Supportive Care For Patients With High-Grade Glioma
(primary brain tumours)

Dr Susan Catt & Professor Lesley Fallowfield

SHORE-C
Sussex Health Outcomes Research & Education in Cancer
Partners

Mr Giles Critchley
Consultant Neurosurgeon
Hurstwood Park Neurological Centre, Haywards Heath

Professor Anthony Chalmers
Consultant Neuro-Oncologist
Institute of Cancer Sciences, University of Glasgow

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Primary brain tumours (glioma)

- differ from cancer that’s spread to the brain
- originate in the cells (glial cells) of the brain
- rarely migrate to other parts of the body
Primary brain tumours are graded

- grade 1: pilocytic astrocytoma
  - low grade
  - children only, curable

- grade 2: very slow growing astrocytoma
  - (survival up to 20 years)

- grade 3: anaplastic astrocytoma
  - high grade
  - anaplastic oligodendroglioma
  - survival 1 - 5 years

- grade 4: glioblastoma multiforme
  - survival 3 months - 2 years
How common are primary brain tumours?

- 2% of adult cancers = 4,500 per year in UK
- 70-80% are High-Grade Glioma (HGG)
  - incurable with low life expectancy
- most common between 45-65 years
- seen more in men than women
Effects of the tumour

Depends on location, grade and size

Destroys normal brain tissue
• visual or speech problems
• limb weakness
• personality changes
• memory loss
• poor concentration

 Raises the pressure inside the skull
• headache, nausea, vomiting, fits, confusion, drowsiness, loss of consciousness
Diagnosis & treatment

Diagnosis

• brain scan

Immediate treatment

• reduce raised intracranial pressure
  • steroids
• control seizures
  • anti-epileptic drugs
Neurosurgery

• require tissue for diagnosis (biopsy)

• maximum removal of tumour whilst preserving the healthy brain

• surgical options
  • biopsy only
  • craniotomy / “awake craniotomy”
Radiotherapy doubles life expectancy

- only administered once due to toxicity
- a short, palliative course of radiotherapy is given to those who are less fit or older

- can improve or control symptoms
- allows the steroid dose to be reduced/stopped
Chemotherapy

- effectiveness is limited by blood-brain barrier
- doses needed often cause toxic side-effects
- wafers containing chemotherapy sometimes inserted into the cavity after tumour removal

Temozolomide (2006)
- tablet, taken during radiotherapy and after too
- small survival gain
Unwanted side-effects

Steroids
• physical - fluid retention, weight gain, bruising, immunosuppression
• psychological - irritability, insomnia, increased appetite, psychosis

Surgery
• removal/damage of healthy brain tissue
Unwanted side-effects

Radiotherapy
• damage to healthy tissue, permanent hair loss, fatigue, sleep disturbance, sore scalp

• late effects – tissue atrophy, necrosis, memory and concentration problems, personality changes

Chemotherapy
• nausea, fatigue, myelosuppression, rash
After initial treatment

- Palliative Radiotherapy
  - End of life care

- Radiotherapy +/- temozolomide
  - 1st Relapse
    - more surgery
    - chemotherapy
  - Relapse
    - more surgery
    - chemotherapy
Some questions posed locally

• from the perspective of patients & families what is the purpose of follow-up (FU)
• how useful is it
• how frequently should FU be done
• who should be consulting with these patients
• should patients see deteriorating brain scans
• how much does practise differ between centres
Literature review

• **The Lancet Oncology** vol.9, Sept 2008, 884-891
  Psychosocial & supportive-care needs in high-grade glioma

• **Neuro-Oncology** vol.14, April 2012, 392-404
  Systematic review of supportive care needs in patients with primary malignant brain tumours
What is known

- group with a wide variety of needs and very shortened life expectancy

- fatigue, anxiety, depression, personality changes and cognitive deficits prominent problems

- preservation of QoL, realistic hope, normality in everyday living, and existential issues paramount
What is known

• some research suggests routine FU & information does not meet the needs of patients & relatives

• limited evidence about best FU practice between completion of 1st treatment and management by palliative team

• no studies comparing different FU practices
UK Guidance

• 1st published guidelines (Davies & Hopkins 1997) were limited and subsequently criticised (Davies & Higginson 2003)

• current NICE (2006) Improving Outcomes Guidance is detailed on clinical management, but lacks good evidence and practice guidance on the supportive aspects of care
Programme of work

Phase 1
Pilot study
April – September 2006
Psychology, Health & Medicine 2011, Vol.16, 357-65

Phase 2
National Clinician Survey
June – October 2008

Phase 3
Comparative Observational Study
January 2009 – January 2011
CNS Oncology 2012, Vol.1, 39-48
Pilot work
Hurstwood Park Neurological Centre

Objectives

develop tools for:-
• services survey tool
• patient interview schedule
• carer questionnaire

Methods

• qualitative exploratory interviews with patients and healthcare professionals
National Clinician Survey

Objectives
• UK-wide survey of current FU practice

Methods
• all UK Cancer Networks asked to identify doctors responsible for care of patients with HGG
• electronic/postal services survey
Survey Results

• 68/102 (84%) doctors responded

• 3-monthly clinic visits to see an oncologist with *ad hoc* specialist nurse support was the norm

• a few centres conducted joint consultation clinics

• nurse-led telephone FU instead of visits was rare

• regular brain scanning was usual practice

• access to allied supportive services was considered useful, but actual levels of need and achievement of delivery was unknown
Comparative Study of Follow-Up Care

Objectives

• to evaluate and compare from the perspective of patients and caregivers oncologist-led FU with a joint consultation FU method

Services compared

• oncologist-led FU, a 2-step process, first visit for a brain scan, then return a week or so later for the results

• joint FU is a single visit with the scan done on arrival followed by a consultation with the team for results
Methods

- longitudinal observational study
- recruitment from 2 UK centres providing oncologist-led FU and 1 using joint consultations
- assessments at baseline, 3- and 6-months
- patients: 40, 32, 26
- caregivers: 32, 25, 19
Methods

Face-to-face interviews with patients
• recording services accessed
• ratings of experiences of care
• quality of life (FACTBr) measurement
• identification of unmet care needs (POS)

Caregivers completed questionnaires
• wellbeing assessed (GHQ-12)
• questions parallel to the patient interview about services accessed & experiences of care
## Experiences of care

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

<table>
<thead>
<tr>
<th>Statements</th>
<th>Strongly agreeing or agreeing (%)</th>
<th>Patients</th>
<th>Caregivers</th>
<th>Patients</th>
<th>Caregivers</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Oncologist FU</td>
<td>Group FU</td>
<td>Oncologist FU</td>
<td>Group FU</td>
<td></td>
</tr>
<tr>
<td>Staff treat patients respectfully</td>
<td>96.2</td>
<td>95.6</td>
<td>100</td>
<td>96.4</td>
<td></td>
</tr>
<tr>
<td>Staff treat patients as individuals</td>
<td>98.1</td>
<td>91.1</td>
<td>100</td>
<td>100</td>
<td></td>
</tr>
<tr>
<td>Staff tell patients the truth about their illness</td>
<td>92.5</td>
<td>95.6</td>
<td>100</td>
<td>96.3</td>
<td></td>
</tr>
<tr>
<td>Patients generally get to see the same staff</td>
<td>77.4*</td>
<td>95.6*</td>
<td>85.7*</td>
<td>100*</td>
<td></td>
</tr>
<tr>
<td>Care is well coordinated</td>
<td>81.1</td>
<td>82.2</td>
<td>93.8</td>
<td>85.7</td>
<td></td>
</tr>
<tr>
<td>Sufficient information is always provided</td>
<td>79.2</td>
<td>77.8</td>
<td>87.4</td>
<td>78.6</td>
<td></td>
</tr>
<tr>
<td>Bad news is always managed sensitively</td>
<td>85.1</td>
<td>78.9</td>
<td>87.5</td>
<td>88.5</td>
<td></td>
</tr>
<tr>
<td>There is always an opportunity to ask questions</td>
<td>88.7</td>
<td>95.6</td>
<td>93.8</td>
<td>85.7</td>
<td></td>
</tr>
<tr>
<td>Staff check information is understandable to patients</td>
<td>81.1*</td>
<td>97.7*</td>
<td>95.8</td>
<td>96.4</td>
<td></td>
</tr>
<tr>
<td>There is always enough consultation time</td>
<td>86.8</td>
<td>88.9</td>
<td>89.8</td>
<td>78.6</td>
<td></td>
</tr>
<tr>
<td>Staff accommodate patient decision-making preferences</td>
<td>85.7</td>
<td>75.0</td>
<td>81.3</td>
<td>85.7</td>
<td></td>
</tr>
<tr>
<td>Follow-up is an intrusive reminder of the illness</td>
<td>24.5</td>
<td>15.9</td>
<td>10.4</td>
<td>14.3</td>
<td></td>
</tr>
<tr>
<td>Follow-up is inclusive of family/caregivers</td>
<td>96.2</td>
<td>95.6</td>
<td>89.8</td>
<td>100</td>
<td></td>
</tr>
<tr>
<td>Follow-up is burdensome</td>
<td>1.9</td>
<td>0</td>
<td>4.3</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Written information is always of high quality</td>
<td>80.8</td>
<td>77.1</td>
<td>73.3</td>
<td>63.0</td>
<td></td>
</tr>
<tr>
<td>I would prefer fewer staff at the follow-up consultation</td>
<td>15.1</td>
<td>20.0</td>
<td>23.4</td>
<td>25.0</td>
<td></td>
</tr>
<tr>
<td>Follow-up ensures changes can be addressed early</td>
<td>90.4</td>
<td>95.6</td>
<td>93.6</td>
<td>89.3</td>
<td></td>
</tr>
<tr>
<td>Follow-up provides support</td>
<td>81.1</td>
<td>88.9</td>
<td>95.5</td>
<td>89.3</td>
<td></td>
</tr>
<tr>
<td>Staff always maintain patient privacy in consultations</td>
<td>92.5</td>
<td>95.6</td>
<td>98.0</td>
<td>96.4</td>
<td></td>
</tr>
<tr>
<td>The time taken by follow-up visits is wasted time</td>
<td>2.9</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Test results/scans are always available when required</td>
<td>79.2*</td>
<td>100*</td>
<td>93.2</td>
<td>96.4</td>
<td></td>
</tr>
<tr>
<td>Travel to follow-up clinic is burdensome</td>
<td>34.0</td>
<td>24.4</td>
<td>25.0</td>
<td>10.7</td>
<td></td>
</tr>
</tbody>
</table>

* denotes significant effect of FU method p < 0.05 (Pearson chi-square).
Patients quality of life (QoL) and caregivers wellbeing

- QoL either improved or was stable during the 6 months of the study, no effect of FU method

- similar QoL to other samples with HGG or other metastatic cancer (lung, breast, gynae)

- results showed 56% of caregivers suffered probable psychiatric morbidity (general population = 12%), no effect of FU method
Unmet care needs

No effect of FU method, but

Patients most frequent practical problems:
• fatigue
• anxiety
• reduced independence

Desired service improvements:
• better emotional support
• proactive nurse telephone FU
• better information about course of their illness
Conclusions

• as treatment is palliative more efforts are need to ensure good continuity of care best managed through a well functioning team approach

• FU is failing to meet the psychological needs of patients and caregivers

• innovative, integrated, interventions that effectively support caregivers need to be developed
Acknowledgements

• we are especially grateful to all the patients and caregivers for their time and invaluable contributions

• we also could not have done the work without the support and assistance of the doctors and nurses at the collaborating centres

THANK YOU