



National Survey of Follow Up in High-Grade Glioma

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Background

In the UK supportive care practices for patients with high-grade glioma (HGG) after completion of radical radiotherapy are reported anecdotally rather than by investigation. Evidence for 'best practice' in recent clinical guidance is limited. Establishing nationally what care is provided is a first step to better understanding what really helps patients with these rare tumours and complex needs.

Aims

- To conduct a national survey to:-
- measure frequency & commonality of supportive care elements provided
 - elicit the rationale behind services offered
 - identify areas requiring improvement

Method

- Study-specific questionnaire developed covering:-
 - current follow up (FU) services
 - reasons for practices such as regular brain scanning
 - suggestions for service improvement
- Cancer networks contacted to identify all UK neuro-oncology teams
- Neurosurgeons & oncologists in the teams were approached
- Emailed letter explaining the study and inviting participation in an online survey sent to target population (paper version available on request)
- Non-responders were sent reminders
- Text from open-ended questions coded
- Data entered into Excel, descriptive statistics generated

Results

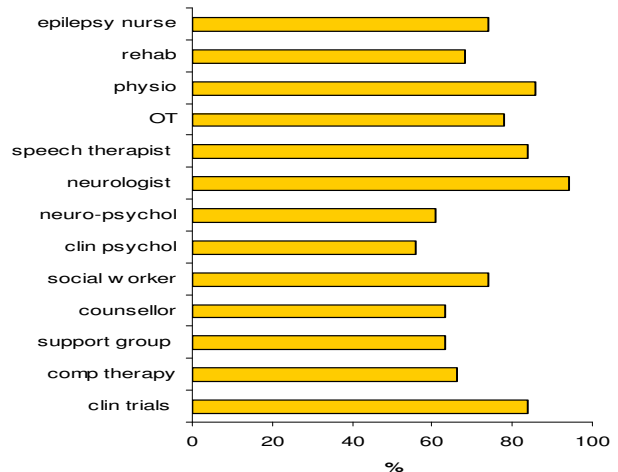
- 86/102 questionnaires completed = 84% response
- Average numbers treated annually 21-40 (modal class) per centre
- Most (56%) used NICE 2006 IOGs to direct FU and report of a local protocol was common (66%)

Services

- Regular FU universally available
- Outpatient consultation with oncologists either alone or with nurse attendance was most common
- A third saw patients as a multi-professional team
- Regular nurse-led phone clinic FU was rarer
- Clinic visit frequency highly variable, dictated by clinical need, but commonly was 3 monthly

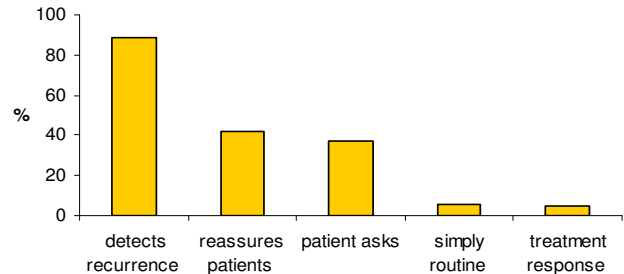
Results

Fig 1: allied service availability varied



- Regular brain scanning used by 80% as a part of FU

Fig 2: reasons for regular scans



Service improvements: 10 most nominated areas

- full-time specialist nurse allocation
- integrated FU/joint or team clinics
- better access to neurology services
- good communication/coordination/continuity of care
- greater access/more opportunities for clinical trials
- immediate access to scanning & quick reporting
- better community support for family
- better access to psychological services
- better access in general to allied services
- better access to community-based physio & OT

Conclusions

This survey highlights variability in practices and areas for improvement. Our next step is a prospective multi-centre observational study with patients and carers exploring their experience of follow up.

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