# Is palliative care appropriate for people with major stroke?

M Kendall, E Cowey, GE Mead, M Barber, S Borthwick, K Boyd, C McAlpine, DJ Stott & SA Murray

## Background

- Mortality rate is 60% at one year for people with Total Anterior Circulation Stroke (TACS)
- Patients are rarely identified for anticipatory care in Scotland or early palliative care internationally

### Methods

- Representative sample of 34 TACS patients recruited from 3 Scottish regions and their informal and professional carers
- Interviewed at 4-8 weeks, 6 months and 12 months after the index stroke, to identify multidimensional illness patterns and care needs
- 3 Questionnaires after each interview: Palliative Care Outcome Scale, Euroqual5D-5L and Carer Strain Index
- Data linkage study of all patients admitted to the same 3 stroke unit regions
- Qualitative thematic longitudinal analysis, and quantitative analysis of questionnaires and data linkage

### Results

High 4

Physica

Low

From the outset, the possibility of dying was clear to all involved, though rarely voiced.

"I felt helplessness, I felt as if my mother was dead but yet she wasn't dead.
Perhaps I shouldn't have phoned the ambulance and then she would have died, and perhaps that would have been better." (Daughter)

Some staff confessed to using unrealistic optimism in order to motivate people for rehabilitation.

"We need her thinking it's going to get better otherwise she won't commit and then you won't get the same outcome. You're very positive even though you think long term it might not happen." (Physiotherapist) Some carers and patients expressed that it would have been better if death had occurred.

"When we came home from that visit [my husband] said to me I wish my mum had just passed away when she took her stroke." (Bereaved daughter-in-law)

"I remember saying to my daughter, I feel so disabled, and that upsets me, because what does the future hold at this moment –nothing worthwhile looking forward to." (Patient)

Returning home was often delayed by pressure on social services and care home beds.

"It's all to do with funding and care availability...
we just have to wait. Then there's the possibility
of boarding." (Hospital based physiotherapist)

Those who returned home had to adjust to a very different life.

"Well I can see things here that are familiar but I knew whenever I was in it I wasn't home... My husband keeps saying I've got to accept it. This is your home and you're in it. But I can't." (L02.2 Patient)

Many would have welcomed more support in realistic planning from day one.

"We started to discover things we felt should have been told at the very, very start of the whole process and it would have created a completely different atmosphere in the way we handled the whole situation." (L11 Bereavement interview with daughter and son-in-law)

acute ward

rehab

community

Stroke

40% dead by 4 weeks

57% dead by 6 months

60% dead by 1 year

Is 'palliative care' appropriate for major stroke?

Some staff viewed 'palliative care' as negative, and applicable only to patients who were clearly dying.

"I wouldn't say she was a palliative patient just yet in terms of helping her to die peacefully or pain free. She's going on to a nursing home" (Stroke unit nurse) "Palliative care" it's you know, no more needles and no more drips and no more antibiotics... (Hospital doctor)

"I sometimes tell the team to scrap the word 'palliative'... It does give the wrong focus... if they're not dying" (L03.1 Hospital doctor)

### Discussion

- Patients with TACS and their family carers faced sudden complex life and death decisions from admission and knew that death was a possibility
- Despite high case fatality, the focus was on active physical rehabilitation, recovery, motivation and hope, with less discussion and preparation for dying
- Sensitive and effective communication frequently occurred but "prognostic paralysis" hindered future care planning

# Conclusions

- The term "palliative care" implied abandonment and dying soon, rather than a positive approach to care
- The principles of palliation in the care of patients should be embedded without using the phrase "palliative care"
- A model of care balancing hoping for the best with preparing for the worst may be acceptable to patients and their carers from admission









