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Citation for final published version:

Baddeley, Elin, Sivell, Stephanie , Retzer, Ameeta, Nelson, Annmarie , Bulbeck, Helen, Seddon, Kathy, Grant, Robin, Adams, Richard , Watts, Colin, Aiyegbusi, Olalekan Lee, Calvert, Melanie and Byrne, Anthony 2025. Wellbeing and coping: key aspects of unmet need of people living with glioma. *Neuro Oncology Practice* 10.1093/nop/npae127

Publishers page: <http://dx.doi.org/10.1093/nop/npae127>

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# Wellbeing and coping: key aspects of unmet need of people living with glioma

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## **Abstract**

Background: The challenges and needs of people with brain tumours are complex and unique, particularly - but not limited to - the neurocognitive impacts they experience. These effects are subsequently impactful on their primary caregivers. Evidence suggests people with glioma and their caregivers experience a range of unmet needs in the clinical care setting.

Methods: Semi-structured interviews with people across the spectrum of glioma, and their caregivers in the UK, as part of a study exploring core outcomes for use across glioma trials. Interviews were analysed using thematic analysis.

Results: Nineteen people with glioma and seven caregivers interviewed. Three major themes were identified: 1. Wellbeing, support and coping; 2. Communication and care; and 3. Impact on caregivers. People with glioma and their caregivers experience uncertainty, and progressive impacts long after diagnosis. People with glioma across the spectrum of the disease have many challenges in common including long-term adjustments, impacts of glioma and its treatment, and communication/information gaps including prognostic uncertainty. These impacts also affect caregivers. While most patients and caregivers engaged in self-directed approaches to mitigate the impacts of glioma, gaps in follow-up support for lasting effects were a major source of frustration, impacting on ability to cope and manage the effects of glioma.

Conclusions: These interviews highlight unmet needs of people with glioma and their caregivers. A consistent, systematic and focused approach to assessing the needs of glioma patients and their caregivers in the clinical setting and support for long term adjustment is required.

## **Keywords**

Glioma; Qualitative Research; Glioblastoma; Astrocytoma; Oligodendroglioma

**Key Points:**

- Patients (and caregivers) across the spectrum of glioma continue to experience challenges in relation to unmet needs.
- Experiences across the spectrum overlap significantly across wider themes impacting wellbeing and coping among these individuals.

**Importance of the Study:**

This study highlights the overlap in unmet need across the spectrum of glioma, for both patients and caregivers. There is an opportunity to develop a systematized approach to assessment across the spectrum of glioma for use in clinical practice.

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## **Introduction**

Gliomas are a heterogeneous group of cancers with variability in outcomes, and are the commonest form of primary brain tumour, accounting for 80% of malignant brain tumours<sup>1,2</sup>. Symptom burden and care needs for those with glioma are substantial and differ significantly from other cancers particularly due to the neurocognitive impacts these patients experience and the impact on their quality of life<sup>3</sup>. However, evidence on the experiences of those with ‘lower grade’ gliomas is more limited, as is exploration of shared needs across the spectrum of glioma which could underpin consistent approaches to needs assessment in the clinical setting. This is particularly relevant to recent changes to the classification of glioma<sup>4</sup> which recognizes developments in molecular diagnostics, permitting a more nuanced range of disease.

We report on the challenges and unmet needs of people across this wider spectrum of glioma, from the patient and caregiver perspective. This qualitative sub-study is a component of the *Patient reported Core Outcomes in Brain tumour trials* (COBra) study to develop a core outcome set for glioma interventional trials<sup>5</sup>. The qualitative sub-study focused on patients’ experiences, from the perspective of those with glioma and their caregivers. Interviews explored what outcomes matter most to patients when thinking about their treatment and priorities for care. In addition to this, our findings provided rich insight into the clinical experience and needs of patients and their caregivers beyond that of the scope of the core outcome set study. This allowed the capture of important concepts to patients and caregivers relevant to the clinical context, highlighting similarities and differences in experiences and priorities, leading to the sub-analysis of these data reported here. This qualitative study adds to the evidence base by capturing perspectives:

- across the spectrum of glioma
- from a variety of time since diagnosis
- across a wide prognostic range

We have captured nuances around individuals' experiences in relation to their life circumstances, age, impact to activities of daily living, symptom burden and tolerability.

## **Methods**

The full methods for the COBra study are published elsewhere<sup>6</sup> and in accordance with the consolidated criteria for reporting qualitative research (COREQ) guidelines<sup>7</sup>.

### **Participants/Sample**

UK adults (aged 18 or above) with primary glioma and their caregivers, were eligible to participate in the qualitative study. Caregivers who participated were interviewed as a patient-caregiver dyad, identified to take part by the patient. Caregivers are defined as informal carers, who could be a family member or friend and would be able to estimate patients' priorities. Participants were recruited across the spectrum of glioma, including astrocytoma, oligodendroglioma, glioblastoma, anaplastic astrocytoma, anaplastic oligodendroglioma, and pleomorphic xanthoastrocytoma (Table 1).

### **Recruitment and consent**

Participants were recruited via *Brainstrust*, *The Brain Tumour Charity* and social media (Twitter, Facebook) across the UK. Open invitations were sent, detailing contact information for the researcher. If a participant contacted the researcher, a study information sheet was provided. Participants interested in participating then arranged a date and time to undertake an interview with the researcher. Recruitment and data saturation were assessed regularly, including discussion with the qualitative researchers and the wider study team as well as pre-defined anticipated recruitment estimates of between 12-20 participants, based on existing qualitative evidence in relation to the brain tumour population<sup>6,8</sup>. The researcher reiterated to participants they were free to withdraw at any time. Participants provided consent via electronic written consent, or verbal consent. Processes were in place to discuss with the Chief Investigator, a senior clinician, in the event of capacity concerns.

### Data collection

A semi-structured interview guide was used to explore patient and caregiver experiences of living with glioma, comprising open-ended questions on diagnosis, symptoms, treatment/treatment side effects, and overall experiences of care to best explore what is most important to patients and caregivers. This allowed for spontaneous exploration of novel topics of importance. The interview guide was reviewed and adapted iteratively as interviews were conducted with the qualitative study team, including patient and public partners (HB, KS).

Interviews took place over a video platform (Zoom/Microsoft Teams), or telephone. In the case of patient-caregiver dyad interviews, efforts were made to ensure both participants were able to express their individual views. Patients interviewed alone were invited to talk about impacts on those around them. Interviews were audio recorded on an encrypted device, transcribed verbatim, and anonymised by the researcher (EB).

### Data Analysis

Interviews were thematically analysed<sup>9</sup> using QSR NVivo 12<sup>10</sup>, allowing for the identification of patterns and themes within the data and to describe the data in rich detail. Analysis of the initial three transcripts were conducted independently by two members of the research team experienced in qualitative research (EB, SS), who familiarised themselves with the transcripts. Initial codes were generated and discussed with the wider qualitative research team (EB, SS, AN, AB, AR) and initial themes discussed. The initial codes were reviewed and discussed with patient and public contributors on the qualitative research team (KS, HB). Themes and codes emerging from these data underwent iterations as more interviews were coded. Themes were reviewed and refined by the researcher (EB) and discussions with the wider qualitative research team. The research team comprised of clinicians, experienced qualitative researchers and patient and public contributors.



### Public involvement

Two public contributors (HB, KS) were involved in research proposal development. During the study, both contributed to patient facing information, recruitment discussions, views on the analytical framework of the interviews and dissemination of findings. Public involvement was tracked using the Public Involvement in Research Impact Toolkit (PIRIT), a publicly launched toolkit to plan and track patient and public involvement in research studies<sup>11</sup>.

### Ethical considerations

The study was approved by Cardiff University Research Ethics Committee on 8<sup>th</sup> July 2021 (Ref. SMREC 21/59).

## **Results**

At total of 19 interviews (7 patient-caregiver dyads) between 10<sup>th</sup> August 2021 to 29<sup>th</sup> October 2021.

Interviews lasted between 33 minutes and 1 hour 29 minutes. Participants reported having been diagnosed from 1 month-14 years (mean: 4.8 years) at time of interview. Patient participants were aged between 27-66 (mean: 46), 63% (12/19) were Male, and 89% (17/19) of patients interviewed were White British (Table 2).

Three themes were identified relating to: wellbeing, support and coping; communication and care; impacts on caregivers. Tables 3 and 4 provides the key themes/sub-themes and more detailed exemplar quotations.

## Theme 1: Wellbeing, support and coping

Within neurocognitive function, impacts on memory and speech/language were prevalent across the spectrum, although impacts to neurocognitive function were reported more often by those with higher grades overall. Participants with high grade gliomas more often reported challenges with managing physical function such as impacts on mobility and weakness in limbs/hemiparesis. They found this to be a cause of frustration, in particular in relation to role functioning. Higher executive functioning and “emotional disconnect” [caregiver of person with glioblastoma - 02], were notable for a lack of options for support, particularly when comparing this with the support offered for speech and language for example. Although less common in those with lower grade tumours, there were exceptions who experienced more severe neurocognitive impacts.

*“The frontal lobe is... it’s the conductor of the whole brain... it would be awful if he ended up with seizures or couldn’t swallow... but in some ways, this part of the brain is, you know, is just so sensitive and, you know, so, much of what makes you what you are.” [Caregiver 11 – person with oligodendroglioma]*

Fatigue and seizure activity were commonly reported across all grades of glioma. Fatigue was found to have significant impacts for many patients interviewed, long after diagnosis and treatment. There was limited expectation of the impact fatigue had on patients.

*“I think you don’t realise how much it’s going to hit you until it hits you, is the fatigue.” [Patient 17 – oligodendroglioma]*

Seizure activity was usually reported as being under control or eradicated entirely after initial diagnosis and treatment. However, participants reported a lingering frustration with the risk of seizure and subsequent impacts this risk had on returning to normal activities, such as being able to drive. Headaches and pain were also an issue for some participants. While these symptoms were not reported by many, the

effects of them were described as debilitating to their wellbeing. This was mainly prevalent among those with higher grade gliomas.

*“It’s the headaches that, specifically that I’m referring to, because, the pain... the headache becomes all encompassing... it’s very difficult to put up with.” [Patient 14 – glioblastoma]*

The symptoms described by patients across the spectrum of glioma resulted in significant challenges to role functioning; specific examples included driving, ability to work, hobbies/physical activities and day-to-day tasks. The impact on driving was almost unanimously described across the spectrum of glioma, the result of which had wide reaching effects. These effects ranged from challenges getting to appointments, going back to work, and having a sense of independence, greatly impacting their ability to manage and cope with the effects of glioma.

Personal goals in relation to role functioning and activities of daily living were varied and had commonalities across the spectrum, usually mentioned by those with higher grade or lower grades with more significant symptom burden. Reaching these goals helped them to manage the effects of glioma and its treatment, and promoted a feeling of accomplishment and return to some normality. This was again common across the spectrum. For example, while challenges to returning to work were prevalent among those with lower grade gliomas, for some with higher grades, they reported similar challenges and desires to return to work.

*“I’m trying to, possibly, go down the line of speaking to, oh, something therapy, I can’t remember... occupational therapists, to try and sort of see whether they can help me find a way back in... even if it is just two or three hours a day... just like, get me, back in there, get me back to, you know, concentrating on sort of like, you know, work flow.” [Patient 14 – glioblastoma]*

Patients described varying and unique impacts to their psychological and emotional wellbeing. A subset of those with lower grade glioma who reported minimal side effects expressed surprise at how well they were feeling. This came with its own challenges, with some expressing guilt at being more well than others, and also highlighted a disconnect with support services. Some patients described the type of support they would prefer was less related to symptoms/function, and more related to how to get back to normal day-to-day life activities, which again was crucial for them to manage their disease.

*“People don’t think I have, you know, that I’m any different, and I don’t have any of the issues, like sometimes when we’ve gone to the, the research groups, cause I was going into work after one, one of the other, people in the group thought that I was the researcher [Laughs]... they had the same diagnosis and the same place... I just think, like, that their body had changed, that they couldn’t, they weren’t mobile.” [Patient 4 – astrocytoma]*

Patients across the spectrum described a loss of confidence and feeling like they were a different person. Some of these impacts stemmed from memory, language and fatigue symptoms. For others, it was the lack of understanding from work colleagues, family and friends about the continuous nature of the disease (no remission), and patients lived with significant uncertainty, constant monitoring and reminders.

*“I’m a different person than I was before and, I can see that, I wouldn’t say they are symptoms as such, but things like confidence is hugely hit... I’m nowhere near as confident as I used to be.” [Patient 16 – oligodendroglioma]*

Patients and caregivers described having to find their own mechanisms to cope to fill in the gaps in support; this disconnect in services was prevalent across the spectrum, however specific support needs tended to diverge across the spectrum, and between each individual. Allied health support (occupational health, speech and language) was reported as invaluable for those who received it. However, longer term supportive care tended to drop off after the initial post-cancer treatment, when many patients still having

lingering brain tumour impacts to contend with. There were also issues with timing of allied health support, which some experienced as delayed. While cancer care and treatment were reported very positively, there was a distinction between the lack of support and follow-up they received in relation to specific brain tumour challenges and effects compared with cancer treatment.

*“The cancer care, that bit of things is fantastic... but the kind of, brain damage bit, just feels like you’re completely on your own, with it. We have asked for a referral to a neuro-psychologist, but there’s one for every 600,000 people in the country... the waiting list is months and months and months, we might get to see them, it might be too late for us...” [Caregiver 2 – person with glioblastoma]*

Some participants suggested the value of having one coordinator to signpost and support practical and symptom concerns. While participants reported the caregivers’ role of practical support as invaluable, caregivers were in the same position of having a lack of information of what support they could ask for. Suggestions of a coordinator with knowledge of all aspects of support was felt to help facilitate coordination of care, and timely support.

*“There could be some sort of coordinator... so some sort of role for someone to have an oversight of somebody’s wellbeing, you know, the medical, the, the physio, because it, and because brain tumours can affect so many different aspects of life...”*  
*[Caregiver 15 – person with anaplastic pilocytic astrocytoma]*

Neurocognitive function, physical function, symptoms, role function and psychological/emotional impacts all contributed to overall wellbeing, highlighting specific areas of unmet need across the spectrum. Patients reported lack of support in areas such as specific neurocognitive impacts and role function, and issues with timely access to allied support services, which once accessed, improved their ability to cope and manage other effects of the disease.

## Theme 2: Communication and care

Experiences of diagnosis were described as being convoluted and lacking in communication for a number of participants across the spectrum of glioma. Experiences ranged from not being told their diagnosis, to a long and stressful lead up to diagnosis. Despite this, once patients were diagnosed, the vast majority reported positive experiences in overall cancer care and treatment; however, these initial experiences still lingered for patients.

*“When I look back at it now, it was, that first week when I was in [hospital] – I think, that, (..) could have been better... they kind of discharged me, without telling me what I had – as we were leaving, my wife read the discharge notes, it was only then that it said the glioma and what it was.” [Patient 4 – astrocytoma]*

Participants across the spectrum also reported prognostic ambiguity and uncertainty, including how they found out certain information later on, such as not being in remission, and the lack of certainty around prognosis. Many still felt they had not been offered, nor had a conversation more generally, about what their tumour meant for them, in particular what would happen to them as their disease progressed. The uncertainty left them with the feeling they were unable to anticipate and prepare for the trajectory of their disease.

*“One of the things that I think has been and was missing, from my diagnosis, was an explanation – as to what exactly was going on, and what it meant. To this day, the only way I ever found that out was by looking it up on the internet... but I kind of expected at some point that one of the doctors may sit down with me... I don’t know, maybe they never would do it.” [Patient 14 – glioblastoma]*

Participants also described the anxiety they felt in the lead up to regular follow-up scans and up until they had the results of the scan (‘scanxiety’). For many with lower grade gliomas, this anxiety had significant impacts, and affected their ability to plan. On the contrary, some patients with higher grade gliomas

found regular scans provided them reassurance; some patients with lower grades reported this also, again highlighting some similarities across the spectrum. The time taken to receive results of a scan and communication of those results were a source of anxiety and emotionally disruptive for many across the spectrum.

*“It kind of plays on your mind, you know, is something happened, is it growing back, so it’s like that, it’s called scan-xiety, so I think we’re all a bit on edge, when I’ve, when I’m awaiting results... it can be 2 to 4 weeks, and I think it’s frustrating... it’s always like, you know, have they discussed it yet, have they forgotten about me, and when am I gonna hear...” [Patient 9 – anaplastic astrocytoma]*

Patients reported gaps in timely communication across their care, which was particularly impactful on support (or lack thereof) that they received (Theme 1). Issues with communication around support options, such as not receiving information until a later point when they could have benefitted from the support earlier, delayed communication and input from allied health support, were challenges described by patients and caregivers; in one case, this led to the patient having to take on the responsibility and arrange for allied health support by communicating to their doctor to arrange this due to previous experience of delayed communication to them in regard to access to the support.

*“The second procedure, um, I actually arranged in advance with my GP to have speech and language therapy sorted... after the first surgery, by the time I went back to work, I’d still hadn’t had my, speech and language therapy assessment - and when they actually rang me, they said let’s book an appointment, and I said I’m in work, I’ve gone back to work.” [Patient 4 – astrocytoma]*

Patients and caregivers described living with significant uncertainty, including delays and lack of communication, which was prevalent across the spectrum. These impacts led to delayed access to support and was impactful on their ability to cope with the effects of glioma. Having a sense of control and

honesty from their clinical team was valued, allowing them to feel more in control and informed, which in turn made coping with other impacts of glioma easier to manage.

### Theme 3: Caregiver impacts

Neurocognitive impacts were the most significant challenge for caregivers, including memory and impacts to higher executive functioning; however mobility, hemiparesis and fatigue were also a concern. Neurocognitive impacts were more prevalent in caregivers of those with higher grade gliomas, and those lower grades with more severe neurocognitive impacts. However, some patients with lower grades described the impacts of short-term memory effect on their loved ones. Caregivers were extremely concerned about further decline in cognitive function, as the effects were psychologically and emotionally impactful on the caregiver and were associated with the loss of their loved one.

*“The timing of the chemotherapy is, so [names patient] was given a choice about when he started it, and he decided to start it sooner rather than later, and I would rather, that, he didn’t, because we weren’t really over the trauma of the initial, operation... it’s very worrying when someone goes into treatment and is worse, in terms of their function, than they were before they started the treatment...” [Caregiver*

*11 – person with oligodendroglioma]*

The physical impacts on caregivers were reported by patients, including impacts such as fatigue and overall health decline. Some patients reported that the caregiver was struggling more than the patient themselves. This was most evident in those with higher grade gliomas and/or more symptomatic lower grades. For caregivers across the spectrum of glioma, the changes to role functioning, from relationships, work and social interactions were a significant element to their experience, with varying degrees across the spectrum, from becoming a ‘full time’ caregiver, to adjustments to their relationship role and work



arrangements and practical support for the patient. Caregivers' needs and wellbeing could be quite different from the patients, with some patients reporting their caregiver coping worse than the patient themselves.

*“My wife, who’s my full time carer, that’s had a real impact... it’s been massively impactful on her, she really struggles at times, she’s very tired, she’s also exhausted, she’s doing 24/7 care... and that has taken a toll on her. Her health is not good... if you know somebody that’s ill, it’s the carer that’s the one that’s struggling.” [Patient 6 – anaplastic oligodendroglioma]*

Impacts on caregivers were nuanced and varied over the course of a patients' disease. Patients were deeply concerned for their loved one's wellbeing. The significant role of the caregiver in the context of glioma suggests addressing caregivers' unmet needs alongside patients will help both to manage the disease and feel supported in this.

## **Discussion**

This study captures the experiences and perspectives of people with glioma across the spectrum, and their caregivers, highlighting commonalities and differences in experiences (Fig. 1). The study reports a range of experiences and perspectives, including comparison with the lesser explored overall experiences of those with lower grade gliomas.

The impact of glioma and its treatment on wellbeing and subsequent ability to manage these effects are a consistent thread, impacting patients and caregivers perceived ability to cope. Unmet needs for patients were nuanced and varied, but evident across the spectrum of glioma. The concept of coping incorporated self-management strategies, timely and accurate information and communication to support preparedness, and addressing caregiver impacts – all of which were considered essential to patients' management of

their disease and contributed to their ability to mitigate and tolerate the effects of glioma and its treatment. The challenges faced by those with higher grade gliomas is well documented<sup>12</sup>. Existing evidence for glioblastoma highlights a range of physical symptoms, including cognitive impairment, fatigue, pain and seizures<sup>13</sup>. Many qualitative studies focus on specific experiences of glioma, including symptoms, self-management, supportive care, or ACP planning<sup>14-16</sup>. A recent paper has also highlighted the importance of addressing subjective wellbeing of patients with glioblastoma through personalised support<sup>17</sup>. However, the patient and caregiver perspective of those with lower grade gliomas are more limited, although there is emerging evidence around patient experiences of returning to work<sup>18-20</sup>, coping, self-management strategies<sup>21-22</sup> and caregiver impacts<sup>23</sup>.

Key areas of unmet need include lack of support in aspects specific to the unique impacts of glioma, particularly neurocognitive impacts but also practical challenges and support. Participants described a range of symptoms; most notably neurocognitive symptoms and fatigue had significant impacts on participants' activities of daily living and overall wellbeing. These symptoms are well described in existing literature, in relation specifically to the unique neurocognitive challenges those with glioma are faced with<sup>24</sup>, and also the multifaceted nature of fatigue<sup>25,26</sup>. Support for neurocognitive symptoms and fatigue is commonly highlighted as key effects requiring specific support<sup>27</sup>. While most patients reported feeling supported during active cancer treatment, in the longer term, support was reported to drop off, despite patients experiencing many progressive brain tumour specific impacts over time, also evidenced in the literature<sup>28</sup>. This had accumulating impacts on their wellbeing, and their ability to manage and cope with their glioma. People with glioma used various methods to manage and cope with their disease, well described in the interviews, particularly around acceptance over time, routines and goal setting and keeping busy; this is also evidenced in the literature<sup>29,30</sup>. However, neurocognitive impacts, specifically impacts to memory and executive functioning, remain particularly difficult to adapt to, with lack of support for these specific effects. Timely support is essential, with challenges around delayed support in many aspects of care; assessment of needs should be an ongoing process, and go beyond that of the initial

cancer treatment/care stages. Specific neurocognitive impacts around memory and executive functioning do not have clear supportive care networks, compared with speech or mobility. Fatigue remains a significant ongoing challenge across the spectrum. This supports existing evidence relating to substantial unmet needs not being address by the current medical system<sup>31</sup>.

Patients and caregivers described many issues around communication, issues of which significantly impacted their overall experience, particularly emotional wellbeing and ability to tolerate and cope with other aspects of their disease. Patients faced a great deal of uncertainty, which was highly impactful on both patients' and caregivers' wellbeing, including prognostication, and how the disease and their symptoms will progress, as seen in other studies of chronic conditions<sup>32</sup>, and the brain tumour population<sup>8, 30, 33</sup>. While a certain level of uncertainty was accepted, delayed and lack of communication resulted in issues with care coordination, from delayed allied health support, delay in signposting to practical support, and resulted in a great deal of anxiety, all of which added to the overall burden of glioma significantly.. Patients and caregivers felt there were specific areas of communication that were missing, and existing literature highlight the importance of communication for glioblastoma patients<sup>34</sup>.

Caregivers were described as a significant support network for patients. Both patient and caregivers' needs were intricately interlinked, and may need to be addressed in conjunction; existing evidence highlights the importance of keeping in mind potential fluctuations in support needs that deviate between patients and caregivers<sup>35</sup>. Support and communication to caregivers is a key area of unmet need. Impacts on caregivers of those with glioma fluctuate with patients' needs, and at times describe needing more support than patients themselves at particular timepoints; this supports existing evidence of caregivers reporting varying concerns, notably around neurocognitive impacts, and support for caring for those with glioma<sup>36-38</sup>. Caregivers of this population are well documented in having significant and unique challenges compared with that of other cancers<sup>39</sup>. These impacts are coupled with a lack of support, particularly practical support and ways to support patients with neurocognitive impacts<sup>40</sup> and remain common issues to date, despite existing research documenting these impacts<sup>41</sup>. Prioritising support and

addressing unmet needs of caregivers will also support addressing patients' concerns; caregivers want to ensure they are supporting their loved ones, and report needing information and support to help them do so<sup>42</sup>. These challenges are seen across the spectrum of glioma, of which the majority of the supporting literature relates to caregivers of patients with higher grade gliomas; however, there are emerging data on the emotional and social support needs of caregivers of people with lower grade glioma<sup>43,44</sup>.

In summary, our main study findings identified a Core Outcome Set for use in glioma trials<sup>5</sup> consisting of seven domains. This paper identifies additional requirements for consideration in clinical settings, across the spectrum of glioma. In particular, consistent and structured clinical assessment of unmet need in the additional areas of:

- Role function and coping
- Psychological and emotional wellbeing
- Communication and information needs
- Management of delayed effects of glioma and its treatment following anticancer treatment.

For the individual clinician, understanding the pervasiveness of living with uncertainty, ambiguity in communication, and challenges to integrated role function as threats to coping with glioma and its treatment, offers opportunities for additional elements of interaction, even in busy clinics. Adapting conversation to acknowledge the challenges of uncertainty, and empowering both patients and caregivers with information to support preparedness for the future legitimizes the importance of wellbeing and coping as part of everybody's business across the multidisciplinary team – not just a subgroup. These concepts of acknowledgement and empowerment resonate strongly with the adaptive coping responses in other literature<sup>45</sup>.

### Strengths and limitations

Our data provided an insight into commonalities in unmet needs based on the lived experience of glioma patients and caregivers across the spectrum of glioma. However, the distinction between challenges faced by those with lower grades and those with higher grades of glioma is not clearly defined; there is significant overlapping of unmet need across the grades, and while some differences were evident, these data suggest there is opportunity to develop a systematized approach to assessment across the glioma spectrum. Qualitative methods allowed us to identify important nuances in patients' unmet needs; some of the longer-term supportive needs may diverge based on symptom burden and progression of the disease, fluctuate over time, with different concerns becoming more or less prominent over the course of their disease. The research team comprised of individuals from a range of disciplines and experiences, including palliative care, neuro-oncology, health psychology, and trialists, with experience in qualitative methods, systematic reviews, core outcome set development, as well as patient and public partners. This has influenced the study overall, and led to the identification of specific interest in understanding the nuances in unmet needs beyond that of the scope of the core outcome set study.

Flexibility in our recruitment strategy allowed us to purposively sample to ensure an even representation of participants across the spectrum of glioma. Our population consisted of a range of ages and gender (slight lean towards male participants; no one interviewed over the age of 65). Some participants were interviewed as a patient-caregiver dyad. While a strength, this potentially could have constrained individuals' perspectives in the dyad dynamic; however the dyad interview was the choice of the patient alone, potentially mitigating constrained views. Recruitment channels and remote interviewing allowed for representation across the UK. However, the recruitment channels for this study may have introduced selection bias as these participants may have different experiences of support compared to those not signed up to charities well known to provide support. The study does rely on self-reported data, which is subject to recall bias. The majority of participants were White British, with some representation from

Asian British population, which may affect generalisability. Restrictions related to data protection meant we were unable to purposively sample on the basis of ethnicity.

## **Conclusions**

Patients and caregivers across the spectrum of glioma continue to face challenges in relation to unmet needs with underlying variations in needs, in part, informed by ability to cope with effects of the glioma and its treatment. Understanding the patient and caregiver experience is integral to truly understanding patient and caregivers' experiences of glioma and identifying unmet needs. These findings highlight the ongoing necessity for a consistent and structured assessment of needs for those with glioma and their caregivers in the clinical context, to address unmet need across the spectrum of glioma. Caregiver needs are just as integral to this, and it is beneficial to address unmet needs as a consistent patient-caregiver unit.

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## **Declarations**

**Acknowledgements** The authors wish to thank the Brain Tumour Charity and Brainstrust for their invaluable support in participant recruitment.

**Authorship** AB, AN, AR, MC, RG, RA, CW, HB, KS, SS were involved in the conception of the study. All authors contributed to protocol development. EB, SS, AN and AB led on data collection and analyses of the qualitative study, HB and KS provided direct insight on data collection and analysis. EB led on writing this manuscript, with oversight of data collection, analysis and writing by SS, AB, and AR. All authors read, reviewed and approved the final manuscript.

**Funding** This work was supported by the Brain Tumour Charity, grant number GN-000704.

### **Conflicts of interest**

EB, SS, AR, RG, CW, KS, HB, AN have no conflicts of interest to disclose.

Melanie Calvert is the Director of Birmingham Health Partners Centre for Regulatory Science and Innovation and Centre for Patient Reported Outcomes Research and a National Institute for Health and Care Research (NIHR) senior investigator; has received funding from Anthony Nolan, European Regional Development Fund-Demand Hub and Health Data Research UK, Gilead, GlaxoSmithKline, Janssen, Macmillan Cancer Support, Merck, NIHR, NIHR ARC WM, NIHR Birmingham BRC, NIHR BTRU Precision and Cellular Therapeutics, UCB Pharma, UKRI, and UK SPINE; and has received consultancy fees from Aparito, Astellas, CIS Oncology, Daiichi Sankyo, Gilead, Glaukos, GlaxoSmithKline, Halfloop, Merck, Patient-Centered Outcomes Research Institute, Pfizer, Takeda, and Vertex Pharmaceuticals Incorporated.

Prof Richard Adams is Director of the Centre for Trials Research Cardiff University. He has received speakers fees and consultancy fees from Servier, Amgen, Bayer, Artios, Takeda, Seagen.

Dr Aiyegbusi receives funding from the National Institute for Health and Care Research (NIHR) Birmingham Biomedical Research Centre (BRC), NIHR Blood and Transplant Research Unit (BTRU) in Precision Transplant and Cellular Therapeutics, NIHR Applied Research Collaboration (ARC) West Midlands, UKRI, LifeArc, Health Foundation, Merck, Gilead, Anthony Nolan, UKRI, Sarcoma UK, and GSK. He declares personal fees from Gilead Sciences Ltd, Merck and GSK outside the submitted work.

**Ethics and Consent** This study is part of an overarching study to develop a Core Outcome Set for glioma interventional trials. The full study was reviewed and approved by the Cardiff University School of Medicine Research Ethics Committee, 8<sup>th</sup> July 2021 (Ref: SMREC 21/59).

**Data Sharing** Data analysis files are available from the corresponding author on reasonable request.

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**Figure legend (Fig. 1):**

Overlapping areas of unmet need between people interviewed with high grade and low grade gliomas.

Areas of unmet need more central to figure represent their presence across the spectrum of glioma.

Areas of unmet need on the periphery indicate more common areas of unmet need more specific to higher grade or lower grade gliomas, based on patients interviewed.

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<b>People with glioma</b>	
<i>Inclusion Criteria</i>	<i>Exclusion Criteria</i>
<ul style="list-style-type: none"> <li>- Adult (aged 18 and above)</li> <li>- Histologically diagnosed with primary glioma (including astrocytoma, oligodendroglioma, oligoastrocytoma, ependymoma, astroblastoma, anaplastic ganglioglioma, glioblastoma, glioblastoma multiforme)</li> </ul>	<ul style="list-style-type: none"> <li>- Unable to consent on their own behalf and undertake a 30-60 minute interview</li> </ul>
<b>Caregivers</b>	
<i>Inclusion Criteria</i>	<i>Exclusion Criteria</i>
<ul style="list-style-type: none"> <li>- Adult (aged 18 and above)</li> <li>- Defined as informal carers, who provides the majority of the support to the patient and is able to estimate the patients' priorities (family member/partner, or friend)</li> </ul>	

Table 1: Inclusion and exclusion criteria

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Demographics	Patients	Caregivers
TOTAL	19	7
Age (mean, range)	46, 27-66	50, 39-60
	N, (%)	N, (%)
Gender		
- Female	7 (37)	5 (71)
- Male	12 (63)	2 (29)
Ethnicity		
- White, British	17 (89)	6 (86)
- Asian/Asian British	2 (11)	0 (0)
- Unclear/did not specify	0 (0)	1 (14)
Diagnosis	2007-2021	-
Time since diagnosis since interview	<1 month – 14 years	-
Glioma type		
- Glioblastoma	6 (32)	3 (44)
- Astrocytoma	4 (21)	1 (14)
- Oligodendroglioma	3 (16)	1 (14)
- Anaplastic astrocytoma	2 (11)	0 (0)
- Anaplastic pilocytic astrocytoma	1 (5)	1 (14)
- Anaplastic oligodendroglioma	1 (5)	0 (0)
- PXA tumour	1 (5)	0 (0)
- Grade 3 glioma	1 (5)	1 (14)
Glioma grade		
- Grade 2	8 (42)	2 (29)
- Grade 3	4 (21)	2 (29)
- Grade 4	7 (37)	3 (42)

Table 2: Patient and caregiver demographics

<i>Themes</i>		
<i>Wellbeing, support and coping</i>	Physical function	Mobility Hemiparesis
	Neurocognitive function	Memory Processing Executive functioning Language/speech
	Role function	Driving Work Social interaction Hobbies Physical activity Daily household activities
	Symptoms	Fatigue Seizure activity Other symptoms
	Psychological/emotional wellbeing	Confidence Loss of independence Worry Guilt
	<i>Communication and care</i>	Diagnosis
Prognosis		Prognostic uncertainty Recurrence, not remission
Follow-up care		Longer term follow up Scan anxiety ('scanxiety') Brain tumour versus cancer care
Supportive care		Access to support (delayed) Lack of specific support
<i>Caregiver impacts</i>	Patients' symptoms	Neurocognitive Fatigue Mobility/hemiparesis
	Role function	Practical management Family/social role Primary caregiver role Driving Relationship dynamics Impact on work
	Psychological/emotional wellbeing	Worry Stress
	Physical impacts	Overall health Fatigue

Table 3: Themes and areas of unmet need

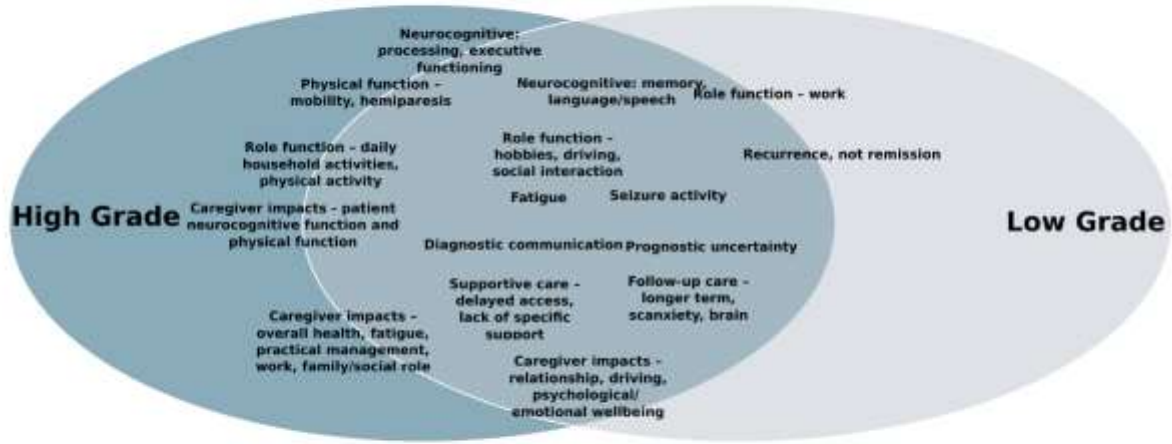
<b>Wellbeing, support and coping</b>	
<i>Themes/sub-themes</i>	<i>Quotes</i>
<b>Neurocognitive impacts</b>	<p><i>"It's massively upsetting... but no amount of trying hard, but you know, according to occupational therapy, those parts of the brain are not going to recover." [COBc02 – caregiver of glioblastoma patient]</i></p> <p><i>"I used to be, I am, well I am, I used to be one of these people, you know, you ask me something I did three years ago on Tuesday, I could probably have told you, and now I can't remember what I did last Tuesday, that really grates on me... I find very, very difficult to deal with. I have to write everything down if I want to remember it." [COBp14 - glioblastoma]</i></p> <p><i>"Having issues sometimes with, with language skills, that's an issue, I've told people in work... is hard when you've got a 7 and an 8 year old, telling you you've made mistakes..." [COBp04 - astrocytoma]</i></p> <p><i>"The bit of the brain that's gone, or impacted on, it's, it's my uh, memory... I have a great deal of difficulty, even remembering what happened, yesterday. I certainly can't remember what happened last week, but my short term memory, um, and my ability to plan, and organise, and, uh, has, has no doubt, my, as [names spouse] will tell you, all my feelings have, uh, disappeared." [COBp11]</i></p> <p><i>"That's very depressing. So, and there seems to be, you know, every day you seem to get worse, you know, the short term memory is terrible..." [COBp05 - astrocytoma]</i></p>
<b>Physical function</b>	<p><i>"So the strength was a little bit reduced but it's more the initiation... when I'm tired, like I just forget that my left hand is there to be used. So, if I've got a knife and fork and I'm tired [I'll be using like my right hand to tear the food off (laughter) with that rather than just, you know, use the left hand as well. And, he prompted, it's fine, like my husband says, like use your left hand, it's fine, I can do that. Um, it's just it's not spontaneous anymore." [COBp17 - oligodendroglioma]</i></p> <p><i>"The right arm still has some weakness and my hand. So, if anything like erm, you know, fine motor skills and things, like doing things with my hand. So, I avoid trying to like, if I ever do shoelaces, I buy them and put the shoes on and off like a lazy person." [COBp18 – anaplastic astrocytoma]</i></p>
<b>Symptoms</b>	<p><i>"If this tumour is going to kill me one day, it's not the end of the world so long as I live the best version of my life now. And I suppose that's why it's so important for me to get the pain sorted out, so I can do that." [COBp18 – anaplastic astrocytoma]</i></p> <p><i>P: "Probably the fatigue is the main effect on me, day to day, so it was really bad, if I were to do, I don't do much, yeah.</i></p> <p><i>C: Like we were away for the weekend for our wedding anniversary, and we went for dinner, and [Names patient] just so fatigued that, he just wasn't really there, he was just completely vague and, almost not capable of having a conversation, and, you know, if then, you've got to do that big adjustment." [COBc02 – caregiver of glioblastoma patient]</i></p> <p><i>"I can't play a lot of sports, I can't do any cycling, anything like that, or I get a seizure. Um, the other, like I said, my memory seems, loss, seems to accelerate. I heard other people say that's cause of the, um, one of the drugs that I have for epilepsy but, I don't know." [COBp05 – astrocytoma]</i></p>
<b>Role function</b>	<p><i>"It does, takes my mind off things, getting into work, you know, do the work, sometimes I do think about it, you know, it's just one of those constant things." [COBp07 – pleomorphic</i></p>

	<p><i>xanthoastrocytoma]</i></p> <p><i>“One of the biggest challenges was (...) kind of the first thing they do is take your driving license away, um, and actually, that’s probably a time when you need it more than ever.” [COBp16 - oligodendroglioma]</i></p>
<b>Psychological/emotional wellbeing</b>	<p><i>“One thing I never do is say ‘my tumour’, it’s the tumour, just because I don’t want it to be a part of me, it is an intruder.” [COBp01 - oligodendroglioma]</i></p> <p><i>“Sometimes I do think about it, you know, it’s just one of those constant things – uh, people say like a ticking time bomb – and yeah, that always goes through my head as well, you know, especially if I get new symptoms, is it changing, is it not, you know, CT scans, the last CT scans, could be related, you know...” [COBp07 – pleomorphic xanthoastrocytoma]</i></p> <p><i>“I know it sounds strange, but I preferred that [surgery] to the other treatment. Because it, I felt I like I recovered from that quicker, if you know what I mean, there’s not so many long term, there are long term effects, but things I can deal with if you know what I mean. So, I had the surgery on the Monday, erm, and then I think, yeah, I went home on the Thursday afternoon.” [COBp18 – anaplastic astrocytoma]</i></p>
<b>Communication and Care</b>	
<i>Themes/sub-themes</i>	<i>Quotes</i>
<b>Diagnosis</b>	<p><i>“That was probably the most awful, when you reflect on it, at the time, you were just in shock, um, (...) I don’t, I went into shock... we tried to, this doctor who came to my bedside... I never traced him, and nobody took responsibility for it. That was probably the worst.” [COBp06 – anaplastic oligodendroglioma]</i></p> <p><i>“you put yourself in the hands, that you trust the people who say this is a grade 4, it’s an urgent operation... and then it turns out it’s not grade 4, and perhaps wasn’t as urgent, and maybe a biopsy would have been better...” [COBc11 – caregiver of oligodendroglioma patient]</i></p>
<b>Prognosis</b>	<p><i>“I think, we do know that the type of tumours grow again – so we had to gear that, I think when we first meeting, I thought that once it’s removed, it’s like any other treatment, where, you know, after 5 years, you would be in remission.” [COBp04 – astrocytoma]</i></p> <p><i>“I mean I’ve looked up, you know, the prognosis, he’s never given me a prognosis, when I first saw him, it could be years, it could be decades, and I think for him to even say that, it’s quite a big deal...” [COBp01 – oligodendroglioma]</i></p>
<b>Follow-up</b>	<p><i>“I think follow-up could be better because it’s either a case that once you’ve gone through your treatment... apart from like the follow-up scans which, you know, you have no contact in between, you’re left to your own devices. I think some kind of follow-up would be nice... I think that kind of, how have you been, have you had any lasting side effects kind of conversation would be nice to be had.” [COBp13 – glioblastoma]</i></p> <p><i>“We won’t know, that anything that we’re doing has worked for another month or two... we wait until all that stuff settles down, so, I do, we just ish that we could fast forward two months...” [COBc08 – caregiver of glioblastoma patient]</i></p> <p><i>“that’s the one thing, knowing that the NHS has stopped my treatment, and I’ve got nothing in the foreseeable at the minute... my concern is, you know, my tumour grew back bigger in that 5 week period that I had no treatment either...” [COBp08 – glioblastoma patient]</i></p> <p><i>“the thing that has given me the most confidence is having regular scans, so then you can see the change over time.” [COBp03 - astrocytoma]</i></p>

<b>Supportive care</b>	<p><i>"I think the second procedure, um, I actually arranged in advance with my GP to have speech and language therapy sorted for the, when I very first started, by the time I'd had, after the first surgery, by the time I went back to work, I'd still hadn't had my, um, speech and language therapy assessment, and when they actually rang me, they said let's book an appointment, and I said I'm in work, I've gone back to work..." [COBp04 - astrocytoma]</i></p> <p><i>"Luckily for us, they came three times a week, an occupational therapist, a speech therapist, um, a physiotherapist, uh, and [Names patient] worked really hard, for, uh, 6 months, 4 to 6 months with them, and uh, and made a, you know, a massive recovery, so we started off with, um, adaptations in the loo, and the shower, seats and, uh, you know, supervision and all the rest of it, um, and then, gradually we moved those things as he got better and better and physically, improved..." [COBc11 – caregiver of oligodendroglioma patient]</i></p>
<b>Impact on caregivers</b>	
<i>Themes/sub-themes</i>	<i>Quotes</i>
<b>Patient symptoms/effects</b>	<i>"... suffers quite badly from fatigue, so we – so we have to plan, if she's got something, for example, going to our daughter's assembly in school, we have to make sure that [names patient] rested beforehand, and she'll feel quite tired afterwards, things like that." [COBc10 – 'glioma grade 3']</i>
<b>Role function</b>	<p><i>"It's been a major difficulty, because [names patient] and I, live, pretty independent lives as man and wife, really, um, and, but obviously, that's had to change, and there's been quite a lot of resentment on both sides." [COBc11 - oligodendroglioma]</i></p> <p><i>"Dramatic effect, and then, as far as the families concerned, um, so I was full time... I've actually stopped completely... the life that I'm having now, is completely different from what it would have been... it's obviously had a serious emotional effect on, on all the family... life is unrecognisable really." [COBc15 – anaplastic pilocytic astrocytoma]</i></p>
<b>Psychological/emotional wellbeing</b>	<p><i>"it's been a big impact with the kids, they've had difficulties, um, with you know, relationships with others." [COBc11 – caregiver of oligodendroglioma patient]</i></p> <p><i>"If you have more uncertainty, because appointments don't arrive, or things get cancelled, or somebody says something and then doesn't follow it up, for me, that's a horrible trigger at the moment, it's just way too much more uncertainty - so, having clinicians who do what they say they're gonna do, when they say they're gonna do it, and give you clear information, is absolutely priceless to us." [COBc02 – caregiver of glioblastoma patient]</i></p>
<b>Physical impacts</b>	<i>"It's just been massively impactful on her, she's, she really struggles at times, she's very tired, she's also exhausted – she's doing 24/7 care... she's just giving me 24/7 – and that has taken a toll on her. Her health is not good. [cobb06 – anaplastic oligodendroglioma]</i>

Table 4: additional quotes

Fig. 1. Overlapping areas of unmet need across the spectrum of glioma



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