Palliative care in acute stroke: research findings and recommendations

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Background

• Stroke results in high levels of mortality and morbidity, and can cause a wide range of distressing symptoms and problems.
• It is the third most common cause of death in the UK, with 26,400 people dying each year, and direct costs to the NHS of around £2.8 billion.
• Patients with stroke tend not to get referred to palliative care or hospice services.
Palliative care in acute stroke: what are the issues?

- Patients with stroke and their families face major challenges in the initial period
- Approximately 20% of patients will die in the first 28 days after stroke
- Certain treatment decisions raise complex ethical dilemmas
- Family members face considerable uncertainty and have support and information needs.
International Observatory on End of Life Care

Policy Guidance in the UK

- All stroke patients should have access to specialist palliative care expertise.
- All staff providing this care should have appropriate training.

**NHS End of Life Care Programme** (2005)
- Focus predominantly on cancer care

**NHS End of Life Care Strategy**
(forthcoming summer 2008)
- Aims to improve the end of life care for all patients irrespective of diagnosis.
Aim and Objectives

Objectives:

• To identify how the principles and practice of palliative care can improve acute stroke care
• Identification of patient and family preferences for management
• Identification of service and professional barriers to incorporating palliative care in acute stroke services.
Methods

Two phases

Assessment – patient and family
• Sheffield Profile of Assessment and Referral
• Retrospective audit of case notes
• Brief interview with patient
• Brief assessment with patient and, where possible, with family member or carer

Health professionals working with stroke patients
• Focus groups
Patient characteristics (n=191)

- Gender: 100 (52.4%) male
- 91 (41.6%) were living alone
- Median length of stay: 5 days (range 1-49 days)
- Stroke hemisphere: 76 (39.8%) Left; 106 (55.5%) Right
- Barthel score: 93 (48.7%) 15 or more; 98 (51.3%) >15
Findings – symptom experience

• Physical issues
  – Nearly 80% of our sample experienced some form of communication problems after their stroke.
  – Over 50% reported moderate to significant problems with ‘feeling weak’, ‘feeling tired’ or ‘being sleepy during the day’.
  – Approximately 50% reported problems with ‘pain’, ‘memory loss’, ‘headache’, ‘restlessness’ or ‘bladder problems’.

• Psychological issues
  – 70% of the sample reported ‘feeling everything’s an effort’.
  – Approximately 50% experienced some form of psychological distress such as ‘anxiety’, ‘low mood’, ‘confusion’, ‘poor concentration’ and ‘loneliness’.

• Religious and spiritual issues
  – One in every four stroke patients had some concerns about death or dying.
Findings – social issues

• Dependence and disability issues
  – Approximately 66% of our sample had concerns relating to dependence and disability.

• Family and social issues
  – Over 50% were worried about the effects of their stroke on others within their support network.
  – 25% felt that they needed more help than their family could provide.

"I think my mum is dying, or it is the beginning of the end. My mum is 89. I just want her to have a quiet, peaceful, pain free, dignified (death) - that's what I want for my mum. They said there had been a very severe bleed and they were not expecting her to recover. It was handled very calmly and very sensitively".

(Daughter of stroke patient, 46)
Findings – end of life care

- Recordings of discussion about prognosis - 71 (38%)
- Do not resuscitate orders – 27 (but only 13 completed correctly)
- Pain assessment – 97%
- Depression assessment – 34 (18%)
- Specialist palliative care team referral – none.
Predictors of need

- A final model of the data was constructed using the four factors shown to be significant in regressions for each SPARC domain (Barthel Index, Gender, Age and Co-morbidity).

- Significant main effects:
  - Barthel Index score (F1,123 = 12.640 p=0.001)
  - Age (F4,123 = 3.022 p=0.020)

- Three-factor interaction:
  - Barthel Index score, Age and Co-morbidities (F9,123 = 2.199 p=0.026).
Conclusions

- Stroke patients experience high levels of morbidity.
- More effective *general* palliative care is required for those dying in stroke units.
- Greater education on *general* palliative care and communication about end of life issues is recommended for staff in stroke units.
- Access to *specialist* palliative care is desirable for certain patients.