self-management care plans for support recipients and their family).[14] However, little is known about how HCPs perceive their role in providing self-management support (SMS) for people with LGG. In a study of advanced cancer (which did not focus on brain tumours), HCPs differed in their practices, adopting varied instructive, collaborative or advisory approaches to SMS.[15]

There was a recent 'call to action' for self-management in cancer care, calling for a shift in care culture from people being passive recipients to active partners in their care, to embed co-created person-centred SMS.[16] Therefore, attitudes towards, and the acceptability of SMS, are crucial implementation considerations[17] which need to be understood from both the HCP and support recipient perspective. Furthermore, for SMS to be successful, the barriers to implementation at the organisational and HCP level also need to be understood and overcome.[18]

In other cancers, the few available studies indicate that key HCP barriers to implementation of SMS included time, communication between HCPs and appropriate knowledge and training[19,20]; in addition, lack of HCP confidence in providing SMS led to reduced motivation.[21] A competency framework has been developed to inform SMS training for cancer nurses[22]; however, healthcare organisations need to be ready and willing to implement SMS, which requires a process of change.[23] For people with LGG specifically, the considerations required to implement SMS are poorly understood.

Normalisation process theory (NPT)[24] offers a generalisable framework outlining the generative mechanisms of social action and the considerations required to implement a new practice into routine care. NPT has been used in a diverse range of healthcare settings to explain the implementation processes of complex interventions.[25] Therefore, our study aimed, for the first time, to use the lens of NPT to identify and understand the considerations required to implement SMS for people living with an LGG, from the perspectives of HCPs and people with LGG.

2 | METHODS

2.1 | Design

This qualitative study, part of the wider Ways Ahead project,[26] generated data on HCPs' and people with LGGs' experiences of (supporting someone) living with an LGG; the present analysis focused on the considerations that may influence the implementation of SMS. Ways Ahead was reviewed and approved by the Wales Research Ethics Committee (REC ref: 20/WA/0118).

2.2 | Participants and recruitment

HCPs were eligible if they were a member of a relevant multidisciplinary team (MDT), involved in the care of adults with brain tumours (e.g., clinical nurse specialist); or were involved in the support of adults with brain tumours outside of National Health Service (NHS) care pathways (e.g., counsellors).

People with a diagnosis of grade 2 or 3 oligodendroglioma or grade 2 astrocytoma, based on histology or molecular features[27] were eligible if they were aged ≥18 years at diagnosis, resident in the United Kingdom, and were stable under observation, or had completed primary treatment; hereafter, we refer to these as people with LGG.

We identified potentially eligible HCPs and people with LGG through collaborating NHS sites and The Brain Tumour Charity networks. People with LGG require multidisciplinary management, so in addition to consultant clinical oncologists and neurosurgeons, there are clinical nurse specialists, and some services may have additional roles (e.g., Occupational Therapist, Clinical Neuropsychologist). Therefore, we used purposive sampling to ensure HCP recruitment comprised a range of healthcare professions, across the United Kingdom. Recruitment of people with LGG comprised of a range of ages, sex, diagnoses and time since diagnosis (1–5, 6–10, >10 years).

For NHS sites, HCPs within their respective MDTs, and people with LGG identified from medical records, were given an information sheet by the principal investigator or another HCP at the site. For The Brain Tumour Charity networks, B. R. linked the information sheet to a study advertisement, which was disseminated through the charity's newsletters. HCPs and people with LGG were asked to register their interest by calling or emailing the study team; B. R. called each interested person to answer any potential questions, then if confirmed as eligible and willing to participate, arranged a convenient date and time for interview. We conducted recruitment between August 2020 and May 2022; recruitment continued until we judged that reasonable data sufficiency was achieved.[28]

2.3 | Data generation

B. R. and L. D., both trained and experienced in qualitative research, remotely conducted semistructured interviews, via a phone or video call (e.g., Zoom or Teams), as per interviewee preference. Immediately before each interview, audio-recorded consent was acquired, and demographic information was collected (e.g., from people with LGG: sex, age, diagnosis, treatment; from HCPs: profession, years working with people with brain tumours).

We used separate topic guides for HCP and people with LGG interviews (Files S1 and S2); each comprised open questions informed by the literature and expert knowledge. Both topic guides were reviewed by HCPs (J. L. and S. W.); the topic guide for people with LGG was also reviewed by a brain tumour Patient and Public Involvement panel and modified appropriately. Any new issues raised in an interview were added to the respective guide, to be explored in subsequent interviews.

For HCP interviews, participants were first asked to broadly reflect on their role in supporting people living with a brain tumour. We then explored participants' views on the support needs of people with LGG, how these needs are identified, what support is available following treatment completion, including their perception of, and role in supporting, self-management and any challenges faced in providing support.

For interviews with people with LGG, participants were first asked to broadly reflect on life following their diagnosis. We then explored participants' views on how they had been impacted by the tumour and its treatment, how they had managed, their perceived support needs and whether support was received, including their experiences with seeking, receiving, and engaging with, healthcare support. People with LGG were offered a £20 voucher as a thank you for their time and given details of relevant charities and helplines on a postinterview sheet, which they could consult if they wanted further information or support.

Across both interview sets, we used probing questions to explore further, and all participants were afforded the opportunity to raise any additional issues of importance to them. We audio-recorded each interview; interviews lasted on average 72 min (48–93 min) for HCPs and 102 min (54–167 min) for people with LGG.

2.4 | Data analysis

Interviews were transcribed verbatim and anonymised; transcripts were checked for accuracy against the audio-recordings. The present analysis aimed to identify and understand what might influence the implementation of SMS for people with LGG. We commenced

TABLE 1 Normalisation process theory construct definitions, key findings and supporting quotes.

NPT construct	Key finding	Supporting quotes
Coherence—The sense-making work that people do individually and collectively when they are faced with the problem of operationalising some set of practices		
Differentiation Understanding how a set of practices are different from each other.	• HCP: aim to promote independence • BUT people with LGG: loss of independence	• We want to make these patients as independent as we absolutely can. You know, we want them to take responsibility of their cancer, of how things are. HCP14 (Clinical Nurse Specialist) • It's all about self-management as well, trying to give them the strength and the confidence to access what they need when they need it and be a bit more independent. HCP33 (Clinical Nurse Specialist) • I try and work around what the issue is so that the person can still stay independent in making themselves a meal, but they would do it differently. They just wouldn't do it from scratch in maybe the traditional way that they would do it. HCP49 (Occupational Therapist) • The loss of my licence and independence. I think loss of independence is probably the biggest [challenge]. I suppose having to rely on others to do a lot of things. Pa22 (aged 43, female, grade 2 astrocytoma)
Communal specification People working together to build a shared understanding of the aims, objectives, and expected benefits of a set of practices.	• HCP: who takes responsibility (not one individual's responsibility) • HCP and people with LGG: perceived importance of support network	• Helping [the support recipient] to understand that they have responsibilities too. They can have the responsibility to self-manage themselves by changing the way that they think. HCP21 (Physiotherapist) • We can give information and be a sounding board and we can help them to make a decision, but we can't tell them what the right thing is for them because they know themselves best. We quite often use those phrases, 'You're the experts about yourself. You know yourself best. So, we can give you the information to help you make a decision but it's your decision'. HCP43 (Specialist allied health professional) • There is a large degree of responsibility that falls on family and relatives to keep [the support] going. HCP36 (Occupational Therapist) • When you're married and working, you've got your support group and you've got your life. But when you're on your own and quite poorly, you've got nothing. Pa20 (aged 47, female, grade 3 oligodendroglioma)
Individual specification The individual's understanding of their specific tasks and responsibilities around a set of practices.	• HCP: perceived role in self-management support (empowering people with brain tumours and family, providing tools, listening to needs to develop goals) • BUT people with LGG: support is treatment focused	• Our role is helping to just make sure the patients have got the information that they need, that they are signposted to information and support about health and wellbeing and helping to make sure that the patients have got good quality of life really. (HCP45, Clinical Nurse Specialist) • There's lots of other ways that we can help people to have psychological wellbeing which doesn't necessarily

TABLE 1 (Continued)

NPT construct	Key finding	Supporting quotes
		mean a one-to-one session, there are leaflets, websites, self-help, group work, peer support, charity, third sectors, all of that I think is relevant. So, I think I see it as structured or supported self-management. HCP18 (Clinical Neuropsychologist) • It's very much listening and knowing the patient, knowing where they're at in terms of their journey, their pathway and unpicking what sort of things can be put in. So, it's not just a psychological thing, physical thing, it's all of them basically. HCP39 (Clinical Nurse Specialist) • There are some things I can do for you. And there's some things you can do for yourself. And what is missing is the second bit from consultations. It's all about what they can do to you to treat your tumour, not treat you as a person. Pa17 (aged 51, female, grade 3 oligodendroglioma)
Internalisation Understanding the value, benefits and importance of a set of practices.	• HCP: perception of self-management	• Self-management, as I understand it, is being able to upscale or educate the patient in ways that they can actually look after themselves with regards to any issues that have come in, being aware of red flags that then they would need to contact us. HCP49 (Occupational Therapist) • Self-management to me is about empowering somebody with the right information and resource, access to resource to be able to take more ownership on your health and wellbeing and actually you're saying what you want done basically. HCP39 (Clinical Nurse Specialist) • For epilepsy, I would say [self-management] is more about keeping yourself seizure free so it's about good compliance, keeping yourself healthy and sharing that you've reduced all your triggers and reaching for help as soon as you see a decrease in your seizure control. HCP52 (Epilepsy Nurse Specialist)
Cognitive participation—The relational work that people do to build and sustain a community of practice		
Initiation Whether or not key participants are working to drive a new set of practices forward.	• HCP and People with LGG: engagement in help-seeking (insight, desire not to be a burden) • HCP and People with LGG: signposting to available support • People with LGG: support has to be sought	• It's hard, isn't it, to say in an appointment, 'Well, this has really traumatised me. I need some help with this'. It's quite difficult to say that. Pa10 (aged 37, female, grade 2 oligodendroglioma) • Patients don't tend to recognise how they've changed, or they don't really want to tell you that something's changed in their needs. HCP48 (Neurooncology Support Sister) • I'm actually in the process of developing a leaflet to give to all patients with [support] details on so that they've got it so if and when they feel like they need some support there's options, websites and things. HCP18 (Clinical Neuropsychologist)

(Continues)

TABLE 1 (Continued)

NPT construct	Key finding	Supporting quotes
		- The lack of information is probably worse—you know, not being able to find it, from not being told about what is available, and not knowing about [hospital] or the outreach services, community outreach, things like that. All of this stuff I have found, basically, it came up by accident. Pa13 (aged 52, male, grade 3 oligodendroglioma) - I think it's sometimes like it's for me to put the pieces together. I'm not sure everybody would really be in the position to do that, so I think that's one thing I've learnt about the health service, it's in compartments and joining those compartments is down to you sometimes. Pa28 (aged 66, male, grade 2 astrocytoma)
Enrolment Need for people to organise or reorganise themselves and others to collectively contribute to the new practices.	- HCP and People with LGG: Influence of support network on self-management - People with LGG: need for reliance on others - HCP: availability of/challenges accessing available support	- Everybody's got a different story, a different amount of support mechanisms, so some people need more support than others. Some have huge family support and friend support and don't maybe need as much help, really. HCP21 (Physiotherapist) - They're only 15 minutes or something when you see your doctor. I'll come out and I won't remember any of it. I always have to have either my dad or my partner with me, or I need it to be written down and summarised or emailed. Pa26 (aged 37, female, grade 2 oligodendroglioma)
		- I only go to the pub, for example, if I'm going with a friend, I could not go on my own to somewhere like that. When I've been on my own and I've had seizures before in the public, well it's something that I really don't like. Pa25 (aged 45, male, grade 2 oligodendroglioma) - [People with brain tumours] lack a lot of the support stuff that other cancers get. You know, if you look at breast cancer—the media interest in that, the number of celebrities that have been … you know, brain tumours are the poor relation and have been for years. HCP29 (Consultant Clinical Oncologist) - In the community, there are a variety of brain injury services. So, they offer rehabilitation for clients who have neurological conditions. Unfortunately, for many of our clients, they are excluded from those services though, basically because they're considered to have a condition that is progressive. HCP37 (Clinical Neuropsychologist)
Legitimation Ensuring that participants believe it is right for them to be involved and they can make a valid contribution.	- HCP and People with LGG: resistance to support (beliefs: acceptance, desire for 'normality') - HCP and People with LGG: support accessibility (location)	- Unless people can accept or reach a point where they're kind of accepting they can't really put in those changes or they struggle to really put those changes in and the ones that do better with me are the ones that are working through that grieving process and that

TABLE 1 (Continued)

NPT construct	Key finding	Supporting quotes
		process of my identity's completely changing and coming to that place of acceptance. Whereas the ones that I find really hard to engage are the ones that are really struggling with that process. HCP3 (Occupational Therapist) • If I'm totally frank there are still lots of moments where I don't really believe [I have a brain tumour], I obviously do believe it, I've had the surgery but where you, I don't know how to describe it, where you look at yourself in the mirror and you think, 'I can't believe this is happening'. Pa40 (aged 31, female, grade 2 astrocytoma) • Each area has different services, so we've still got that postcode lottery problem. HCP43 (Specialist allied health professional) • Sometimes brain care teams only support based on the postcode that your doctor is in. This lady came back to me and said, 'I can't get the support. The doctor is in a different area'. Pa18 (aged 55, female, grade 3 oligodendroglioma)
Activation Participants need to collectively define the actions and procedures needed to sustain a practice and stay involved.	• HCP: identifying those with support needs (keeping tabs) • HCP and people with LGG: opportunity to report needs; need for sustained support • HCP and People with LGG:	• Once [the support recipient] is in the system and they're known to us, there's options but I guess I'm a bit worried about those whose needs never get identified. HCP18 (Clinical Neuropsychologist) • I feel like some patients probably do

TABLE 1 (Continued)

NPT construct	Key finding	Supporting quotes
	maintaining awareness of available support • HCP and people with LGG: resistance to support (actions: nonattendance/compliance)	get lost into the system a little bit and we are reliant on them ringing us and not everybody does that. They just don't want to bother you, or they feel like you might be too busy. HCP21 (Physiotherapist) • We introduced, quite a while ago, the screening tool, which has been sent out to compliment that consultation but allows them an opportunity, they should get it before the consultation, so it brings to mind what—so that they think about what difficulties am I having? HCP37 (Clinical Neuropsychologist) • I think it depends a lot on individuals. How can they find their way through all this themselves because I think you are, at the moment, thrown back on your own resource system to make your way through this minefield. Pa28 (aged 66, male, grade 2 astrocytoma) • I think from our point of view it's probably the information side and probably reiterating where they can get information from later down the line if they don't want to use it there and then because quite often people aren't ready to accept their diagnosis so it's about recapping it later on and catching back up with them. HCP52 (Epilepsy Nurse Specialist) • I think the difficulty we have as health professionals is

(Continues)

TABLE 1 (Continued)

NPT construct	Key finding	Supporting quotes
		knowing exactly what [support] is out there and what changes and what's available. We do try and have a database, but it changes. So, keeping up to date with what's available as well is quite difficult. HCP21 (Physiotherapist) • It's the lack of access to stuff that is probably the biggest problem, and it doesn't help. Not knowing about what you can get access to is probably the biggest problem. Pa13 (aged 52, male, grade 3 oligodendroglioma) • You've got your patients who you just try and help, and you try and encourage, but they'll ring you up and they want help, but then they don't accept your advice or offers to signpost or whatever or refer to whatever. HCP33 (Clinical Nurse Specialist)
Collective action—The operational work that people do to enact a set of practices		
Interactional workability The interactional work that people do with each other and elements of a set of practices, when they seek to operationalise in everyday settings.	• HCP: co-ordination between HCPs (referral pathways) • HCP: co-operation of other HCPs (jointly delivered support) • People with LGG: communication between HCPs • HCP and People with LGG: including family in support provision	• The nurses will sometimes refer people in. Most of our referrals come from the inpatient occupational therapists. We really struggle with getting the consultants to refer to us. I don't know why. HCP3 (Occupational Therapist) • Everything's being dealt with as a separate entity. And I think if we can get one service to merge into another, to then merge into another, that line of communication, that line of smoothness, I think we'd be looking at increasing somebody's quality of care with these brain tumours. HCP1 (Clinical Nurse Specialist) • [neuro-consultant] dealt with the first bit of [care] and then she handed me on to, they had lots of multidisciplinary team meetings and you're part of that, and then you get passed onto the appropriate person, in this case it was the neurosurgeon. And so, information seemed to get lost in some of that. You're sort of passed around. Pa5 (aged 56, male, grade 2 oligodendroglioma) • Where possible we try and involve family in discharge planning discussions and kind of future planning discussions. We involve them as much as we can because it's as much their tumour as it is the patient's tumour in some senses, especially when you're looking at the low-grade tumours that have got quite a long life expectancy. HCP36 (Occupational Therapist) • [partners] need to understand what's going on. They need to be supporting you, yes, definitely. I don't know where I'd be without my wife. Pa33 (aged 45, male, grade 2 oligodendroglioma)
Relational integration The knowledge work that people do to	• HCP and people with LGG: importance of HCP-support recipient	• Some of my patients, they feel as if you're the one ... because I do my job, I'm the one who should be there

TABLE 1 (Continued)

NPT construct	Key finding	Supporting quotes
build accountability and maintain confidence in a set of practices and in each other as they use them.	relationships (social skills, trust, reassurance)	for their beck and call. I'm the one that should be making the decisions. I'm the one that, you know, that's my job. They don't particularly take on responsibility. HCP2 (Clinical Nurse Specialist) • We think that you're at this level and this is why and just giving them examples. But you have to have a good rapport with that patient to be able to talk like that. It's a fine line between agitating them and trying to get them to realise that there's a problem. HCP44 (Occupational Therapist) • I'm sure that all [healthcare professionals] are medically highly skilled, but obviously that's not the only bit of the job is it. You have to understand people. Understand how they're're feeling. Know how to speak to them. Make them feel reassured at what is a very frightening period in their life. Pa28 (aged 66, male, grade 2 astrocytoma) • As soon as we went in there [the consultant] was almost like, 'I want to put your mind at rest about this', kind of thing. Even though it's become more serious … I think she even said, 'The treatment for this we can get for you is better'. So, it's worse but we can do more for you for it, kind of thing. Whatever she said was really reassuring. Pa32 (aged 46, female, grade 3 oligodendroglioma)

TABLE 1 (Continued)

NPT construct	Key finding	Supporting quotes
Skill set workability The allocation work that underpins the division of labour that is built up around a set of practices as they are operationalised in the real world.	• HCP: expertise and training needs • HCP and people with LGG: cognitive and symptom challenges • HCP and People with LGG: health and technology literacy	• If you are managing or leading a service, you sometimes lead to your strengths, just as I am doing. And our support, unknowingly, has been missing out on a few key aspects because that's not within my expertise. HCP17 (Macmillan centre manager) • It's very hard to self-manage if a memory deficit is there because at the end of the day a prompt is needed to set the prompt. Because she couldn't write the list herself or couldn't set the phone reminders reliably. So, I think if you're truly isolated, that has a massive impact on how successful you are going to be. HCP28 (Consultant Clinical Oncologist) • The reminders on the iPhone are good but you try to remember things. That again that adds to your brain ache if you like, you're trying to collate all this stuff while you're worrying about it. Pa5 (aged 56, male, grade 2 oligodendroglioma) • My concern is those people that need more than [support groups] or can't access it for barriers of communication, digital, financial or cognitive or visual or purely because they don't have the digital knowledge to be able or the wish to access the support in that way. HCP50 (Specialist allied health professional) • All sorts of ages and technical competences and some people won't [access the

(Continues)

TABLE 1 (Continued)

NPT construct	Key finding	Supporting quotes
		support], if they've got to do it online. It's hard, it's difficult. Pa16 (aged 69, male, grade 3 oligodendroglioma)
Contextual integration Managing a set of practices through the allocation of different kinds of resources and the execution of protocols, policies, and procedures.	• HCP: financial and equipment resources • HCP: time, flexibility, and waiting lists • HCP: staff availability • People with LGG: transport and financial resources	• Financial I suppose is just about the biggest and probably the only [challenge], you could say this for any service across the NHS, couldn't you, that it could be better and more comprehensive in an ideal world if there were more resources. HCP51 (Speech and Language Therapist) • There is always room for service improvement. There is always room to benchmark against other centres, and to improve outcomes for patients, and I think it's just … sometimes that gets lost in amongst the rotation of just dealing with everyday … day to day things, you know. HCP14 (Clinical Nurse Specialist) • Our low-grade glioma patients, quite often after their surgery, the only person that's in contact with them is me or the physio. The support pathway after that isn't very well established or there. Then after me, they might have a three-month post-op meeting with the consultant but that will be the next time they see someone. HCP3 (Occupational Therapist) • When I saw my naturopath … and again, I was paying, like, £60 a session. So, I saw him for a while, but I couldn't … and

TABLE 1 (Continued)

NPT construct	Key finding	Supporting quotes
		then in between there was always things to buy and it just got too expensive. Pa17 (aged 51, female, grade 3 oligodendroglioma)
Reflexive monitoring—The appraisal work that people do to assess and understand the ways that a new set of practices affect them and others around them		
Systemisation Participants seek to determine how effective and useful the set of practices are for them and for others.	• HCP and people with LGG: need to avoid information overload • HCP: developing support recipient identity and control • HCP: managing expectations	• They do say that [the amount of information] is too much. You know, quite often, we … well, I'll acknowledge, and they will acknowledge that I have given them a huge amount of information. HCP29 (Consultant Clinical Oncologist) • In an ideal world you'd have all of this information at your fingertips because anybody with a brain tumour doesn't want to receive a plethora of post with loads of paper because you're still getting to grips with the fact that you have a debilitating, longstanding illness and it's a tumour and it's cancerous. Pa18 (aged 55 female, grade 3 oligodendroglioma) • So that they can take control and they are part of the decision-making, rather than just a person or a number. It's bringing it to life, isn't it, and empowering them to see that they can take an active participation in that treatment and support. HCP17 (Macmillan centre manager) • One of the lessons that I need to learn and to remind myself of, is the importance of self-care which can be done in a way that is not selfish in

TABLE 1 (Continued)

NPT construct	Key finding	Supporting quotes
		orientation but needful to make the most of. You can't give to the world if you're not giving to yourself in a way. Pa14 (aged 66, male, grade 2 oligodendroglioma) • With a lot of the brain tumour patients we've got to help them to be quite realistic and support that as an ongoing thing. So, I guess it's important to address that although support might help them, it's not going to fix all of their problems but help them manage their problems themselves. HCP36 (Occupational Therapist)
Communal appraisal Participants work together to evaluate the worth of a set of practices.	• HCP: scope of support provision (number reached; variation in needs) • HCP: clarify benefits to end-users	• The numbers are low. So, I get some rare cancer types and people go, 'I just want to talk to another person with the same cancer as me'. That person is probably in Scotland, or that person is in Brighton. You know, the numbers just aren't there. HCP17 (Macmillan centre manager) • [Offered support] is going to depend on the individual, where they're at in their journey and what they need and what they prefer as well. HCP18 (Clinical Neuropsychologist) • I think self-management would need to be promoted as a really ... 'This is the reason we are doing it. It's a really positive thing, and we need you to help us identify these bits, because we can positively make a difference. We can help you by x, y, and z'. So, in a way, it's about telling people why you are doing it —'with this in mind ... it's going to make a difference because...' HCP29 (Consultant Clinical Oncologist)
Individual appraisal Participants work experientially as individuals to appraise its effects on them and the contexts in which they are set.	• HCP and people with LGG: perception of support groups (social comparisons) • People with LGG: appreciation of self-management support	• The Maggie's centre works with the cancer nurse specialists, and they have some great [support groups], so we encourage and suggest those groups or look at where the patient lives. HCP17 (Macmillan centre manager) • Some people if they've got a low-grade tumour and they're aware that could progress over time, might not want to face that in a support group really. They might want to deal with it themselves. So, they might not want to see people further down the line and sort of see what's going to happen. HCP45 (Clinical Nurse Specialist) • The thing with brain tumour sufferers, patients or whatever, is that everyone's different. Everyone, because the brain is such a complicated organ, depending on where it is, what it is, everyone's different. It's so difficult to get common ground with other brain tumour patients. Pa5 (aged 56, male, grade 2 oligodendroglioma) • I go on the brain tumour support groups. So, I use that for a lot of information. Plus, you

(Continues)

TABLE 1 (Continued)

NPT construct	Key finding	Supporting quotes
		can give advice to other people and people can give advice to you of their experiences and that which is quite a good help sometimes. Pa30 (aged 61, male, grade 3 oligodendroglioma) • The thing is I know that if that situation changes, then the good thing is through the medical team, the multi-district team at [hospital], through family and friends, and through things like The Brain Tumour Charity, that there will be the support for me, should those situations change. Pa15 (aged 55, male, grade 2 astrocytoma)
Reconfiguration Appraisal may lead to attempts to redefine procedures or modify practices.	• HCP: including family requires careful consideration (need permission)	• We'll quite happily, if someone wants us to speak to their partner, as long as [the support recipient] gives permission we'll give them a ring and chat through. HCP52 (Epilepsy Nurse Specialist) • I've had an issue where I had a lady and a son and daughter, she couldn't communicate together. And basically, the patient was, like, piggy in the middle. And I would have the three of them phoning every single day, even discovering different versions of the story, and it became very intense for myself, and I tried to offer advice that only one of them liaise with mum and it's about working together as a family. HCP48 (Neurooncology Support Sister) • Occasionally, we get ex-partners, and we don't know whether the patient wants us to talk to them. It can come from a bad place. So, we do try to be careful to check that the patient is okay with us talking. HCP28 (Consultant Clinical Oncologist)

Abbreviations: HCP, healthcare professional; LGG, lower-grade glioma.

analysis with an inductive, open coding approach; B. R. and M. B., both trained in qualitative analysis, independently generated initial codes following familiarisation with a subset of transcripts of people with LGG ($n = 6$ of 28) and HCPs ($n = 5$ of 25). The coding frame was refined following discussion between the researchers; the remaining transcripts were then coded by B. R. As coding progressed, findings and uncertainties were discussed with M. B. and L. S. Data sufficiency was reached when we judged that sufficient data had been generated to support and understand the implementation considerations for SMS.[28]

Following this, we deductively mapped our codes to the four constructs of NPT,[24] namely: 'Coherence', 'Cognitive participation', 'Collective action' and 'Reflexive monitoring'. Each construct has four related subconstructs that were used to guide the deductive mapping (e.g., 'Cognitive participation' encompasses *initiation*, *enrolment*, *legitimation*, and *activation*); construct descriptions are provided in Table 1. Initial deductive coding included discussion with L. S. and T. F., who is an expert in NPT; the mapping of codes was then revised and finalised. Overall, we examined how our codes corresponded to each generative mechanism of social action in the context of implementing SMS for people with LGG.

As NPT is a theory more traditionally used to describe and explain implementation as the activity of professional providers, we started by mapping the HCP data to the NPT constructs, then interrogated each of these mappings with reference to the experiences and perspectives of the support recipients. We have explored and reported elsewhere the self-management strategies used by people with LGG.[13] Here, we wanted to explicitly explore the alignment (or otherwise) of the data from people with LGG with HCPs' experiences and perspectives relating to issues of SMS implementation. If data relevant to a particular (sub-)construct was seen amongst people with LGG, but had not been raised by HCPs, this was added to the analysis.

3 | RESULTS

3.1 | Participant characteristics

Fifty-two HCPs registered interest in taking part, 46 were eligible (not involved in the support of adults with brain tumours, *n* = 4; and practised outside the United Kingdom, *n* = 2), and 25 were purposively selected for interview (recruitment route: NHS sites *n* = 16; The Brain Tumour Charity *n* = 9). During the interview, participants had on average 11.6 years (range 1–25 years) experience working with people with brain tumours. Participants worked across nine geographical regions of the United Kingdom and 12 different healthcare professions, most commonly: Clinical Nurse Specialist (*n* = 6), Occupational Therapist (*n* = 4) and Clinical Neuropsychologist (*n* = 3) (Table 2).

Thirty-nine people with LGG registered interest in taking part, 35 were eligible (noncompletion of primary treatment, *n* = 2; residence outside the United Kingdom, *n* = 1; and ineligible diagnosis, *n* = 1), and 28 were purposively selected for interview (recruitment route: NHS sites *n* = 10; The Brain Tumour Charity, *n* = 18). At interview, participants were aged on average 50.4 years (range 22–69 years); male (*n* = 16), female (*n* = 12); diagnosed with a grade 2 oligodendroglioma (*n* = 10: IDH1-mutant, yes *n* = 7, no *n* = 2, unknown *n* = 1; 1p/19q codeletion, yes *n* = 9, unknown *n* = 1), grade 3 oligodendroglioma (*n* = 9: IDH1 mutant, yes *n* = 6, no *n* = 1, unknown *n* = 2; 1p/19q codeletion, yes *n* = 7, unknown *n* = 2), or grade 2 astrocytoma (*n* = 9: IDH1-mutant, yes *n* = 6, no *n* = 1, unknown *n* = 2; 1p/19q codeletion, no *n* = 7, unknown *n* = 2) (Table 3). The average time since diagnosis was 8.7 years (range 1–18 years); the treatment received were surgery (*n* = 28), radiotherapy (*n* = 22) and chemotherapy (*n* = 17).

3.2 | Overview of findings

HCPs spoke about how the impact of the tumour and its treatment on people with LGG (e.g., cognitive deficits) created specific challenges for effective engagement in self-management for this population. The data we generated mapped extensively to all four NPT constructs and related subconstructs; some subconstructs were more supported by the data than others (Table 1). Our findings, described below by construct with supporting quotes throughout, outline the considerations required to operationalise, sustain and appraise the implementation of SMS for people with LGG.

3.2.1 | Coherence

Coherence encompassed HCPs' sense-making of self-management, and their perceived role and responsibilities in providing SMS. Most HCPs expressed an internalised perception of the importance of providing SMS; they highlighted the value of 'empowering' people with LGG to 'look after themselves' beyond the clinical care setting.

> Self-management to me is about empowering somebody with the right information and resource, access to resource to be able to take more ownership on their health and wellbeing, and actually [the support recipient] is saying what they want done basically. HCP39 (Clinical Nurse Specialist)

The key differentiation between self-management and other healthcare support was HCPs' perception that supporting self-management is about promoting independence, so that people with LGG can 'take responsibility' for managing their condition. However,

TABLE 2 Healthcare professional participants' characteristics at the time of the interview.

Characteristic	*n*	Characteristic	*n*
Profession		*Geographical region*	
Clinical Nurse Specialist	6	Tyne and Wear	9
Occupational Therapist	4	North Yorkshire	4
Clinical Neuropsychologist	3	Lothian	3
Consultant Clinical Oncologist	2	Greater Manchester	3
Physiotherapist	2	South Wales	2
Specialist allied health professional	2	Leicestershire	1
Consultant Neurosurgeon	1	Merseyside	1
Consultant Neuroradiologist	1	Shropshire	1
Epilepsy Nurse Specialist	1	West Yorkshire	1
Macmillan Centre Manager	1		*Mean (range)*
Neurooncology Support Sister	1	*Time working with people with brain tumours (years)*	11.6 (1–25)
Speech and Language Therapist	1		

TABLE 3 Lower-grade glioma participants' characteristics at the time of the interview.

Characteristic	*n*	Characteristic	Mean (range)
Diagnosis[a]		*Time since diagnosis (years)*[a]	8.7 (1–18)
Grade 2 oligodendroglioma	10	*Time since radiotherapy (years)*[a,b]	6.9 (0.7–17.8)
Grade 3 oligodendroglioma	9	*Time since chemotherapy (years)*[a,b]	3.4 (0.1–13.5)
Grade 2 astrocytoma	9	*Full-time education (years)*	15.8 (11–20)
IDH-mutation status[a]		*Sex*	*n*
Yes	19	Female	12
No	4	Male	16
Unknown[c]	5	*Age*	
1p/19q codeletion status[a,d]		≤40	4
Yes	16	41–50	8
No	7	51–60	11
Unknown[c]	5	>60	5
Treatment[a]		*Dependents*	
Surgery	28	None	18
Radiotherapy	22	One	3
Chemotherapy	17	Two	6
Tumour location[a]		Three	1
Frontal	18	*Employment status*	
Temporal	3	Full-time employee	8
Parietal	3	Part-time employee	4
Overlapping regions	3	Retired	4
Unknown	1	Medically retired	6
Tumour laterality[a]		Unable to work	6
Right hemisphere	13	*Relationship status*	
Left hemisphere	15	Married	21
Dominant hemisphere	13	In a relationship	3
Nondominant hemisphere	15	Single	2
		Widowed	2

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

[b] Time since radiotherapy and chemotherapy were not available for two participants.

[c] Some participants were diagnosed before mutation status was routinely assessed.

[d] All participants with 1p/19q codeletion were people with oligodendroglioma; all participants without 1p/19q codeletion were people with astrocytoma.

the desire to promote independence may not always be achievable; several people with LGG described how they experienced challenges with a loss of independence and reported having to be reliant on others (e.g., due to losing their driving licence), which was not always something they desired.

> The loss of my licence and independence. I think loss of independence is probably the biggest [challenge]. I suppose having to rely on others to do a lot of things. Pa22 (aged 43, female, grade 2 astrocytoma)

Most HCPs outlined an understanding of the specific role and responsibilities they have in supporting self-management, working with the person's own realities and preferences to provide personalised support. This included: appropriate signposting to information and support; providing tools (i.e., suggesting specific self-management strategies) to empower both people with LGG and families; and listening to individual's needs to co-develop goals.

> It's very much listening and knowing the patient, knowing where they're at in terms of their journey, their pathway and unpicking what sort of things can be put in. So, it's not just a psychological thing, physical thing, it's all of them basically. HCP39 (Clinical Nurse Specialist)

However, some people with LGG felt that the support received was focused on 'what they can do to treat your tumour, not treat you as a person'.

Several HCPs spoke about a desire to build a shared understanding with people with LGG that self-management is not one individual's responsibility; they acknowledged the importance of a communal approach to self-management, with people with LGG assuming their own responsibilities, and close family and friends assuming support responsibilities in the home environment. Aligned with this, people with LGG recognised that the role and strength of their support networks influenced their ability to engage with self-management, for example, through the provision of practical support with housework and transport.

3.2.2 | Cognitive participation

Cognitive participation encompassed the relational work of HCPs and people with LGG to build and sustain a 'community' of supporting self-management. To initiate SMS, both HCPs and people with LGG outlined the importance of signposting to relevant information and available support. However, many people with LGG expressed that this was often lacking and that they had to proactively seek support. Several HCPs conveyed that, due to a lack of insight (often because of the impairments that the tumour can cause) or desire not to be a burden, some people with LGG do not seek the help they need.

People with LGG contended that help-seeking can be difficult to initiate within the opportunities presented.

> Patients don't tend to recognise how they've changed, or they don't really want to tell you that something's changed in their needs. HCP48 (Neurooncology Support Sister)

> It's hard, isn't it, to say in an appointment, 'Well, this has really traumatised me. I need some help with this.' It's quite difficult to say that. Pa10 (aged 37, female, grade 2 oligodendroglioma)

People with LGGs' initiation of self-management, and HCPs' perception of the amount of support required, was also influenced by the presence and strength of the support recipient's support network to collectively contribute to their self-management. For example, one person with LGG felt unable to go out in public without company, in case they had a seizure.

Several HCPs stated that the support available to which people with LGG could be signposted is poor in comparison to other cancers; where brain injury rehabilitation services were available, people with LGG were often excluded due to the progressive nature of their condition. HCPs and people with LGG similarly reported that access to support can also be influenced by the services available within the person's location.

> Each area has different services, so we've still got that postcode lottery problem. HCP43 (Specialist allied health professional)

HCPs spoke about how their perception of whether they could make a valid contribution to supporting self-management was influenced by challenges with the support recipient's acceptance. This was corroborated by some people with LGG who described how they were struggling to process the consequences of their condition and were resistant to having an active role in their own self-management.

To collectively sustain engagement in (supporting) self-management, HCPs and people with LGG acknowledged the importance of regular opportunities to report support needs to someone involved in their care (e.g., through a screening tool) and having ways to maintain awareness of available support beyond initial signposting. Several HCPs outlined difficulties with 'keeping up to date' with what support is available, especially in the community (e.g., charities); changes in available support evoked challenges with distributing information resources.

> I think the difficulty we have as health professionals is knowing exactly what [support] is out there and what changes and what's available. We do try and have a database, but it changes. So, keeping up to date with what's available as well is quite difficult. HCP21 (Physiotherapist)

Most HCPs expressed concerns with keeping track of support needs, particularly of those that do not seek help, stating the importance of active participation from both HCP and people with LGG to recognise needs and sustain SMS. Still, some HCPs outlined that there are people who seek support, but then resist the support that is offered.

> You've got your patients who you just try and help, and you try and encourage, but they'll ring you up and they want help, but then they don't accept your advice or offers to signpost or whatever or refer to whatever. HCP33 (Clinical Nurse Specialist)

3.2.3 | Collective action

Collective action encompassed the considerations required to operationalise the implementation of SMS, to 'make it work' in practice. Several HCPs highlighted the importance of coordination between HCPs for them to become aware of someone with support needs; this was particularly important for allied HCPs offering a specific service (e.g., occupational therapy). People with LGG expressed that communication between HCPs was often not streamlined, with information getting lost as they were 'passed around'. Some HCPs echoed this sentiment and suggested that quality of care would improve with improved HCP cooperation, rather than dealing with each support need as a 'separate entity'.

Most HCPs expressed the value of building a good rapport with their support recipients to facilitate effective communication about their support needs. People with LGG appreciated when HCPs showed strong social skills; this generated trust and helped them feel reassured.

> I'm sure that all [healthcare professionals] are medically highly skilled, but obviously that's not the only bit of the job is it. You have to understand people. Understand how they're feeling. Know how to speak to them. Make them feel reassured at what is a very frightening period in their life. Pa28 (aged 66, male, grade 2 astrocytoma)

Still, some HCPs spoke about how there is a 'fine line' in these relationships; some HCPs wanted people with LGG to assume more responsibility in the decision making concerning desired support.

Both HCPs and people with LGG outlined the value of including close family and friends in support to ensure they understood the condition and its consequences, and how they can be involved in supporting self-management. Particularly, both groups identified challenges with cognitive deficits that mean additional assistance in the home environment can be beneficial.

> It's very hard to self-manage if a memory deficit is there because at the end of the day a prompt is needed to set the prompt. Because she couldn't write the list herself or couldn't set the phone reminders reliably. So, I think if you're truly isolated, that has a massive impact on how successful you are going to be. HCP28 (Consultant Clinical Oncologist)

Both HCPs and people with LGG outlined the implications of poor technology literacy on access to, and engagement with, support, acknowledging that 'some people won't [access the support] if they've got to do it online'. Several HCPs identified their own training needs to deliver support, linking this to the need for cooperation between HCPs; they noted that if they were not trained to provide particular types of support, or not aware that support could be provided for particular problems beyond their expertise, this would often be missing from their service.

> If you are managing or leading a service, you sometimes lead to your strengths, just as I am doing. And our support, unknowingly, has been missing out on a few key aspects because that's not within my expertise. HCP17 (Macmillan centre manager)

All HCPs stressed the impact of resources on the execution of support provision. This largely encompassed financial constraints within the service, and time; the lack of availability and flexibility of HCPs meant several HCPs felt unable to 'benchmark against other centres' to improve their services or maintain the desired continuity of care. Most people with LGG expressed additional concerns, primarily with transport challenges to attend support, and their own financial resources to acquire equipment.

3.2.4 | Reflexive monitoring

Reflexive monitoring encompassed HCPs' appraisal of the worth and effectiveness of implementing SMS. Several HCPs acknowledged the need to avoid information overload when providing SMS, as sharing too much information at once could be overwhelming for the recipient. Similarly, people with LGG reflected on the importance of appropriately timed information sharing, and the need to consider the time it takes to accept their condition; they suggested it would be most effective to have access 'at your fingertips' for when it is required.

HCPs determined that implementing SMS was useful for empowering people with LGG to take an active role in their care. An important element of this was managing the expectations of people with LGG to help them work towards realistic goals.

> With a lot of the brain tumour patients we've got to help them to be quite realistic and support that as an ongoing thing. So, I guess it's important to address that although support might help them, it's not going to fix all of their problems but help them manage their problems themselves. HCP36 (Occupational Therapist)

Most HCPs outlined how the relative rarity of LGGs, and the wide-ranging support needs of people living with these tumours present challenges for the types of SMS that can be provided; for example, opportunities for people with LGG to share advice and experiences with similar others may be hindered by their disparate locations. Where group support was available for people with LGG, attendance was tentatively encouraged by HCPs, with the awareness that individual journeys and preferences may influence the value of this type of support; this was corroborated by people with LGG:

> Some people if they've got a low-grade tumour and they're aware that could progress over time, might not want to face that in a support group really. They might want to deal with it themselves. So, they might not want to see people further down the line and sort of see what's going to happen. HCP45 (Clinical Nurse Specialist)

> The thing with brain tumour sufferers, patients or whatever, is that everyone's different. Everyone, because the brain is such a complicated organ, depending on where it is, what it is, everyone's different. It's so difficult to get common ground with other brain tumour patients. Pa5 (aged 56, male, grade 2 oligodendroglioma)

People with LGG expressed considerable appreciation for available support, once they were aware of potential avenues of access; for some, the knowledge that resources were available should they be needed in the future, was highly valued. Several HCPs acknowledged a need to promote self-management and explain the potential benefits to people with LGG to improve understanding of why self-management is important, and how HCPs and people with LGG can work collectively to make a difference. HCPs highlighted that including close family and friends into the collective action of SMS requires careful consideration; family often assumed the responsibility of help-seeking without permission from the support recipient, leading HCPs to reconfigure the involvement of family.

> We'll quite happily, if someone wants us to speak to their partner, as long as [the person with the brain tumour] gives permission we'll give them a ring and chat through. HCP52 (Epilepsy nurse specialist)

4 | DISCUSSION

People with LGG can have complex, multi-faceted supportive care needs.[10] Amongst people with cancer, clinical and psychosocial outcomes can be improved through effective engagement in self-management[29]; this requires support from HCPs, family, and friends.[4] The considerations required to implement SMS for people with LGG are poorly understood. We aimed to identify and understand these implementation considerations, through the lens of NPT, from the perspectives of HCPs and people with LGG.

We generated extensive supporting evidence for all four NPT constructs and related subconstructs, namely: 'Coherence', 'Cognitive participation', 'Collective action' and 'Reflexive monitoring'. Overall, our findings demonstrate the ways that SMS for people with LGG should be understood as a collective and collaborative activity. We offer important insights into: (1) how people with LGG can both be supported and enabled to support themselves effectively through service provision; and (2) the challenges that need to be addressed to facilitate implementation of SMS.

In our findings, HCPs recognised the value of their role in self-management. This included providing the information and support to promote independence and empower people to confidently engage in self-management. Integrating the perspective of people with LGG highlighted that independence can be difficult to maintain or achieve. This, in turn, emphasises a need for sustained support over time. There are potential organisational constraints with HCP time and flexibility in relation to being able to assess individual's support needs, and maintain SMS provision, over the longer-term. HCPs emphasised that participation goes both ways, requiring help seeking from the support recipient, so that HCPs can identify and maintain awareness of supportive care needs. This may be influenced by the possibility that people with LGG could underestimate, and thus not seek help for, cognitive, psychological or social changes.[30] Still, people with LGG outlined the importance of building trust in their relationships with HCPs and expressed difficulties with reporting needs within the opportunities provided, as these are often focused on the treatment for the tumour. Particularly, psychological support is a challenging aspect of SMS to implement and embed for support providers, as this is an area that people reported to be especially difficult to seek and access help for.

Our findings also highlight the critical importance of interaction between HCPs to operationalise SMS provision. HCPs and people with LGG recognised key areas for improvement in the structure and provision of services, including: improved referral pathways to allied HCPs (e.g., Occupational Therapists); encouraging (and enabling) cooperation between HCPs to deliver combined support, where possible and communication between HCPs, so that there is interdisciplinary awareness of what support is needed by, and what has already been provided for, the support recipient. Altogether, these considerations would help ensure SMS is more integrated and holistic enabling people to be more effectively supported to self-manage. Further, our findings also acknowledge that HCPs may have training needs, and support provision may be influenced by locally available expertise; hence, consideration of a SMS training programme could be beneficial. Such a programme has improved confidence in SMS provision for HCPs in other cancers.[31] In the United Kingdom, the Tessa Jowell Academy Programme connects brain tumour centres and provides a space to tackle challenges[32]; this is an example of a platform that could help support emergent training needs.

A pertinent challenge to the continuous provision of SMS was the availability of support services for people with LGG; from both perspectives, this was influenced by location, eligibility and keeping up to date with the changing landscape of available support. Where support was available and signposted, HCPs highlighted difficulties with the willingness of people with LGG to engage with the support being offered. Both HCPs and people with LGG recognised that acceptance of the diagnosis influenced engagement with SMS[33]; this indicates the importance of appropriately timed information sharing, so that people can access support when they are ready.[34] However, a 2021 environmental scan found that most online self-management resources concern active treatment, with few specifically directed at people with brain tumours, particularly those with LGG, living longer-term.[35] Our findings also outlined further challenges with accessibility, due to technology literacy and cognitive deficits; hence, online support may be lacking, not preferred, or require support to access.[36]

We outline, from both perspectives, the pivotal role of a person's support network in bridging the gap between provision of SMS from the HCP, to the implementation of self-management strategies in the home environment; this was particularly important for those with cognitive deficits. Thus, available support may be a key determinant of successful self-management for people with LGG. In further analyses from the Ways Ahead project, to be reported elsewhere, we have found from interviews with informal caregivers that family and friends provide wide-ranging support (e.g., practical, emotional, cognitive) for people with LGG. Nonetheless, the data reported in the current paper suggests that including informal caregivers in SMS requires careful consideration to ensure self-management remains person-centred. Informal caregivers may have their own perspectives of what is, or should be, important to the support recipient, and these should not dominate the priorities of the people with LGG themselves. Moreover, informal caregivers may have their own supportive care needs, particularly related to emotional burden,[37,38] and, while they are important, how these can best be met requires further consideration. For example, informal caregivers of people with a brain tumour desire stronger connections with HCPs to help them feel able to provide support.[39] While we acknowledged the value of this in our findings, we would concur with HCPs in our study who stressed the importance of permission from the support recipient to ensure inclusion of informal caregivers into SMS is appropriately managed.

Overall, we have an advanced understanding of the mechanisms of SMS implementation by demonstrating and emphasising the collective nature of SMS for people with LGG. Due to the importance of engagement from HCPs, people with LGG, and informal caregivers, it is crucial that SMS is seen as a collective activity, requiring the kinds of interactions and communications that support effective self-management for people with LGG. Improved partnership working between HCPs and people with LGG also needs to recognise the importance of the autonomy, agency, and capacity of the support recipient. This closer partnership might be facilitated by providing HCPs with the skills and confidence to work with peoples' concerns that are 'non-treatment focused'. Co-created with service users to develop more personalised models of care, the Bridges approach to SMS emphasises the collaborative nature of SMS and involves training practitioners to use language and other techniques as part of everyday practice.[40] In stroke and neurorehabilitation across 24 UK NHS Trusts, successful implementation and integration of the Bridges approach to supported self-management demonstrated increased skills and confidence in providing SMS. Still, a key distinction between care pathways for stroke patients and people with LGG is the incurable nature and likelihood of progression in people with LGG, which may influence the approach to rehabilitation.

Viewed as collective activity, SMS must be acceptable and feasible for all stakeholders. This underlines the need for a detailed understanding of the desired support and design preferences for SMS from the perspective of each stakeholder. For example, support groups may appear to be a valuable platform for sharing advice and experiences; however, functional challenges (e.g. location, timing) and issues with heterogeneity across people with LGG, may preclude engagement, which has potential implications for the scope of providing group support. Ultimately, future development of supported self-management interventions for people with LGG[26] should include comprehensive co-design with all stakeholders, to acknowledge and look to overcome the challenges and constraints highlighted in our findings. In other research guided by NPT, Mäkelä et al.[41] demonstrated the feasibility of co-designing SMS approaches with people with traumatic brain injury (TBI) and showed promise in addressing implementation challenges related to complex service pathways for people with TBI.

4.1 | Strengths and limitations

The overarching strength of our study was the novel contribution to a very limited evidence base concerning the implementation of SMS for people with LGG. This was underpinned by several methodological strengths, including: (1) our application of NPT, which provided a deeper understanding of the mechanisms of social action, that underpin implementation processes[42]; (2) involvement of multiple stakeholders (HCPs and people with LGG), which allowed us to understand SMS implementation considerations from the perspectives of service providers and support recipients[43]; (3) inclusion of a wide range of healthcare professions, which helped us capture the challenges faced by different roles within SMS provision and (4) inclusion of HCPs from numerous regions across the United Kingdom, which provided diverse experiences with implementation challenges from within different provider settings, representing different levels of organisation readiness to support self-management.

A key limitation of our study, however, was that people with LGG with more limited capacity may have been discouraged from taking part, due to the expected interview length (approximately 90 min). This means those with greater support needs or challenges engaging with self-management, may have been missed; multiple, shorter interviews could be considered in future research to mitigate risk of fatigue. Moreover, although telephone interviews have previously been shown to be effective for discussing sensitive issues,[44] in this context, in-person interviews may have helped the interviewer to better gauge the impairment of the participant.

Our eligibility criteria included people with grade 3 oligodendrogliomas; while such diagnoses would not necessarily be considered low-grade, we included them because they have a similar prognosis to those with low-grade brain tumours.[8] The people with LGG were up to 18 years postdiagnosis. Molecular assessment of tumours became routine after some of the participants were diagnosed, and for that reason, we included participants with either eligible molecular features or a diagnosis based on histology only. Recruitment across the United Kingdom and through The Brain Tumour Charity networks means that HCPs and people with LGG involved in this study could be in different services; hence, some instances where people with LGG provided contrasting experiences to the practice described by HCPs might be because their local services did not include the elements, or did not operate in the way, described by the interviewed HCPs. Further, HCPs often spoke more widely about the services provided for people with brain tumours rather than focusing only on LGG. Those with different types of brain tumours may share similar experiences of impairments, functional limitations, and reduced life expectancy.[45] Therefore, our findings are likely to also have relevance for SMS provision for people with other types of brain tumours.

5 | CONCLUSION

This study provided, for the first time, a comprehensive insight into the collective nature of, and individual roles within, supported self-management and outlined the considerations required to operationalise, sustain and appraise the implementation of SMS for people with LGG, through the lens of NPT. This provides a crucial first step towards creating a shift in care culture to embed co-created SMS, by shedding light on factors influencing implementation that need to be overcome at the organisation, HCP and support recipient levels. Our findings can inform the development of supported self-management interventions for people with LGG, ensuring these have a line of sight to future implementation into routine care.

AUTHOR CONTRIBUTIONS

Ben Rimmer: Writing—original draft; investigation; methodology; writing—review and editing; project administration; formal analysis. **Tracy Finch**: Conceptualisation; funding acquisition; writing—review and editing; formal analysis; supervision. **Michelle Balla**: Formal analysis; methodology; writing—review and editing. **Lizzie Dutton**: Methodology; investigation; writing—review and editing. **Sophie Williams**: Conceptualisation; funding acquisition; writing—review and editing; investigation. **Joanne Lewis**: Conceptualisation; funding acquisition; writing—review and editing; investigation. **Pamela Gallagher**: Conceptualisation; funding acquisition; writing—review and editing. **Richéal Burns**: Conceptualisation; funding acquisition; writing—review and editing. **Vera Araújo-Soares**: Conceptualisation; funding acquisition; writing—review and editing. **Fiona Menger**: Writing— review and editing; supervision. **Linda Sharp**: Conceptualisation; supervision; writing—review and editing; funding acquisition; formal analysis; project administration.

ACKNOWLEDGEMENTS

This is an output for the Ways Ahead project (research.ncl.ac.uk/waysahead). The authors would like to thank all of the healthcare professionals and people with lower-grade gliomas that took the time to participate in this study. We would also like to thank our collaborating NHS sites, Newcastle upon Tyne Hospitals NHS Foundation Trust, NHS Lothian, South Tees Hospitals NHS Foundation Trust and The Christie NHS Foundation Trust, for their assistance with recruitment to the project. They would extend their thanks to colleagues at The Brain Tumour Charity. This work was supported by funding from The Brain Tumour Charity (GN-000435).

CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

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.

ETHICS STATEMENT

The study was approved by the Wales Research Ethics Committee (REC ref: 20/WA/0118). Informed consent was obtained from all individual participants included in the study. All participants signed informed consent regarding publishing their anonymised data.

ORCID

Ben Rimmer http://orcid.org/0000-0003-4110-0588

REFERENCES

1. Foster C, Brown J, Killen M, Brearley S. The NCRI Cancer Experiences Collaborative: defining self management. *Eur J Oncol Nurs*. 2007;11(4):295-297. doi:10.1016/J.EJON.2007.08.002
2. Rimmer B, Brown MC, Sotire T, et al. Characteristics and components of self-management interventions for improving quality of life in cancer survivors: a systematic review. *Cancers*. 2023;16(1):14. doi:10.3390/CANCERS16010014
3. Zhang X, Ma L, Feng L. Web-based self-management intervention for patients with cancer: a meta-analysis and systematic review. *J Nurs Scholarsh*. 2022;54(5):598-606. doi:10.1111/JNU.12774
4. Dwarswaard J, Bakker EJM, van Staa A, Boeije HR. Self-management support from the perspective of patients with a chronic condition: a thematic synthesis of qualitative studies. *Health Expect*. 2016;19(2):194-208. doi:10.1111/HEX.12346
5. de Silva D. *Helping People Help Themselves: A Review of the Evidence Considering Whether It Is Worthwhile to Support Self-Management*. Health Foundation; 2011.
6. Sung H, Ferlay J, Siegel RL, et al. Global cancer statistics 2020: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. *CA Cancer J Clin*. 2021;71(3):209-249. doi:10.3322/caac.21660
7. Miller KD, Ostrom QT, Kruchko C, et al. Brain and other central nervous system tumor statistics, 2021. *CA Cancer J Clin*. 2021;71(5):381-406. doi:10.3322/caac.21693
8. Bauchet L. Epidemiology of diffuse low grade gliomas. In: Duffau H, ed. *Diffuse Low-Grade Gliomas in Adults*. Springer; 2017:13-53. doi:10.1007/978-3-319-55466-2_2
9. Dixit K, Raizer J. Newer strategies for the management of low-grade gliomas. *Oncology*. 2017;31(9):680-685.
10. Rimmer B, Bolnykh I, Dutton L, et al. Health-related quality of life in adults with low-grade gliomas: a systematic review. *Qual Life Res*. 2023;32(3):625-651. doi:10.1007/S11136-022-03207-X
11. Rimmer B, Balla M, Dutton L, et al. "It changes everything" Understanding how people experience the impact of living with a lower-grade glioma. *Neurooncol Pract*. 2024:1-11. doi:10.1093/NOP/NPAE006
12. Boele FW, Den Otter PWM, Reijneveld JC, et al. Long-term wellbeing and neurocognitive functioning of diffuse low-grade glioma patients and their caregivers: a longitudinal study spanning two decades. *Neuro Oncol*. 2022;25(2):351-364. doi:10.1093/NEUONC/NOAC185
13. Rimmer B, Balla M, Dutton L, et al. Identifying and understanding how people living with a lower-grade glioma engage in self-management. *J Cancer Surviv*. 2023:1-14. doi:10.1007/S11764-023-01425-X
14. Paterson C, Roberts C, Li J, et al. What are the experiences of supportive care in people affected by brain cancer and their informal caregivers: a qualitative systematic review. *J Cancer Surviv*. 2023:1-22. doi:10.1007/S11764-023-01401-5/TABLES/3
15. van Dongen SI, Stoevelaar R, Kranenburg LW, et al. The views of healthcare professionals on self-management of patients with advanced cancer: an interview study. *Patient Educ Couns*. 2022;105(1):136-144. doi:10.1016/J.PEC.2021.05.021
16. Howell D, Mayer DK, Fielding R, et al. Management of cancer and health after the clinic visit: a call to action for self-management in cancer care. *J Natl Cancer Inst*. 2021;113(5):523-531. doi:10.1093/jnci/djaa083
17. Rimmer B, Sharp L. Implementation of self-management interventions in cancer survivors: why are we not there yet? *J Cancer Educ*. 2021;36(6):1355-1358. doi:10.1007/s13187-021-02021-2
18. Foster C. The need for quality self-management support in cancer care. *BMJ Qual Saf*. 2022;31(1):1-4. doi:10.1136/BMJQS-2021-013366
19. Kantilal K, Hardeman W, Whiteside H, Karapanagiotou E, Small M, Bhattacharya D. Facilitating healthcare practitioners to deliver self-management support in adult cancer survivors: a realist review. *Res Soc Admin Pharm*. 2022;18:3870-3883. doi:10.1016/J.SAPHARM.2022.05.011
20. Papadakos J, Samoil D, Catton C, et al. Prostate cancer survivor capacity to engage in survivorship self-management: a comparison of perceptions between oncology specialists, primary care, and survivors. *Supp Care Cancer*. 2022;30(8):6909-6922. doi:10.1007/S00520-022-07114-2/TABLES/5

21. Obro LF, Osther PJS, Ammentorp J, Pihl GT, Krogh PG, Handberg C. Healthcare professionals' experiences and perspectives of facilitating self-management support for patients with low-risk localized prostate cancer via mhealth and health coaching. *Int J Environ Res Public Health*. 2022;20(1):346. doi:10.3390/IJERPH20010346
22. Chan RJ, Agbejule OA, Crawford-Williams F, et al. Development of an international competency framework for nurses in the provision of self-management support to cancer populations. *Cancer Nurs*. 2023;46:477-487.doi:10.1097/NCC.0000000000001143
23. Howell D, Powis M, Kirkby R, et al. Improving the quality of self-management support in ambulatory cancer care: a mixed-method study of organisational and clinician readiness, barriers and enablers for tailoring of implementation strategies to multisites. *BMJ Qual Saf*. 2022;31(1):12-22. doi:10.1136/BMJQS-2020-012051
24. May CR, Mair F, Finch T, et al. Development of a theory of implementation and integration: normalization process theory. *Implement Sci*. 2009;4(1):29. doi:10.1186/1748-5908-4-29/COMMENTS
25. May CR, Cummings A, Girling M, et al. Using normalization process theory in feasibility studies and process evaluations of complex healthcare interventions: a systematic review. *Implement Sci*. 2018;13(1):80. doi:10.1186/S13012-018-0758-1
26. Rimmer B, Dutton L, Lewis J, et al. 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. doi:10.1136/bmjopen-2020-041465
27. Louis DN, Perry A, Wesseling P, et al. The 2021 WHO classification of tumors of the central nervous system: a summary. *Neuro Oncol*. 2021;23(8):1231-1251. doi:10.1093/NEUONC/NOAB106
28. Low J. A pragmatic definition of the concept of theoretical saturation. *Sociol Focus*. 2019;52(2):131-139. doi:10.1080/00380237.2018.1544514
29. Howell D, Harth T, Brown J, Bennett C, Boyko S. Self-management education interventions for patients with cancer: a systematic review. *Supp Care Cancer*. 2017;25(4):1323-1355. doi:10.1007/S00520-016-3500-Z/FIGURES/2
30. Andrewes HE, Drummond KJ, Rosenthal M, Bucknill A, Andrewes DG. Awareness of psychological and relationship problems amongst brain tumour patients and its association with carer distress. *Psychooncology*. 2013;22(10):2200-2205. doi:10.1002/pon.3274
31. Howell D, McGowan P, Bryant-Lukosius D, et al. Impact of a training program on oncology nurses' confidence in the provision of self-management support and 5As behavioral counseling skills. *Cancers*. 2023;15(6):1811. doi:10.3390/CANCERS15061811/S1
32. Tessa Jowell Brain Cancer Mission (TJBCM). Tessa Jowell Academy Programme Impact Report 2021-22. 2022. Accessed December 15, 2023. https://www.tessajowellbraincancermission.org/news/read-the-tessa-jowell-academy-impact-report-now/
33. Schulman-Green D, Jaser S, Martin F, et al. Processes of self-management in chronic illness. *J Nurs Scholarsh*. 2012;44(2):136-144. doi:10.1111/J.1547-5069.2012.01444.X
34. Hämel K, Röhnsch G, Heumann M, Backes DS, Toso BRGO, Giovanella L. How do nurses support chronically ill clients' participation and self-management in primary care? A cross-country qualitative study. *BMC Prim Care*. 2022;23(1):85. doi:10.1186/S12875-022-01687-X/TABLES/1
35. Schaefer I, Heneka N, Luckett T, et al. Quality of online self-management resources for adults living with primary brain cancer, and their carers: a systematic environmental scan. *BMC Palliat Care*. 2021;20(1):22. doi:10.1186/s12904-021-00715-4
36. Kassberg AC, Malinowsky C, Jacobsson L, Lund ML. Ability to manage everyday technology after acquired brain injury. *Brain Inj*. 2013;27(13-14):1583-1588. doi:10.3109/02699052.2013.837196
37. Tallant J, Pakzad-Shahabi L, Lambert SD, Williams M, Wells M. Quality of life in caregivers of patients with brain tumours: a systematic review and thematic analysis. *Eur J Cancer Care*. 2023;2023:1-12. doi:10.1155/2023/2882837
38. Rimmer B, Balla M, Dutton L, et al. 'A Constant Black Cloud': the emotional impact of informal caregiving for someone with a lower-grade glioma. *Qual Health Res*. 2024;34(3):227-238. doi:10.1177/10497323231204740
39. Guldager R, Nordentoft S, Poulsen I, Aadal L, Loft MI. Wants and needs for involvement reported by relatives of patients with a malignant brain tumor: a scoping review. *JBI Evid Synth*. 2023;21:2188-2210. doi:10.11124/JBIES-22-00311
40. Hancock NJ, Houghton J, Jones F. Integrating an approach to personalised self-management support in stroke and neurorehabilitation service contexts: People1st—a quality improvement initiative. *Disabil Rehabil*. 2023;45(19):3034-3045. doi:10.1080/09638288.2022.2127930
41. Mäkelä P, Jones F, de Sousa de Abreu MI, Hollinshead L, Ling J. Supporting self-management after traumatic brain injury: codesign and evaluation of a new intervention across a trauma pathway. *Health Expect*. 2019;22(4):632-642. doi:10.1111/HEX.12898
42. MacFarlane A, O'Reilly-De Brún M. Using a theory-driven conceptual framework in qualitative health research. *Qual Health Res*. 2012;22(5):607-618. doi:10.1177/1049732311431898/ASSET/IMAGES/LARGE/10.1177_1049732311431898-FIG.1.JPEG
43. McEvoy R, Ballini L, Maltoni S, O'Donnell CA, Mair FS, MacFarlane A. A qualitative systematic review of studies using the normalization process theory to research implementation processes. *Implement Sci*. 2014;9(1):2. doi:10.1186/1748-5908-9-2/TABLES/2
44. Drabble L, Trocki KF, Salcedo B, Walker PC, Korcha RA. Conducting qualitative interviews by telephone: lessons learned from a study of alcohol use among sexual minority and heterosexual women. *Qual Soc Work*. 2016;15(1):118-133. doi:10.1177/1473325015585613
45. Baker PD, Bambrough J, Fox JRE, Kyle SD. Health-related quality of life and psychological functioning in patients with primary malignant brain tumors: a systematic review of clinical, demographic and mental health factors. *Neurooncol Pract*. 2016;3(4):211-221. doi:10.1093/NOP/NPV042

SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

How to cite this article: Rimmer B, Finch T, Balla M, et al. Understanding supported self-management for people living with a lower-grade glioma: implementation considerations through the lens of normalisation process theory. *Health Expect*. 2024;27:e14073. doi:10.1111/hex.14073

6.2.1 PP6 commentary

This qualitative study presents novel and comprehensive understanding of the implementation considerations for supported self-management in people with brain tumours. Applying the framework method[93] for data analysis was considered appropriate here, combining inductive and deductive coding approaches to understand how, and the extent to which, data-driven implementation considerations mapped to the NPT constructs. The use of NPT[116] helped recognise the generative mechanisms of social action that may promote or inhibit the implementation of self-management support for people with LGG. This analysis benefitted from the expert input of Professor Tracy Finch, who was one of the co-authors involved in the development of NPT[116]; Professor Finch's guidance helped to ensure that the findings were appropriately mapped and captured the essence of the different NPT constructs.

Integrating the perspectives of HCPs and people with LGG in the analysis highlighted where, how, and why the experience of these two groups do not align. A prominent example pertains to the variation in barriers to identifying support needs, with HCPs putting more onus on help-seeking, while people with LGG felt the opportunities to report support needs were insufficient. This reinforces a need to improve the identification of support needs, as introduced in chapter 3.3.1 and discussed further in chapter 7.4.1. This particularly resonates with Howell et al.[18]'s recommended action two (introduced in chapter 1.1.3), which calls for a shift in care culture to support patients as partners in co-creating approaches to self-management support. The key contribution to knowledge of PP6[52] is the progress these findings offer towards establishing what is acceptable and feasible to the support provider and recipient. While this publication was in press, a study presenting a survey of HCPs' perspectives on inequalities in access to neuro-oncology supportive care was published[135]. This included participants from 23 countries (including 19 European nations). The findings corroborated some of the challenges outlined by HCPs in PP6[52] (e.g. lack of suitable referral options, shortage of HCPs). This reinforced the finding that challenges around supporting self-management for people with LGG and, likely, more generally, are prominent beyond the individual level, with considerable healthcare service barriers to also overcome.

6.3 Chapter summary

The work presented in this chapter recognises the (lack of) alignment in the experiences and perspectives of people with LGG and HCPs regarding the implementation of self-management support. Understanding where and how these perspectives are conflicting is crucial towards identifying where action is required to facilitate the provision of, and equitable access to, self-management support for people with LGG. Overall, this chapter provides comprehensive understanding of the collective nature of supported self-management and offers several considerations to help ensure the feasibility and acceptability of implementing such support. This has crucial future research and clinical implications, as discussed further in chapters 7.3.1 and 7.4.2.

Chapter 7: Discussion

The overall aim of this thesis was to understand the lived experiences of people with LGG and the potential for supported self-management, from multiple perspectives. This work included a systematic review of quantitative studies and multiple approaches to the qualitative analysis of three interview sets, across six core publications (PP1-PP6[47–52]).

The chapter is organised as follows: summary of main findings; overall strengths and limitations; future research implications; clinical implications; conclusion.

7.1 Summary of main findings

Here, the main findings of each of the core publications are related to the research objectives outlined in chapter 1.2.2, followed by an overview of how the findings are interconnected and develop further across each core publication.

Objective 1: Identify and understand the impact of life with a LGG

People with LGG can experience extensive, often co-occurring, symptoms and impairments, with wide-ranging implications on day-to-day life, as presented in chapter 3. The systematic review of quantitative studies assessing HRQoL in adults with LGG (PP1[47]) indicated that people with LGG have poor HRQoL, particularly concerning cognitive and emotional functioning, and fatigue. Though HRQoL was comparatively better than in people with HGG, it was worse than in non-cancer controls and over time, remained poor, but stable. Seizure burden was most consistently associated with worse HRQoL. The inductive thematic analysis of data from interviews with people with LGG in PP2[48] developed this understanding further by highlighting how the consequences of the condition and its treatment are experienced in day-to-day life. This pertained to the ways that symptoms and impairments (e.g. seizures, cognitive impairment), and the emotional consequences of living with an incurable condition, may drive impacts on day-to-day life (including on work, relationships, social activities, and transport).

Key conclusions:

- PP1[47] findings inform understanding of the types and timings of support that may be needed by people with LGG.
- PP2[48] recognises what QoL means to people with LGG to inform understanding of how the support context might be personalised to meet individual needs (e.g. addressing the impact of seizures on work).

Objective 2: Identify and understand how people with LGG currently engage in self-management

People with LGG demonstrate varied levels of engagement in self-management, as presented in chapter 4. The directed content analysis of data from interviews with people with LGG in PP3[49] provided understanding of how people may use numerous and diverse self-management strategies to manage their health and well-being. This analysis identified 123 specific self-management strategies across 20 self-management strategy types. The most frequently reported strategy types were *Using support* (e.g. receiving support from family and friends), *Creating a healthy environment* (e.g. acquiring knowledge about the tumour and available support), *Meaning making* (e.g. appreciation of life), and *Self-monitoring* (e.g. monitoring emotions).

Chapter 4 also presents findings which indicate that people with LGG experience multiple, often co-occurring, challenges across 18 factors (within five categories) influencing self-management (PP4[50]). These primarily concerned knowledge and acceptance of their incurable condition, the impact of seizures and cognitive impairment, transport difficulties, and access to (in)formal support. Several factors could present as *either* a barrier or facilitator to self-management, depending where an individual fell on a continuum. For example, experiencing more seizures was a barrier, whereas absence of seizures was a facilitator to self-management.

Key conclusions:

- PP3[49] raises the possibility that people with LGG may be open to interventions that support them to self-manage and provides an initial understanding of their capacity to engage in self-management.
- PP4[50] improves awareness of the challenges that may be experienced by people with LGG around self-management. This informs the expertise across different disciplines (e.g. Neuropsychologist) that may be needed within a self-management intervention.

Objective 3: Identify and understand the current and potential roles of ICs and HCPs in supporting self-management for people with LGG

Self-management constitutes a collective activity; the important supportive roles for ICs and HCPs are presented in chapters 5 and 6. The inductive thematic analysis of IC interview data (PP5[51]) highlighted that partners and family-members often identified as a ‘carer’. ICs reported varying levels of providing cognitive, emotional, and practical support, as well as being a healthcare advocate, for people with LGG. The qualitative analysis of HCP interview data (PP6[52]) found that HCPs recognised the importance of self-management. They perceived themselves to have a key role in empowering people with LGG and their family, by providing appropriate tools and information, and developing personalised goals (e.g. returning to work). HCPs also acknowledged the influence of an individual’s support network, recognising that ICs often provide support to help people with LGG to self-manage in day-to-day life. However, they noted that inclusion of ICs in formal support provision needs to be carefully considered to make sure that support aligns with patient wishes, and support is not compromised for people with weaker informal support networks.

Key conclusions:

- PP5[51] demonstrates a need to acknowledge how the self-management support needs of people with LGG may be influenced by the strength of their informal support networks.
- PP6[52] provides comprehensive insight into the collective nature of, and individual roles within, supported self-management.

Objective 4: Identify and understand the challenges faced by ICs and HCPs in supporting self-management for people with LGG

There are wide-ranging challenges faced by ICs and HCPs in fulfilling the collective action of supported self-management in the context of the healthcare system. The inductive thematic analysis of IC interview data (PP5[51]) presented in chapter 5 highlighted that ICs often felt ‘abandoned’ by healthcare services to provide required care. ICs also reported managing conflicts with work and childcare, and being mindful to balance support provision without inhibiting the care recipient’s independence. The qualitative analysis of HCP and people with LGG interview data using NPT (PP6[52]) in chapter 6, identified challenges with identifying support needs (influenced by people with LGG's engagement in help-seeking), resistance to support (e.g. technology literacy/accessibility), training for HCPs, and HCP collaboration (i.e. HCP communication and cooperation to provide combined support). To operationalise, sustain, and appraise the implementation of self-management support for people with LGG, key considerations included: ensuring awareness of, and access to, support; building strong HCP-support recipient relationships; and careful inclusion of ICs.

Key conclusions:

- PP5[51] highlights the importance of implementing self-management strategies that are acceptable to, and support the autonomy and independence of, people with LGG.
- PP6[52] outlines the implementation challenges to overcome at the HCP, support recipient, and healthcare system levels. This provides a crucial first step towards creating a shift in care culture to embed co-created self-management support.

Overview of how this work is interconnected

The intention of this section is to explicitly indicate how the findings of each paper inspired the need for the subsequent paper. Overall, the six core publications (PP1-PP6[47–52]) presented in this thesis combine to demonstrate the need and potential for, supported self-management for people with LGG; the future research and clinical implications of this are discussed in sections 7.3 and 7.4.

1. PP1[47] identified the symptoms and impairments that people with LGG might experience, including how these might be influenced, change over time, and compare to other patient populations.
2. PP2[48] built on this to emphasise how people with LGG might experience these impacts in day-to-day life, to further understanding of the contexts where support may be required.
3. PP3[49] identified the strategies currently used by people with LGG to self-manage this impact; '*Using support*' (e.g. receiving support from family/friends) was the most reported self-management strategy type.
4. PP4[50] identified the factors that may influence people with LGG's ability to self-manage; for example, '*Psychosocial resources*' (e.g. informal support networks) can be a barrier or facilitator to self-management, depending on the level of support provided by ICs.
5. PP5[51] provided an understanding of the wide-ranging responsibilities perceived by ICs in supporting someone with a LGG, and identified the challenges faced by ICs, particularly with maintaining the care recipient's independence. This indicated the importance of support from 'formal' networks for people with LGG.
6. PP6[52] examined the alignment in perspectives of HCPs and people with LGG for the challenges of implementing self-management support to empower the autonomy and independence of the support recipient. The careful inclusion of ICs in support was acknowledged as one of the key considerations.

7.2 Overall strengths and limitations

Each of the core publications presented in this thesis include a section that considers the strengths and limitations of that work. The strengths and limitations presented here include some reiteration but with focus on how the strength or limitation is applicable across the body of work.

7.2.1 Novelty and value of this work

The primary strength of this work is the highly novel contributions to the evidence base on the lived experiences of, and potential for supported self-management in, people with LGG. Much of this work had not previously been explored for this underserved population. The findings of this thesis provide valuable insights for research funders, service commissioners, and HCPs, including: (1) understanding and improving ways to identify and meet the support needs of people with LGG (see sections 7.3.1 and 7.4.1); (2) understanding the actions required to implement self-management support for people with LGG (see section 7.4.2); and (3) improving representation across people with LGG in future research (see section 7.3.2).

While this thesis focused on people with LGG, it has been highlighted throughout that the evidence base on self-management in people with brain tumours is limited. Therefore, there is scope for the relevance of these findings to extend beyond people with LGG, since there are commonalities in the support needs of people with different types of brain tumours[43]. For example, this work could inform the foundation of supported self-management for people with brain tumours that have general (e.g. fatigue, mobility) and tumour-specific (e.g. seizures, cognitive impairment) symptoms and impairments, regardless of prospective prognosis. Consequently, this work provides a platform for future research to further develop understanding in this area and consider whether engagement in self-management is nuanced for people with different types of brain tumours (e.g. HGG, grade 1).

The value of this work could also apply to other patient populations, including other cancers and acquired or progressive neurological conditions (e.g. stroke, Parkinson’s disease). Specifically, findings on the self-management of emotional issues around living with uncertainty may have relevance to people with advanced cancers that are treatable but incurable[136]. Further, quantitative evidence suggests that engagement in self-management is low in stroke survivors[137], which may be influenced by the barrier that cognitive functioning (e.g. impaired decision making, communication) can present to self-management[138]. The understanding in this work of the skills required by HCPs, and challenges to overcome, to provide self-management support for people with cognitive impairment (emphasised in section 7.4.2), could be valuable for improving engagement in self-management for people with progressive neurological conditions.

The work added to the self-management strategies taxonomy in PP3[49] provides a wider contribution to cancer survivorship research beyond understanding self-management engagement in people with LGG. This is because the revised iteration of the taxonomy can be used to aid the exploration of self-management engagement in other cancers. PP6[52] demonstrates how different perspectives can be brought together within NPT to shed more light on implementation considerations than relying on the HCP perspective alone. This presents a way to ensure that the patient perspective is heard in the implementation phase of intervention development that can be adopted in wider cancer survivorship research.

7.2.2 Methodological critique

Patient and public involvement was considered throughout the conceptualisation, data collection, interpretation, and dissemination of the Ways Ahead project, as outlined in chapter 2.4. This was in line with key objectives of the ongoing NIHR PPI strategy[139] and strategies for meaningful PPI in neuro-oncological research[140]. Specifically, the research design was inclusive and informed by widely accessible PPI activities, with assurance that the research questions mattered to the brain tumour community. Further, lay dissemination of project findings (e.g. through blog posts) and presentations at (inter)national conferences (see ‘Outputs during PhD candidature’), ensured that results were shared with multiple stakeholders.

This work benefitted from the participation of multiple stakeholders across the three interview sets with people with LGG, ICs, and HCPs. Further, the use of semi-structured interviews and inclusion of a wide range of topics within each topic guide, provided the freedom to explore different contexts and recognise what was important for each individual. Combined, this was valuable in capturing *how* and *why* people experience different roles and challenges in (supporting) self-management. Understanding the lived experiences of people with LGG is pivotal for achieving patient-centred quality care[141]. Further, including the perspectives of support providers and recipients provided wider insights into the acceptability and feasibility of supported self-management for people with LGG. This was particularly exemplified in PP6[52], which explored the (lack of) alignment in the perspectives of HCPs and people with LGG. Nonetheless, there are still potentially valuable perspectives missing from this body of work. The availability of specialist support and variation in 'models' of patient follow-up in some geographic locations means there may be some reliance on community support for people with LGG. Therefore, speaking to general practitioners or community support professionals (e.g. Speech and Language Therapists in the community) to understand whether they face specific challenges to providing support could add value to the insights presented in this work; the importance of this is expanded in section 7.4.2. Further, acquiring direct accounts from service commissioners may illuminate additional factors that influence the decision making process when determining whether a support service is both necessary and feasible for implementation.

COVID-19 had a substantial impact on the conduct of Ways Ahead. Since recruitment looked to commence at the onset of the pandemic, there were considerable delays with NHS site set-up. Consequently, there was more reliance on charity recruitment pathways at the study outset, than originally planned. While the Brain Tumour Charity were instrumental in facilitating sufficient recruitment, the possibility cannot be discounted that some participants were self-selected. For example, recruiting people with LGG with more time, interest, and capacity to take part, or ICs who were more 'active' in their caregiving role, might have influenced the breadth of experiences represented in these samples. Nonetheless, NHS recruitment does not eliminate the risk of selection bias, as the recruiting HCP could be selective in determining who they feel are appropriate to approach.

In accordance with the purposive sampling strata used in participant recruitment (outlined in chapter 2.2), the desired diversity was achieved across each sample (e.g. range of time since diagnosis for people with LGG, inclusion of male ICs, and a range of healthcare professions). This helped elicit an extensive range of views and experiences. However, despite a wide range of time since diagnosis, the cross-sectional nature of the interviews means it is unclear how people's lived experiences may change over time. Consequently, future research may benefit from collecting longitudinal data, for example, to explore whether engagement in self-management changes as time elapses and the individual has had more time to adapt to their condition.

It is important to note that ethnicity was not a collected demographic characteristic, nor a sampling stratum, though participants were mostly White British. Ethnicity has been evidenced to influence the self-care behaviours of cancer survivors, due to the greater prevalence of fatalistic thinking in some cultures[142]. Thus, achieving greater ethnic diversity may have helped to understand the emotional challenges, particularly with acceptance of the incurable condition, reported by people with LGG in PP4[50]. Recently there is much more awareness and focus on ethnicity to improve the inclusion of underserved groups in healthcare research[143]; therefore, future research should seek to focus on minoritised populations in their samples.

Again, due to COVID-19, the planned approach to data collection changed from face-to-face to all interviews being conducted remotely. A strength of this was that it facilitated data collection across the United Kingdom[144], as travel did not need to be considered. This meant, for example, that data from interviews with HCPs encapsulated diverse experiences with implementation challenges from different ‘models’ of patient follow-up and support, and levels of organisation readiness to support self-management. Further, participants may have felt more comfortable discussing sensitive issues, with greater perceived anonymity[145]. However, with remote interviews, there are potential challenges with technology literacy and accessibility, and it is more difficult to notice non-verbal cues, such as fatigue. This has implications for the participation of people with memory and processing speed limitations, which could exacerbate the demands of an interview or limit the richness of data. In-person interviews may have made it easier to gauge the impairment of the participant and respond accordingly (e.g. acknowledge when the participant needs a break). Hence, although attempts were made to support the participation of people who may have had cognitive impairment (e.g. with advanced provision of a topic overview, outlined in chapter 2.3), more needs to be done to facilitate inclusion across people with LGG. This is discussed further in section 7.3.2.

Reasonable data sufficiency was judged to have been achieved across all three interview sets, as there was extensive data to support and understand each of the research questions, supported by multiple quotes within each paper[55]. This work also benefitted from the use of different approaches to qualitative analysis, each carefully selected to appropriately address the relevant research question. To summarise, the flexibility of the inductive thematic analysis[79] used in PP2[48] and PP5[51] helped develop patterns of meaning, driven by the content, to examine the impact of life with a LGG and support role of ICs, respectively. The directed content analysis[92] used in PP3[49] highlighted the potential for self-management in people with LGG, in accordance with an existing taxonomy of wide-ranging self-management strategies[85]. Finally, the combination of inductive open coding, followed by deductive mapping to the framework of factors influencing self-management[88] in PP4[50] and NPT constructs[116] in PP6[52], identified the specific challenges to (implementing support in the healthcare system for) self-management in people with LGG.

7.2.3 Reflexivity

Throughout Ways Ahead, I have been critical in evaluating how reflexivity has helped to develop rigour, particularly in the qualitative data collection and analysis processes[146]. This includes personal, interpersonal, methodological, and contextual reflexivity. I approached this research as someone with a background in Health Psychology with experience of conducting qualitative research on QoL in cancer survivorship (as introduced in chapter 2). To exemplify ‘personal reflexivity’, it is possible that my background influenced my expectations of the topics that would be covered in interviews and the probing questions that I asked to explore topics further. Hence, my personal experience may have guided the direction and content of the interviews. I sought training with navigating sensitive issues in qualitative research. This helped me respond appropriately to the intense emotions that were often triggered for participants when discussing their experiences (e.g. with fear of tumour progression). Through engagement with different stakeholder groups, I developed an understanding of how to be sensitive and accurate in the language used to ‘define’ the target population. This development is evident from ‘low- and intermediate-grade glioma survivors’ in the protocol[46] to ‘people with lower-grade gliomas’ in later publications[48]. Hence, I am now mindful to avoid terms like ‘patient’ and ‘survivor’ in write-up and interactions, as people with LGG may live long-term with an incurable condition.

‘Interpersonal reflexivity’ between me and the participants is exemplified by allowing the topic guides to evolve as interviews progressed and more information was shared. Further, as I do not have a clinical background, HCPs may have spoken more in-depth about organisational challenges, as they would be unlikely to assume that I have prior knowledge. Similarly, people with LGG may have been more incentivised to discuss their healthcare support experiences with me, knowing that I do not have any clinical involvement. ‘Interpersonal reflexivity’ is also evident between me and the research team, for example, drawing on the different expertise within the team when developing my understanding of the research area and the generated data. To exemplify ‘methodological reflexivity’, I reacted to the generated data to make informed decisions about the most appropriate qualitative analysis approach for each research question. Finally, ‘contextual reflexivity’ is evident from the evaluation of, and reaction to, the impact of COVID-19 on recruitment and data collection procedures.

7.3 Future research implications

The findings from this thesis inform two key directions for future research: (1) the development of a supported self-management intervention for people with LGG; and (2) improving the representation of people with cognitive and communication impairments in brain tumour research.

7.3.1 Development of a supported self-management intervention for people with lower-grade gliomas

The work presented in this thesis represents the groundwork required to inform the design and development of a supported self-management intervention for people with LGG. The systematic review from Ways Ahead[27] (*Appendix B.4*) found that there were no existing self-management interventions for people with brain tumours, so this will be a novel development for this population. This is important because the content of existing self-management interventions for cancer survivors is unlikely to be fully transferable to the tumour-specific problems (e.g. seizures, cognitive impairment) experienced by people with LGG, that were highlighted in PP1[47] and PP2[48].

Ways Ahead has followed the early steps in INDEX[147] and Medical Research Council[148] guidance to the development of complex healthcare interventions:

1. A multi-disciplinary research team was established with expertise in the development, evaluation and implementation of behaviour change interventions; clinical, psychosocial, and cognitive function of people with brain tumours; and QoL in cancer survivorship. This expertise was drawn upon in the conduct and write-up of the publications presented in this thesis (see *Appendix A*). It is worth noting that there were specialisms (e.g. Physiotherapist, Occupational Therapist) absent from the project team that may have provided valuable expertise regarding physical and role function of people with brain tumours.
2. Published research evidence was reviewed in PP1[47] and the systematic review of self-management interventions[27] (*Appendix B.4*). This identified the wide-ranging HRQoL consequences in people with LGG, and the potential for self-management interventions to improve QoL, respectively. The absence of self-management interventions for people with brain tumours highlighted such development as a priority area.
3. Primary data collection through means of qualitative research was undertaken to establish and understand context. This comprised the engagement of multiple stakeholders across three interview sets with people with LGG, ICs, and HCPs. Patient and public involvement activities (outlined in chapter 2.4) were carefully incorporated throughout to ensure the research was being conducted *with* the end-user, not *for* them.
    a. Programme theory was developed in PP2[48] and PP3[49] by understanding the lived experiences of people with LGG, in the context of how QoL is impacted in day-to-day life and how they

currently engage in self-management, respectively. This elicited key insights into the needs and behaviours of this group, to inform the areas where support may be required in an intervention.

b. Key uncertainties were identified in PP4[50], PP5[51], and PP6[52] at the individual, IC, HCP, and healthcare system level, recognising the future implementation challenges to be overcome. This provided understanding of individual perceptions of their roles within (supporting) self-management, the barriers faced, and the actions required to facilitate these roles. Overall, these insights are valuable for comprehending the feasibility and acceptability of supported self-management for people with LGG, from the perspectives of support providers and recipients; this is expanded in section 7.4.2.
c. Existing theories were drawn upon throughout Ways Ahead. Firstly, the focus on self-management in the work was underpinned by social cognition theory[12]. The data analysis strategies of PP3[49] and PP4[50] were informed by a taxonomy of self-management strategies in cancer survivors[84,85] and framework of factors influencing self-management in chronic illness[88], respectively. This helped identify commonalities with other conditions and understand how existing frameworks are extended in the context of people with LGG. Finally, the application of NPT in PP6[52] provided understanding of how the findings align with the mechanisms of social action that underpin the implementation processes of a novel practice into routine care.

Development of a supported self-management intervention for people with LGG need not start *de novo*. As mentioned in chapter 6.1.2, the systematic review of self-management interventions (*Appendix B.4*) outlined the intervention components and characteristics shown to be effective in improving QoL in cancer survivors[27]. In accordance with the PRISMS taxonomy[16] of components that can be used to support self-management (introduced in chapter 1.1.2), the components that were consistently associated with improving QoL comprised: 'Information about condition and its management'; 'Training for practical self-management activities'; 'Training for psychological strategies'; and 'Social support'. The work presented in this thesis lends itself to understanding why these components are favourable for adoption in a self-management intervention for people with LGG. Firstly, these components are appropriate for addressing the possible support needs outlined in PP1[47] and PP2[48]; specifically, the emotional consequences of living with an incurable condition, and the impact of fatigue, seizures, and cognitive impairment on day-to-day life (e.g. work, social activities). Further, these components align with the self-management strategy types most reported in PP3[49], namely: 'Using support'; 'Creating a healthy environment'; and 'Meaning making'. Finally, these components could help overcome the barriers to self-management identified in PP4[50], which primarily concerned knowledge and acceptance of the incurable condition, the impact of seizures and cognitive impairment, and access to (in)formal support. These findings are upheld by the National Institute for Health and Care Excellence (NICE) guidelines for supporting people living with a brain tumour; specifically an evidence synthesis of qualitative studies identified emotional (e.g. hope, reassurance), healthcare (e.g. strong relationship with care provider), and information (e.g. about condition and its treatment) support, as the most common support needs[149].

When translating these findings into content for an intervention, this can be split into adjustment- (e.g. reinterpreting negative consequences) and problem-focused elements (e.g. using external aids to overcome cognitive difficulties). A qualitative study with people with glioma and their relatives found that reassurance and support, through information about the condition, were essential for alleviating distress and adjusting to the illness[150]. Still, care needs to be taken to manage expectations with information that is appropriate for the individual. This is because a further qualitative study of people with brain tumours reported anger and dissatisfaction with HCPs when expectations and symptom experiences did not align (e.g. unexpected levels of fatigue)[151]. Therefore, intervention components could include core adjustment-focused elements that apply across cancers, supplemented with problem-focused elements for needs specific to people with LGG.

Section 7.4.2 highlights the importance of considering what is feasible for people with LGG; here the emphasis is on how to optimise the type of self-management support provided. A literature review of supported self-management suggests that inclusion of support providers and recipients in the co-creation of self-management strategies increases the likelihood of positive effects (e.g. improved self-efficacy)[23]. The importance of tailoring support is emphasised in PP2[48] as people's lived experiences can vary depending on what context they consider to be important to their QoL. For example, for someone who wishes to return to work, the strategies and support expertise required to overcome cognitive difficulties in the workplace likely look different to what is necessary to aid cognitive function at home (e.g. when cooking). This links to the need to improve the assessment of support needs to aid the personalisation of support for people with LGG, as outlined in section 7.4.1.

To supplement the work presented in this thesis, participants in each interview set were also asked about desired support and intervention design preferences at the end of the interview. Key findings from this data included the desire for an 'information toolkit' of advice and support (e.g. knowing what to expect, HCP contact details, self-management strategies, links to available support) and access to group support (online or face-to-face) for sharing experiences. In accordance with the TIDieR checklist[128] of intervention characteristics (introduced in chapter 6.1.2), these initial findings indicate a preference for combined individual and group delivery, so that people with LGG can decide what is appropriate for them. This characteristic was most consistently associated with improvements in QoL in existing self-management interventions for cancer survivors[27] (*Appendix B.4*).

Further, people with LGG requested that ICs also have timely access to intervention content, where appropriate, so they know what to expect and how they can help. This aligns with findings from a qualitative systematic review on the experiences of supportive care for people with brain cancer and their ICs[152]. Still, section 7.4.2 stresses the need for careful integration of ICs in support, so that the design of an intervention does not disadvantage those without access to informal support. Beyond this, qualitative evidence of cancer survivors' views towards the design and delivery of self-management interventions found heterogeneity in people's preferences for intervention provider, mode of delivery, and location[153,154]. Moreover, in PP6[52], HCPs appraised the scope for self-management support, acknowledging the variation in desired support and need to manage expectations. Hence, further research was necessary to build upon the desired support and design preferences identified in the Ways Ahead interviews.

The next stages in the development of a supported self-management intervention for people with LGG are ongoing. Four co-design workshops and a survey have been conducted. This included engaging multiple stakeholders (people with brain tumours, ICs, and HCPs) in discussions around the acceptability and feasibility of possible intervention components and characteristics, for the iterative design of a prototype intervention. A brief report of the findings from these co-design activities is being finalised for journal submission. Future funding will be sought to further develop, test, and evaluate the prototype intervention, with constant attention to ensuring it has potential for real world implementation.

7.3.2 Representation and inclusion of people with cognitive and communication impairments in brain tumour research

Critical appraisal of existing evidence in PP1[47] identified a need for greater representation and inclusion of people with cognitive and communication impairments in brain tumour research. This implication is introduced in the discussion of PP1[47], recognising that explicit exclusion of people with cognitive and communication impairments is common in quantitative studies of people with LGG. It was unclear how these impairments were determined, and there were a lack of reported attempts to facilitate their inclusion. Inclusion of people with cognitive and communication impairments is a challenge that extends to qualitative research. It should be noted here that Ways Ahead did not recruit anyone with any substantial speech, language, and communication impairment. Despite the attempts to facilitate participation outlined in chapter 2.3, section 7.2.2 indicates that the demands of taking part in a remote interview may present barriers to inclusion. Further, Åke et al.[155] reported that in people with LGG, communication requires time and effort, with the need for multiple self-management strategies. Consequently, it is possible that cognitive and communication impairments are not yet fully understood for people with LGG.

PP1[47] presents future research suggestions for researchers to facilitate greater inclusivity of people with cognitive and communication impairments. This includes engagement in supportive conversation training, ensuring accessible formatting of study documentation, or involving/consulting Speech and Language Therapists. Prompted by discussions around Ways Ahead and this thesis work, Menger et al.[156] take this a step further in a commentary on “Speaking up for the lost voices”, offering three areas of solutions to improve representation and inclusion of people with cognitive and communication impairment in brain tumour research: (1) Improve the accuracy of reporting of impairment, to improve clarity on whether the person is experiencing speech, language, or communication impairments, either individually or in combination. This is important for recognising what difficulties (e.g. understanding of speech, writing, and non-verbal communication; difficulty staying on topic; word-finding) each participant may need support with to facilitate participation. (2) Be innovative with data collection methods, allowing participants to convey messages by different means (e.g. drawing or gesture). Researchers can complete conversation partner training[157] to improve their confidence with supporting participation in these ways. However, it should be noted there are currently no training programmes aimed at those working with the brain tumour population, so existing training may not be the best fit. (3) Consult Speech and Language Therapists, as they can facilitate the development of accessible study documentation (e.g. video that presents audio version of PIS), advise on appropriate communication methods, and support mental capacity assessments.

To work towards realising these solutions, I am a co-applicant on a recently awarded NIHR grant (see ‘Outputs during PhD candidature’) to improve speech and language therapy support for adults living with brain tumours. This project proposes to: (1) describe the impact of speech, language, and communication difficulties for people with gliomas and their communication partners, to identify support needs; and (2) explore HCPs perspectives and experiences on current support for these difficulties. Should this project achieve its outcomes, it will produce recommendations for how support could be improved for people with speech, language, and communication difficulties, due to glioma. This will help guide multi-disciplinary teams with how to work with people with gliomas and inform the development of meaningful partnerships with research teams.

Overall, all ongoing and future planned studies involving people with brain tumours should consider what can be done to facilitate inclusion of people with cognitive and communication impairments, to improve their representation in research. This should be carefully considered with thoughtful PPI engagement at multiple timepoints to identify the appropriate solutions for the study design (e.g. supportive conversation training for qualitative studies; use of validated accessible scales for quantitative studies). Seeking participant feedback to evaluate the perceived helpfulness of the implemented solutions will allow the approach to be adapted appropriately[158]. This could help improve researchers' confidence with including people with cognitive and communication impairments, and provide a more accurate understanding of such impairments for people with LGG. Achieving this will be influential for expanding understanding of the lived experiences of people with LGG and further inform problem-focused elements of supported self-management interventions for this population.

7.4 Clinical implications

The findings from this thesis have highlighted two key clinical implications: (1) practical implications for identifying the support needs of people with LGG; and (2) the implementation of self-management support for people with LGG in policy and practice.

7.4.1 Practical implications for identifying the support needs of people with lower-grade gliomas

The work presented in this thesis identified a need to improve the identification of the problems faced by, and the unmet support needs of, people with LGG. This implication was introduced in the discussion of PP2[48], acknowledging the value of comprehensiveness regarding the measured symptoms and concerns, and contextualising the problems to appreciate what is important to each individual. This is expanded here to recognise how support needs are, or can be, currently assessed, and identify areas for improvement. With the desire for improved routine measurement of patient-reported outcomes in cancer care (introduced in chapter 1.1.1)[8], it is critical that the selected measure is appropriate for the intended outcome and population.

A systematic review of patient-reported outcome measures in brain tumour studies[76] found that the EORTC QLQ-BN20[61] and FACT-Br[62] are the most frequently used brain tumour-specific measures of HRQoL. While EORTC and FACT measures follow a development process, the review authors called for greater clarity on whether these measures exhibit good content validity (the extent to which the measure is comprehensive and relevant for the construct being measured). This is important because in a separate systematic review of HRQoL measures used in people with LGG, Fountain et al.[75] reported that none of the measures used across included studies (including EORTC QLQ-BN20 and FACT-Br) have been validated in people with LGG. This raises concerns over how appropriate existing measures are for identifying the problems faced by people with LGG, as introduced in chapter 3.1.3. To exemplify this, PP1[47] and PP2[48] indicated that seizures can have a substantial impact on the lives of people with LGG. Although EORTC QLQ-BN20 and FACT-Br both include items concerning the presence of seizures, both measures fail to contextualise the impact of seizures on the individual. Further Ways Ahead findings from interviews with people with LGG (*Appendix B.7*) suggest seizure activity might worsen due to work-related stress or present a barrier to employment[159]. Since returning to work may be a priority for people with LGG[41], this exemplifies that symptoms should not be identified in isolation of their context. Consequently, as others have acknowledged for people with gliomas[160], existing static measures with fixed item sets may be insufficient for identifying the problems faced by people with LGG. Important context may be obtained by supplementing HRQoL measures with measures of IADLs, such as EORTC IADL-BN32 (introduced in chapter 3.1.2), as this will allow identified problems to be cross-referenced with a range of IADLs.

While measures of HRQoL may infer support needs, needs assessment tools are designed to identify the level of need for support with each concern. However, a systematic review of needs assessment tools in advanced cancer, conducted as part of Ways Ahead (*Appendix B.3*), found that people with brain tumours were not represented in the development or validation of any of the existing measures[77]. Still, such measures have potential value as they often ask about needs for support around the fear of disease progression, rather than recurrence, which aligns with the incurable nature of a LGG. Identifying support needs could help HCPs understand whether self-management strategies are achievable or need to be adapted, acknowledging the potential barriers to engagement highlighted in PP4[50]. For example, medication management may be hindered by an identified issue with cognitive impairment (e.g. attention deficits); thus, the support required might concern providing equipment (e.g. dosette box) or strategies (e.g. setting reminders/alarms) to overcome these challenges. Still, cognitive impairment can be multi-faceted and require comprehensive assessment to identify individual strengths and needs; thus, for cognitive functioning, the discussed measures should only serve to identify a need for further exploration, which can then be followed up by a Neuropsychologist or Speech and Language Therapist, for example.

Although most HCPs declare that they routinely screen and refer brain tumour patients for physical, cognitive, and emotional issues[135], PP6[52] highlights that people with LGG feel the opportunities to report their support needs are insufficient. Darlix et al.[80] recommend the use of clinical interviews to holistically explore subjective complaints and patient experiences, and present sufficient opportunity for the expression of HRQoL concerns. HCPs could use these interviews to complement and contextualise the findings of HRQoL measures or needs assessments, to then work with the support recipient on how best to meet identified needs. The development of follow-up care plans should have a focus on how self-management can be supported to facilitate autonomy and independence.

Overall, addressing this implication in practice could help ensure that identified problems and support needs are tailored to the experience of having a LGG, while capturing important context to aid the personalisation of support to the individual[161].

7.4.2 Implementation of self-management support for people with lower-grade gliomas in policy and practice

At the outset of Ways Ahead, a commentary (*Appendix B.2*) was published with five recommendations (outlined in chapter 6.1.2) for improving the implementation of self-management interventions for cancer survivors[123]. The work presented in this thesis provides valuable insights into understanding the ‘adaptability’ and ‘acceptability’ of such interventions. This draws on the perspectives of multiple stakeholders to comprehend the actions required to facilitate effective engagement in (supporting) self-management for people with LGG.

Adaptability relates to the extent to which a self-management intervention is flexible across people, cancers, and time. To achieve this, the use of effective core components across self-management interventions is encouraged. Section 7.3.1 expands on the components worth adopting from existing interventions for cancer survivors (e.g. ‘Information about condition and its management’)[27] (*Appendix B.4*), including why such components may be favourable in the development of a self-management intervention for people with LGG. Here, the emphasis is on flexibility across people and time. The timings of support and identifying those in need of support have been identified as ‘pressing questions’ requiring investigation to inform policy and practice for supported self-management in cancer care[26] (as introduced in chapter 1.1.3). Thus, implementation of self-management support must consider the diversity of need within the target population.

Regarding flexibility across time, PP1[47] suggests that HRQoL remains poor over time, indicating a sustained need for self-management in people with LGG. PP3[49] extends this to imply that different approaches to self-management may be needed at different timepoints since diagnosis. For example, people may have an initial need to self-manage (the risk of) seizures, that in the long-term are stabilised with the appropriate dosage of antiepileptic medication. Further, self-management of emotional distress is variable as people may need time to accept their incurable condition[162]. Finally, returning to, and managing, occupational roles may be longer-term issues as people attempt to return to 'normality', find a 'new normal' or work towards specific and achievable goals via rehabilitation.

Regarding flexibility across people, self-management interventions may attract those who are well-educated and already self-manage well[129], so it is important that those with greater support needs receive the required attention. However, PP6[52] raised concerns from the HCP perspective around identifying and keeping track of people with support needs, citing partial reliance on the support recipient seeking help. PP4[50] suggests that help seeking can be influenced by knowledge of their condition, including what symptoms and impairments they might experience. To address the presented issues with adaptability across people and time, HCPs in PP6[52] suggested the possibility of reiterating available information and support at regular intervals over time, though also stressed the need to avoid 'information overload'. Thus, self-management interventions could be packaged with repeat needs assessments to ensure that the support provided aligns with the needs of the individual at different timepoints since diagnosis. This emphasises the importance of using appropriate measures to identify the support needs of people with LGG, as outlined in section 7.4.1.

Acceptability involves ensuring that (supporting) self-management is perceived as positive, necessary, and most importantly, feasible to all stakeholders, as the implementation of a self-management intervention requires a whole-system approach[17]. As detailed in section 7.1, PP3[49] and PP6[52] indicate that self-management is well perceived by people with LGG and HCPs. The challenges with acceptability stem from the feasibility of supported self-management for people with LGG; the insights provided by PP6[52] around current acceptability are summarised in chapter 6.2.1. Exploring acceptability through the lens of NPT helped to clarify the actions required to facilitate implementation (e.g. HCP collaboration, careful integration of ICs). In this section, the emphasis is on the importance of these actions and possible next steps.

The work presented in this thesis aligns with actions one (preparing people for active involvement in care) and two (embed self-management support into care pathways) of Howell et al.'s call to action for self-management in cancer care[18] (introduced in chapter 1.1.3). These insights are described in chapter 4.3.1 and 6.2.1; to expand on this here, action one also calls for the preparation of ICs for active involvement in care. Although receiving support from informal networks was a commonly reported self-management strategy type in PP3[49] and facilitator to self-management in PP4[50], care needs to be taken to ensure an intervention is widely accessible to people with LGG, irrespective of the strength of their informal support networks. Furthermore, PP5[51] highlights the '*delicate dance*' that ICs experience in their attempts to provide support without inhibiting the care recipient's independence. Therefore, the integration of ICs in the delivery of a self-management intervention needs to be appropriately managed and should align with the desires and priorities of the care recipient, on a case-by-case basis. This will help to ensure that support remains person-centred and encourages independence.

While self-management support aims to improve self-efficacy and independence in the support recipient, it is important to consider whether this is fully achievable for people with LGG. Findings from PP2[48] and PP4[50] improve awareness of the potential challenges (e.g. with cognitive impairment and acceptance of their incurable condition) faced by people with LGG around self-management. This raises concerns over their potential to be supported to self-manage, as cognitive challenges, such as memory or attention deficits may hinder their ability to implement a self-management strategy (e.g. using calendar prompts to remember health appointments). HCPs in PP6[52] also note that people with LGG who are experiencing difficulties with insight (i.e. awareness of a problem) or acceptance, are likely to resist support, and have low motivation to engage in self-management. Consequently, for people with LGG there is a need to consider whether an individual first recognises a need to self-manage, then whether they have both the ability and the motivation or can be supported to self-manage as a rehabilitation goal. This links back to the question raised in chapter 1.1.4 about whether existing self-management interventions are accessible for people with substantial impairments.

PP2[48] emphasised the benefits of considering what QoL means to people with LGG, to tailor the support context to the individual. Here, the implication for implementing self-management support is on finding the appropriate expertise to approach different issues. For example, cognitive impairment may require support from a Neuropsychologist, yet if the impairment is affecting an individual's capacity to work, they could also require support from an Occupational Therapist. This thesis acknowledges the role of diverse multidisciplinary skills and highlights the need for collaboration between HCPs to provide combined support. Still, PP6[52] outlined the organisational challenges that need to be overcome, including limited access to specialist professionals, staffing and resource issues, and deficits in communication (e.g. referral pathways) between support services. These barriers to self-management support provision are corroborated in surveys of HCPs' views on the barriers to rehabilitation for people with brain tumours[43] and inequalities in access to neuro-oncology supportive care (introduced in chapter 6.2.1)[135].

Another important aspect of collective action outlined in PP6[52] is the need for strong HCP-support recipient relationships. This was mentioned in chapter 6.1, noted as a key consideration for guiding patient-centred care in neuro-oncology[81], and acknowledged in section 7.3.1 as one of the most common healthcare support needs in NICE guidelines for supporting people living with a brain tumour[149]. While HCPs may be the enablers of a self-management intervention, developing strong relationships with the support recipient can facilitate the co-creation of an action plan[14], which clearly delineates the role and responsibilities of the support provider and recipient. This includes building trust through communication and reassurance, and helps the HCP to determine whether an instructive, collaborative, or advisory supportive role will be appropriate for supporting that individual (as introduced in chapter 6.1.1)[118].

HCPs in PP6[52] suggested that quality of care would improve with enhanced HCP collaboration and strong relationships with support recipients. However, they also noted that certain areas of support (e.g. psychological) could be unavailable if there is no access to the appropriate expertise in their service. Therefore, the feasibility of implementation strategies, such as HCP collaboration may be hindered by resource-constrained environments, particularly where staffing levels and access to specialist professionals may be limited[119]. Further, section 7.2.2 introduced the potential reliance on people accessing support in community settings. A survey of HCPs' views on the rehabilitation needs of people with brain tumours expressed concerns that community support professionals may lack the skills and capacity to provide specialist support; this is because they often do not have sufficient experience in providing support for people with brain tumours[43]. This concern may extend to general practitioners in primary care, or HCPs who are newly qualified. Overall, this identifies a pertinent need to consider training for HCPs to ensure they have the skills required to support self-management for people with brain tumours. Indeed, education for HCPs on neuro-oncological supportive care was the service improvement suggestion with the most endorsement in a 2023 survey of HCPs' views of inequalities in access to neuro-oncological supportive care[135].

Chapter 6.1.1 introduced the effectiveness of a self-management support training programme for oncology nurses and cancer coaches[120], finding improved confidence with 15 support skills, such as establishing rapport, tailoring strategies, and developing action plans. These support skills align with the discussed implementation strategies, indicating the potential for such training to be applicable to HCPs involved in supporting people with brain tumours. The findings presented in this thesis go beyond this to acknowledge the unique challenges of cognitive and communication impairments in people with LGG, as many HCPs might not be explicitly trained in how to make adaptations for these types of needs. This includes, for example, consideration of how the HCP communicates with, or provides written information for, the support recipient, emphasising the importance of the recommendations outlined in section 7.3.2. Overall, these training suggestions align with action three (prepare the workforce in the knowledge and skills necessary to facilitate effective self-management) of Howell et al.'s call to action for self-management in cancer care[18].

The implications presented in this section provide valuable insight into the key factors underpinning HCPs' engagement in supporting self-management (introduced in chapter 6.1.1)[121]. Specifically, the training recommendations could help ensure that HCPs have the appropriate knowledge and consultation skills. Further, suggestions for strengthening HCP-support recipient relationships may help provide clear delineation of roles and responsibilities in (supporting) self-management. Overall, the outlined changes required at the organisation level could assist in the re-configuration of healthcare systems to facilitate ease of support delivery.

Improving readiness to implement self-management support for people with LGG at the HCP and organisation level has potentially wide-ranging benefits. For example, if successful, as introduced in chapter 1.1.3, self-management interventions can reduce healthcare utilisation (e.g. hospitalisation rates), without compromising health outcomes[22]. This is important because, thinking beyond the work presented in this thesis, evidence on cost-effectiveness is also critical for policy makers and service providers when making implementation decisions[123] (*Appendix B.2*). However, the Ways Ahead systematic review of self-management interventions (*Appendix B.4*) found limited and inconclusive evidence for the cost-effectiveness of existing interventions[27]. To address this, in Ways Ahead, Dr Richéal Burns is leading an ongoing economic evaluation, to estimate the cost-effectiveness of supporting self-management for people with brain tumours. Early insights suggest that a self-management intervention could alleviate the impact on ICs, offsetting the costs related to easing the burden of caregiving experienced by ICs of people with LGG (*Appendix B.5* and *B.6*)[96,97].

Overall, this thesis represents critical groundwork for the implementation of self-management support for people with LGG in policy and practice. As introduced in section 7.2.1, the value of these findings and implications extend to research funders and service commissioners. Specifically, this supports the research required to advance understanding of supported self-management for people with brain tumours, and the actions required to prepare for, and facilitate implementation. Further progress in this area will help ensure that the call to action recommendations for self-management in cancer care[18] continue to be met; fostering performance accountability (action four) and understanding the effectiveness (action five) and reach (action six) of self-management support for people with brain tumours is still required.

7.5 Conclusion

The overarching aim of this thesis was to understand the lived experiences of people with LGG and the potential for supported self-management. The findings presented across the core publications (PP1-PP6[47–52]) provide comprehensive and novel insights on this topic, from the perspectives of multiple stakeholders. These findings combine to present a cohesive understanding of current lived experiences, and the actions required to facilitate engagement in self-management for people with LGG. Overall, this work has valuable implications for the development and implementation of person-centred self-management support, that: (1) is acceptable and feasible across multiple stakeholders, with representation of people with cognitive and communication impairments; (2) recognises individual needs and the influence of informal support networks; and (3) facilitates the autonomy and independence of people with LGG. This evidence has scope for potential applicability to other brain tumours, advanced cancers, and progressive neurological conditions, beyond people with LGG. This thesis represents the foundations needed to inform future research and clinical efforts, to improve the QoL of this underserved population.

References

1. Watson, E. K., Rose, P. W., Loftus, R., & Devane, C. (2011). Cancer survivorship: the impact on primary care. *British Journal of General Practice*, *61*(592), e763–e765. https://doi.org/10.3399/BJGP11X606771

2. Allemani, C., Matsuda, T., Di Carlo, V., Harewood, R., Matz, M., Nikšić, M., Bonaventure, A., Valkov, M., Johnson, C. J., & Estève, J. (2018). Global surveillance of trends in cancer survival 2000–14 (CONCORD-3): analysis of individual records for 37 513 025 patients diagnosed with one of 18 cancers from 322 population-based registries in 71 countries. *The Lancet*, *391*(10125), 1023–1075. https://doi.org/10.1016/S0140-6736(17)33326-3

3. Arnold, M., Rutherford, M. J., Bardot, A., Ferlay, J., Andersson, T. M. L., Myklebust, T. Å., Tervonen, H., Thursfield, V., Ransom, D., & Shack, L. (2019). Progress in cancer survival, mortality, and incidence in seven high-income countries 1995–2014 (ICBP SURVMARK-2): a population-based study. *The Lancet Oncology*, *20*(11), 1493–1505. https://doi.org/10.1016/S1470-2045(19)30456-5

4. Schmidt, M. E., Goldschmidt, S., Hermann, S., & Steindorf, K. (2021). Late effects, long-term problems and unmet needs of cancer survivors. *International Journal of Cancer*, *151*(8), 1280–1290. https://doi.org/10.1002/ijc.34152

5. Cook, S. A., Salmon, P., Hayes, G., Byrne, A., & Fisher, P. L. (2018). Predictors of emotional distress a year or more after diagnosis of cancer: a systematic review of the literature. *Psycho-oncology*, *27*(3), 791–801. https://doi.org/10.1002/pon.4601

6. de Boer, A. G., Torp, S., Popa, A., Horsboel, T., Zadnik, V., Rottenberg, Y., Bardi, E., Bultmann, U., & Sharp, L. (2020). Long-term work retention after treatment for cancer: a systematic review and meta-analysis. *Journal of Cancer Survivorship*, *14*(2), 135–150. https://doi.org/10.1007/S11764-020-00862-2

7. Costa, D. S. J., Mercieca-Bebber, R., Rutherford, C., Gabb, L., & King, M. T. (2016). The Impact of Cancer on Psychological and Social Outcomes. *Australian Psychologist*, *51*(2), 89–99. https://doi.org/10.1111/AP.12165

8. Richards, M., Corner, J., & Maher, J. (2011). The National Cancer Survivorship Initiative: new and emerging evidence on the ongoing needs of cancer survivors. *British Journal of Cancer*, *105*(1), S1–S4. https://doi.org/10.1038/BJC.2011.416

9. Stovall, E., Greenfield, S., & Hewitt, M. (2005). *From cancer patient to cancer survivor: lost in transition*. National Academies Press.

10. Chan, R. J., Nekhlyudov, L., Duijts, S. F. A., Hudson, S. V., Jones, J. M., Keogh, J., Love, B., Lustberg, M. B., Mehnert-Theuerkauf, A., Nathan, P., Ness, K. K., Sheppard, V. B., Smith, K., Tevaarwerk, A., Yu, X., & Feuerstein, M. (2021). Future research in cancer survivorship. *Journal of Cancer Survivorship*, *15*(5), 659–667. https://doi.org/10.1007/S11764-021-01102-X

11. Foster, C., Brown, J., Killen, M., & Brearley, S. (2007). The NCRI Cancer Experiences Collaborative: Defining self management. *European Journal of Oncology Nursing*, *11*(4), 295–297. https://doi.org/10.1016/J.EJON.2007.08.002

12. Bandura, A. (1986). *Social foundations of thought and action. Englewoods Cliffs*. NJ: Prentice-Hall.

13. Dwarswaard, J., Bakker, E. J. M., van Staa, A., & Boeije, H. R. (2016). Self-management support from the perspective of patients with a chronic condition: a thematic synthesis of qualitative studies. *Health Expectations*, *19*(2), 194–208. https://doi.org/10.1111/HEX.12346

14. McCorkle, R., Ercolano, E., Lazenby, M., Schulman-Green, D., Schilling, L. S., Lorig, K., & Wagner, E. H. (2011). Self-management: Enabling and empowering patients living with cancer as a chronic illness. *CA: A Cancer Journal for Clinicians*, *61*(1), 50–62. https://doi.org/10.3322/caac.20093

15. Foster, C., & Fenlon, D. (2011). Recovery and self-management support following primary cancer treatment. *British Journal of Cancer*, *105*(1), S21–S28. https://doi.org/10.1038/bjc.2011.419

16. Pearce, G., Parke, H. L., Pinnock, H., Epiphaniou, E., Bourne, C. L. A., Sheikh, A., & Taylor, S. J. C. (2016). The PRISMS taxonomy of self-management support: derivation of a novel taxonomy and initial

testing of its utility. *Journal of Health Services Research & Policy*, *21*(2), 73–82. https://doi.org/10.1177/1355819615602725

17. Taylor, S. J. C., Pinnock, H., Epiphaniou, E., Pearce, G., Parke, H. L., Schwappach, A., Purushotham, N., Jacob, S., Griffiths, C. J., & Greenhalgh, T. (2015). A rapid synthesis of the evidence on interventions supporting self-management for people with long-term conditions: PRISMS–Practical systematic Review of Self-Management Support for long-term conditions. *Health and Social Care Delivery Research*, *2*(53). https://doi.org/10.3310/hsdr02530

18. Howell, D., Mayer, D. K., Fielding, R., Eicher, M., Verdonck-De Leeuw, I. M., Johansen, C., Soto-Perez-De-Celis, E., Foster, C., Chan, R., Alfano, C. M., Hudson, S. V., Jefford, M., Lam, W. W. T., Loerzel, V., Pravettoni, G., Rammant, E., Schapira, L., Stein, K. D., & Koczwara, B. (2021). Management of cancer and health after the clinic visit: A call to action for self-management in cancer care. *Journal of the National Cancer Institute*, *113*(5), 523–531. https://doi.org/10.1093/jnci/djaa083

19. Kim, S. H., Kim, K., & Mayer, D. K. (2017). Self-Management Intervention for Adult Cancer Survivors After Treatment: A Systematic Review and Meta-Analysis. *Oncology Nursing Forum*, *44*(6), 719. https://doi.org/10.1188/17.ONF.719-728

20. Howell, D., Harth, T., Brown, J., Bennett, C., & Boyko, S. (2017). Self-management education interventions for patients with cancer: a systematic review. *Supportive Care in Cancer*, *25*(4), 1323–1355. https://doi.org/10.1007/S00520-016-3500-Z

21. Boland, L., Bennett, K., & Connolly, D. (2018). Self-management interventions for cancer survivors: a systematic review. *Supportive Care in Cancer*, *26*(5), 1585–1595. https://doi.org/10.1007/s00520-017-3999-7

22. Panagioti, M., Richardson, G., Small, N., Murray, E., Rogers, A., Kennedy, A., Newman, S., & Bower, P. (2014). Self-management support interventions to reduce health care utilisation without compromising outcomes: a systematic review and meta-analysis. *BMC Health Services Research*, *14*(1), 1–14. https://doi.org/10.1186/1472-6963-14-356

23. de Silva, D. (2011). *Helping people help themselves: a review of the evidence considering whether it is worthwhile to support self-management*. Health Foundation.

24. Cuthbert, C. A., Farragher, J. F., Hemmelgarn, B. R., Ding, Q., McKinnon, G. P., & Cheung, W. Y. (2019). Self-management interventions for cancer survivors: a systematic review and evaluation of intervention content and theories. *Psycho-Oncology*, *28*(11), 2119–2140. https://doi.org/10.1002/pon.5215

25. Gallicchio, L., Tonorezos, E., De Moor, J. S., Elena, J., Farrell, M., Green, P., Mitchell, S. A., Mollica, M. A., Perna, F., Saiontz, N. G., Zhu, L., Rowland, J., & Mayer, D. K. (2021). Evidence Gaps in Cancer Survivorship Care: A Report From the 2019 National Cancer Institute Cancer Survivorship Workshop. *JNCI Journal of the National Cancer Institute*, *113*(9), 1136. https://doi.org/10.1093/JNCI/DJAB049

26. Foster, C., Calman, L., Richardson, A., Pimperton, H., & Nash, R. (2018). Improving the lives of people living with and beyond cancer: Generating the evidence needed to inform policy and practice. *Journal of Cancer Policy*, *15*, 92–95. https://doi.org/10.1016/J.JCPO.2018.02.004

27. Rimmer, B., Brown, M. C., Sotire, T., Beyer, F., Bolnykh, I., Balla, M., Richmond, C., Dutton, L., Williams, S., Araújo-Soares, V., Finch, T., Gallagher, P., Lewis, J., Burns, R., & Sharp, L. (2023). Characteristics and Components of Self-Management Interventions for Improving Quality of Life in Cancer Survivors: A Systematic Review. *Cancers*, *16*(1), 14. https://doi.org/10.3390/CANCERS16010014

28. Miller, K. D., Ostrom, Q. T., Kruchko, C., Patil, N., Tihan, T., Cioffi, G., Fuchs, H. E., Waite, K. A., Jemal, A., & Siegel, R. L. (2021). Brain and other central nervous system tumor statistics, 2021. *CA: A Cancer Journal for Clinicians*, *71*(5), 381–406. https://doi.org/10.3322/caac.21693

29. Louis, D. N., Perry, A., Wesseling, P., Brat, D. J., Cree, I. A., Figarella-Branger, D., Hawkins, C., Ng, H. K., Pfister, S. M., Reifenberger, G., Soffietti, R., Von Deimling, A., & Ellison, D. W. (2021). The 2021 WHO classification of tumors of the central nervous system: A summary. *Neuro-Oncology*, *23*(8), 1231–1251. https://doi.org/10.1093/neuonc/noab106

30. Bray, F., Laversanne, M., Hyuna, S., Ferlay, J., Siegel, R., Soerjomataram, I., & Ahmedin, J. (2024). Global cancer statistics 2022: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. *CA: A Cancer Journal for Clinicians*, *74*(3), 229–263. https://doi.org/10.3322/CAAC.21834

31. van den Bent, M. J., Geurts, M., French, P. J., Smits, M., Capper, D., Bromberg, J. E. C., & Chang, S. M. (2023). Primary brain tumours in adults. *The Lancet*, *402*(10412), 1564–1579. https://doi.org/10.1016/S0140-6736(23)01054-1

32. Schirrmacher, V. (2018). From chemotherapy to biological therapy: A review of novel concepts to reduce the side effects of systemic cancer treatment (Review). *International Journal of Oncology*, *54*(2), 407–419. https://doi.org/10.3892/IJO.2018.4661

33. Mohan, G., Hamna, A., Jijo, A. J., Devi, S., Narayanasamy, A., & Vellingiri, B. (2019). Recent advances in radiotherapy and its associated side effects in cancer—a review. *The Journal of Basic and Applied Zoology*, *80*(1), 1–10. https://doi.org/10.1186/S41936-019-0083-5

34. Khan, F., & Amatya, B. (2013). Factors associated with long-term functional outcomes, psychological sequelae and quality of life in persons after primary brain tumour. *Journal of Neuro-Oncology*, *111*(3), 355–366. https://doi.org/10.1007/S11060-012-1024-Z

35. Liu, R., Page, M., Solheim, K., Fox, S., & Chang, S. M. (2009). Quality of life in adults with brain tumors: Current knowledge and future directions. *Neuro-Oncology, 11*(3), 330–339. https://doi.org/10.1215/15228517-2008-093

36. Boele, F. W., Klein, M., Reijneveld, J. C., Verdonck-de Leeuw, I. M., & Heimans, J. J. (2014). Symptom management and quality of life in glioma patients. *CNS Oncology*, *3*(1), 37–47. https://doi.org/10.2217/cns.13.65

37. Bauchet, L. (2017). Epidemiology of Diffuse Low Grade Gliomas. *Diffuse Low-Grade Gliomas in Adults*, 13–53. https://doi.org/10.1007/978-3-319-55466-2_2

38. Claus, E. B., Walsh, K. M., Wiencke, J. K., Molinaro, A. M., Wiemels, J. L., Schildkraut, J. M., Bondy, M. L., Berger, M., Jenkins, R., & Wrensch, M. (2015). Survival and low-grade glioma: The emergence of genetic information. *Neurosurgical Focus*, *38*(1), E6. https://doi.org/10.3171/2014.10.FOCUS12367

39. Dixit, K., & Raizer, J. (2017). Newer Strategies for the Management of Low-Grade Gliomas. *Oncology (Williston Park, N.Y.), 31*(9), 680–682, 684. https://europepmc.org/article/med/29071695

40. Affronti, M. Lou, Randazzo, D., Lipp, E. S., Peters, K. B., Herndon, S. C., Woodring, S., Healy, P., Cone, C. K., Herndon, J. E., & Schneider, S. M. (2018). Pilot Study to Describe the Trajectory of Symptoms and Adaptive Strategies of Adults Living with Low-grade Glioma. *Seminars in Oncology Nursing*, *34*(5), 472–485. https://doi.org/10.1016/j.soncn.2018.10.006

41. Pascual, J. S. G., & Duffau, H. (2022). The need to consider return to work as a main outcome in patients undergoing surgery for diffuse low-grade glioma: a systematic review. *Acta Neurochirurgica*, *164*(10), 2789–2809. https://doi.org/10.1007/S00701-022-05339-Y

42. Pellerino, A., Caccese, M., Padovan, M., Cerretti, G., & Lombardi, G. (2022). Epidemiology, risk factors, and prognostic factors of gliomas. *Clinical and Translational Imaging 2022*, *10*, 467–475. https://doi.org/10.1007/S40336-022-00489-6

43. O'Donovan, B., Malone, A., Carroll, P., Cowie, E., MacNally, S., O'Connor, R. J., MacFarlane, J., O'Keeffe, S., Bennett, K., & Horgan, F. (2025). Rehabilitation needs of people with brain tumours in Ireland ("BRAIN-RESTORE"): a survey of healthcare professionals' views. *Disability and Rehabilitation*, 1–8. https://doi.org/10.1080/09638288.2025.2462209

44. Edvardsson, T., & Ahlström, G. (2005). Illness-related problems and coping among persons with low-grade glioma. *Psycho-Oncology*, *14*(9), 728–737. https://doi.org/10.1002/PON.898

45. Langbecker, D., Ekberg, S., & Yates, P. (2017). Don't need help, don't want help, can't get help: How patients with brain tumors account for not using rehabilitation, psychosocial and community services. *Patient Education and Counseling*, *100*(9), 1744–1750. https://doi.org/10.1016/J.PEC.2017.04.004

46. Rimmer, B., Dutton, L., Lewis, J., Burns, R., Gallagher, P., Williams, S., Araujo-Soares, V., Finch, T., & Sharp, L. (2020). 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*, *10*(7), e041465. https://doi.org/10.1136/bmjopen-2020-041465

47. Rimmer, B., Bolnykh, I., Dutton, L., Lewis, J., Burns, R., Gallagher, P., Williams, S., Araújo-Soares, V., Menger, F., & Sharp, L. (2023). Health-related quality of life in adults with low-grade gliomas: a systematic review. *Quality of Life Research*, *32*(3), 625–651. https://doi.org/10.1007/S11136-022-03207-X

48. Rimmer, B., Balla, M., Dutton, L., Williams, S., Lewis, J., Gallagher, P., Finch, T., Burns, R., Araujo-Soares, V., Menger, F., Sharp, L., & team, W. A. study. (2024). "It changes everything" Understanding how people experience the impact of living with a lower-grade glioma. *Neuro-Oncology Practice*, *11*(3), 255–265. https://doi.org/10.1093/NOP/NPAE006

49. Rimmer, B., Balla, M., Dutton, L., Lewis, J., Brown, M. C., Burns, R., Gallagher, P., Williams, S., Araújo-Soares, V., Finch, T., Menger, F., & Sharp, L. (2024). Identifying and understanding how people living with a lower-grade glioma engage in self-management. *Journal of Cancer Survivorship*, *18*(1), 1837–1850. https://doi.org/10.1007/S11764-023-01425-X

50. Rimmer, B., Balla, M., Dutton, L., Williams, S., Araújo-Soares, V., Gallagher, P., Finch, T., Lewis, J., Burns, R., Menger, F., & Sharp, L. (2024). Barriers and facilitators to self-management in people living with a lower-grade glioma. *Journal of Cancer Survivorship*, 1–14. https://doi.org/10.1007/S11764-024-01572-9

51. Rimmer, B., Balla, M., Dutton, L., Burns, R., Araújo-Soares, V., Finch, T., Lewis, J., Gallagher, P., Williams, S., Menger, F., & Sharp, L. (2024). "It's a delicate dance": How informal caregivers experience the role and responsibilities of supporting someone living with a lower-grade glioma. *Neuro-Oncology Practice*, *12*(2), 340–350. https://doi.org/10.1093/NOP/NPAE096

52. Rimmer, B., Finch, T., Balla, M., Dutton, L., Williams, S., Lewis, J., Gallagher, P., Burns, R., Araújo-Soares, V., Menger, F., & Sharp, L. (2024). Understanding supported self-management for people living with a lower-grade glioma: Implementation considerations through the lens of normalisation process theory. *Health Expectations*, *27*(3), e14073. https://doi.org/10.1111/HEX.14073

53. Creswell, J. W., & Poth, C. N. (2016). *Qualitative inquiry and research design: Choosing among five approaches*. Sage publications.

54. Doyle, L., McCabe, C., Keogh, B., Brady, A., & McCann, M. (2020). An overview of the qualitative descriptive design within nursing research. *Journal of Research in Nursing: JRN*, *25*(5), 443. https://doi.org/10.1177/1744987119880234

55. Low, J. (2019). A pragmatic definition of the concept of theoretical saturation. *Sociological Focus*, *52*(2), 131–139. https://doi.org/10.1080/00380237.2018.1544514

56. *WHOQOL - Measuring Quality of Life| The World Health Organization*. (n.d.). Retrieved May 1, 2024, from https://www.who.int/tools/whoqol

57. Bottomley, A. (2002). The Cancer Patient and Quality of Life; The Cancer Patient and Quality of Life. *The Oncologist*, *7*, 120–125. https://doi.org/10.1634/theoncologist.7-2-120

58. Dirven, L., Koekkoek, J. A. F., Reijneveld, J. C., & Taphoorn, M. J. B. (2016). Health-related quality of life in brain tumor patients: as an endpoint in clinical trials and its value in clinical care. *Expert Review of Quality of Life in Cancer Care*, *1*(1), 37–44. https://doi.org/10.1080/23809000.2016.1136793

59. Aaronson, N. K., Muller, M., Cohen, P. D. A., Essink-Bot, M.-L., Fekkes, M., Sanderman, R., Sprangers, M. A. G., Te Velde, A., & Verrips, E. (1998). Translation, validation, and norming of the Dutch language version of the SF-36 Health Survey in community and chronic disease populations. *Journal of Clinical Epidemiology*, *51*(11), 1055–1068. https://doi.org/10.1016/S0895-4356(98)00097-3

60. Aaronson, N. K., Ahmedzai, S., Bergman, B., Bullinger, M., Cull, A., Duez, N. J., Filiberti, A., Flechtner, H., Fleishman, S. B., & de Haes, J. C. J. M. (1993). The European Organization for Research and Treatment of Cancer QLQ-C30: a quality-of-life instrument for use in international clinical trials in

oncology. *JNCI: Journal of the National Cancer Institute*, *85*(5), 365–376. https://doi.org/10.1093/jnci/85.5.365

61. Taphoorn, M. J. B., Claassens, L., Aaronson, N. K., Coens, C., Mauer, M., Osoba, D., Stupp, R., Mirimanoff, R. O., van den Bent, M. J., & Bottomley, A. (2010). An international validation study of the EORTC brain cancer module (EORTC QLQ-BN20) for assessing health-related quality of life and symptoms in brain cancer patients. *European Journal of Cancer*, *46*(6), 1033–1040. https://doi.org/10.1016/j.ejca.2010.01.012

62. Weitzner, M. A., Meyers, C. A., Gelke, C. K., Byrne, K. S., Levin, V. A., & Cella, D. F. (1995). The Functional Assessment of Cancer Therapy (FACT) scale. Development of a brain subscale and revalidation of the general version (FACT-G) in patients with primary brain tumors. *Cancer*, *75*(5), 1151–1161. https://doi.org/10.1002/1097-0142(19950301)75:5<1151::AID-CNCR2820750515>3.0.CO;2-Q

63. Armstrong, T. S., Dirven, L., Arons, D., Bates, A., Chang, S. M., Coens, C., Espinasse, C., Gilbert, M. R., Jenkinson, D., Kluetz, P., Mendoza, T., Rubinstein, L., Sul, J., Weller, M., Wen, P. Y., van den Bent, M. J., & Taphoorn, M. J. B. (2020). Glioma patient-reported outcome assessment in clinical care and research: a Response Assessment in Neuro-Oncology collaborative report. *The Lancet Oncology*, *21*(2), e97–e103. https://doi.org/10.1016/S1470-2045(19)30796-X

64. Scheepens, J. C. C., Taphoorn, M. J. B., & Koekkoek, J. A. F. (2024). Patient-reported outcomes in neuro-oncology. *Current Opinion in Oncology*, *36*(6), 560–568. https://doi.org/10.1097/CCO.0000000000001078

65. Baker, P. D., Bambrough, J., Fox, J. R. E., & Kyle, S. D. (2016). Health-related quality of life and psychological functioning in patients with primary malignant brain tumors: a systematic review of clinical, demographic and mental health factors. *Neuro-Oncology Practice*, *3*(4), 211–221. https://doi.org/10.1093/NOP/NPV042

66. Dirven, L., Reijneveld, J. C., Aaronson, N. K., Bottomley, A., Uitdehaag, B. M. J., & Taphoorn, M. J. B. (2013). Health-related quality of life in patients with brain tumors: Limitations and additional outcome measures. *Current Neurology and Neuroscience Reports*, *13*(7), 1–9. https://doi.org/10.1007/S11910-013-0359-Y

67. Guo, H. J., & Sapra, A. (2022). Instrumental Activity of Daily Living. *Encyclopedia of Gerontology and Population Aging*, 2635–2635. https://doi.org/10.1007/978-3-030-22009-9_301267

68. Oort, Q., Dirven, L., Sikkes, S. A. M., Aaronson, N., Boele, F., Brannan, C., Egeter, J., Grant, R., Klein, M., Lips, I., Narita, Y., Sato, H., Sztankay, M., Stockhammer, G., Talacchi, A., Uitdehaag, B. M. J., Reijneveld, J. C., & Taphoorn, M. J. B. (2021). Development of an EORTC questionnaire measuring instrumental activities of daily living (IADL) in patients with brain tumours: phase I–III. *Quality of Life Research*, *30*(5), 1491–1502. https://doi.org/10.1007/S11136-020-02738-5

69. World Health Organisation. (2001). *IFC: International Classification of Functioning, Disability and Health*.

70. Khan, F., & Amatya, B. (2013). Use of the international Classification of Functioning, Disability and Health (ICF) to describe patient -reported disability in primary brain tumour in an Australian community cohort. *Journal of Rehabilitation Medicine*, *45*(5), 434–445. https://doi.org/10.2340/16501977-1132

71. The Brain Tumour Charity. (2015). *Losing myself: the reality of life with a brain tumour*. http://publications.cancerresearchuk.org/publicationformat/formatfactsheet/keyfactsbrain.html

72. Habets, E. J. J., Taphoorn, M. J. B., Nederend, S., Klein, M., Delgadillo, D., Hoang-Xuan, K., Bottomley, A., Allgeier, A., Seute, T., Gijtenbeek, A. M. M., De Gans, J., Enting, R. H., Tijssen, C. C., Van Den Bent, M. J., & Reijneveld, J. C. (2014). Health-related quality of life and cognitive functioning in long-term anaplastic oligodendroglioma and oligoastrocytoma survivors. *Journal of Neuro-Oncology*, *116*(1), 161–168. https://doi.org/10.1007/S11060-013-1278-0

73. Cubis, L., Ownsworth, T., Pinkham, M. B., Foote, M., Green, H., & Chambers, S. (2023). “Hey, I’m still here!”: Maintaining, managing and rebuilding social connections after brain tumour. *Neuropsychological Rehabilitation*, *33*(3), 454–479. https://doi.org/10.1080/09602011.2022.2028640

74. Cubis, L., Ownsworth, T., Pinkham, M. B., Foote, M., Legg, M., & Chambers, S. (2019). The importance of staying connected: Mediating and moderating effects of social group memberships on psychological well-being after brain tumor. *Psycho-Oncology*, *28*(7), 1537–1543. https://doi.org/10.1002/PON.5125

75. Fountain, D. M., Allen, D., Joannides, A. J., Nandi, D., Santarius, T., & Chari, A. (2016). Reporting of patient-reported health-related quality of life in adults with diffuse low-grade glioma: a systematic review. *Neuro-Oncology*, *18*(11), 1475–1486. https://doi.org/10.1093/NEUONC/NOW107

76. Dirven, L., Vos, M. E., Walbert, T., Armstrong, T. S., Arons, D., Van Den Bent, M. J., Blakeley, J., Brown, P. D., Bulbeck, H., Chang, S. M., Coens, C., Gilbert, M. R., Grant, R., Jalali, R., Leach, D., Leeper, H., Mendoza, T., Nayak, L., Oliver, K., … Taphoorn, M. J. B. (2021). Systematic review on the use of patient-reported outcome measures in brain tumor studies: part of the Response Assessment in Neuro-Oncology Patient-Reported Outcome (RANO-PRO) initiative. *Neuro-Oncology Practice*, *8*(4), 417–425. https://doi.org/10.1093/NOP/NPAB013

77. Rimmer, B., Crowe, L., Todd, A., & Sharp, L. (2022). Assessing unmet needs in advanced cancer patients: a systematic review of the development, content, and quality of available instruments. *Journal of Cancer Survivorship*, *16*(5), 960–975. https://doi.org/10.1007/s11764-021-01088-6

78. Frances, S. M., Velikova, G., Klein, M., Short, S. C., Murray, L., Wright, J. M., & Boele, F. (2022). Long-term impact of adult WHO grade II or III gliomas on health-related quality of life: A systematic review. *Neuro-Oncology Practice*, *9*(1), 3–17. https://doi.org/10.1093/nop/npab062

79. Clarke, V., & Braun, V. (2021). *Thematic analysis: A practical guide*. Sage.

80. Darlix, A., & Guerdoux, E. (2024). Life with a lower-grade glioma: How can neuro-oncologists advance its understanding and management? *Neuro-Oncology Practice*, *11*(3), 223–225. https://doi.org/10.1093/nop/npae031

81. Loughan, A. R., Reid, M., Willis, K. D., Davies, A., Boutté, R. L., Barrett, S., & Lo, K. (2022). The burden of a brain tumor: guiding patient centric care in neuro-oncology. *Journal of Neuro-Oncology*, *157*(3), 487–498. https://doi.org/10.1007/S11060-022-03993-X

82. Jansen, F., van Uden-Kraan, C. F., van Zwieten, V., Witte, B. I., & Verdonck-de Leeuw, I. M. (2015). Cancer survivors' perceived need for supportive care and their attitude towards self-management and eHealth. *Supportive Care in Cancer*, *23*(6), 1679–1688. https://doi.org/10.1007/S00520-014-2514-7

83. Yun, Y. H., Jung, J. Y., Sim, J. A., Choi, H., Lee, J. M., Noh, D. Y., Han, W., Park, K. J., Jeong, S. Y., Park, J. W., Wu, H. G., Chie, E. K., Kim, H. J., Lee, J. H., Zo, Z. I., Kim, S., Lee, J. E., Nam, S. J., Lee, E. S., … Shim, Y. M. (2015). Patient-reported assessment of self-management strategies of health in cancer patients: development and validation of the Smart Management Strategy for Health Assessment Tool (SAT). *Psycho-Oncology*, *24*(12), 1723–1730. https://doi.org/10.1002/PON.3839

84. Dunne, S., Mooney, O., Coffey, L., Sharp, L., Timmons, A., Desmond, D., Gooberman-Hill, R., O'Sullivan, E., Keogh, I., Timon, C., & Gallagher, P. (2017). Self-management strategies used by head and neck cancer survivors following completion of primary treatment: A directed content analysis. *Psycho-Oncology*, *26*(12), 2194–2200. https://doi.org/10.1002/pon.4447

85. Brown, M. C., Haste, A., Araújo-Soares, V., Skinner, R., & Sharp, L. (2021). Identifying and exploring the self-management strategies used by childhood cancer survivors. *Journal of Cancer Survivorship*, *15*(2), 344–357. https://doi.org/10.1007/s11764-020-00935-2

86. Jung, J. Y., & Yun, Y. H. (2023). Self-Management Strategy Clustering, Quality of Life, and Health Status in Cancer Patients Considering Cancer Stages. *International Journal of Behavioral Medicine*, *30*(5), 769–776. https://doi.org/10.1007/S12529-022-10128-Z

87. Been-Dahmen, J. M. J., van der Stege, H., Oldenmenger, W. H., Braat, C., van der Lans, M. C. M., Scheper, M., van Staa, A. L., & Ista, E. (2024). What factors contribute to cancer survivors' self-management skills? A cross-sectional observational study. *European Journal of Oncology Nursing*, *69*, 102539. https://doi.org/10.1016/j.ejon.2024.102539

88. Schulman-Green, D., Jaser, S. S., Park, C., & Whittemore, R. (2016). A metasynthesis of factors affecting self-management of chronic illness. *Journal of Advanced Nursing*, *72*(7), 1469–1489. https://doi.org/10.1111/JAN.12902

89. Russell, S., Ogunbayo, O. J., Newham, J. J., Heslop-Marshall, K., Netts, P., Hanratty, B., Beyer, F., & Kaner, E. (2018). Qualitative systematic review of barriers and facilitators to self-management of chronic obstructive pulmonary disease: views of patients and healthcare professionals. *Npj Primary Care Respiratory Medicine*, *28*(1), 1–13. https://doi.org/10.1038/s41533-017-0069-z

90. Desborough, J., Brunoro, C., Parkinson, A., Chisholm, K., Elisha, M., Drew, J., Fanning, V., Lueck, C., Bruestle, A., Cook, M., Suominen, H., Tricoli, A., Henschke, A., & Phillips, C. (2020). 'It struck at the heart of who I thought I was': A meta-synthesis of the qualitative literature examining the experiences of people with multiple sclerosis. *Health Expectations*, *23*(5), 1007–1027. https://doi.org/10.1111/HEX.13093

91. van Dongen, S. I., de Nooijer, K., Cramm, J. M., Francke, A. L., Oldenmenger, W. H., Korfage, I. J., Witkamp, F. E., Stoevelaar, R., van der Heide, A., & Rietjens, J. A. C. (2020). Self-management of patients with advanced cancer: A systematic review of experiences and attitudes. *Palliative Medicine*, *34*(2), 160–178. https://doi.org/10.1177/0269216319883976

92. Assarroudi, A., Heshmati Nabavi, F., Armat, M. R., Ebadi, A., & Vaismoradi, M. (2018). Directed qualitative content analysis: the description and elaboration of its underpinning methods and data analysis process. *Journal of Research in Nursing*, *23*(1), 42–55. https://doi.org/10.1177/1744987117741667

93. Gale, N. K., Heath, G., Cameron, E., Rashid, S., & Redwood, S. (2013). Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Medical Research Methodology*, *13*(1), 1–8. https://doi.org/10.1186/1471-2288-13-117

94. Ullgren, H., Tsitsi, T., Papastavrou, E., & Charalambous, A. (2018). How family caregivers of cancer patients manage symptoms at home: A systematic review. *International Journal of Nursing Studies*, *85*, 68–79. https://doi.org/10.1016/J.IJNURSTU.2018.05.004

95. Schulman-Green, D., Feder, S. L., Dionne-Odom, J. N., Batten, J., En Long, V. J., Harris, Y., Wilpers, A., Wong, T., & Whittemore, R. (2021). Family Caregiver Support of Patient Self-Management During Chronic, Life-Limiting Illness: A Qualitative Metasynthesis. *Journal of Family Nursing*, *27*(1), 55–72. https://doi.org/10.1177/1074840720977180

96. Murrell, A. J., Rimmer, B., Dutton, L., Lewis, J., Burns, R., Gallagher, P., Williams, S., Araújo-Soares, V., Finch, T., & Sharp, L. (2023). The Nature and Quality of Support from Informal Networks for Informal Caregivers of Low-Grade Glioma Patients: A Qualitative Analysis within the Ways Ahead Study. *European Journal of Cancer Care*, *2023*(1), 4149412. https://doi.org/10.1155/2023/4149412

97. Rimmer, B., Balla, M., Dutton, L., Lewis, J., Burns, R., Gallagher, P., Williams, S., Araújo-Soares, V., Finch, T., & Sharp, L. (2024). 'A Constant Black Cloud': The Emotional Impact of Informal Caregiving for Someone with a Lower-Grade Glioma. *Qualitative Health Research*, *34*(3), 227–238. https://doi.org/10.1177/10497323231204740

98. House, J. S. (1981). *Work Stress and Social Support Addison*. Wesley Publishing Company.

99. Palmer Kelly, E., Meara, A., Hyer, M., Payne, N., & Pawlik, T. M. (2019). Understanding the Type of Support Offered Within the Caregiver, Family, and Spiritual/Religious Contexts of Cancer Patients. *Journal of Pain and Symptom Management*, *58*(1), 56–64. https://doi.org/10.1016/J.JPAINSYMMAN.2019.03.003

100. Frambes, D., Given, B., Lehto, R., Sikorskii, A., & Wyatt, G. (2018). Informal Caregivers of Cancer Patients: Review of Interventions, Care Activities, and Outcomes. *Western Journal of Nursing Research*, *40*(7), 1069–1097. https://doi.org/10.1177/0193945917699364

101. Zeng, Q., Ling, D., Chen, W., Liao, Y., An, R., & He, L. (2022). Family Caregivers' Experiences of Caring for Patients With Head and Neck Cancer: A Systematic Review and Metasynthesis of Qualitative Studies. *Cancer Nursing*, *46*(1), E41–E61. https://doi.org/10.1097/NCC.0000000000001096

102. Madsen, K., & Poulsen, H. S. (2011). Needs for everyday life support for brain tumour patients' relatives: systematic literature review. *European Journal of Cancer Care*, *20*(1), 33–43. https://doi.org/10.1111/J.1365-2354.2010.01184.X

103. McConigley, R., Halkett, G., Lobb, E., & Nowak, A. (2010). Caring for someone with high-grade glioma: A time of rapid change for caregivers. *Palliative Medicine*, *24*(5), 473–479. https://doi.org/10.1177/0269216309360118

104. Molassiotis, A., & Wang, M. (2022). Understanding and Supporting Informal Cancer Caregivers. *Current Treatment Options in Oncology*, *23*(4), 494–513. https://doi.org/10.1007/S11864-022-00955-3

105. Mcleroy, K. R., Bibeau, D., Steckler, A., & Glanz, K. (1988). An ecological perspective on health promotion programs. *Health Education Quarterly*, *15*(4), 351–377. https://doi.org/10.1177/109019818801500401

106. Mohammed, S., Swami, N., Pope, A., Rodin, G., Hannon, B., Nissim, R., Hales, S., & Zimmermann, C. (2018). "I didn't want to be in charge and yet I was": Bereaved caregivers' accounts of providing home care for family members with advanced cancer. *Psycho-Oncology*, *27*(4), 1229–1236. https://doi.org/10.1002/PON.4657

107. Wang, T., Molassiotis, A., Chung, B. P. M., & Tan, J. Y. (2018). Unmet care needs of advanced cancer patients and their informal caregivers: a systematic review. *BMC Palliative Care*, *17*(1), 1–29. https://doi.org/10.1186/S12904-018-0346-9

108. Tallant, J., Pakzad-Shahabi, L., Lambert, S. D., Williams, M., & Wells, M. (2023). Quality of Life in Caregivers of Patients with Brain Tumours: A Systematic Review and Thematic Analysis. *European Journal of Cancer Care*, *2023*(1), 2882837. https://doi.org/10.1155/2023/2882837

109. Chen, D., Zhu, J., Xu, Q., Wang, F., Ji, C., Di, H., Yuan, P., Bai, X., & Chen, L. (2021). The role of informal caregivers for patients with glioma: a systematic review and meta-synthesis of qualitative studies. *Annals of Translational Medicine*, *9*(12), 1020–1020. https://doi.org/10.21037/atm-21-2761

110. Boele, F., Grant, R., & Sherwood, P. (2017). Challenges and support for family caregivers of glioma patients. *British Journal of Neuroscience Nursing*, *13*(1), 8–16. https://doi.org/10.12968/BJNN.2017.13.1.8

111. Thana, K., Lehto, R., Sikorskii, A., & Wyatt, G. (2021). Informal caregiver burden for solid tumour cancer patients: a review and future directions. *Psychology & Health*, *36*(12), 1514–1535. https://doi.org/10.1080/08870446.2020.1867136

112. Pointon, L., Grant, R., Peoples, S., Erridge, S., Sherwood, P., Klein, M., & Boele, F. (2023). Unmet needs and wish for support of family caregivers of primary brain tumor patients. *Neuro-Oncology Practice*, *10*(3), 271–280. https://doi.org/10.1093/NOP/NPAC099

113. Gambe, R. G., Clark, J., Meddick-Dyson, S. A., Ukoha-Kalu, B. O., Nyaaba, G. N., & Murtagh, F. E. M. (2023). The roles and experiences of informal carers providing care to people with advanced cancer in Africa—A systematic review and critical interpretive analysis. *PLOS Global Public Health*, *3*(4), e0001785. https://doi.org/10.1371/JOURNAL.PGPH.0001785

114. Xiang, E., Guzman, P., Mims, M., & Badr, H. (2022). Balancing Work and Cancer Care: Challenges Faced by Employed Informal Caregivers. *Cancers*, *14*(17), 4146. https://doi.org/10.3390/CANCERS14174146

115. Cai, Y., Simons, A., Toland, S., Zhang, J., & Zheng, K. (2021). Informal caregivers' quality of life and management strategies following the transformation of their cancer caregiving role: A qualitative systematic review. *International Journal of Nursing Sciences*, *8*(2), 227–236. https://doi.org/10.1016/J.IJNSS.2021.03.006

116. May, C. R., Mair, F., Finch, T., MacFarlane, A., Dowrick, C., Treweek, S., Rapley, T., Ballini, L., Ong, B. N., Rogers, A., Murray, E., Elwyn, G., Légaré, F., Gunn, J., & Montori, V. M. (2009). Development of a theory of implementation and integration: Normalization Process Theory. *Implementation Science*, *4*(1), 1–9. https://doi.org/10.1186/1748-5908-4-29

117. Hughes, N. D., Closs, S. J., Flemming, K., & Bennett, M. I. (2016). Supporting self-management of pain by patients with advanced cancer: views of palliative care professionals. *Supportive Care in Cancer*, *24*(12), 5049–5057. https://doi.org/10.1007/S00520-016-3372-2

118. van Dongen, S. I., Stoevelaar, R., Kranenburg, L. W., Noorlandt, H. W., Witkamp, F. E., van der Rijt, C. C. D., van der Heide, A., & Rietjens, J. A. C. (2022). The views of healthcare professionals on self-management of patients with advanced cancer: An interview study. *Patient Education and Counseling*, *105*(1), 136–144. https://doi.org/10.1016/J.PEC.2021.05.021

119. Howell, D., Powis, M., Kirkby, R., Amernic, H., Moody, L., Bryant-Lukosius, D., O'Brien, M. A., Rask, S., & Krzyzanowska, M. (2022). Improving the quality of self-management support in ambulatory cancer care: a mixed-method study of organisational and clinician readiness, barriers and enablers for tailoring of implementation strategies to multisites. *BMJ Quality & Safety*, *31*(1), 12–22. https://doi.org/10.1136/BMJQS-2020-012051

120. Howell, D., McGowan, P., Bryant-Lukosius, D., Kirkby, R., Powis, M., Sherifali, D., Kukreti, V., Rask, S., & Krzyzanowska, M. K. (2023). Impact of a Training Program on Oncology Nurses' Confidence in the Provision of Self-Management Support and 5As Behavioral Counseling Skills. *Cancers*, *15*(6), 1811. https://doi.org/10.3390/CANCERS15061811

121. Kantilal, K., Hardeman, W., Whiteside, H., Karapanagiotou, E., Small, M., & Bhattacharya, D. (2022). Facilitating healthcare practitioners to deliver self-management support in adult cancer survivors: A realist review. *Research in Social and Administrative Pharmacy*, *18*(11), 3870–3883. https://doi.org/10.1016/J.SAPHARM.2022.05.011

122. Matthijs de Wit, L., van Uden-Kraan, C. F., Lissenberg-Witte, B. I., Melissant, H. C., Fleuren, M. A. H., Cuijpers, P., & Verdonck-de Leeuw, I. M. (2019). Adoption and implementation of a web-based self-management application "Oncokompas" in routine cancer care: a national pilot study. *Supportive Care in Cancer*, *27*(8), 2911–2920. https://doi.org/10.1007/S00520-018-4591-5

123. Rimmer, B., & Sharp, L. (2021). Implementation of Self-Management Interventions in Cancer Survivors: Why Are We Not There Yet? *Journal of Cancer Education*, *36*(6), 1355–1358. https://doi.org/10.1007/s13187-021-02021-2

124. Adeola, B. A., Ivana, D., Orlando, R., Wu, V. S., Anthony, A., Geoff P, D., & Afaf, G. (2022). Supporting cancer patients to self-manage: Extent of use and perceptions of "trusted" online self-management resources. *Patient Education and Counseling*, *105*(7), 2240–2247. https://doi.org/10.1016/J.PEC.2022.03.017

125. Schaefer, I., Heneka, N., Luckett, T., Agar, M. R., Chambers, S. K., Currow, D. C., Halkett, G., Disalvo, D., Amgarth-Duff, I., Anderiesz, C., & Phillips, J. L. (2021). Quality of online self-management resources for adults living with primary brain cancer, and their carers: a systematic environmental scan. *BMC Palliative Care*, *20*(1). https://doi.org/10.1186/s12904-021-00715-4

126. Johansson, S., Gulliksen, J., & Gustavsson, C. (2021). Disability digital divide: the use of the internet, smartphones, computers and tablets among people with disabilities in Sweden. *Universal Access in the Information Society*, *20*(1), 105–120. https://doi.org/10.1007/S10209-020-00714-X

127. McAuley, A. (2014). Digital health interventions: widening access or widening inequalities? *Public Health*, *128*(12), 1118–1120. https://doi.org/10.1016/J.PUHE.2014.10.008

128. Hoffmann, T. C., Glasziou, P. P., Boutron, I., Milne, R., Perera, R., Moher, D., Altman, D. G., Barbour, V., Macdonald, H., & Johnston, M. (2014). Better reporting of interventions: template for intervention description and replication (TIDieR) checklist and guide. *BMJ*, *348*, g1687. https://doi.org/10.1136/bmj.g1687

129. Foster, C. (2022). The need for quality self-management support in cancer care. *BMJ Quality & Safety*, *31*(1), 1–4. https://doi.org/10.1136/BMJQS-2021-013366

130. Grant, A., Dreischulte, T., & Guthrie, B. (2017). Process evaluation of the data-driven quality improvement in primary care (DQIP) trial: Active and less active ingredients of a multi-component complex intervention to reduce high-risk primary care prescribing. *Implementation Science*, *12*(1), 1–11. https://doi.org/10.1186/S13012-016-0531-2

131. Hoberg, A. A., Vickers, K. S., Ericksen, J., Bauer, G., Kung, S., Stone, R., Williams, M., Moore, M. J., & Frye, M. A. (2013). Feasibility Evaluation of an Interpersonal and Social Rhythm Therapy Group Delivery Model. *Archives of Psychiatric Nursing*, *27*(6), 271–277. https://doi.org/10.1016/J.APNU.2013.08.002

132. Leon, N., Lewin, S., & Mathews, C. (2013). Implementing a provider-initiated testing and counselling (PITC) intervention in Cape town, South Africa: A process evaluation using the normalisation process model. *Implementation Science*, *8*(1), 1–17. https://doi.org/10.1186/1748-5908-8-97

133. May, C. R., Cummings, A., Girling, M., Bracher, M., Mair, F. S., May, C. M., Murray, E., Myall, M., Rapley, T., & Finch, T. (2018). Using Normalization Process Theory in feasibility studies and process evaluations of complex healthcare interventions: a systematic review. *Implementation Science*, *13*(1), 1–27. https://doi.org/10.1186/S13012-018-0758-1

134. Murray, E., Treweek, S., Pope, C., MacFarlane, A., Ballini, L., Dowrick, C., Finch, T., Kennedy, A., Mair, F., O'Donnell, C., Ong, B. N., Rapley, T., Rogers, A., & May, C. (2010). Normalisation process theory: A framework for developing, evaluating and implementing complex interventions. *BMC Medicine*, *8*(1), 1–11. https://doi.org/10.1186/1741-7015-8-63

135. Boele, F., Rosenlund, L., Nordentoft, S., Melhuish, S., Nicklin, E., Rydén, I., Williamson, A., Donders-Kamphuis, M., Preusser, M., Le Rhun, E., Kiesel, B., Minniti, G., Furtner, J., Dirven, L., Taphoorn, M., Galldiks, N., Rudà, R., Chalmers, A., Short, S. C., & Piil, K. (2024). Inequalities in access to neuro-oncology supportive care and rehabilitation: A survey of healthcare professionals' perspectives. *Neuro-Oncology Practice*, *11*(4), 484–493. https://doi.org/10.1093/NOP/NPAE023

136. Calman, L., Radcliffe, E., Berman, R., Demain, S., Restorick-Banks, S., Richardson, A., Wagland, R., & Foster, C. (2020). The ENABLE study protocol: Understanding and characterising the value and role of self-management support for people living with cancer that is treatable but not curable. *European Journal of Cancer Care*, *29*(2), e13217. https://doi.org/10.1111/ECC.13217

137. Vemuri, A. K., Hejazian, S. S., Vafaei Sadr, A., Zhou, S., Decker, K., Hakun, J., Abedi, V., & Zand, R. (2024). Self-Management among Stroke Survivors in the United States, 2016 to 2021. *Journal of Clinical Medicine*, *13*(15), 4338. https://doi.org/10.3390/JCM13154338

138. Boger, E. J., Demain, S. H., & Latter, S. M. (2015). Stroke self-management: A focus group study to identify the factors influencing self-management following stroke. *International Journal of Nursing Studies*, *52*(1), 175–187. https://doi.org/10.1016/J.IJNURSTU.2014.05.006

139. *Patient and Public Involvement, Engagement and Participation (PPIE) Strategy 2022-2027 - Cambridge Biomedical Research Centre*. (n.d.). Retrieved April 4, 2024, from https://cambridgebrc.nihr.ac.uk/public/patient-and-public-involvement-engagement-and-participation-ppie-strategy-2022-2027/

140. Piil, K., Johannessen, K. B., & Pappot, H. (2024). Strategies for meaningful patient and public involvement in neuro-oncological research. *Neuro-Oncology Practice*, *11*(2), 109–110. https://doi.org/10.1093/NOP/NPAD080

141. Loughan, A. R., Reid, M., Willis, K. D., Barrett, S., & Lo, K. (2023). The emotional journey of neuro-oncology: Primary brain tumor patients share their experience during this life-threatening disease. *Neuro-Oncology Practice*, *10*(1), 71–78. https://doi.org/10.1093/NOP/NPAC067

142. Yeom, J. W., Yeom, I. S., Park, H. Y., & Lim, S. H. (2022). Cultural factors affecting the self-care of cancer survivors: An integrative review. *European Journal of Oncology Nursing*, *59*, 102165. https://doi.org/10.1016/J.EJON.2022.102165

143. Treweek, S., Banister, K., Bower, P., Cotton, S., Devane, D., Gardner, H. R., Isaacs, T., Nestor, G., Oshisanya, A., Parker, A., Rochester, L., Soulsby, I., Williams, H., & Witham, M. D. (2021). Developing the INCLUDE Ethnicity Framework—a tool to help trialists design trials that better reflect the communities they serve. *Trials*, *22*(1). https://doi.org/10.1186/S13063-021-05276-8

144. Gray, L. M., Wong-Wylie, G., Rempel, G. R., & Cook, K. (2020). Expanding Qualitative Research Interviewing Strategies: Zoom Video Communications. *The Qualitative Report*, *25*(5), 1292–1301.

145. Drabble, L., Trocki, K. F., Salcedo, B., Walker, P. C., & Korcha, R. A. (2016). Conducting qualitative interviews by telephone: Lessons learned from a study of alcohol use among sexual minority and heterosexual women. *Qualitative Social Work*, *15*(1), 118–133. https://doi.org/10.1177/1473325015585613

146. Olmos-Vega, F. M., Stalmeijer, R. E., Varpio, L., & Kahlke, R. (2023). A practical guide to reflexivity in qualitative research: AMEE Guide No. 149. *Medical Teacher*, *45*(3), 241–251. https://doi.org/10.1080/0142159X.2022.2057287

147. O'Cathain, A., Croot, L., Duncan, E., Rousseau, N., Sworn, K., Turner, K. M., Yardley, L., & Hoddinott, P. (2019). Guidance on how to develop complex interventions to improve health and healthcare. *BMJ Open*, *9*(8), e029954. https://doi.org/10.1136/BMJOPEN-2019-029954

148. Skivington, K., Matthews, L., Simpson, S. A., Craig, P., Baird, J., Blazeby, J. M., Boyd, K. A., Craig, N., French, D. P., McIntosh, E., Petticrew, M., Rycroft-Malone, J., White, M., & Moore, L. (2021). A new framework for developing and evaluating complex interventions: update of Medical Research Council guidance. *BMJ*, *374*. https://doi.org/10.1136/BMJ.N2061

149. *Brain tumours (primary) and brain metastases in adults Evidence reviews for supporting people living with a brain tumour NICE guideline NG99*. (2018).

150. Cavers, D., Hacking, B., Erridge, S. C., Morris, P. G., Kendall, M., & Murray, S. A. (2013). Adjustment and support needs of glioma patients and their relatives: Serial interviews. *Psycho-Oncology*, *22*(6), 1299–1305. https://doi.org/10.1002/pon.3136

151. Molassiotis, A., Wilson, B., Brunton, L., Chaudhary, H., Gattamaneni, R., & McBain, C. (2010). Symptom experience in patients with primary brain tumours: A longitudinal exploratory study. *European Journal of Oncology Nursing*, *14*(5), 410–416. https://doi.org/10.1016/j.ejon.2010.03.001

152. Paterson, C., Roberts, C., Li, J., Chapman, M., Strickland, K., Johnston, N., Law, E., Bacon, R., Turner, M., Mohanty, I., Pranavan, G., & Toohey, K. (2023). What are the experiences of supportive care in people affected by brain cancer and their informal caregivers: A qualitative systematic review. *Journal of Cancer Survivorship*, *18*(1), 1608–1629. https://doi.org/10.1007/S11764-023-01401-5

153. Coffey, L., Mooney, O., Dunne, S., Sharp, L., Timmons, A., Desmond, D., O'Sullivan, E., Timon, C., Gooberman-Hill, R., & Gallagher, P. (2016). Cancer survivors' perspectives on adjustment-focused self-management interventions: a qualitative meta-synthesis. *Journal of Cancer Survivorship*, *10*(6), 1012–1034. https://doi.org/10.1007/s11764-016-0546-3

154. Iglesias Urrutia, C. P., Erdem, S., Birks, Y. F., Taylor, S. J. C., Richardson, G., Bower, P., van den Berg, B., & Manca, A. (2022). People's preferences for self-management support. *Health Services Research*, *57*(1), 91–101. https://doi.org/10.1111/1475-6773.13635

155. Åke, S., Hartelius, L., Jakola, A. S., & Antonsson, M. (2023). Experiences of language and communication after brain-tumour treatment: A long-term follow-up after glioma surgery. *Neuropsychological Rehabilitation*, *33*(7), 1225–1261. https://doi.org/10.1080/09602011.2022.2080720

156. Menger, F., Cresswell, H., Lewis, J., Volkmer, A., & Sharp, L. (2023). Speaking up for the lost voices: representation and inclusion of people with communication impairment in brain tumour research. *Supportive Care in Cancer*, *31*(6), 355. https://doi.org/10.1007/s00520-023-07804-5

157. Beeke, S., Volkmer, A., & Farrington-Douglas, C. (2021). TeleCPT: Delivery of a Better Conversations Approach to Communication Partner Training During a Global Pandemic and Beyond. *Perspectives of the ASHA Special Interest Groups*, *6*(6), 1776–1785. https://doi.org/10.1044/2021_PERSP-21-00160

158. Power, E., & Morrow, R. (2024). Digital, co-created implementation of communication partner training programs for stroke, brain injury, and dementia: Past, present, and future. *International Journal of Speech-Language Pathology*, *26*(3), 317–333. https://doi.org/10.1080/17549507.2024.2362856

159. Walker, H., Rimmer, B., Dutton, L., Finch, T., Gallagher, P., Lewis, J., Burns, R., Araújo-Soares, V., Williams, S., & Sharp, L. (2023). Experiences of work for people living with a grade 2/3 oligodendroglioma: a qualitative analysis within the Ways Ahead study. *BMJ Open*, *13*(9), e074151. https://doi.org/10.1136/BMJOPEN-2023-074151

160. Dirven, L. (2022). Importance of evaluating health-related quality of life issues in survivors of WHO grade II or III gliomas. *Neuro-Oncology Practice*, *9*(1), 1–2. https://doi.org/10.1093/NOP/NPAB067

161. Sainsbury, K., Walburn, J., Foster, L., Morgan, M., Sarkany, R., Weinman, J., & Araujo-Soares, V. (2020). Improving photoprotection in adults with xeroderma pigmentosum: personalisation and tailoring in the 'XPAND' intervention. *Health Psychology and Behavioral Medicine*, *8*(1), 543–572. https://doi.org/10.1080/21642850.2020.1840379

162. Keeling, M., Bambrough, J., & Simpson, J. (2013). Depression, anxiety and positive affect in people diagnosed with low-grade tumours: The role of illness perceptions. *Psycho-Oncology*, *22*(6), 1421–1427. https://doi.org/10.1002/PON.3158

Appendix A: Co-authorship forms

Expertise and involvement of the Ways Ahead project team:

All members of the Ways Ahead project team engaged in regular meetings throughout the project to discuss progress and next steps, ensuring that the conduct of the research drew upon the multidisciplinary expertise of the team.

I was the lead researcher on the Ways Ahead project. My background is in Health Psychology, with a focus on cancer survivorship. I prepared the study protocol and relevant documents, arranged ethical approvals, some PPI activities (see chapter 2.4), site set-up and recruitment (through NHS sites and the Brain Tumour Charity), interview data collection (n=53 of 72), data analysis, and write-up of all presented publications. I also led the conduct of the systematic review of quantitative studies (PP1[47]).

Linda Sharp was the chief investigator on the Ways Ahead project and the lead supervisor of this PhD. They are a Professor of Cancer Epidemiology with expertise in cancer research and vast research experience of QoL in cancer survivorship. They oversaw the project and provided me with guidance, where necessary. They also provided feedback on the first draft of each paper prior to sharing the draft with other co-authors.

Lizzie Dutton was the other researcher on the Ways Ahead project. Their background is in healthcare design. They conducted early PPI activities (see chapter 2.4), some interview data collection (n=19 of 72), and provided feedback on draft papers prior to journal submission.

Michelle Balla was a research intern on the Ways Ahead project. Their background is in public health. They independently double coded a sample of transcripts as part of data analysis and provided feedback on draft papers prior to journal submission.

Iakov Bolnykh was a medical student intern on the Ways Ahead project. They assisted with the conduct of the systematic review of quantitative studies (PP1[47]), including second screening and data checking, and provided feedback on the draft paper prior to journal submission.

Fiona Menger was a member of the Ways Ahead project team and the secondary supervisor of this PhD. Their expertise is in speech and language therapy, with a focus on progressive and acquired neurological conditions. They provided me with general guidance, where necessary, and provided feedback on draft papers prior to journal submission.

Sophie Williams was a member of the Ways Ahead project team. They are a Clinical Neuropsychologist with expertise in the psychosocial and cognitive function of people with brain tumours. They assisted with recruitment, aided the interpretation of findings related to cognitive function, and provided feedback on draft papers prior to journal submission.

Joanne Lewis was a member of the Ways Ahead project team. They are a Consultant Clinical Oncologist with expertise in the clinical aspects of brain tumours. They assisted with recruitment and collaborations with NHS sites, aided with decisions of participant eligibility, and provided feedback on draft papers prior to journal submission.

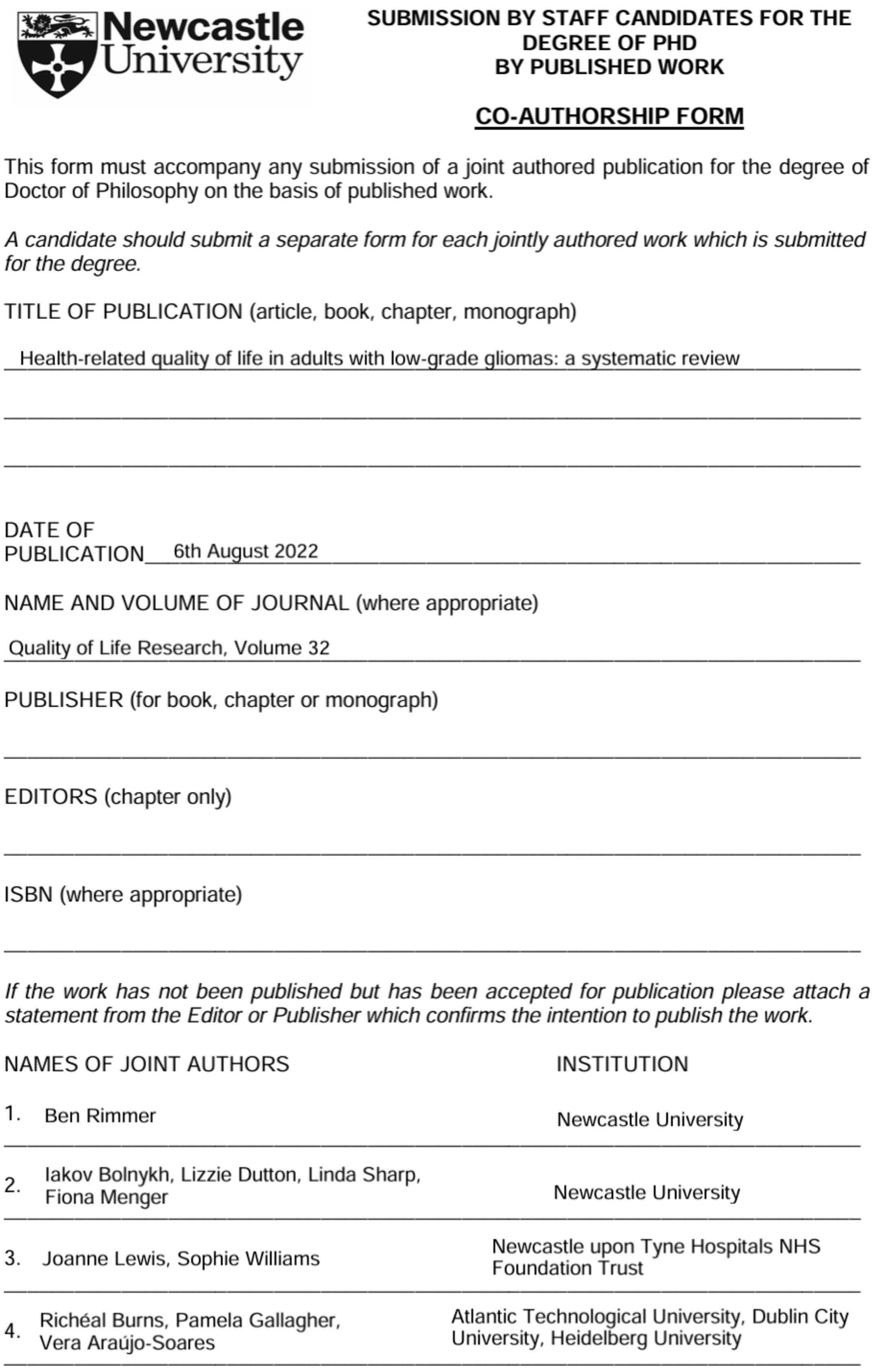
Tracy Finch was a member of the Ways Ahead project team. They are a Professor of Healthcare and Implementation Science with expertise in the implementation of new healthcare interventions. They provided guidance on the use of NPT in PP6[52] and provided feedback on draft papers prior to journal submission.

Vera Araújo-Soares was a member of the Ways Ahead project team. They are a Professor of Health Psychology with expertise in the development and evaluation of health behaviour change interventions. They provided guidance on how the findings can be used to inform intervention development and provided feedback on draft papers prior to journal submission.

Pamela Gallagher was a member of the Ways Ahead project team. They are a Professor of Psychology with expertise in cancer survivorship and health services research and previous experience on a closely related project on self-management in head and neck cancer survivors. They provided guidance on self-management in cancer survivors and provided feedback on draft papers prior to journal submission.

Richéal Burns was a member of the Ways Ahead project team. Their expertise is in health economics in cancer and burden of illness studies. They assisted with interpretation of findings from a health economic perspective and provided feedback on draft papers prior to journal submission.

PP1 Co-authorship form:



Newcastle University

SUBMISSION BY STAFF CANDIDATES FOR THE DEGREE OF PHD
BY PUBLISHED WORK

CO-AUTHORSHIP FORM

This form must accompany any submission of a joint authored publication for the degree of Doctor of Philosophy on the basis of published work.

A candidate should submit a separate form for each jointly authored work which is submitted for the degree.

TITLE OF PUBLICATION (article, book, chapter, monograph)

Health-related quality of life in adults with low-grade gliomas: a systematic review

DATE OF PUBLICATION 6th August 2022

NAME AND VOLUME OF JOURNAL (where appropriate)

Quality of Life Research, Volume 32

PUBLISHER (for book, chapter or monograph)

EDITORS (chapter only)

ISBN (where appropriate)

If the work has not been published but has been accepted for publication please attach a statement from the Editor or Publisher which confirms the intention to publish the work.

NAMES OF JOINT AUTHORS	INSTITUTION
1. Ben Rimmer	Newcastle University
2. Iakov Bolnykh, Lizzie Dutton, Linda Sharp, Fiona Menger	Newcastle University
3. Joanne Lewis, Sophie Williams	Newcastle upon Tyne Hospitals NHS Foundation Trust
4. Richéal Burns, Pamela Gallagher, Vera Araújo-Soares	Atlantic Technological University, Dublin City University, Heidelberg University

CONTRIBUTION OF THE CANDIDATE TO THIS WORK (%)

Design of investigation 65%

Conduct of research 60%

Analysis of outcome 80%

Preparation for publication 80%

TOTAL 75% *(To be an average of, or at least consistent with, the above figures)*

This statement should be endorsed by all of the co-authors.

I confirm that the above is a true estimate of the candidate's contribution to this work.

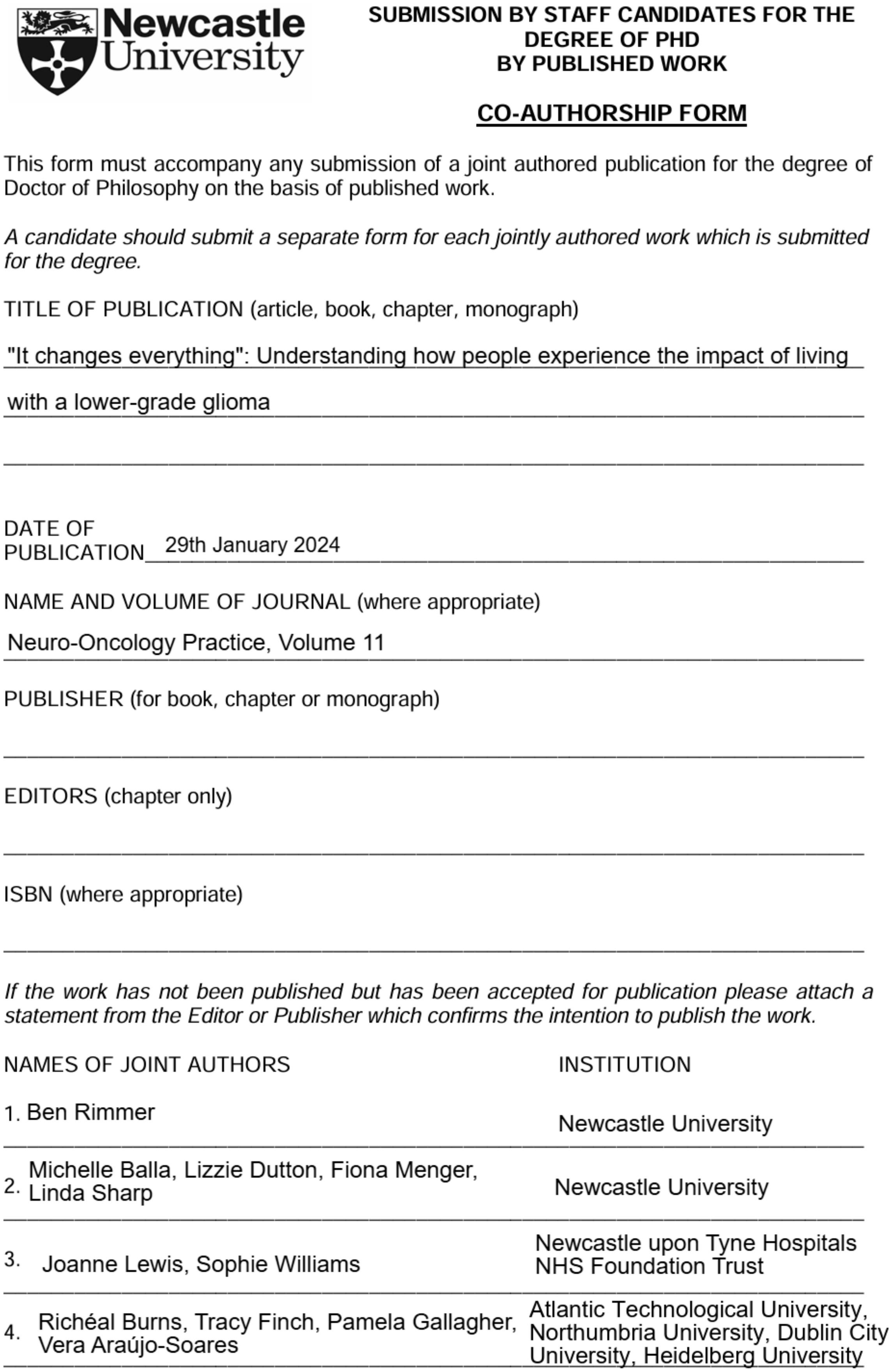
Signature 1 Linda Sharp

Signature 2 Pamela Gallagher

Signature 3 Richard Burrows

Signature 4 Vera Araujo-Soares

PP2 Co-authorship form:



SUBMISSION BY STAFF CANDIDATES FOR THE DEGREE OF PHD BY PUBLISHED WORK

CO-AUTHORSHIP FORM

This form must accompany any submission of a joint authored publication for the degree of Doctor of Philosophy on the basis of published work.

A candidate should submit a separate form for each jointly authored work which is submitted for the degree.

TITLE OF PUBLICATION (article, book, chapter, monograph)

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

DATE OF PUBLICATION 29th January 2024

NAME AND VOLUME OF JOURNAL (where appropriate)

Neuro-Oncology Practice, Volume 11

PUBLISHER (for book, chapter or monograph)

EDITORS (chapter only)

ISBN (where appropriate)

If the work has not been published but has been accepted for publication please attach a statement from the Editor or Publisher which confirms the intention to publish the work.

NAMES OF JOINT AUTHORS	INSTITUTION
1. Ben Rimmer	Newcastle University
2. Michelle Balla, Lizzie Dutton, Fiona Menger, Linda Sharp	Newcastle University
3. Joanne Lewis, Sophie Williams	Newcastle upon Tyne Hospitals NHS Foundation Trust
4. Richéal Burns, Tracy Finch, Pamela Gallagher, Vera Araújo-Soares	Atlantic Technological University, Northumbria University, Dublin City University, Heidelberg University

CONTRIBUTION OF THE CANDIDATE TO THIS WORK (%)

Design of investigation 20%

Conduct of research 65%

Analysis of outcome 75%

Preparation for publication 70%

TOTAL 70% *(To be an average of, or at least consistent with, the above figures)*

This statement should be endorsed by all of the co-authors.

I confirm that the above is a true estimate of the candidate's contribution to this work.

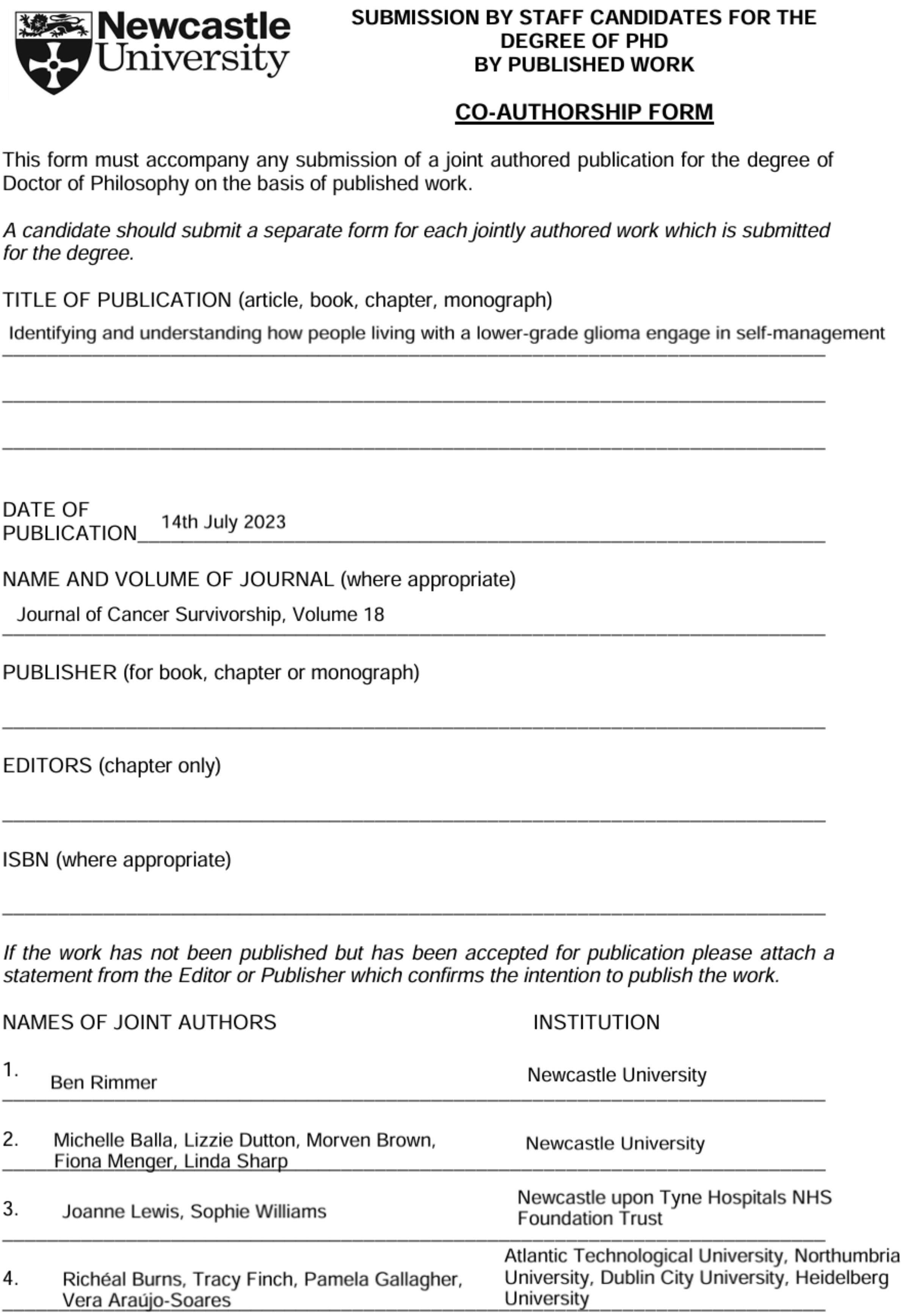
Signature 1 Linda Sharp

Signature 2

Signature 3 Richard Burns Pamela Gallagher

Signature 4 Michelle Balla

PP3 Co-authorship form:



Newcastle University

SUBMISSION BY STAFF CANDIDATES FOR THE DEGREE OF PHD BY PUBLISHED WORK

CO-AUTHORSHIP FORM

This form must accompany any submission of a joint authored publication for the degree of Doctor of Philosophy on the basis of published work.

A candidate should submit a separate form for each jointly authored work which is submitted for the degree.

TITLE OF PUBLICATION (article, book, chapter, monograph)

Identifying and understanding how people living with a lower-grade glioma engage in self-management

DATE OF PUBLICATION 14th July 2023

NAME AND VOLUME OF JOURNAL (where appropriate)

Journal of Cancer Survivorship, Volume 18

PUBLISHER (for book, chapter or monograph)

EDITORS (chapter only)

ISBN (where appropriate)

If the work has not been published but has been accepted for publication please attach a statement from the Editor or Publisher which confirms the intention to publish the work.

NAMES OF JOINT AUTHORS	INSTITUTION
1. Ben Rimmer	Newcastle University
2. Michelle Balla, Lizzie Dutton, Morven Brown, Fiona Menger, Linda Sharp	Newcastle University
3. Joanne Lewis, Sophie Williams	Newcastle upon Tyne Hospitals NHS Foundation Trust
4. Richéal Burns, Tracy Finch, Pamela Gallagher, Vera Araújo-Soares	Atlantic Technological University, Northumbria University, Dublin City University, Heidelberg University

CONTRIBUTION OF THE CANDIDATE TO THIS WORK (%)

Design of investigation 20%

Conduct of research 65%

Analysis of outcome 65%

Preparation for publication 70%

TOTAL 60% *(To be an average of, or at least consistent with, the above figures)*

This statement should be endorsed by all of the co-authors.

I confirm that the above is a true estimate of the candidate's contribution to this work.

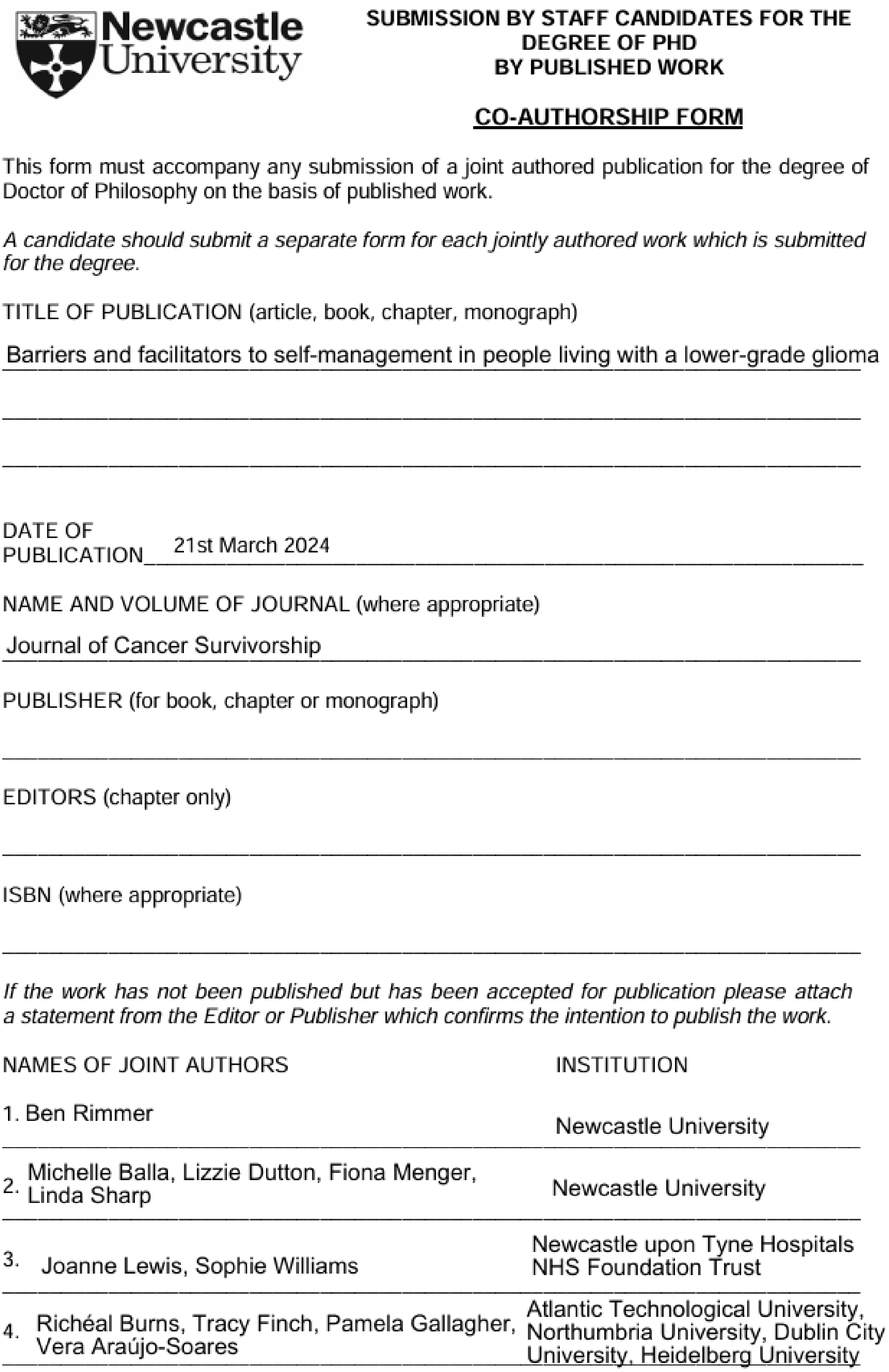
Signature 1 Linda Sharp

Signature 2 Maren

Signature 3 Richard Burns Pamela Gallagher

Signature 4 Michelle Balla Vera

PP4 Co-authorship form:



SUBMISSION BY STAFF CANDIDATES FOR THE DEGREE OF PHD BY PUBLISHED WORK

CO-AUTHORSHIP FORM

This form must accompany any submission of a joint authored publication for the degree of Doctor of Philosophy on the basis of published work.

A candidate should submit a separate form for each jointly authored work which is submitted for the degree.

TITLE OF PUBLICATION (article, book, chapter, monograph)

Barriers and facilitators to self-management in people living with a lower-grade glioma

DATE OF PUBLICATION 21st March 2024

NAME AND VOLUME OF JOURNAL (where appropriate)

Journal of Cancer Survivorship

PUBLISHER (for book, chapter or monograph)

EDITORS (chapter only)

ISBN (where appropriate)

If the work has not been published but has been accepted for publication please attach a statement from the Editor or Publisher which confirms the intention to publish the work.

NAMES OF JOINT AUTHORS	INSTITUTION
1. Ben Rimmer	Newcastle University
2. Michelle Balla, Lizzie Dutton, Fiona Menger, Linda Sharp	Newcastle University
3. Joanne Lewis, Sophie Williams	Newcastle upon Tyne Hospitals NHS Foundation Trust
4. Richéal Burns, Tracy Finch, Pamela Gallagher, Vera Araújo-Soares	Atlantic Technological University, Northumbria University, Dublin City University, Heidelberg University

CONTRIBUTION OF THE CANDIDATE TO THIS WORK (%)

Design of investigation	20%
Conduct of research	65%
Analysis of outcome	75%
Preparation for publication	70%
TOTAL	70% *(To be an average of, or at least consistent with, the above figures)*

This statement should be endorsed by all of the co-authors.

I confirm that the above is a true estimate of the candidate's contribution to this work.

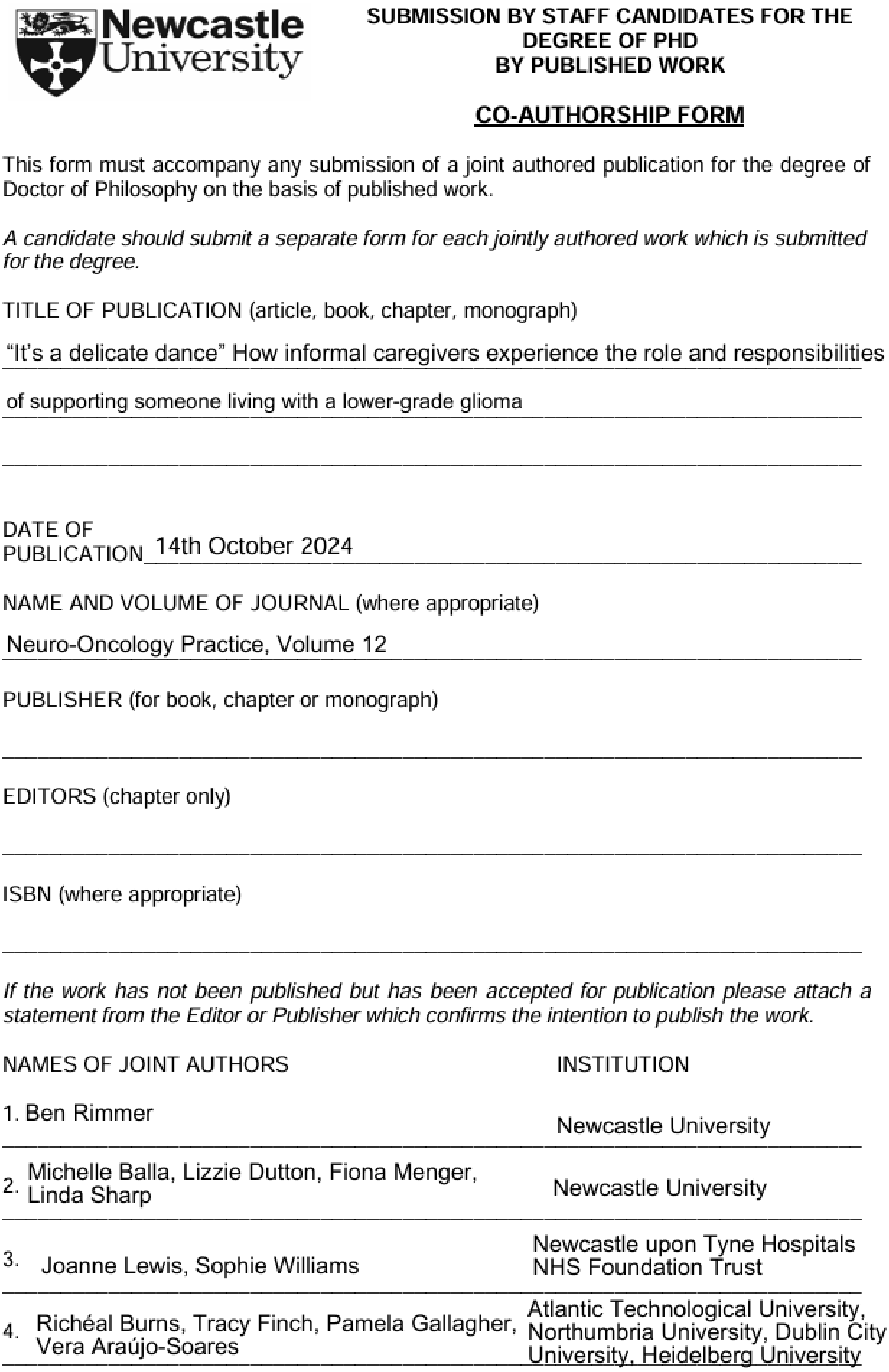
Signature 1 Linda Sharp

Signature 2

Signature 3 Richard Burns Pamela Gallagher

Signature 4 Michelle Balla

PP5 Co-authorship form:



SUBMISSION BY STAFF CANDIDATES FOR THE DEGREE OF PHD BY PUBLISHED WORK

CO-AUTHORSHIP FORM

This form must accompany any submission of a joint authored publication for the degree of Doctor of Philosophy on the basis of published work.

A candidate should submit a separate form for each jointly authored work which is submitted for the degree.

TITLE OF PUBLICATION (article, book, chapter, monograph)

"It's a delicate dance" How informal caregivers experience the role and responsibilities of supporting someone living with a lower-grade glioma

DATE OF PUBLICATION 14th October 2024

NAME AND VOLUME OF JOURNAL (where appropriate)

Neuro-Oncology Practice, Volume 12

PUBLISHER (for book, chapter or monograph)

EDITORS (chapter only)

ISBN (where appropriate)

If the work has not been published but has been accepted for publication please attach a statement from the Editor or Publisher which confirms the intention to publish the work.

NAMES OF JOINT AUTHORS	INSTITUTION
1. Ben Rimmer	Newcastle University
2. Michelle Balla, Lizzie Dutton, Fiona Menger, Linda Sharp	Newcastle University
3. Joanne Lewis, Sophie Williams	Newcastle upon Tyne Hospitals NHS Foundation Trust
4. Richéal Burns, Tracy Finch, Pamela Gallagher, Vera Araújo-Soares	Atlantic Technological University, Northumbria University, Dublin City University, Heidelberg University

CONTRIBUTION OF THE CANDIDATE TO THIS WORK (%)

Design of investigation 20%

Conduct of research 75%

Analysis of outcome 75%

Preparation for publication 70%

TOTAL 70% *(To be an average of, or at least consistent with, the above figures)*

This statement should be endorsed by all of the co-authors.

I confirm that the above is a true estimate of the candidate's contribution to this work.

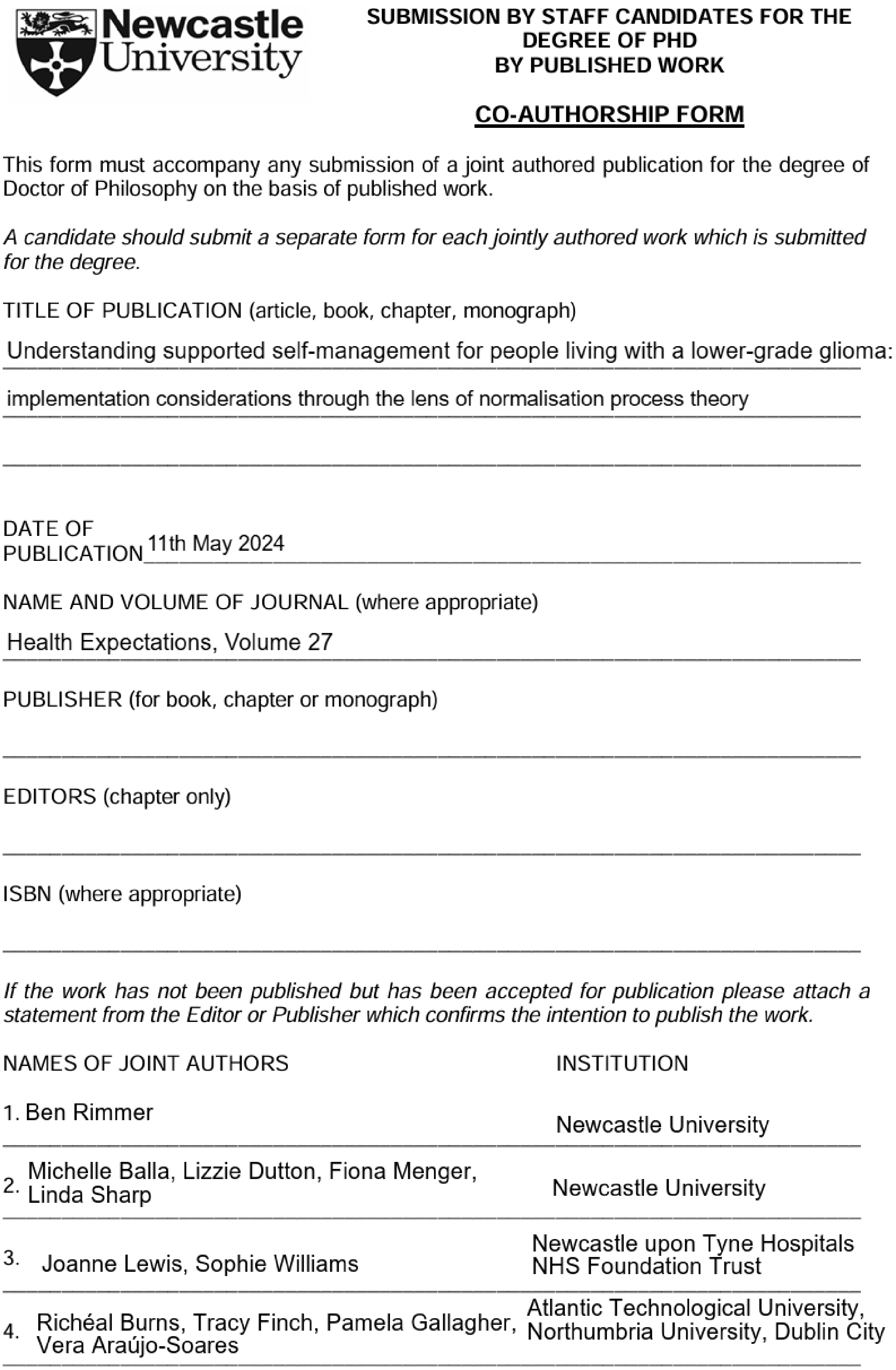
Signature 1 Linda Sharp

Signature 2

Signature 3 Richard Burns Pamela Gallagher

Signature 4 Michelle Balla

PP6 Co-authorship form:



Newcastle University

SUBMISSION BY STAFF CANDIDATES FOR THE DEGREE OF PHD BY PUBLISHED WORK

CO-AUTHORSHIP FORM

This form must accompany any submission of a joint authored publication for the degree of Doctor of Philosophy on the basis of published work.

A candidate should submit a separate form for each jointly authored work which is submitted for the degree.

TITLE OF PUBLICATION (article, book, chapter, monograph)

Understanding supported self-management for people living with a lower-grade glioma: implementation considerations through the lens of normalisation process theory

DATE OF PUBLICATION 11th May 2024

NAME AND VOLUME OF JOURNAL (where appropriate)

Health Expectations, Volume 27

PUBLISHER (for book, chapter or monograph)

EDITORS (chapter only)

ISBN (where appropriate)

If the work has not been published but has been accepted for publication please attach a statement from the Editor or Publisher which confirms the intention to publish the work.

NAMES OF JOINT AUTHORS	INSTITUTION
1. Ben Rimmer	Newcastle University
2. Michelle Balla, Lizzie Dutton, Fiona Menger, Linda Sharp	Newcastle University
3. Joanne Lewis, Sophie Williams	Newcastle upon Tyne Hospitals NHS Foundation Trust
4. Richéal Burns, Tracy Finch, Pamela Gallagher, Vera Araújo-Soares	Atlantic Technological University, Northumbria University, Dublin City

CONTRIBUTION OF THE CANDIDATE TO THIS WORK (%)

Design of investigation 20%

Conduct of research 65%

Analysis of outcome 70%

Preparation for publication 70%

TOTAL 70% *(To be an average of, or at least consistent with, the above figures)*

This statement should be endorsed by all of the co-authors.

I confirm that the above is a true estimate of the candidate's contribution to this work.

Signature 1 Linda Sharp

Signature 2

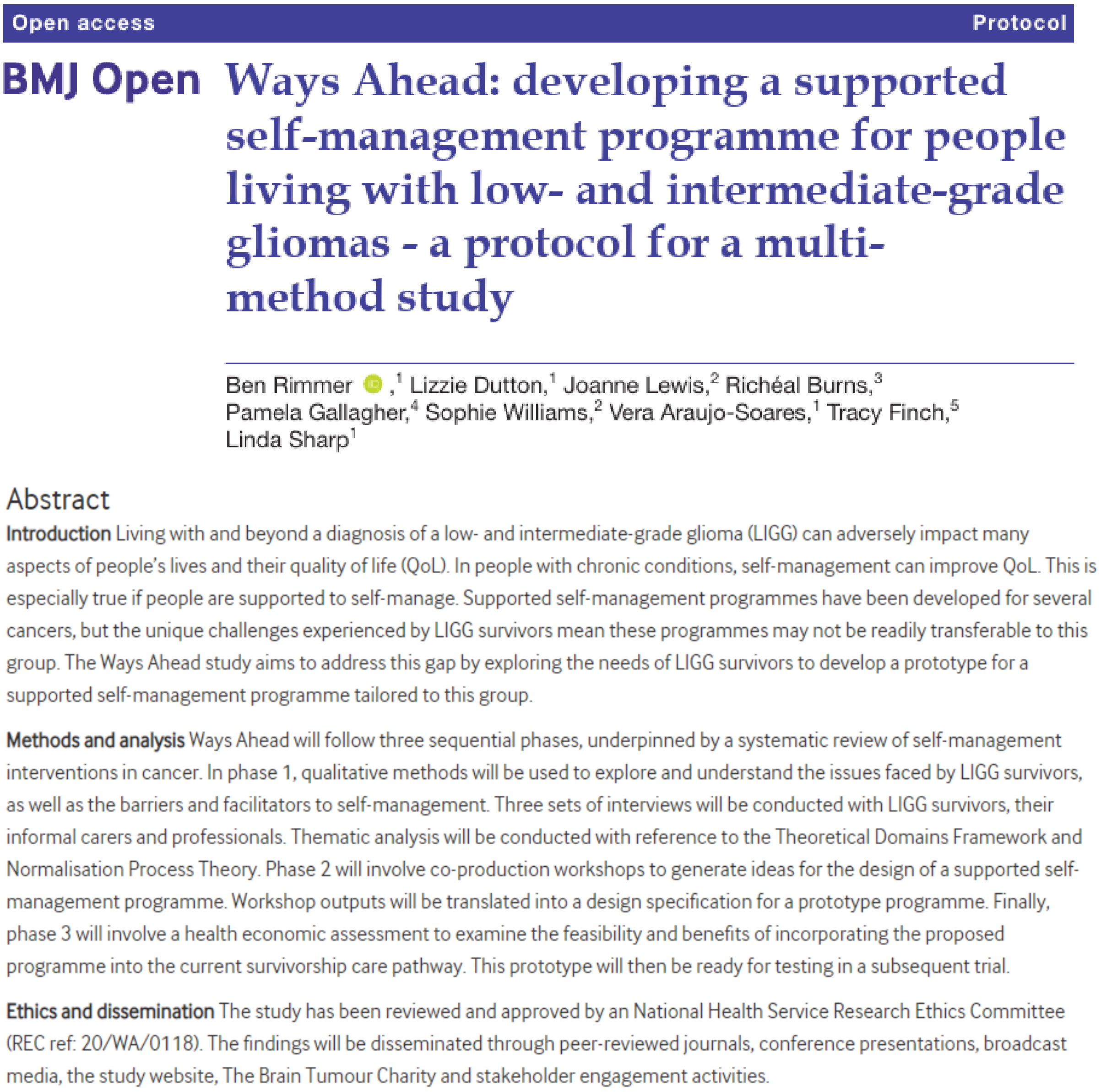
Signature 3 Richard Burns Pamela Gallagher

Signature 4 Michelle Balla

Appendix B: Abstracts of additional publications

1. **Rimmer, B.,** Dutton, L., Lewis, J., Burns, R., Gallagher, P., Williams, S., Araújo-Soares, V., Finch, T., & Sharp, L. (2020). 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, 10(7), e041465. http://dx.doi.org/10.1136/bmjopen-2020-041465
2. **Rimmer, B.,** & Sharp, L. (2021). Implementation of Self-Management Interventions in Cancer Survivors: Why Are We Not There Yet? Journal of Cancer Education, 36(6), 1355–1358. https://doi.org/10.1007/s13187-021-02021-2
3. **Rimmer, B.,** Crowe, L., Todd, A., & Sharp, L. (2022). Assessing unmet needs in advanced cancer patients: a systematic review of the development, content, and quality of available instruments. Journal of Cancer Survivorship, 16(5), 960–975. https://doi.org/10.1007/s11764-021-01088-6
4. **Rimmer, B.,** Brown, M. C., Sotire, T., Beyer, F., Bolnykh, I., Balla, M., Richmond, C., Dutton, L., Williams, S., Araújo-Soares, V., Finch, T., Gallagher, P., Lewis, J., Burns, R., & Sharp, L. (2023). Characteristics and Components of Self-Management Interventions for Improving Quality of Life in Cancer Survivors: A Systematic Review. Cancers, 16(1), 14. https://doi.org/10.3390/cancers16010014
5. **Rimmer, B.,** Balla, M., Dutton, L., Lewis, J., Burns, R., Gallagher, P., Williams, S., Araújo-Soares, V., Finch, T., & Sharp, L. (2024). 'A Constant Black Cloud': The Emotional Impact of Informal Caregiving for Someone With a Lower-Grade Glioma. Qualitative Health Research, 34(3), 227–238. https://doi.org/10.1177/10497323231204740
6. Murrell, A. J., **Rimmer, B.,** Dutton, L., Lewis, J., Burns, R., Gallagher, P., Williams, S., Araújo-Soares, V., Finch, T., & Sharp, L. (2023). The Nature and Quality of Support from Informal Networks for Informal Caregivers of Low-Grade Glioma Patients: A Qualitative Analysis within the Ways Ahead Study. European Journal of Cancer Care, 2023(1), 4149412. https://doi.org/10.1155/2023/4149412
7. Walker, H., **Rimmer, B.,** Dutton, L., Finch, T., Gallagher, P., Lewis, J., Burns, R., Araújo-Soares, V., Williams, S., & Sharp, L. (2023). Experiences of work for people living with a grade 2/3 oligodendroglioma: a qualitative analysis within the Ways Ahead study. BMJ Open, 13(9), e074151. https://doi.org/10.1136/bmjopen-2023-074151

Appendix B.1:



Open access **Protocol**

BMJ Open

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

Ben Rimmer,[1] Lizzie Dutton,[1] Joanne Lewis,[2] Richéal Burns,[3]
Pamela Gallagher,[4] Sophie Williams,[2] Vera Araujo-Soares,[1] Tracy Finch,[5]
Linda Sharp[1]

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.

Appendix B.2:

Journal of Cancer Education (2021) 36:1355–1358
https://doi.org/10.1007/s13187-021-02021-2

REFLECTIONS

Implementation of Self-Management Interventions in Cancer Survivors: Why Are We Not There Yet?

Ben Rimmer[1] · **Linda Sharp**[1] · **on behalf of Ways Ahead study team**

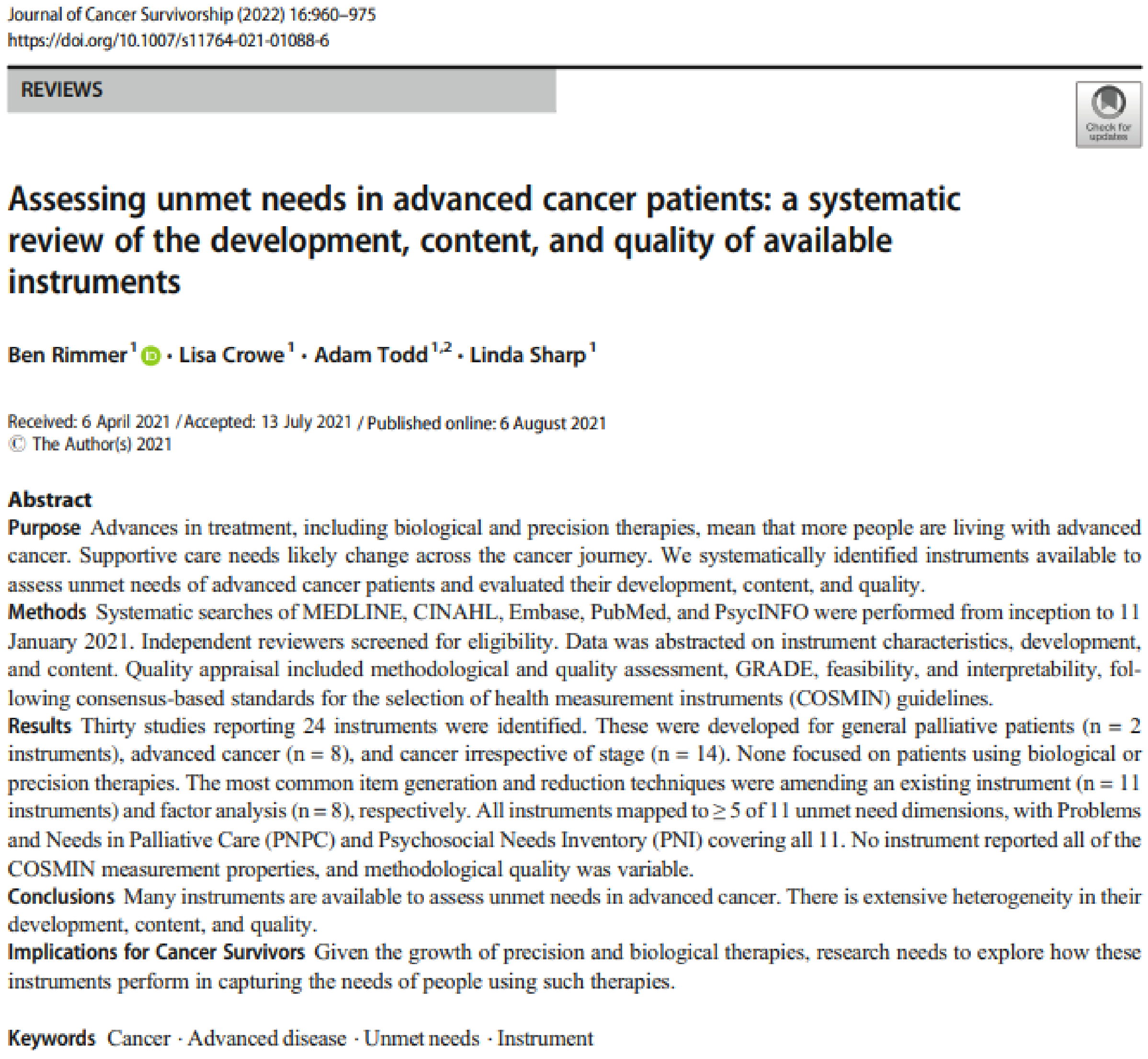
Accepted: 25 April 2021

Abstract

Despite the growing evidence base for supported self-management for the improvement of quality of life, there is a lack of widespread implementation of self-management interventions for cancer survivors. We propose five key areas that, if addressed, would optimise the development and evaluation of these interventions, namely: (1) improving intervention adaptability to different survivor populations; (2) establishing intervention acceptability (and feasibility); (3) ensuring systematic description of interventions, their content, and active ingredients; (4) conducting process evaluations; and (5) assessing cost-effectiveness. These areas are an essential prerequisite for translation of self-management interventions from research into routine cancer care.

Keywords Self-management · Cancer · Survivorship · Interventions

Appendix B.3:



Journal of Cancer Survivorship (2022) 16:960–975
https://doi.org/10.1007/s11764-021-01088-6

REVIEWS

Assessing unmet needs in advanced cancer patients: a systematic review of the development, content, and quality of available instruments

Ben Rimmer[1] · Lisa Crowe[1] · Adam Todd[1,2] · Linda Sharp[1]

Received: 6 April 2021 / Accepted: 13 July 2021 / Published online: 6 August 2021

Abstract

Purpose Advances in treatment, including biological and precision therapies, mean that more people are living with advanced cancer. Supportive care needs likely change across the cancer journey. We systematically identified instruments available to assess unmet needs of advanced cancer patients and evaluated their development, content, and quality.

Methods Systematic searches of MEDLINE, CINAHL, Embase, PubMed, and PsycINFO were performed from inception to 11 January 2021. Independent reviewers screened for eligibility. Data was abstracted on instrument characteristics, development, and content. Quality appraisal included methodological and quality assessment, GRADE, feasibility, and interpretability, following consensus-based standards for the selection of health measurement instruments (COSMIN) guidelines.

Results Thirty studies reporting 24 instruments were identified. These were developed for general palliative patients (n = 2 instruments), advanced cancer (n = 8), and cancer irrespective of stage (n = 14). None focused on patients using biological or precision therapies. The most common item generation and reduction techniques were amending an existing instrument (n = 11 instruments) and factor analysis (n = 8), respectively. All instruments mapped to ≥ 5 of 11 unmet need dimensions, with Problems and Needs in Palliative Care (PNPC) and Psychosocial Needs Inventory (PNI) covering all 11. No instrument reported all of the COSMIN measurement properties, and methodological quality was variable.

Conclusions Many instruments are available to assess unmet needs in advanced cancer. There is extensive heterogeneity in their development, content, and quality.

Implications for Cancer Survivors Given the growth of precision and biological therapies, research needs to explore how these instruments perform in capturing the needs of people using such therapies.

Keywords Cancer · Advanced disease · Unmet needs · Instrument

Appendix B.4:

cancers

Systematic Review

Characteristics and Components of Self-Management Interventions for Improving Quality of Life in Cancer Survivors: A Systematic Review

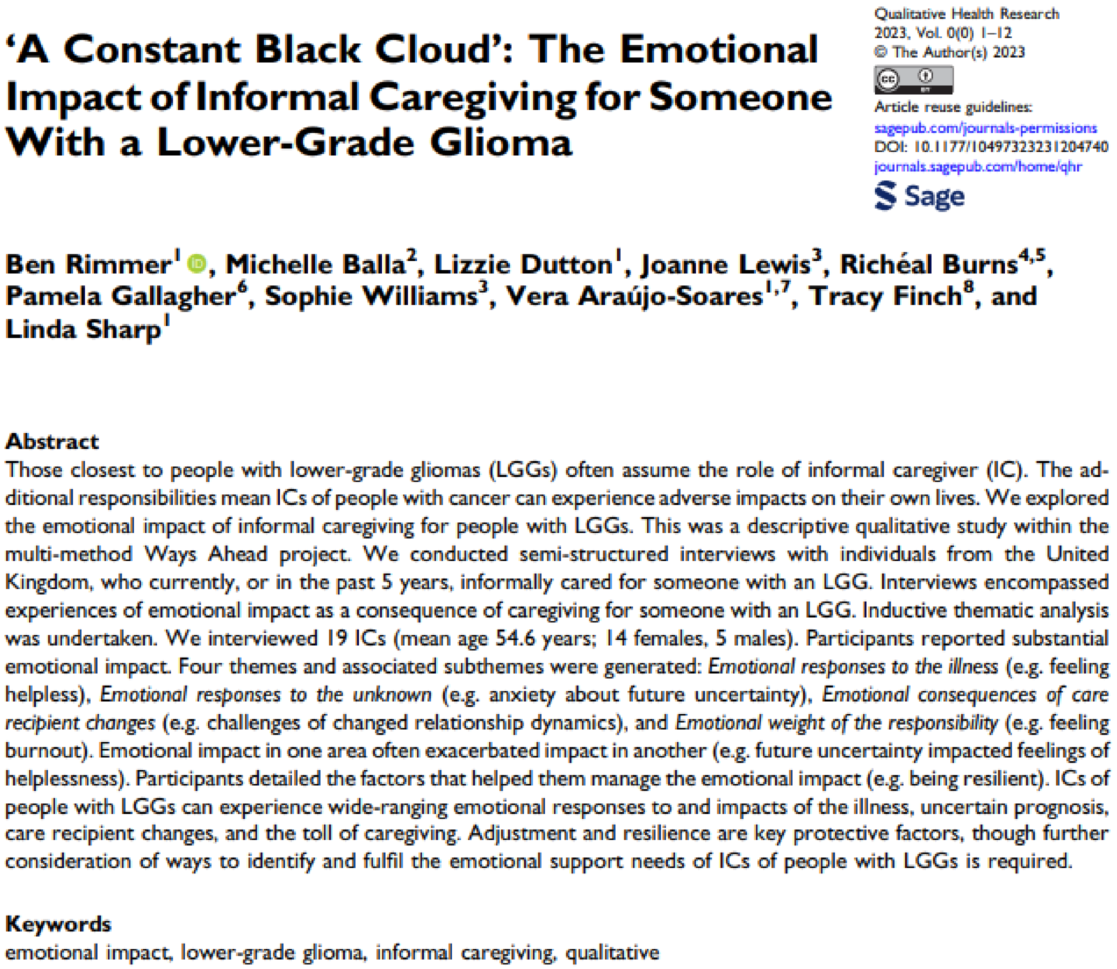
Ben Rimmer [1,2,*], Morven C. Brown [1,2], Tumi Sotire [2], Fiona Beyer [2], Iakov Bolnykh [3], Michelle Balla [3], Catherine Richmond [2], Lizzie Dutton [1,2], Sophie Williams [4], Vera Araújo-Soares [1,2,5], Tracy Finch [6], Pamela Gallagher [7], Joanne Lewis [4], Richéal Burns [8,9] and Linda Sharp [1,2]

Abstract:

Self-management can improve clinical and psychosocial outcomes in cancer survivors. Which intervention characteristics and components are beneficial is unclear, hindering implementation into practice. We systematically searched six databases from inception to 17 November 2021 for studies evaluating self-management interventions for adult cancer survivors post-treatment. Independent reviewers screened for eligibility. Data extraction included population and study characteristics, intervention characteristics (TIDieR) and components (PRISMS), (associations with) quality of life (QoL), self-efficacy, and economic outcomes. Study quality was appraised, and narrative synthesis was conducted. We identified 53 papers reporting 32 interventions. Studies had varying quality. They were most often randomised controlled trials (n = 20), targeted at survivors of breast (n = 10), prostate (n = 7), or mixed cancers (n = 11). Intervention characteristics (e.g., provider, location) varied considerably. On average, five (range 1–10) self-management components were delivered, mostly “Information about condition and its management” (n = 26). Twenty-two studies reported significant QoL improvements (6 also reported significant self-efficacy improvements); these were associated most consistently with combined individual and group delivery. Economic evaluations were limited and inconclusive. Self-management interventions showed promise for improving QoL, but study quality was variable, with substantial heterogeneity in intervention characteristics and components. By identifying what to adapt from existing interventions, these findings can inform development and implementation of self-management interventions in cancer.

Keywords: self-management; interventions; cancer; survivorship; quality of life

Appendix B.5:



Qualitative Health Research
2023, Vol. 0(0) 1–12

Article reuse guidelines:
sagepub.com/journals-permissions
DOI: 10.1177/10497323231204740
journals.sagepub.com/home/qhr
Sage

'A Constant Black Cloud': The Emotional Impact of Informal Caregiving for Someone With a Lower-Grade Glioma

Ben Rimmer[1], Michelle Balla[2], Lizzie Dutton[1], Joanne Lewis[3], Richéal Burns[4,5], Pamela Gallagher[6], Sophie Williams[3], Vera Araújo-Soares[1,7], Tracy Finch[8], and Linda Sharp[1]

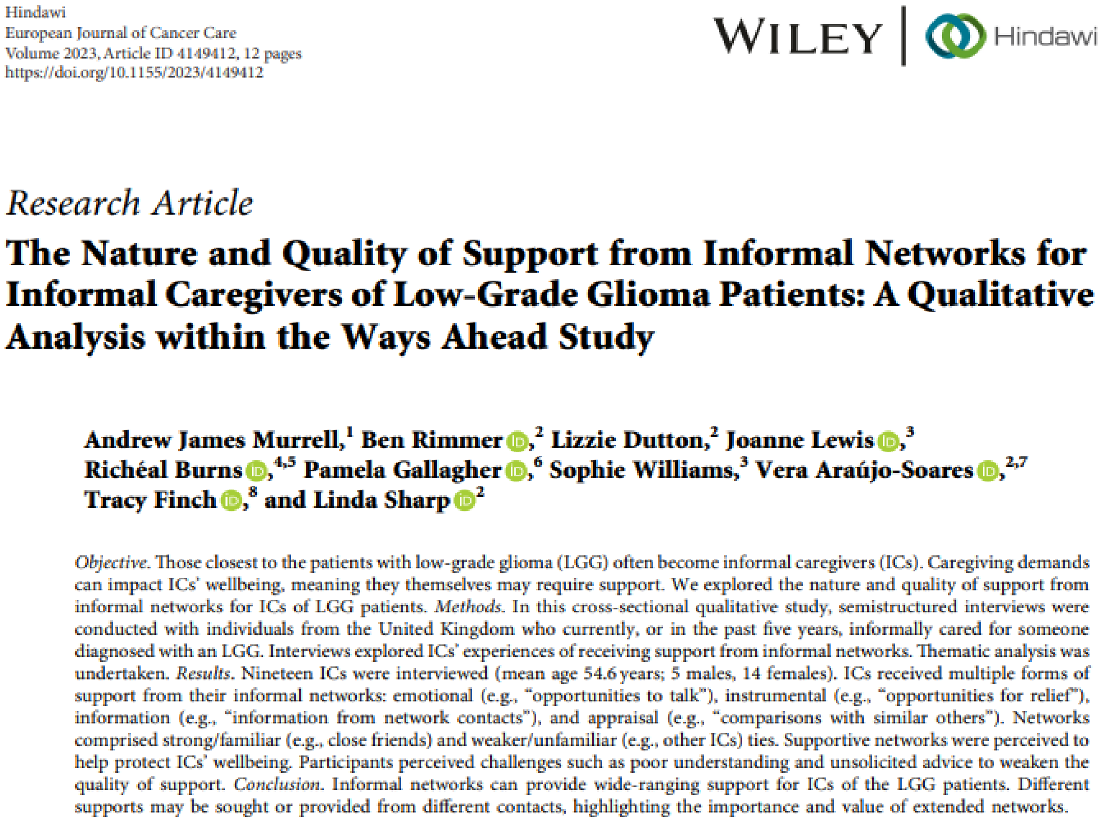
Abstract

Those closest to people with lower-grade gliomas (LGGs) often assume the role of informal caregiver (IC). The additional responsibilities mean ICs of people with cancer can experience adverse impacts on their own lives. We explored the emotional impact of informal caregiving for people with LGGs. This was a descriptive qualitative study within the multi-method Ways Ahead project. We conducted semi-structured interviews with individuals from the United Kingdom, who currently, or in the past 5 years, informally cared for someone with an LGG. Interviews encompassed experiences of emotional impact as a consequence of caregiving for someone with an LGG. Inductive thematic analysis was undertaken. We interviewed 19 ICs (mean age 54.6 years; 14 females, 5 males). Participants reported substantial emotional impact. Four themes and associated subthemes were generated: *Emotional responses to the illness* (e.g. feeling helpless), *Emotional responses to the unknown* (e.g. anxiety about future uncertainty), *Emotional consequences of care recipient changes* (e.g. challenges of changed relationship dynamics), and *Emotional weight of the responsibility* (e.g. feeling burnout). Emotional impact in one area often exacerbated impact in another (e.g. future uncertainty impacted feelings of helplessness). Participants detailed the factors that helped them manage the emotional impact (e.g. being resilient). ICs of people with LGGs can experience wide-ranging emotional responses to and impacts of the illness, uncertain prognosis, care recipient changes, and the toll of caregiving. Adjustment and resilience are key protective factors, though further consideration of ways to identify and fulfil the emotional support needs of ICs of people with LGGs is required.

Keywords

emotional impact, lower-grade glioma, informal caregiving, qualitative

Appendix B.6:



Hindawi
European Journal of Cancer Care
Volume 2023, Article ID 4149412, 12 pages
https://doi.org/10.1155/2023/4149412

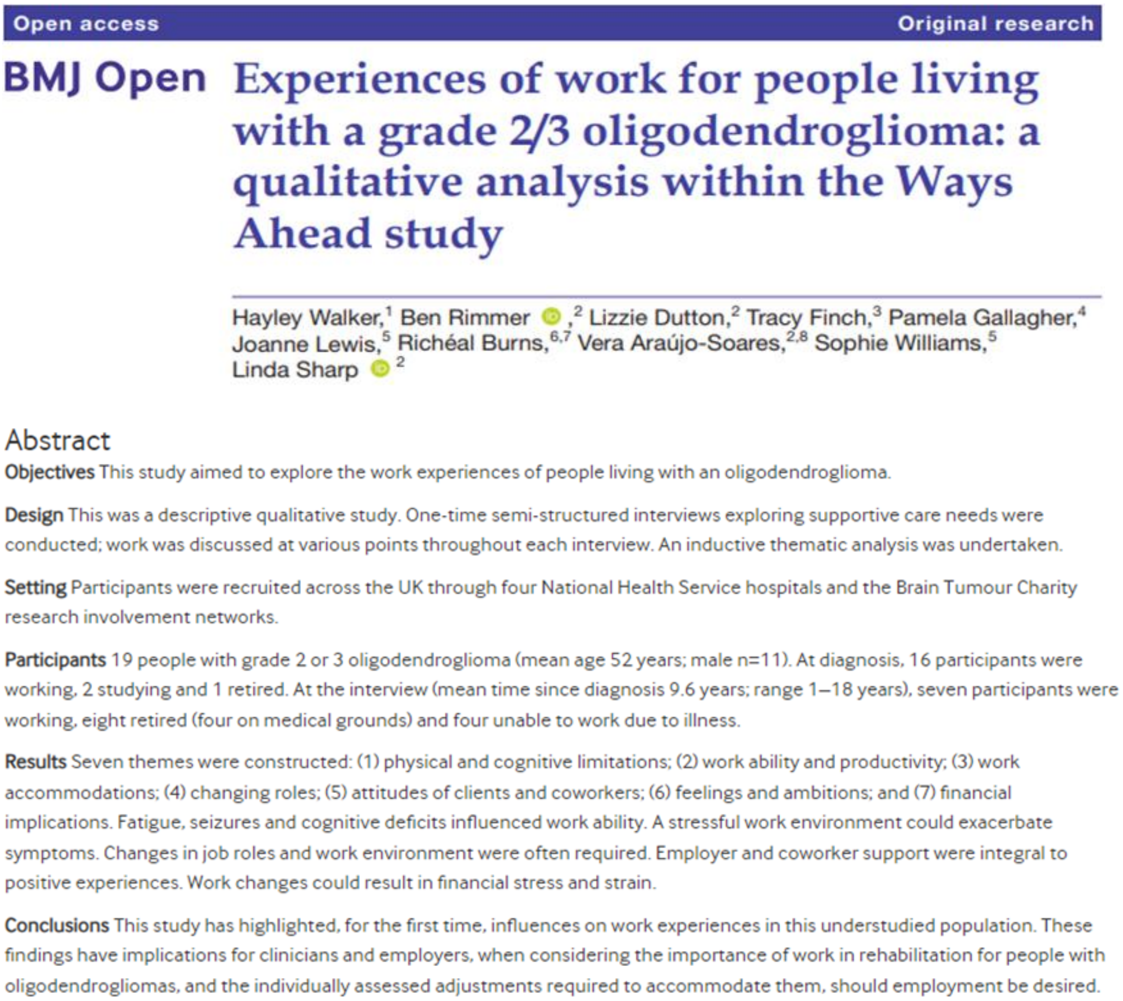
Research Article

The Nature and Quality of Support from Informal Networks for Informal Caregivers of Low-Grade Glioma Patients: A Qualitative Analysis within the Ways Ahead Study

Andrew James Murrell,[1] Ben Rimmer,[2] Lizzie Dutton,[2] Joanne Lewis,[3] Richéal Burns,[4,5] Pamela Gallagher,[6] Sophie Williams,[3] Vera Araújo-Soares,[2,7] Tracy Finch,[8] and Linda Sharp[2]

Objective. Those closest to the patients with low-grade glioma (LGG) often become informal caregivers (ICs). Caregiving demands can impact ICs' wellbeing, meaning they themselves may require support. We explored the nature and quality of support from informal networks for ICs of LGG patients. *Methods*. In this cross-sectional qualitative study, semistructured interviews were conducted with individuals from the United Kingdom who currently, or in the past five years, informally cared for someone diagnosed with an LGG. Interviews explored ICs' experiences of receiving support from informal networks. Thematic analysis was undertaken. *Results*. Nineteen ICs were interviewed (mean age 54.6 years; 5 males, 14 females). ICs received multiple forms of support from their informal networks: emotional (e.g., "opportunities to talk"), instrumental (e.g., "opportunities for relief"), information (e.g., "information from network contacts"), and appraisal (e.g., "comparisons with similar others"). Networks comprised strong/familiar (e.g., close friends) and weaker/unfamiliar (e.g., other ICs) ties. Supportive networks were perceived to help protect ICs' wellbeing. Participants perceived challenges such as poor understanding and unsolicited advice to weaken the quality of support. *Conclusion*. Informal networks can provide wide-ranging support for ICs of the LGG patients. Different supports may be sought or provided from different contacts, highlighting the importance and value of extended networks.

Appendix B.7:



Open access Original research

BMJ Open

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

Hayley Walker,[1] Ben Rimmer ,[2] Lizzie Dutton,[2] Tracy Finch,[3] Pamela Gallagher,[4] Joanne Lewis,[5] Richéal Burns,[6,7] Vera Araújo-Soares,[2,8] Sophie Williams,[5] Linda Sharp [2]

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 UK through four National Health Service hospitals and the Brain Tumour Charity research involvement networks.

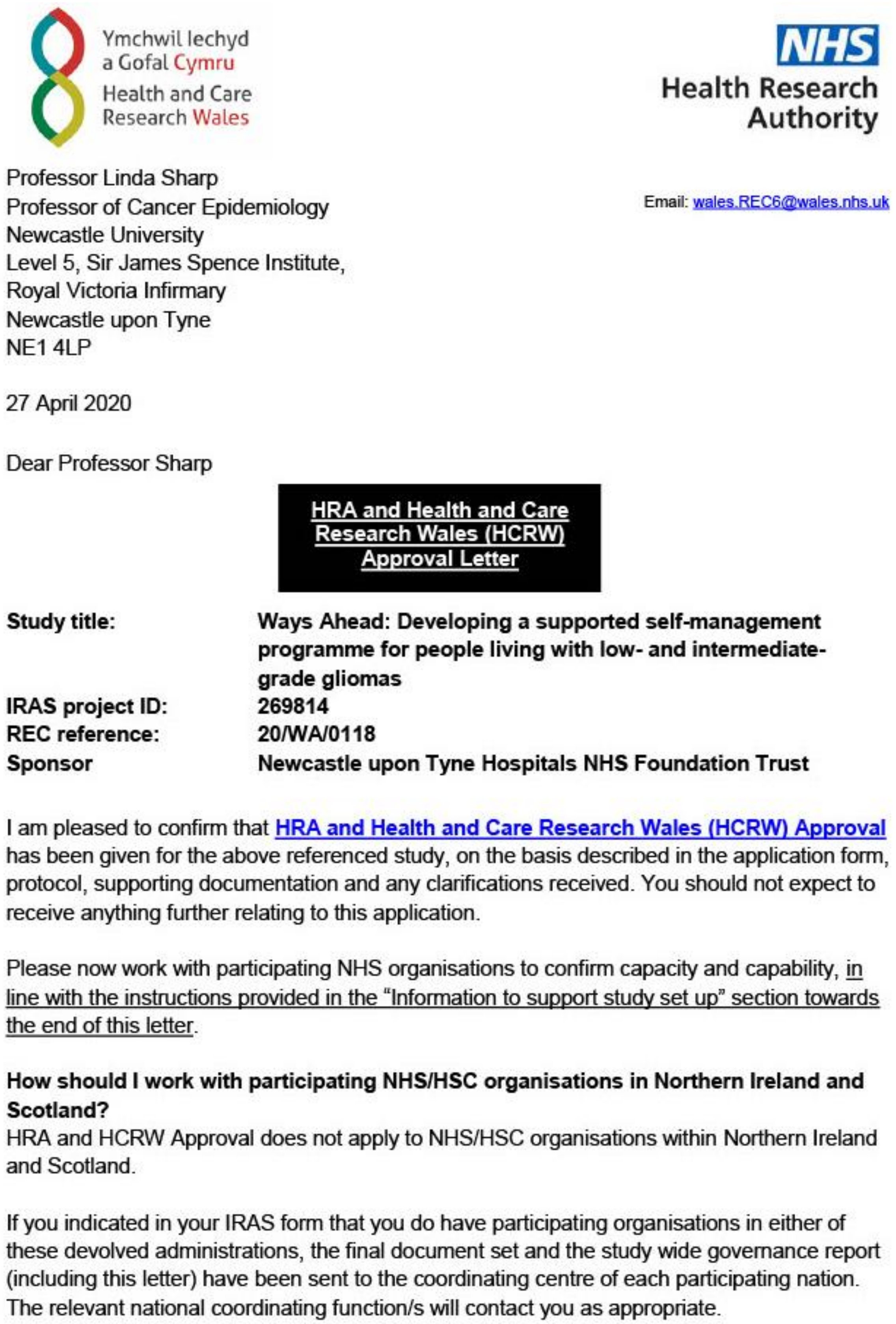
Participants 19 people with grade 2 or 3 oligodendroglioma (mean age 52 years; male n=11). At diagnosis, 16 participants were working, 2 studying and 1 retired. At the interview (mean time since diagnosis 9.6 years; range 1–18 years), seven participants were working, eight retired (four on medical grounds) and four unable to work due to illness.

Results Seven themes were constructed: (1) physical and cognitive limitations; (2) work ability and productivity; (3) work accommodations; (4) changing roles; (5) attitudes of clients and coworkers; (6) feelings and ambitions; and (7) 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 coworker 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 understudied 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.

Appendix C: Ethical approval documentation

HRA approval letter:



Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

NHS
Health Research Authority

Professor Linda Sharp
Professor of Cancer Epidemiology
Newcastle University
Level 5, Sir James Spence Institute,
Royal Victoria Infirmary
Newcastle upon Tyne
NE1 4LP

Email: wales.REC6@wales.nhs.uk

27 April 2020

Dear Professor Sharp

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**Ways Ahead: Developing a supported self-management programme for people living with low- and intermediate-grade gliomas**
IRAS project ID:	**269814**
REC reference:	**20/WA/0118**
Sponsor	**Newcastle upon Tyne Hospitals NHS Foundation Trust**

I am pleased to confirm that HRA and Health and Care Research Wales (HCRW) Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?

HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The standard conditions document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

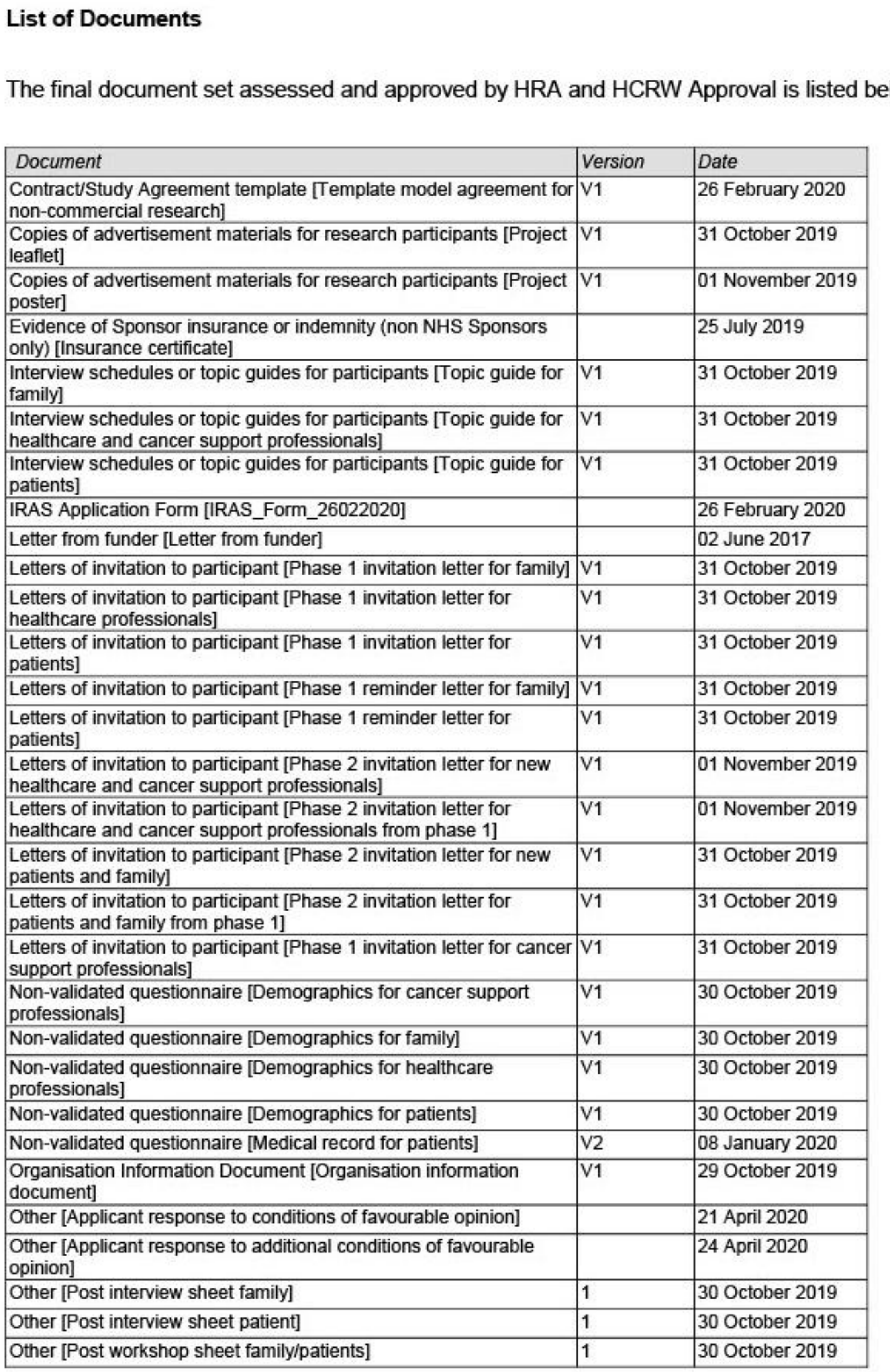
Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **269814**. Please quote this on all correspondence.

Yours sincerely,
Ann Parry

Email: Wales.REC6@wales.nhs.uk

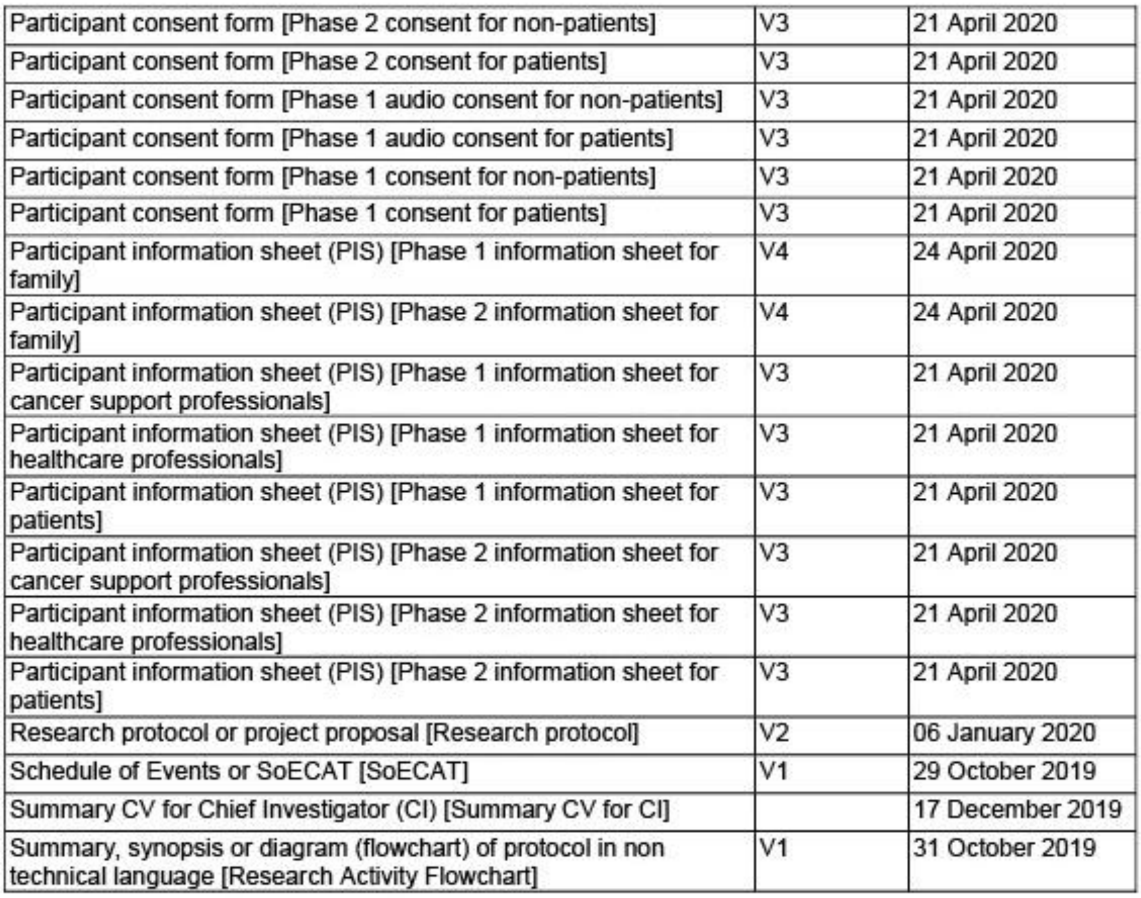
Copy to: *Mrs Alexis Burn, Newcastle upon Tyne Hospitals*



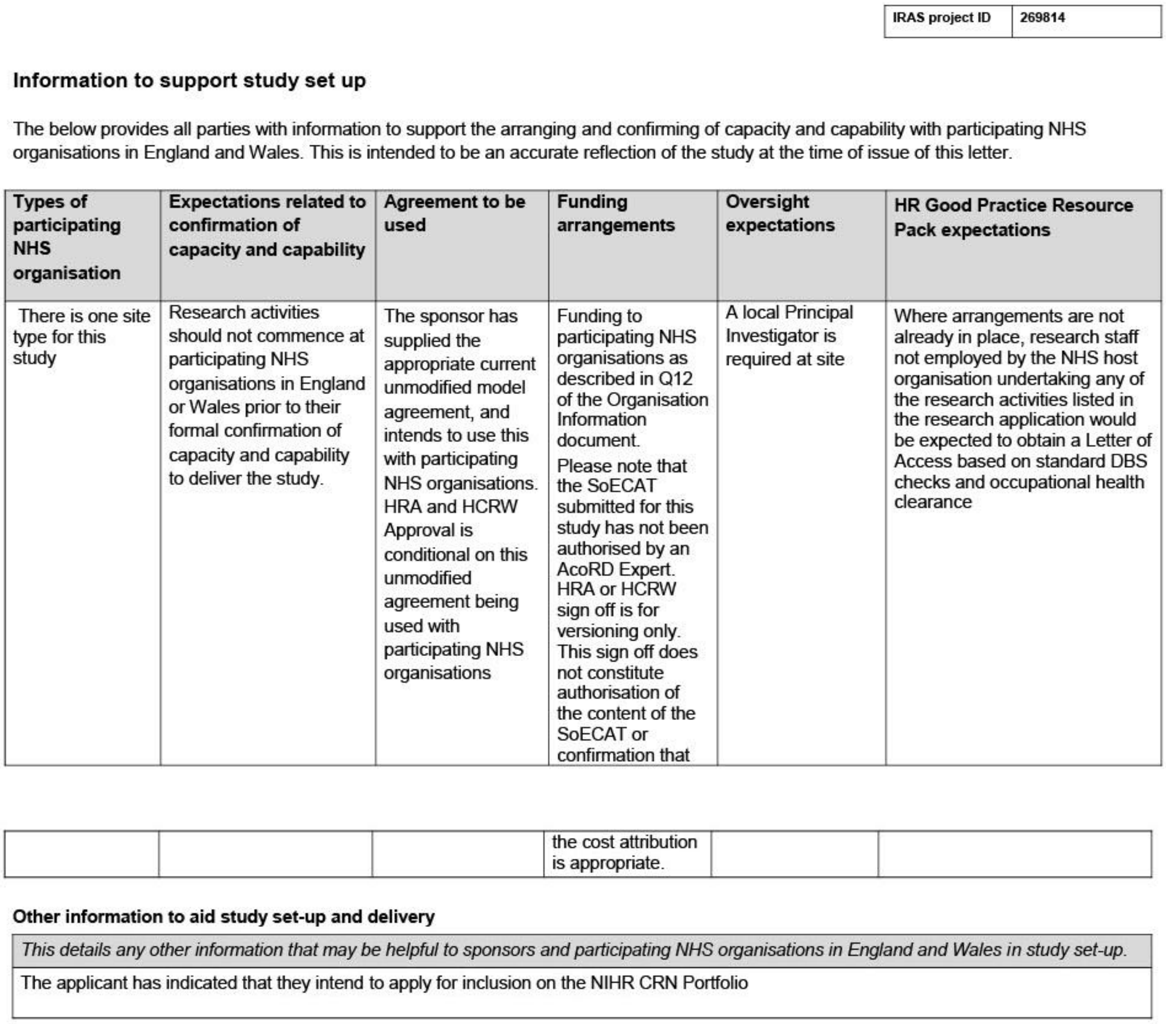
List of Documents

The final document set assessed and approved by HRA and HCRW Approval is listed below.

Document	*Version*	*Date*
Contract/Study Agreement template [Template model agreement for non-commercial research]	V1	26 February 2020
Copies of advertisement materials for research participants [Project leaflet]	V1	31 October 2019
Copies of advertisement materials for research participants [Project poster]	V1	01 November 2019
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance certificate]		25 July 2019
Interview schedules or topic guides for participants [Topic guide for family]	V1	31 October 2019
Interview schedules or topic guides for participants [Topic guide for healthcare and cancer support professionals]	V1	31 October 2019
Interview schedules or topic guides for participants [Topic guide for patients]	V1	31 October 2019
IRAS Application Form [IRAS_Form_26022020]		26 February 2020
Letter from funder [Letter from funder]		02 June 2017
Letters of invitation to participant [Phase 1 invitation letter for family]	V1	31 October 2019
Letters of invitation to participant [Phase 1 invitation letter for healthcare professionals]	V1	31 October 2019
Letters of invitation to participant [Phase 1 invitation letter for patients]	V1	31 October 2019
Letters of invitation to participant [Phase 1 reminder letter for family]	V1	31 October 2019
Letters of invitation to participant [Phase 1 reminder letter for patients]	V1	31 October 2019
Letters of invitation to participant [Phase 2 invitation letter for new healthcare and cancer support professionals]	V1	01 November 2019
Letters of invitation to participant [Phase 2 invitation letter for healthcare and cancer support professionals from phase 1]	V1	01 November 2019
Letters of invitation to participant [Phase 2 invitation letter for new patients and family]	V1	31 October 2019
Letters of invitation to participant [Phase 2 invitation letter for patients and family from phase 1]	V1	31 October 2019
Letters of invitation to participant [Phase 1 invitation letter for cancer support professionals]	V1	31 October 2019
Non-validated questionnaire [Demographics for cancer support professionals]	V1	30 October 2019
Non-validated questionnaire [Demographics for family]	V1	30 October 2019
Non-validated questionnaire [Demographics for healthcare professionals]	V1	30 October 2019
Non-validated questionnaire [Demographics for patients]	V1	30 October 2019
Non-validated questionnaire [Medical record for patients]	V2	08 January 2020
Organisation Information Document [Organisation information document]	V1	29 October 2019
Other [Applicant response to conditions of favourable opinion]		21 April 2020
Other [Applicant response to additional conditions of favourable opinion]		24 April 2020
Other [Post interview sheet family]	1	30 October 2019
Other [Post interview sheet patient]	1	30 October 2019
Other [Post workshop sheet family/patients]	1	30 October 2019



Participant consent form [Phase 2 consent for non-patients]	V3	21 April 2020
Participant consent form [Phase 2 consent for patients]	V3	21 April 2020
Participant consent form [Phase 1 audio consent for non-patients]	V3	21 April 2020
Participant consent form [Phase 1 audio consent for patients]	V3	21 April 2020
Participant consent form [Phase 1 consent for non-patients]	V3	21 April 2020
Participant consent form [Phase 1 consent for patients]	V3	21 April 2020
Participant information sheet (PIS) [Phase 1 information sheet for family]	V4	24 April 2020
Participant information sheet (PIS) [Phase 2 information sheet for family]	V4	24 April 2020
Participant information sheet (PIS) [Phase 1 information sheet for cancer support professionals]	V3	21 April 2020
Participant information sheet (PIS) [Phase 1 information sheet for healthcare professionals]	V3	21 April 2020
Participant information sheet (PIS) [Phase 1 information sheet for patients]	V3	21 April 2020
Participant information sheet (PIS) [Phase 2 information sheet for cancer support professionals]	V3	21 April 2020
Participant information sheet (PIS) [Phase 2 information sheet for healthcare professionals]	V3	21 April 2020
Participant information sheet (PIS) [Phase 2 information sheet for patients]	V3	21 April 2020
Research protocol or project proposal [Research protocol]	V2	06 January 2020
Schedule of Events or SoECAT [SoECAT]	V1	29 October 2019
Summary CV for Chief Investigator (CI) [Summary CV for CI]		17 December 2019
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Research Activity Flowchart]	V1	31 October 2019



IRAS project ID	269814

Information to support study set up

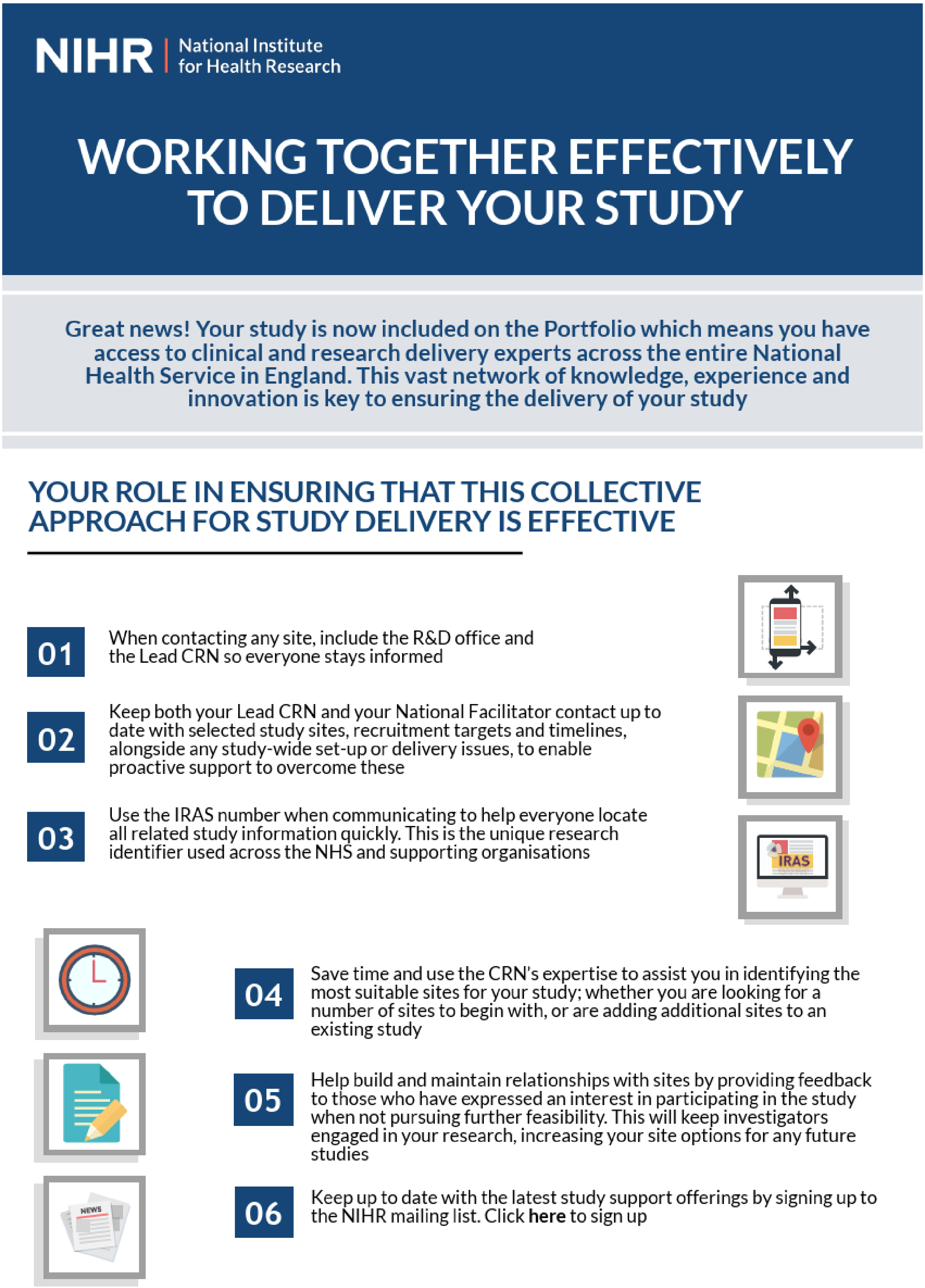
The below provides all parties with information to support the arranging and confirming of capacity and capability with participating NHS organisations in England and Wales. This is intended to be an accurate reflection of the study at the time of issue of this letter.

Types of participating NHS organisation	**Expectations related to confirmation of capacity and capability**	**Agreement to be used**	**Funding arrangements**	**Oversight expectations**	**HR Good Practice Resource Pack expectations**
There is one site type for this study	Research activities should not commence at participating NHS organisations in England or Wales prior to their formal confirmation of capacity and capability to deliver the study.	The sponsor has supplied the appropriate current unmodified model agreement, and intends to use this with participating NHS organisations. HRA and HCRW Approval is conditional on this unmodified agreement being used with participating NHS organisations	Funding to participating NHS organisations as described in Q12 of the Organisation Information document. Please note that the SoECAT submitted for this study has not been authorised by an AcoRD Expert. HRA or HCRW sign off is for versioning only. This sign off does not constitute authorisation of the content of the SoECAT or confirmation that the cost attribution is appropriate.	A local Principal Investigator is required at site	Where arrangements are not already in place, research staff not employed by the NHS host organisation undertaking any of the research activities listed in the research application would be expected to obtain a Letter of Access based on standard DBS checks and occupational health clearance

Other information to aid study set-up and delivery

This details any other information that may be helpful to sponsors and participating NHS organisations in England and Wales in study set-up.
The applicant has indicated that they intend to apply for inclusion on the NIHR CRN Portfolio

NIHR portfolio certificate (CPMS ID: 44917):



NIHR | National Institute for Health Research

WORKING TOGETHER EFFECTIVELY TO DELIVER YOUR STUDY

Great news! Your study is now included on the Portfolio which means you have access to clinical and research delivery experts across the entire National Health Service in England. This vast network of knowledge, experience and innovation is key to ensuring the delivery of your study

YOUR ROLE IN ENSURING THAT THIS COLLECTIVE APPROACH FOR STUDY DELIVERY IS EFFECTIVE

01 When contacting any site, include the R&D office and the Lead CRN so everyone stays informed

02 Keep both your Lead CRN and your National Facilitator contact up to date with selected study sites, recruitment targets and timelines, alongside any study-wide set-up or delivery issues, to enable proactive support to overcome these

03 Use the IRAS number when communicating to help everyone locate all related study information quickly. This is the unique research identifier used across the NHS and supporting organisations

04 Save time and use the CRN's expertise to assist you in identifying the most suitable sites for your study; whether you are looking for a number of sites to begin with, or are adding additional sites to an existing study

05 Help build and maintain relationships with sites by providing feedback to those who have expressed an interest in participating in the study when not pursuing further feasibility. This will keep investigators engaged in your research, increasing your site options for any future studies

06 Keep up to date with the latest study support offerings by signing up to the NIHR mailing list. Click **here** to sign up

Appendix D: Study documents

Please note that there were multiple versions of each study document with tweaked wording for applicability to each interview set. Provided here are examples of the invitation letter, participant information sheet, consent form, demographics form, and post-interview sheet for people with LGG, in addition to the topic guide for all three interview sets.

Invitation letter for NHS recruitment of people with LGG:

Edinburgh Cancer Centre
Western General Hospital
Edinburgh
EH4 2XU
XX Date XX

Delete before sending: Note that wording of this letter can be tweaked as appropriate for your site's recruitment approach.

Dear [Name]

I am writing to invite you to take part in a research study called *Ways Ahead: Improving Support for People with Brain Tumours*. The study is being led by researchers from Newcastle University. It aims to develop a new programme to help people living with a brain tumour manage their health and wellbeing.

The research team would like to talk to you about your experiences of living with a brain tumour and your thoughts about what might help someone living with a brain tumour. The enclosed information booklet describes the research and what is involved in taking part.

If you would like to know more about the research, or might be interested in taking part, you can let me, or someone else in the clinic team, know or contact the research team directly (by calling Ben Rimmer on 07704 300 509, or emailing waysahead@newcastle.ac.uk).

This research will only be successful if people like you tell the research team about your experiences. We very much hope that you will be interested in taking part in this important study.

Yours sincerely

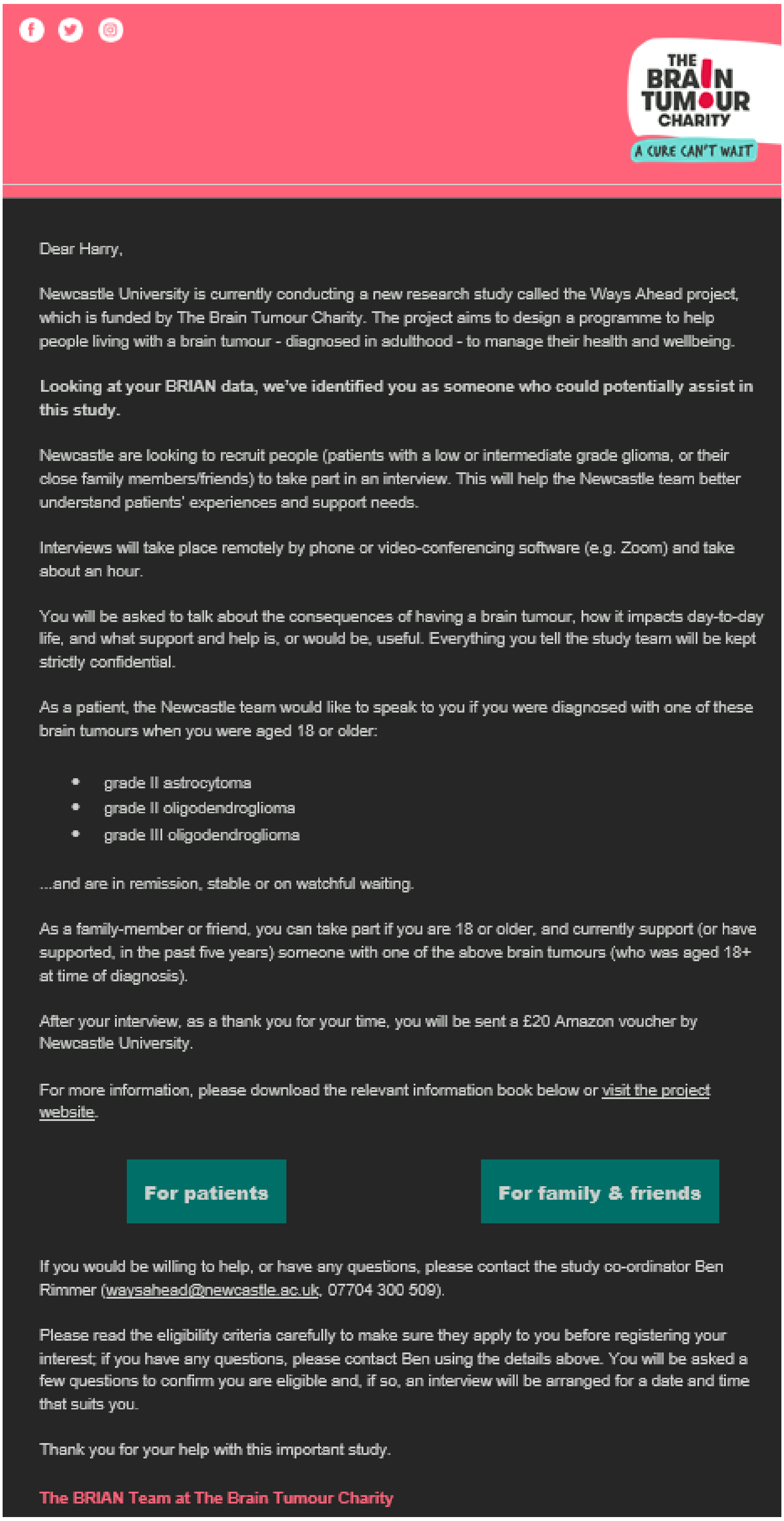
XXXX Clinician's name XXXXXX
XXXX Clinician's job title XXXXX
XXXX Name of NHS site XXXXX

Need a large print or audio version?

☎ 07704 300 509

@ waysahead@newcastle.ac.uk

Invitation letter for charity recruitment of people with LGG:



Dear Harry,

Newcastle University is currently conducting a new research study called the Ways Ahead project, which is funded by The Brain Tumour Charity. The project aims to design a programme to help people living with a brain tumour - diagnosed in adulthood - to manage their health and wellbeing.

Looking at your BRIAN data, we've identified you as someone who could potentially assist in this study.

Newcastle are looking to recruit people (patients with a low or intermediate grade glioma, or their close family members/friends) to take part in an interview. This will help the Newcastle team better understand patients' experiences and support needs.

Interviews will take place remotely by phone or video-conferencing software (e.g. Zoom) and take about an hour.

You will be asked to talk about the consequences of having a brain tumour, how it impacts day-to-day life, and what support and help is, or would be, useful. Everything you tell the study team will be kept strictly confidential.

As a patient, the Newcastle team would like to speak to you if you were diagnosed with one of these brain tumours when you were aged 18 or older:

- grade II astrocytoma
- grade II oligodendroglioma
- grade III oligodendroglioma

...and are in remission, stable or on watchful waiting.

As a family-member or friend, you can take part if you are 18 or older, and currently support (or have supported, in the past five years) someone with one of the above brain tumours (who was aged 18+ at time of diagnosis).

After your interview, as a thank you for your time, you will be sent a £20 Amazon voucher by Newcastle University.

For more information, please download the relevant information book below or visit the project website.

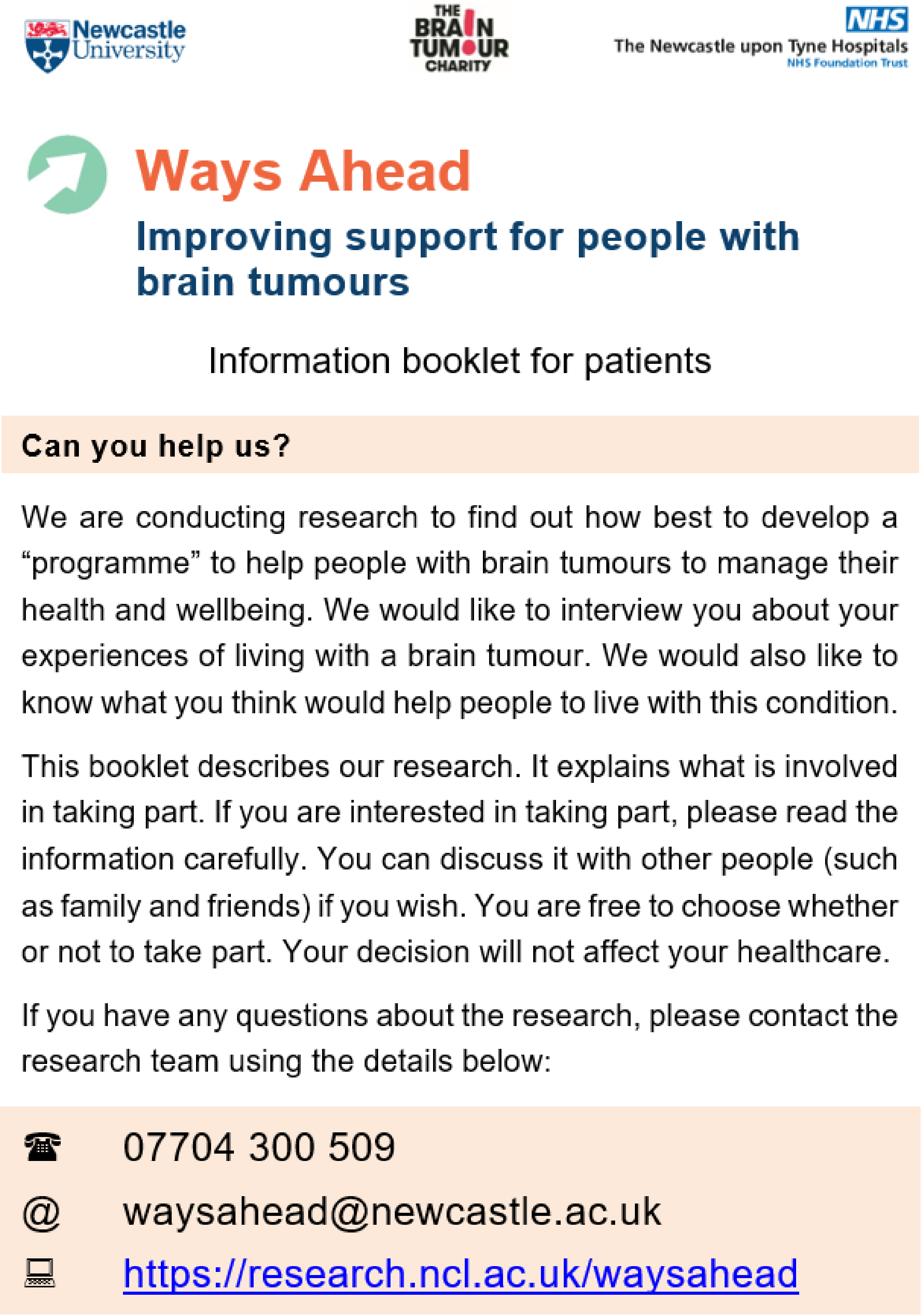
If you would be willing to help, or have any questions, please contact the study co-ordinator Ben Rimmer (waysahead@newcastle.ac.uk, 07704 300 509).

Please read the eligibility criteria carefully to make sure they apply to you before registering your interest; if you have any questions, please contact Ben using the details above. You will be asked a few questions to confirm you are eligible and, if so, an interview will be arranged for a date and time that suits you.

Thank you for your help with this important study.

The BRIAN Team at The Brain Tumour Charity

Participant information sheet for people with LGG:



Newcastle University

THE BRAIN TUMOUR CHARITY

NHS
The Newcastle upon Tyne Hospitals
NHS Foundation Trust

Ways Ahead

Improving support for people with brain tumours

Information booklet for patients

Can you help us?

We are conducting research to find out how best to develop a “programme” to help people with brain tumours to manage their health and wellbeing. We would like to interview you about your experiences of living with a brain tumour. We would also like to know what you think would help people to live with this condition.

This booklet describes our research. It explains what is involved in taking part. If you are interested in taking part, please read the information carefully. You can discuss it with other people (such as family and friends) if you wish. You are free to choose whether or not to take part. Your decision will not affect your healthcare.

If you have any questions about the research, please contact the research team using the details below:

☎ 07704 300 509
@ waysahead@newcastle.ac.uk
💻 https://research.ncl.ac.uk/waysahead

What is this research about?

The aim of this research is to design a “self-management programme” to support people with brain tumours. Self-management programmes can help people to cope with the challenges of living with a long-term condition. They have been found to improve the quality of life of people living with other types of cancer and other illnesses. We want to develop a new programme that meets the needs of people living with brain tumours.

To do this, we plan to interview people with a brain tumour to find out about their experiences and support needs. We also plan to interview people who support an individual with a brain tumour, for instance spouses, family members or close friends. Finally, we plan to interview healthcare professionals (e.g. oncologists and psychologists) and cancer support professionals (e.g. counsellors and benefits advisors) to get their perspectives on what would help people with brain tumours.

Who is conducting the research?

Researchers at Newcastle University are conducting the research. Ben Rimmer and Lizzie Dutton are co-ordinating the research and undertaking the interviews. The research team is led by Professor Linda Sharp.

Ben Rimmer

Lizzie Dutton

Why am I being asked to take part?

We are asking you to take part in this study because you have been diagnosed and completed primary treatment for a grade II astrocytoma, or a grade II or III oligodendroglioma.

For this research to be successful and produce reliable results, we need as many different people as possible to agree to take part. Therefore, we would greatly appreciate your participation. This study has two Phases. You can take part in either Phase one or Phase two, or both Phases.

What does taking part involve?

If you decide to take part in this research, a researcher will arrange an interview with you at a time and place that is convenient for you. This could be:

- through Zoom or a similar video chat service
- by phone
- at your home (dependent on Covid restrictions)
- at a local meeting place (dependent on Covid restrictions)

The interview is expected to last around 60-90 minutes. The length of the interview can be adjusted to suit your availability or if you are worried that it will be too tiring.

If speech or language difficulties would make an interview difficult, please let us know. We will do our best to find another way to include you in this research.

Before the interview starts you will be asked to read and sign a consent form; this is to indicate that you agree to take part. You will then be asked a few questions about your personal details and circumstances.

In the interview, the researcher will ask you questions about:

- your experiences of living with a brain tumour
- the impact of the condition on your daily life, including work, relationships and finances.
- the ways in which you manage your health and wellbeing
- the things you think would help other people with a brain tumour manage their health and wellbeing

Examples of the types of questions we might ask include:

- "Have you experienced changes in your physical health?"
- "Can you tell me about your relationships since being diagnosed with a brain tumour?"
- "What do you think have been the biggest challenges you have faced since your treatment ended?"

There are no right or wrong answers to the questions – we just want to know your views and experiences. You won't be expected to answer the questions if you feel uncomfortable doing so.

If you have any travel or other costs (e.g. childcare) associated with being interviewed, please let us know in advance so that we can arrange reimbursement.

Will the research benefit me?

It is unlikely that taking part will benefit you directly. However, it will give you the opportunity to talk about your experiences with an interested, non-judgmental listener who is not involved in your medical care. You will also have the satisfaction of knowing that you are contributing to research which could help people with brain tumours in the future.

As a thank you for your time, we will also give you a £20 Amazon voucher at the interview.

Are there any disadvantages or risks?

Some people may find it upsetting to talk about their experiences. The interview may bring up difficult or distressing thoughts or memories. You will not be expected to talk about anything you are not comfortable with. You can take a break or stop entirely at any point during the interview. If you want to talk to someone after the interview, contact details of helpful organisations will be provided at the end of the interview.

How will my information be collected and used?

The researcher will ask for your agreement to audio record the interview; if you don't agree they will take written notes instead. The audio recording will be transcribed (typed out word for word). Your name and any identifiable personal details will then be removed so that you cannot be identified. The details of any other people you mention in the interview will also be removed. This anonymous, typed copy of the interview will be used by the research team in their analysis. Your comments may be used in research reports and publications, but your personal details will not be included.

We will also ask for your consent to access your medical records so that we can find out about your brain tumour and the treatments you have had. Any details obtained from your medical records will be held securely and kept confidential.

The researcher will ask you for your contact details. These will only be used to contact you about this research project (e.g. to let you know about the results of the research). We may ask to contact you about the next stages of the research, when we will be designing the programme. You can choose not to be contacted. Even if you are happy to be contacted this does not mean that you have to participate in later stages of the research.

What will happen to my data?

Your data will be kept safe and secure and treated with strict confidence. Your identifiable data will be stored in a safe place on a secure computer database provided by the Newcastle-upon-Tyne NHS Foundation Trust. Any physical copies of your contact details will be stored in a locked cabinet in a secure part of Newcastle University.

The audio files and anonymous transcripts (typed out copies of the interviews) will be stored on secure Newcastle University systems. These will not be stored under your name. The audio files will be destroyed after analysis, and the transcripts will be destroyed after five years.

Your data will be kept in accordance with the General Data Protection Regulation (GDPR). Further details can be found in the privacy notice at the end of this document.

What if I want to stop taking part?

You can decide not to take part at any point, before, during or after the interview. You do not have to give a reason. It will not affect your health care.

If you decide during the interview that you do not want to continue in the study, then you can ask for the audio recording to be deleted. Once the audio-recording has been transcribed it will not be possible to withdraw it from the research.

Who is organising the research?

This research is funded by the Brain Tumour Charity. It is being undertaken by researchers at Newcastle University. The Newcastle upon Tyne Hospitals NHS Foundation Trust is sponsoring this research. Several other hospital trusts will also help us to recruit participants.

All research supported by the NHS is reviewed by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the Wales Research Ethics Committee.

How can I take part?

To take part or to find out more, please contact:

Ben Rimmer on 07704 300 509

email: waysahead@newcastle.ac.uk

We will arrange a suitable time for a telephone conversation. You can then ask any questions you have. We will also ask you a few questions. After this, you can decide whether you want to take part. You can choose not to take part at this point or at any point during the interview.

Concerns or complaints

We do not anticipate any problems arising during this study. However, if you do have a concern or a complaint, please contact Professor Linda Sharp, by email at linda.sharp@newcastle.ac.uk, or by post to: Linda Sharp, Institute of Health and Society, Newcastle University, Sir James Spence Institute, Royal Victoria Infirmary, Queen Victoria Road, Newcastle, NE1 7RU.

If you prefer to raise your concerns with someone not involved in your care, you can contact the Patient Advise and Liaison Service (PALS). This service is confidential and can be contacted on Freephone: 0800 032 0202

Alternatively, if you wish to make a formal complaint you can contact the Patient Relations Department through any of the details below:

Telephone: 0191 223 1382 or 0191 223 1454
Email: patient.relations@nuth.nhs.uk
Address: Patient Relations Department, The Newcastle upon Tyne Hospitals NHS Foundation Trust, The Freeman Hospital, Newcastle upon Tyne, NE7 7DN

Privacy notice

You may have read or heard about the General Data Protection Regulation (GDPR) which came into law in the UK in May 2018. The GDPR aims to protect your personal data and because of this we need to be clear with you about how we will use your personal data, and what your rights are.

Newcastle upon Tyne Hospitals NHS Foundation Trust (NuTH) is the sponsor for this study based in the United Kingdom. We will be using information from you and your medical records in order to undertake this study and will act as the data controller for this study. This means that NuTH are responsible for looking after your information and using it properly. NuTH will keep identifiable information about you for up to five years after the study has finished.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible. You can find out more about how NuTH use your information by contacting the Data Protection Officer for NuTH via email at nuth.dpo@nhs.net.

Newcastle University and your hospital trust will collect information from you and your medical records for this research study in accordance with our instructions.

Newcastle University will keep your name and contact details confidential and will not pass this information to NuTH. Newcastle University will use this information as needed, to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. Certain individuals from NuTH and regulatory organisations may look at your medical and research records to check the accuracy of the research study. NuTH will only receive information without any identifying information. The people who analyse the information will not be able to identify you and will not be able to find out your name or contact details.

NuTH will collect information about you for this research study from your medical records. This information will include your name, contact details, Medical Record Number and health information, which is regarded as a special category of information. We will use this information for the purpose of undertaking the study.

The research team will only retain personal details about you from this study for the purpose of sharing a summary of the study findings. If you do not want a copy of the summary of findings, your personal details will be destroyed once the details of your brain tumour diagnosis and treatment have been abstracted from your medical records.

Audio-consent form for people with LGG:

Study ID Number:

Pa_XX

Ways Ahead

Improving support for people with brain tumours

Consent form for patients

Before recording the consent process, the researcher will read out the following information to the participant:

Before your interview, I will need to ask you some questions and check whether you agree, disagree or have any questions you want to ask about the study. We need to audio record this process, so there is a record that you have been asked if you are happy to take part. The audio recording of your consent will be securely stored by participant ID on the IT systems from Newcastle upon Tyne Hospitals NHS Foundation Trust. This is so the trust can check that consent procedures have been correctly followed. A paper version that I complete will be stored in a paper file held on NHS premises. Both will be kept by Newcastle upon Tyne Hospitals NHS Foundation Trust for five years.

Is it OK to start recording now?

Audio Consent Process

The researcher reads aloud:

I am a researcher from Newcastle University and I am talking to you as you have shown an interest in taking part in the Ways Ahead research study. In this research, we are speaking to brain tumour patients, family and friends, cancer support and healthcare professionals to understand patient experiences, as well as the barriers and facilitators to self-management for people living with a brain tumour.

I will now read through the consent document questions. Please state 'yes' or 'no' to confirm whether you have understood. If you are happy to move to the next step, you should initial next to each question. If our interview is over the phone or a video call, I will initial on your behalf.

Question	**Initials**
Do you confirm that you have read and understood the information sheet (Version 5, dated 19.02.2021) for the study and have had the opportunity to consider the information, ask questions, and have had these questions answered satisfactorily?[1]	
Do you understand that your participation in this research study is voluntary and that you are free to withdraw at any time, without giving a reason?	
Do you understand that if you withdraw from the study, it will not affect your medical care or legal rights?	

Question	**Initials**
Do you understand that the interview will be audio-recorded and typed out, and that any personal details (e.g. your name) will be removed so you cannot be identified? If you do not wish to be audio-recorded, then leave this blank and the interviewer will take written notes instead.	
Do you understand that direct quotations may be taken from what you say during the interview and used in research and publications, but that you will not be identifiable from these quotations?	
Do you understand that anonymous information collected about you, and that you provide, could be shared with other researchers (including students), but that you will not be identifiable in any data that is shared?	
Do you understand that the researchers may need to ask the team in charge of your brain tumour treatment to clarify details about the type of cancer you have had and your treatment?	
Do you understand that if you withdraw during the interview, the partial recording will be discarded, though if you withdraw after the interview has completed, your personal data will be destroyed, but your anonymised interview transcript will be retained?	
Do you understand that in order to ensure good practice in research, data collected during the study may be looked at by individuals from The Newcastle upon Tyne Hospitals NHS Foundation Trust or from regulatory authorities?	
And finally, do you agree to take part in the study?	

This consent serves as documentation that the required elements of informed consent have been presented orally and in written format to the participant. Verbal or written consent to participate in this study has been obtained via the participant's willingness to continue with the interview and by providing agreement to the above questions.

Participant ID:			
Participant's name:			
Participant signature[2]		Date:	
Researcher's name:			
Researchers signature		Date:	

1. *If the person has not read and understood the information sheet, ask them if they have the information and can re-read or if they would like to go through it together. If they would like to read in their own time, arrange to call back and remind them to ask questions if not sure of something.*
2. *Participant signatures will only be possible for in-person interviews.*

Demographics form for people with LGG:

Study ID Number:

Pa_XX

Ways Ahead

Improving support for people with brain tumours

"About You" form for patients

These questions are just to help us know a bit more about the people who take part in our study.

Please leave blank any questions you would rather not answer.

1. What is your age?

☐

2. What is your gender? *(Please tick appropriate box)*

Male ☐ Female ☐ Other ☐ Prefer not to say ☐

3. What is the closest city to where you live?

☐

4. How many years of full-time education have you completed?

☐

5a. Did you do paid work immediately before your diagnosis? *(Please tick appropriate box)*

Yes ☐ No ☐

5b. What is your current employment status? *(Please tick appropriate box)*

Working full-time (30 hours or more per week)	☐
Working part-time (less than 30 hours per week)	☐
Caring for home or family (not seeking paid work)	☐
Unemployed and looking for work	☐
Unable to work due to illness or disability	☐
Student	☐

6. What is your current relationship status? *(Please tick appropriate box)*

Married/cohabiting/legally recognised civil partnership ☐
Divorced/Widowed ☐
In a relationship (but not cohabiting) ☐
Single ☐

7. How many dependents do you have?

Medical record form for people with LGG:

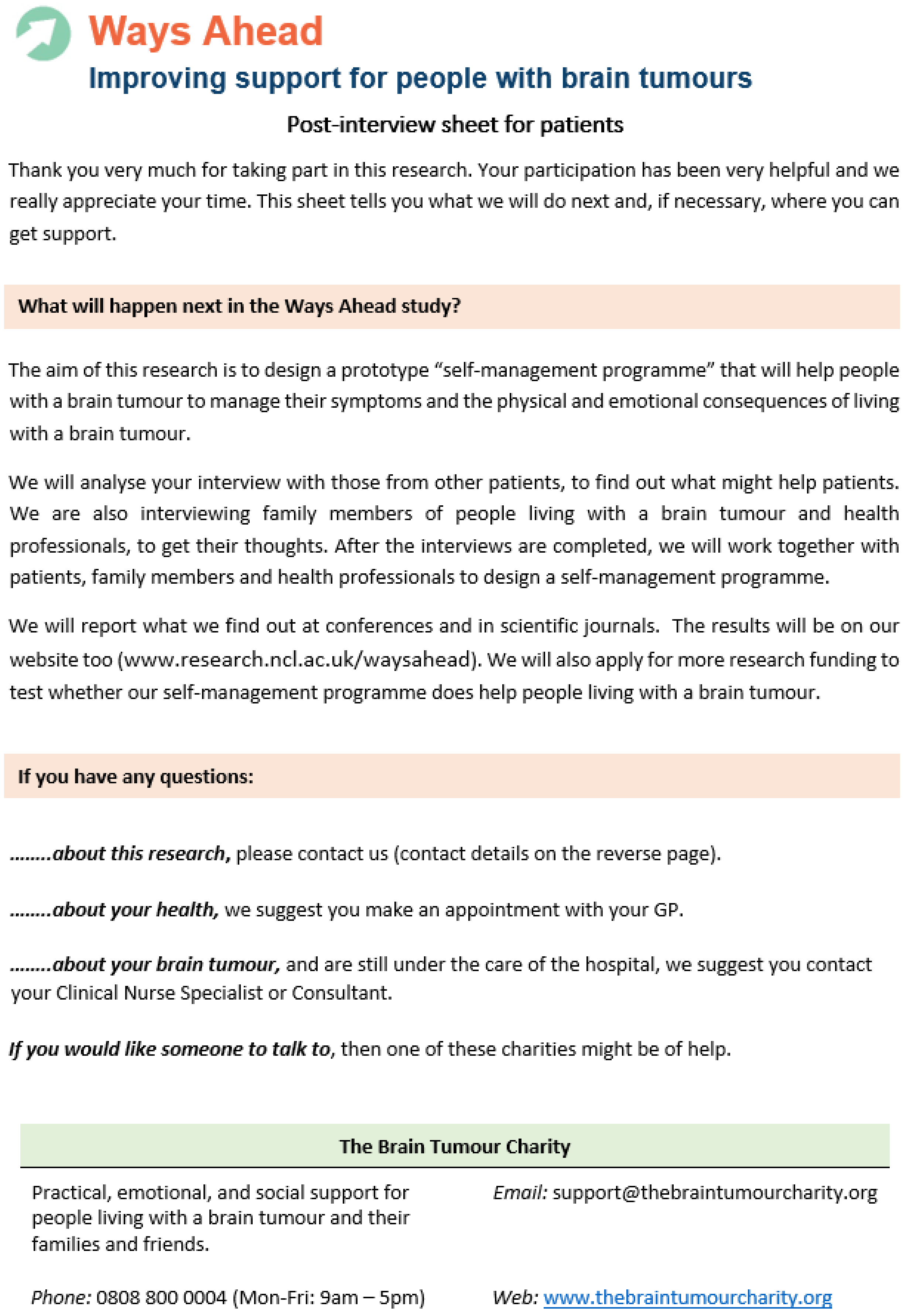
Ways Ahead

Improving support for people with brain tumours

Patient medical record data

NHS site	
Participant number	
Diagnosis	☐ Grade 2 astrocytoma ☐ Grade 2 oligodendroglioma ☐ Grade 3 oligodendroglioma
Deletional status	1P/19q deleted: Yes ☐ No ☐ IDH1 mutation: Yes ☐ No ☐
Predominant site of tumour	☐ Frontal ☐ Occipital ☐ Temporal ☐ Post fossa ☐ Parietal ☐ Overlapping regions
Hemisphere	☐ Right ☐ Left
Dominant/non-dominant	☐ Dominant hemisphere ☐ Non-dominant hemisphere
Month and year of diagnosis	
Surgery	Surgery: Yes ☐ No ☐ Month/year of last surgery: Previous surgery dates:
Treatment	Previous radiotherapy: Yes ☐ No ☐ Month/year of radiotherapy completion: Previous chemotherapy: Yes ☐ No ☐ Month/year of chemotherapy completion:

Post-interview sheet for people with LGG:



Ways Ahead

Improving support for people with brain tumours

Post-interview sheet for patients

Thank you very much for taking part in this research. Your participation has been very helpful and we really appreciate your time. This sheet tells you what we will do next and, if necessary, where you can get support.

What will happen next in the Ways Ahead study?

The aim of this research is to design a prototype "self-management programme" that will help people with a brain tumour to manage their symptoms and the physical and emotional consequences of living with a brain tumour.

We will analyse your interview with those from other patients, to find out what might help patients. We are also interviewing family members of people living with a brain tumour and health professionals, to get their thoughts. After the interviews are completed, we will work together with patients, family members and health professionals to design a self-management programme.

We will report what we find out at conferences and in scientific journals. The results will be on our website too (www.research.ncl.ac.uk/waysahead). We will also apply for more research funding to test whether our self-management programme does help people living with a brain tumour.

If you have any questions:

……..about this research, please contact us (contact details on the reverse page).

……..about your health, we suggest you make an appointment with your GP.

……..about your brain tumour, and are still under the care of the hospital, we suggest you contact your Clinical Nurse Specialist or Consultant.

If you would like someone to talk to, then one of these charities might be of help.

The Brain Tumour Charity	
Practical, emotional, and social support for people living with a brain tumour and their families and friends.	*Email:* support@thebraintumourcharity.org
Phone: 0808 800 0004 (Mon-Fri: 9am – 5pm)	*Web:* www.thebraintumourcharity.org

Maggie's Centres	
Maggie's offers free practical, emotional and social support to people with cancer and their families and friends, through local centres.	*Email:* enquiries@maggiescentres.org
Phone: 0300 123 1801	*Web:* www.maggiescentres.org

Mind Infoline	
Confidential, independent and practical support, advice and signposting around mental health and wellbeing.	*Email:* info@mind.org.uk
Phone: 0300 123 3393 (Mon-Fri: 9am – 6pm)	*Web:* www.mind.org.uk

Samaritans	
Phone and email support for anyone in need of emotional support.	*Email:* jo@samaritans.org
Phone: 116 123 (24 hours a day)	*Web:* www.samaritans.org

Email: Waysahead@newcastle.ac.uk or Call: 07704 300 509 or 0191 208 8306

Website: https://research.ncl.ac.uk/waysahead

Topic guide for people with LGG:

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

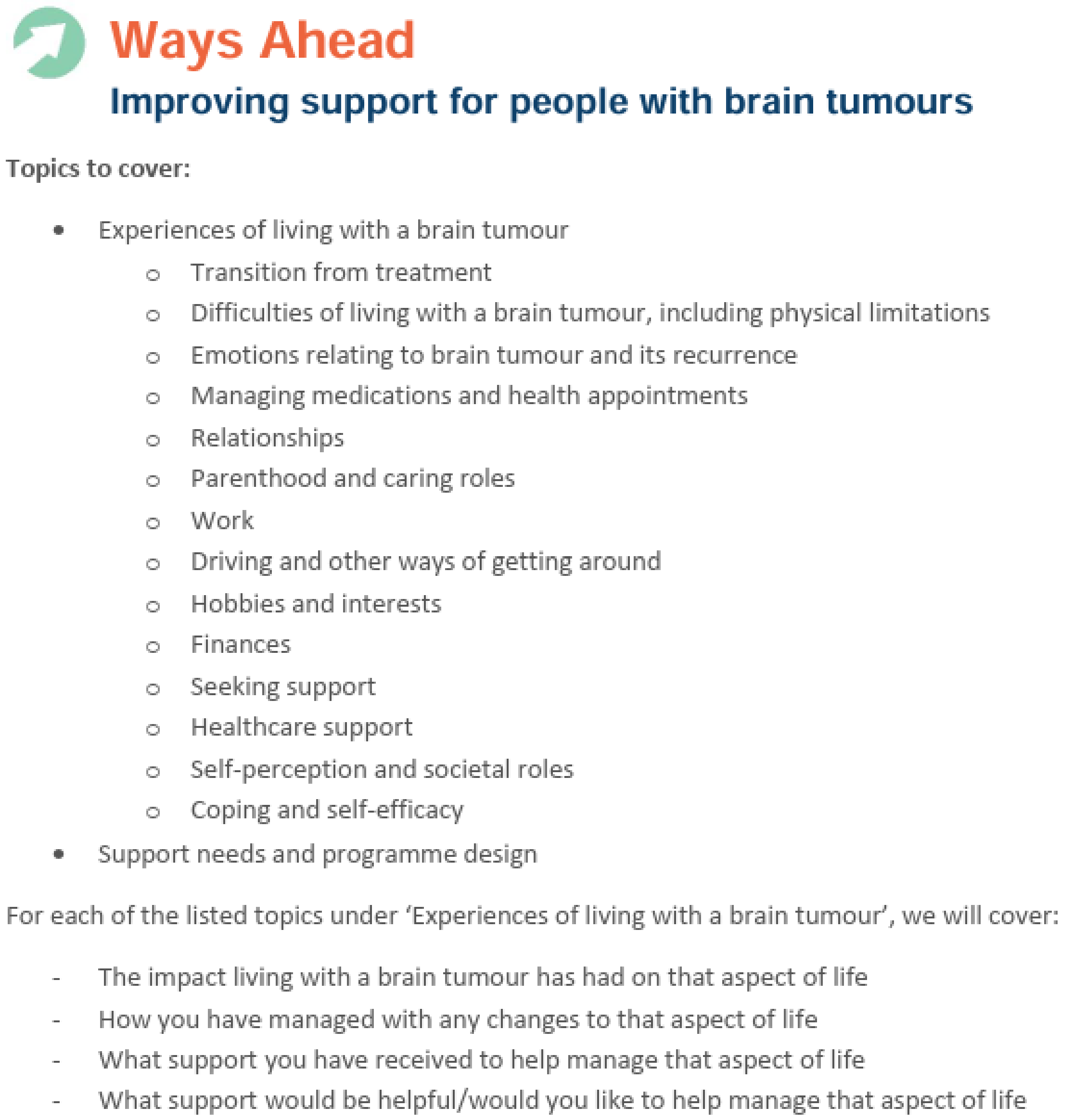
**For each topic, cover the following:*

- 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?

Topic overview offered to people with LGG:



Ways Ahead

Improving support for people with brain tumours

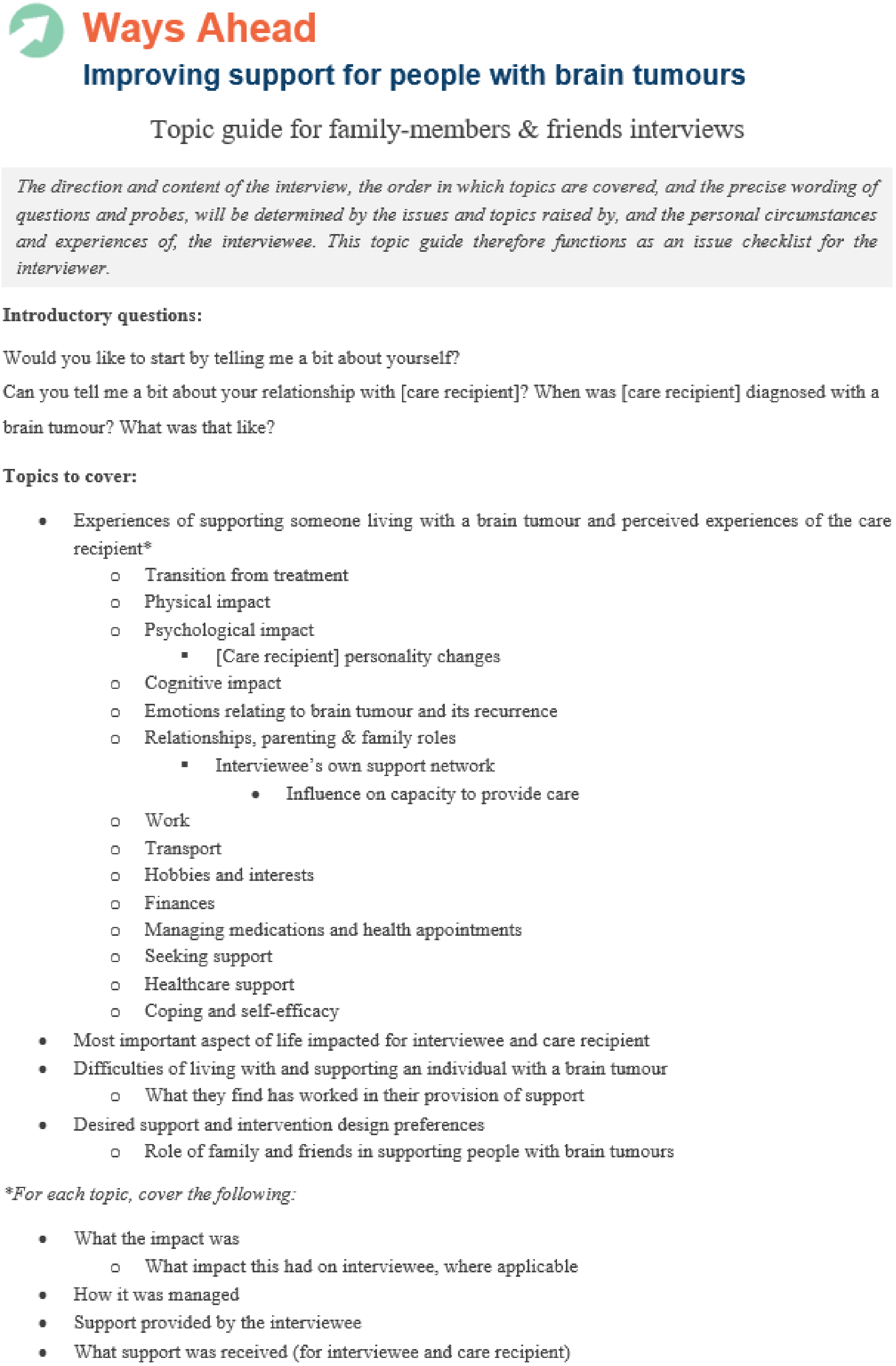
Topics to cover:

- Experiences of living with a brain tumour
    - Transition from treatment
    - Difficulties of living with a brain tumour, including physical limitations
    - Emotions relating to brain tumour and its recurrence
    - Managing medications and health appointments
    - Relationships
    - Parenthood and caring roles
    - Work
    - Driving and other ways of getting around
    - Hobbies and interests
    - Finances
    - Seeking support
    - Healthcare support
    - Self-perception and societal roles
    - Coping and self-efficacy
- Support needs and programme design

For each of the listed topics under ‘Experiences of living with a brain tumour’, we will cover:

- The impact living with a brain tumour has had on that aspect of life
- How you have managed with any changes to that aspect of life
- What support you have received to help manage that aspect of life
- What support would be helpful/would you like to help manage that aspect of life

Topic guide for informal caregivers:



Ways Ahead

Improving support for people with brain tumours

Topic guide for family-members & friends 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?
Can you tell me a bit about your relationship with [care recipient]? When was [care recipient] diagnosed with a brain tumour? What was that like?

Topics to cover:

- Experiences of supporting someone living with a brain tumour and perceived experiences of the care recipient*
    - Transition from treatment
    - Physical impact
    - Psychological impact
        - [Care recipient] personality changes
    - Cognitive impact
    - Emotions relating to brain tumour and its recurrence
    - Relationships, parenting & family roles
        - Interviewee's own support network
            - Influence on capacity to provide care
    - Work
    - Transport
    - Hobbies and interests
    - Finances
    - Managing medications and health appointments
    - Seeking support
    - Healthcare support
    - Coping and self-efficacy
- Most important aspect of life impacted for interviewee and care recipient
- Difficulties of living with and supporting an individual with a brain tumour
    - What they find has worked in their provision of support
- Desired support and intervention design preferences
    - Role of family and friends in supporting people with brain tumours

**For each topic, cover the following:*

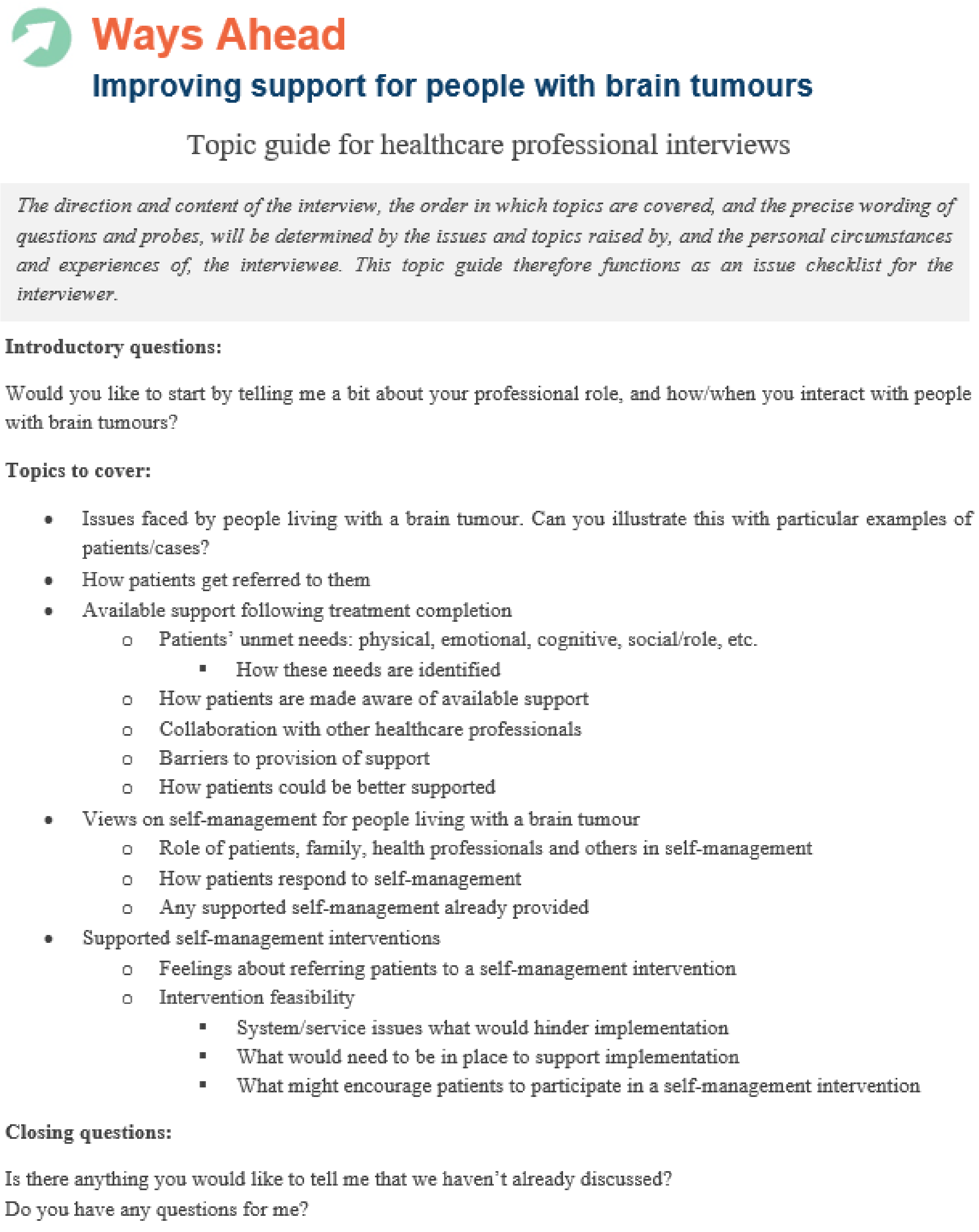
- What the impact was
    - What impact this had on interviewee, where applicable
- How it was managed
- Support provided by the interviewee
- What support was received (for interviewee and care recipient)

- What support was needed (for interviewee and care recipient)
- 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?

Topic guide for healthcare professionals:



Ways Ahead

Improving support for people with brain tumours

Topic guide for healthcare professional 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 your professional role, and how/when you interact with people with brain tumours?

Topics to cover:

- Issues faced by people living with a brain tumour. Can you illustrate this with particular examples of patients/cases?
- How patients get referred to them
- Available support following treatment completion
    - Patients' unmet needs: physical, emotional, cognitive, social/role, etc.
        - How these needs are identified
    - How patients are made aware of available support
    - Collaboration with other healthcare professionals
    - Barriers to provision of support
    - How patients could be better supported
- Views on self-management for people living with a brain tumour
    - Role of patients, family, health professionals and others in self-management
    - How patients respond to self-management
    - Any supported self-management already provided
- Supported self-management interventions
    - Feelings about referring patients to a self-management intervention
    - Intervention feasibility
        - System/service issues what would hinder implementation
        - What would need to be in place to support implementation
        - What might encourage patients to participate in a self-management intervention

Closing questions:

Is there anything you would like to tell me that we haven't already discussed?
Do you have any questions for me?