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.

Policy Guidance in the UK

National Clinical Guidelines for Stroke (2004, updated in 2007)

- 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.

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Aim and Objectives

- Identification of palliative care needs in patients admitted with acute stroke.

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
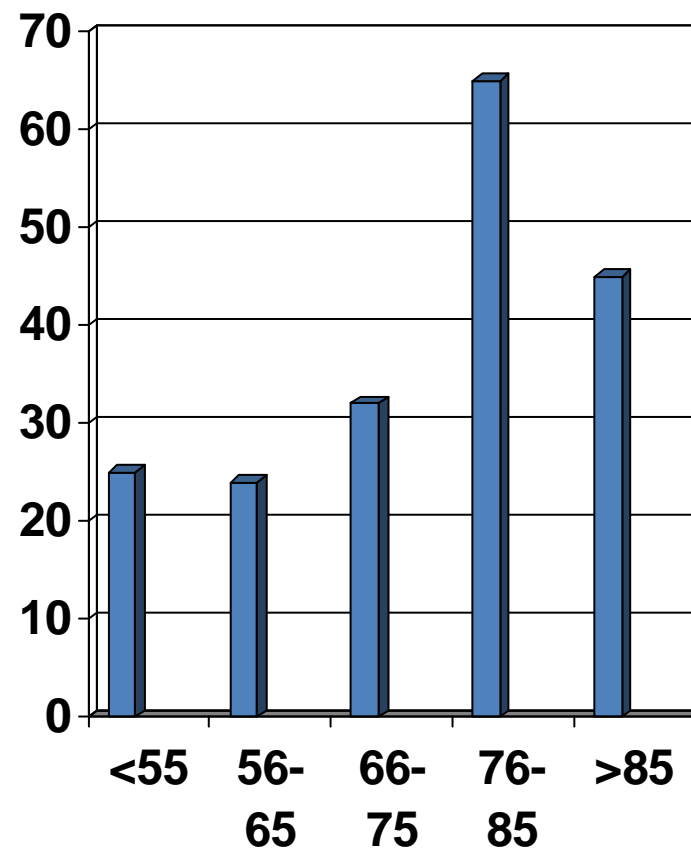- Brief assessment with patient and, where possible, with family member or carer

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

Bar chart with age groups on x-axis: <55, 56-65, 66-75, 76-85, >85 and values 0 to 70 on y-axis.

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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)

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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 ($F_{1,123} = 12.640$ p=0.001)
  - Age ($F_{4,123} = 3.022$ p=0.020)

- Three-factor interaction:
  - Barthel Index score, Age and Co-morbidities ($F_{9,123} = 2.199$ p=0.026).

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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.