RESEARCH ARTICLE

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Supportive follow-up in patients treated with radical intent for high-grade glioma

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Practice Points

- Supportive care pathways for patients and their families differ between hospitals.
- Guidelines either omit important aspects of care and follow-up or are based on assumptions with little empirical support.
- As treatment of these patients is palliative, more efforts are needed to ensure good continuity of care best managed through a well-functioning multidisciplinary team approach.
- Current follow-up is failing to meet the psychological needs of patients and their caregivers.
- There is need for developing innovative and integrated interventions that effectively support caregivers, such as proactive counselling or problem-solving services.

SUMMARY Ongoing supportive follow-up for patients with malignant glioma lacks good evidence to define and guide practice, and certain approaches have previously been criticized. In the UK, it commonly involves routine hospital visits with imaging to monitor treatment effects and detect disease progression. **Aims:** Through use of an observational study evaluate and compare oncologist-led follow-up with a multidisciplinary group follow-up method from the perspective of patients and caregivers. **Materials & methods:** A total of 40 patients, and 32 of their caregivers, were recruited 3 months after completing radical radiotherapy treatment. Face-to-face interviews conducted at home with patients gathered information about access to and experiences of follow-up services. Standardized questionnaires measured patients' quality of life and unmet care needs, and caregivers' psychological wellbeing. Assessment was repeated three times over a 6-month period. **Results:** Inevitable attrition left 26/40 patients and 19/32 caregivers with complete data. Most (65%) patients' quality of life improved or was maintained over the study period. However, psychological support for patients and caregivers was suboptimal, notably 56% of caregivers had probable psychiatric morbidity. Though few significant differences were found between the two follow-up methods, multidisciplinary follow-up provided better continuity of care and more efficient test result provision. **Conclusion:** Innovative interventions are required to ameliorate psychological distress in patients and caregivers.

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High-grade gliomas (HGGs) are rare, accounting for 2% of all adult cancers. Most (80%) are glioblastoma (GBM), which conveys particularly severe morbidity and mortality [1,2]. Adults aged 50–70 years are typically affected, more often men than women (ratio 3:2) [3]. Median survival for GBM is 12–15 months, but for grade 3 gliomas can extend to several years [4,5].

Radical radiotherapy with concomitant and adjuvant temozolomide chemotherapy has become standard treatment for GBM [6], while molecular subtyping of grade 3 gliomas has proven useful in predicting treatment response and outcome [7,8]. New targeted and anti-angiogenic agents are under investigation for the treatment of newly diagnosed and recurrent gliomas but have not become part of standard treatment [9]. Evidence-based medical guidelines for disease management exist [10,101] and updates on clinical developments are regularly published [11]. One center in the UK recently showed that adoption of the integrated multidisciplinary approach advocated in the medical guidelines [101] delivered improved treatments and better patient outcomes

during initial care [12]. Whatever the medical outcome, patients exhibit complex, heterogeneous needs [13] and maximization of quality of life (QoL) is the overall goal of care.

In the past, follow-up of patients involved multiple visits to separate physicians including neurologists, neurosurgeons and oncologists. Research in the early 1990s described diverse patient and caregiver needs that were poorly served by a fragmented care delivery system [14] and led to the first UK good practice clinical guidelines [15]. Routine follow-up requiring monthly visits to an oncologist was criticized as time consuming and burdensome to patients yet largely ineffectual for detecting disease recurrence by physical and neurological examination [16,17]. Appraisal showed that most appointments amounted to ‘advice giving’ that could be delivered by a nurse-led telephone service [18] and the addition of specialist nurse support was strongly recommended [14,16–19]. A recent survey of UK clinicians [20] showed that in nearly half of centers (47%) follow-up of HGG patients takes the form of oncologist-led outpatient clinics with specialist

Table 1. Summary of experiences of follow-up care.

Statements	Strongly agreeing or agreeing (%)			
	Patients		Caregivers	
	Oncologist FU	Group FU	Oncologist FU	Group FU
Staff treat patients respectfully	96.2	95.6	100	96.4
Staff treat patients as individuals	98.1	91.1	100	100
Staff tell patients the truth about their illness	92.5	95.6	100	96.3
Patients generally get to see the same staff	77.4*	95.6*	85.7*	100*
Care is well coordinated	81.1	82.2	93.8	85.7
Sufficient information is always provided	79.2	77.8	87.4	78.6
Bad news is always managed sensitively	85.1	78.9	87.5	88.5
There is always an opportunity to ask questions	88.7	95.6	93.8	85.7
Staff check information is understandable to patients	81.1*	97.7*	95.8	96.4
There is always enough consultation time	86.8	88.9	89.8	78.6
Staff accommodate patient decision-making preferences	85.7	75.0	81.3	85.7
FU is an intrusive reminder of the illness	24.5	15.9	10.4	14.3
FU is inclusive of family/caregivers	96.2	95.6	89.8	100
FU is burdensome	1.9	0	4.3	0
Written information is always of high quality	80.8	77.1	73.3	63.0
I would prefer fewer staff at the FU consultation	15.1	20.0	23.4	25
FU ensures changes can be addressed early	90.4	95.6	93.6	89.3
FU provides support	81.1	88.9	95.5	89.3
Staff always maintain patient privacy in consultations	92.5	95.6	98.0	96.4
The time taken by FU visits is wasted time	0	0	0	0
Test results/scans always available when required	79.2*	100*	93.2	96.4
Travel to FU clinic is burdensome	34.0	24.4	25.0	10.7

*Denotes a significant effect of follow-up method $p < 0.05$ (Pearson χ^2).

FU: Follow-up.

Box 1. Likert scale formats for measuring experiences of care.

You are always given enough time during consultations				
Strongly agree	Agree	Neutral	Disagree	Strongly disagree
How important is it that you are given enough time for consultations?				
Extremely important	Important	Neutral	Unimportant	Extremely unimportant

nurses providing *ad hoc* supportive care. Nurse telephone follow-up in place of clinic visits is uncommon. Some clinicians (38%) reported conducting follow-up care via joint multidisciplinary clinics. Most clinicians (80%) used regular brain imaging as part of follow-up.

Current UK guidance [101] notes difficulties in defining appropriate methods and frequency of follow-up care and acknowledges uncertainty about the value of regular imaging, postulating that it might provoke unnecessary anxiety. It recommends follow-up at a specialist center led by a member of the patient's neuroscience or cancer team, and that joint clinics may facilitate assessment and referral. This guidance is limited by a paucity of good evidence [13,21]. An ideal form of supportive follow-up care remains to be established, and the relative benefits of existing models have not been robustly assessed. The aim of the current study was to compare the perspectives of patients and their caregivers from two different follow-up methods used in the UK after radical treatment.

Materials & methods

Ethical approval (Ref: 05/Q191/88) and all local National Health Service R&D permissions were obtained for the study. Structured interviews and questionnaires were used to assess the experiences and wellbeing of patients in follow-up and those of their primary caregivers. The study was conducted between January 2009 and January 2011.

■ Services compared

Three UK centers treating HGG collaborated in the study. In two of the centers, routine oncologist-led follow-up is conducted (henceforth 'oncologist FU'). This involves a two-step process where patients attend hospital for brain imaging and return for results several weeks later to an outpatient clinic staffed by a neuro-oncologist with *ad hoc* specialist nurse support. The other center conducts follow-up by multidisciplinary group consultation (henceforth 'group FU'). Patients attend an outpatient clinic that provides a one-stop service: brain imaging is conducted immediately prior to the appointment, at which the patient

meets with a neuro-surgeon, neuro-oncologist and specialist nurse.

■ Participants

Patients with a diagnosis of HGG, aged over 18 years, able to speak English, who were undergoing regular follow-up having completed radical radiotherapy treatment at least 3 months previously were invited to participate, along with their primary caregivers.

■ Procedures

Eligible patients were approached consecutively to reduce selection bias. All assessments were conducted by a trained researcher. Patients had face-to-face structured interviews with the researcher whilst caregivers completed questionnaires. Three assessments took place: baseline, 3- and 6-months postbaseline. Suitability for reassessment was checked prior to recontact. Assessments took place at participants' convenience as a home visit unless requested otherwise. On average, initial interviews lasted 45 min and follow-ups lasted 20 min. Caregivers took 15–30 min to complete their questionnaires.

Initial approach

Centers identified and approached eligible patients, briefly explaining the study and providing an invitation pack containing an introductory letter, an information sheet and a reply slip with return postage-paid. On receipt of a reply slip, the researcher contacted patients to answer their questions and arrange a home visit.

Recruitment

Informed consent was obtained at the first visit prior to baseline data collection. With permission patients' general practitioners were informed of their participation. Permission was also obtained for review of the patients' medical records.

■ Measures

Patient interview

A structured interview recorded services accessed by patients, and they rated their experiences of

Table 2. Characteristics of the patients.

	Oncologist FU (n = 23)	Group FU (n = 17)
Sex – male	11 (48%)	8 (47%)
Age		
▪ Mean (SD)	55 years (12.6)	46 years (10.0)
▪ Range (minimum–maximum)	32–72 years	33–65 years
Education		
▪ Secondary (up to aged 14–16 years)	9 (39%)	6 (35%)
▪ Further (up to aged 18 years)	6 (26%)	4 (24%)
▪ University & higher	8 (35%)	7 (41%)
Employment		
▪ Retired or unemployed	19 (82%)	13 (77%)
Marital status		
▪ Married/civil partnership	19 (82%)	13 (77%)
▪ Single/divorced/separated/widowed	4 (18%)	4 (23%)
Patient's offspring		
▪ None	4 (17%)	4 (24%)
▪ Left home	13 (57%)	4 (24%)
▪ Living within the home	6 (26%)	9 (52%)
WHO tumor grade 4	16 (70%)	10 (59%)
Time since diagnosis (at baseline)		
▪ Mean (SD)	6.5 months (3.2)	6.2 months (2.5)
Treatment		
▪ Surgery		
– Resection	14 (61%)	12 (71%)
– Resection with carmustine wafers	2 (9%)	0
– Biopsy only	7 (30%)	5 (29%)
▪ Radiotherapy		
– Alone	13 (57%)	0
– With concurrent temozolomide	10 (43%)	17 (100%)
▪ Adjuvant temozolomide	9 (39%)	14 (82%)
Travel to clinic		
▪ Distance		
– <5 miles	5 (22%)	1 (6%)
– 5–25 miles	13 (57%)	7 (41%)
– 26–50 miles	3 (13%)	9 (53%)
– >50 miles	2 (8%)	0
▪ Time		
– <30 min	7 (30%)	6 (36%)
– 30–60 min	8 (35%)	9 (52%)
– >60 min	8 (35%)	2 (12%)
▪ Method of transport		
– Walk	1 (4%)	1 (6%)
– Hospital transport	4 (17%)	1 (6%)
– Public transport	5 (22%)	2 (12%)
– Driven by other	13 (57%)	13 (76%)

FU: Follow-up; SD: Standard deviation.

care by responding to 24 statements about care provision. These statements were developed from a literature review and a pilot study [22] and covered a broad range of issues (see [Table 1](#)). Ratings were made for each statement on a pair

of Likert scales measuring the level of agreement with the statement and the importance of the issue contained within it; for example see [Box 1](#).

Two standardized questionnaires were completed by patients: the Functional Assessment of

Cancer Therapy (FACT-Br) (version 4) [23] was used to assess patients' QoL, and the Palliative Care Outcome Scale [24] identified unmet care needs.

Caregiver questionnaires

The same questions and statements put to the patients in interview were reproduced in questionnaire format for caregivers to express their views. Caregiver wellbeing was assessed using the 12-item version of General Health Questionnaire (GHQ-12) [25]; a well validated and widely employed self-report measure of general psychological health. A score of ≥ 4 on this measure is indicative of probable psychiatric morbidity.

Data management & analysis

All data were entered into the software package MSAccess 2003™ and exported into SPSS 16.0™ for analysis. Descriptive statistics were generated: counts, percentages and averages. Categorical variables were compared using χ^2 tests and associations by Spearman's rho correlation. Continuous data, such as age and scores

from the FACT QoL measure were compared using t-test and analysis of variance.

Results

Sample

A total of 40/62 (65%) patients approached participated in the study. A total of 33/40 (83%) of these nominated a caregiver, of whom 32/33 (97%) consented to the study.

The patients' characteristics split by follow-up method are displayed in Table 2. On average, patients in group FU were significantly younger ($t[38] = -2.47$; $p = 0.05$) and were more likely to have been treated with adjuvant temozolomide ($\chi^2 [1, n = 40] = 11.2$; $p < 0.05$), no other significant differences were apparent. Apart from the lower average age, no additional reasons were identified to explain why more patients in group FU received chemotherapy as part of their treatment. A total of 40 patient interviews were completed at baseline, 32 at 3 months and 26 at 6 months.

The sociodemographic details of the caregivers are shown in Table 3. Thirty-two caregivers completed questionnaires at baseline, 25 at 3 months and 19 at 6 months.

Table 3. Characteristics of the caregivers.

Characteristics	Oncologist FU (n = 20)	Group FU (n = 12)
Sex – male	8 (40%)	6 (50%)
Age		
▪ Mean (SD)	54 years (14.7)	46 years (9.5)
▪ Range (minimum–maximum)	25–75 years	27–62 years
Education		
▪ Secondary (up to aged 14–16 years)	6 (30%)	5 (42%)
▪ Further (up to aged 18 years)	6 (30%)	3 (25%)
▪ University & higher	8 (40%)	4 (33%)
Employed		
▪ Not working	9 (45%)	1 (8%)
▪ Part-time	5 (25%)	3 (25%)
▪ Full-time	6 (30%)	6 (50%)
▪ Retired	0	2 (17%)
Relationship to patient		
▪ Spouse/partner	17 (85%)	11 (92%)
▪ Sibling	1 (5%)	0
▪ Offspring	2 (10%)	0
▪ Friend	0	1 (8%)
Lifestyle adjustment required to be the caregiver		
▪ None	5 (25%)	1 (8%)
▪ Some	6 (30%)	6 (50%)
▪ Quite a bit	3 (15%)	1 (8%)
▪ Very much	1 (5%)	2 (17%)
▪ Total change	5 (25%)	2 (17%)

FU: Follow-up; SD: Standard deviation.

■ The nature of follow-up

Clinic visits

There was no significant difference between the follow-up methods with regard to frequency of visits; most patients attended at 3-monthly intervals. Figure 1 illustrates the functions that patients perceived follow-up to fulfil.

The majority of patients (89%) associated anxiety with clinic visits, reporting on average a rating of 4.3 (standard deviation [SD]: 3) on a scale that ranged from 0 (not at all anxious) to 10 (extremely anxious). Neither follow-up method nor passage of time significantly influenced this clinic visit anxiety. However, for most patients (84%) the anxiety dissipated immediately after the consultation. Caregivers were more anxious (mean: 6.2; SD: 2.7) about visits than patients.

Regular imaging

There were no significant differences between follow-up methods with regards to imaging. Commonly, scans were performed 3 monthly. 56% of patients always or often wanted to see their brain scans and less than 10% were never interested. Caregivers showed equal interest: 53% always or often wanted to see them while 20% apparently were given no opportunity to view them (subject to patient's permission). Whereas patients' anxiety toward seeing their scans was relatively low (mean of 2.5; SD: 2.7), caregivers experienced more (mean of 5.32; SD: 2.9).

Other supportive activity

Method of follow-up had no significant influence on the levels of other supportive care accessed by

patients. Few patients (20%) received proactive nurse telephone FU, but most (60%) called the nurse sometimes or often when first in follow-up. This contact significantly reduced over time: by the 3- and 6-month assessments 30 and 40%, respectively, were sometimes or often making calls (Friedman's $\chi^2 = 8.58$; degrees of freedom: 2; $p < 0.05$). Allied services most often used by patients were counseling and complementary therapies (28%), physiotherapy and financial/social work assistance (19% each), and occupational health (12%), while 10% reported seeing an epilepsy nurse. Accessed by <10% of patients were speech therapy, rehabilitation, neuropsychology and hospice day care.

■ Wellbeing

Patients (FACTBr)

Table 4 displays summarized baseline QoL data split by follow-up method and shows no significant differences. The table also contains comparative data from other palliative samples [26,27] and population norms [28]. Age was the only demographic significantly associated with QoL; being younger correlated with better scores on the FACT subscales of function ($\rho = -0.51$; $p < 0.001$) and symptom burden ($\rho = 0.39$; $p < 0.05$), and on the overall FACT-Br score ($\rho = 0.37$; $p < 0.05$).

Figure 2 shows the means for all available data for the patients' general QoL (FACT-G) and symptoms (FACT-BS) over time. QoL was significantly improved from baseline at 3 months but not 6 months ($F[2,50] = 6.10$; $p < 0.05$ and Bonferroni *post hoc* $p < 0.05$), and symptom burden was stable ($F[2,50] < 1$, nonsignificant).

Using all available data, no significant effect of follow-up method was found on the FACT-G or symptom subscale with analysis of covariance carried out for both the 3- and 6-month assessments. Age and adjuvant temozolomide treatment were used as covariates in the analyses because patients in group FU differed significantly from those in oncologist FU on these variables at baseline.

Caregivers (GHQ-12)

Caregiver wellbeing was not influenced by follow-up method. The GHQ-12 results showed considerable probable psychological distress amongst the caregivers (Table 5). Examination of caregivers lost to follow-up showed they predominantly had scores above the cut-off for probable psychiatric morbidity (10/13=77%) on their last available assessment and it is likely that their

Figure 1. Functions served by follow-up visits.

Table 4. Summary of baseline functional assessment of cancer therapy results.

FACT scales	Group FU (n = 17)	Oncologist FU (n = 23)	Other HGG sample [†] (n = 50)	Metastatic sample [‡] (n = 286)	Norms [§] (n = 1075)
Physical wellbeing, mean (SD)	17.4 (7.6)	18.6 (5.9)	21.2 (5.9)	19.0 (5.7)	22.7 (5.4)
Social wellbeing, mean (SD)	22.2 (4.6)	21.4 (4.4)	23.3 (4.7)	22.3 (4.6)	19.1 (6.8)
Emotional wellbeing, mean (SD)	17.1 (4.7)	16.3 (5.3)	19.0 (4.4)	17.1 (4.7)	19.9 (4.8)
Functional wellbeing, mean (SD)	15.9 (6.6)	15.5 (6.0)	15.1 (6.8)	16.9 (5.8)	18.5 (6.8)
FACT-G, mean (SD)	72.7 (17.7)	71.8 (14.9)	–	75.2 (15.6)	80.1 (18.1)
Symptom subscale, mean (SD)	50.9 (11.5)	49.8 (11.5)	48.8 (14.3)	–	–
FACT-Br, mean (SD)	123.6 (26.7)	121.5 (24.2)	127.3 (27.2)	–	–

[†]Other primary high-grade brain tumor sample [26].

[‡]Metastatic sample (lung, breast, gynae, genitourinary and gastrointestinal) [27].

[§]Normative general population [28].

FACT-Br: Functional assessment of cancer therapy – brain; FACT-G: Functional assessment of cancer therapy – general; FU: Follow-up; HGG: High-grade glioma.

drop-out accounts for the observed improvement in GHQ-12 scores over time (Table 5).

Psychological morbidity was not significantly associated with age, education or employment, but was associated with being female ($p = 0.37$; $p < 0.05$), relationship status – that is, not being a spouse/partner of the patient ($p = 0.38$; $p < 0.05$), having childcare responsibilities ($p = 0.44$; $p < 0.05$) and having made greater lifestyle adjustments to accommodate the caregiver role ($p = 0.40$; $p < 0.05$).

■ Unmet care needs (Palliative Care Outcome Scale)

Patients' unmet care needs were relatively low. On a scale where 0 is no unmet needs and 4 is overwhelming unmet needs the two areas with highest scores were self-worth/esteem (mean of 1.6; SD: 1.2) and family anxiety (mean of 1.5; SD: 1.4). All other areas assessed, which included pain, other symptoms, patient's anxiety, information needs, sharing feelings, depression, time wasted and practical problems, had mean values below 1. The top three practical problems reported by patients were fatigue, anxiety and reduced independence.

■ Experiences of care

Table 1 summarizes the follow-up experiences of patients and caregivers. Significantly more patients in group FU reported seeing familiar staff, that staff checked information was understandable to them and that their results were always reliably available.

Satisfaction with follow-up

Follow-up method and passage of time had no significant influence on satisfaction. Both patients and caregivers rated satisfaction with

their care highly (mean of 8.2; SD: 1.6 for patients; mean of 7.6; SD: 2.3 for caregivers, on a scale where 0 is not at all satisfied and 10 is completely satisfied). The top suggestions for service improvements were need for emotional support followed by desire for proactive nurse telephone follow-up and better information provision about the course of the illness.

Discussion

Follow-up in this circumscribed group of patients treated radically for their primary HGGs seems to be a preterminal phase in a disease that manifests complex and rapidly changing care needs. The study usefully highlights that HGG patients had similar QoL to those with other metastatic cancers [27] and importantly for the majority it either improved or was stable for a period after radical intervention.

The study had limitations: it was not a randomized controlled trial and had a small sample size that diminished with time, which reduces the extent to which the findings may be generalized. We acknowledge that the two follow-up methods evaluated here are reflective of practices in the UK National Health Service, which may reduce the global applicability of the results since other approaches may be employed elsewhere in the world. However, it is informative in evaluating follow-up practices from the perspectives of service users.

In the context of earlier reports [14,16,17], this study reflects a positive and progressive evolution of follow-up practices in the UK and reports high levels of user satisfaction and service delivery that is not generally perceived as burdensome or a waste of time.

Few significant differences were found between the two methods of follow-up under scrutiny in

Figure 2. Summary of functional assessment of cancer therapy – general, and symptoms over time.
FACT-G: Functional assessment of cancer therapy – general.

terms of impact on patients and caregivers. Group follow-up was perceived to provide greater continuity of care and efficiency of results delivery. This accords with a recent study that reported improved clinical management with increased integration of services [12].

Of interest is the finding that the ‘one-stop’ multidisciplinary clinic, which delivered same day scan results, appeared to provide no advantage in terms of anxiety associated with follow-up. Past investigation has shown a helpful effect of immediate over delayed communication of results in the case of women with symptomatic breast disease undergoing fine-needle aspiration biopsy, but only for those with a benign outcome, which was the majority [29]. Another study on the other hand found rapid prostate-specific antigen testing did not prove to alleviate stress or anxiety associated with receiving results [30]. It is noteworthy that the women with breast symptoms were new patients and the men having prostate-specific antigen testing were under regular review. Reasons why the current study found no differences in reported anxiety include the possibility that a more robust and singularly

focused approach to its measurement is required to reveal disparities. It could also be that familiarity (with the particular processes of follow-up) plays a part in moderating anxiety created by any delay in results delivery. Further research is needed to better elucidate the effects of delay in scan result delivery for patients with HGG followed up with imaging.

A key area of weakness in both follow-up methods appeared to be provision of adequate psychological support to patients and caregivers. Patients reported relatively low levels of unmet care needs, but their self-esteem and family anxiety were areas on the threshold of requiring attention. Their main practical problems were fatigue, anxiety and reduced independence. The primary suggestion from patients for improvement to their follow-up care was for the provision of better emotional support.

Most striking perhaps is the high prevalence (up to 56%) of probable psychiatric morbidity amongst the caregivers. Given that the rate in the UK general population is 17%, this finding warrants attention [31]. This high prevalence is similar to that observed in caregivers of other patient groups, such as those with esophageal cancer [32] and dementia [33], and has been widely reported in palliative care generally [34]. The WHO stipulates that palliative care should improve the QoL of both patients and their families [102], and in the wake of this report published guidelines in the UK (NICE 2004) [103], and other countries (National Consensus Project-USA 2004 [104] and Palliative Care Australia 2005 [105]), have advocated that family and caregivers’ needs should be assessed and addressed. Recent reviews show that the process of improving support to meet these targets is at an early stage [35,36]. Current support for caregivers is often far from ideal and successful interventions have been few, making this a priority for future development of care.

Though increasing the integrated nature of follow-up by providing a ‘one stop service’ and group consultation showed some positive effects,

Table 5. Summary of the caregivers’ general health questionnaire 12 results.						
GHQ-12	Whole sample (n)			Subsample (n; data available at all time points)		
	Baseline	3 months	6 months	Baseline	3 months	6 months
n	32	25	19	19	19	19
Mean (SD)	5.2 (3.5)	3.3 (3.7)	2.9 (3.7)	4.3	3.2	3.0
Above threshold (case ≥4)	18 (56%)	10 (40%)	6 (32%)	8 (42%)	7 (37%)	6 (32%)
GHQ-12: General health questionnaire 12; SD: Standard deviation.						

patient and caregiver evaluations revealed no significant advantages over oncologist-led follow-up. Importantly, both follow-up methods failed to adequately meet psychological supportive needs, indicating that the content and/or delivery of these methods is open to improvement. There is an opportunity for innovative development of intervention(s) to ameliorate emotional distress, for example the provision of a targeted proactive counseling or problem solving service for caregivers. In other oncology settings, early sharing of care with palliative specialists has been shown both to improve patients' QoL and increase survival, so this should be evaluated in the HGG setting [37].

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Ethical conduct of research

The authors state that they have obtained appropriate institutional review board approval or have followed the principles outlined in the Declaration of Helsinki for all human or animal experimental investigations. In addition, for investigations involving human subjects, informed consent has been obtained from the participants involved.

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