

# Is palliative care appropriate for people with major stroke?

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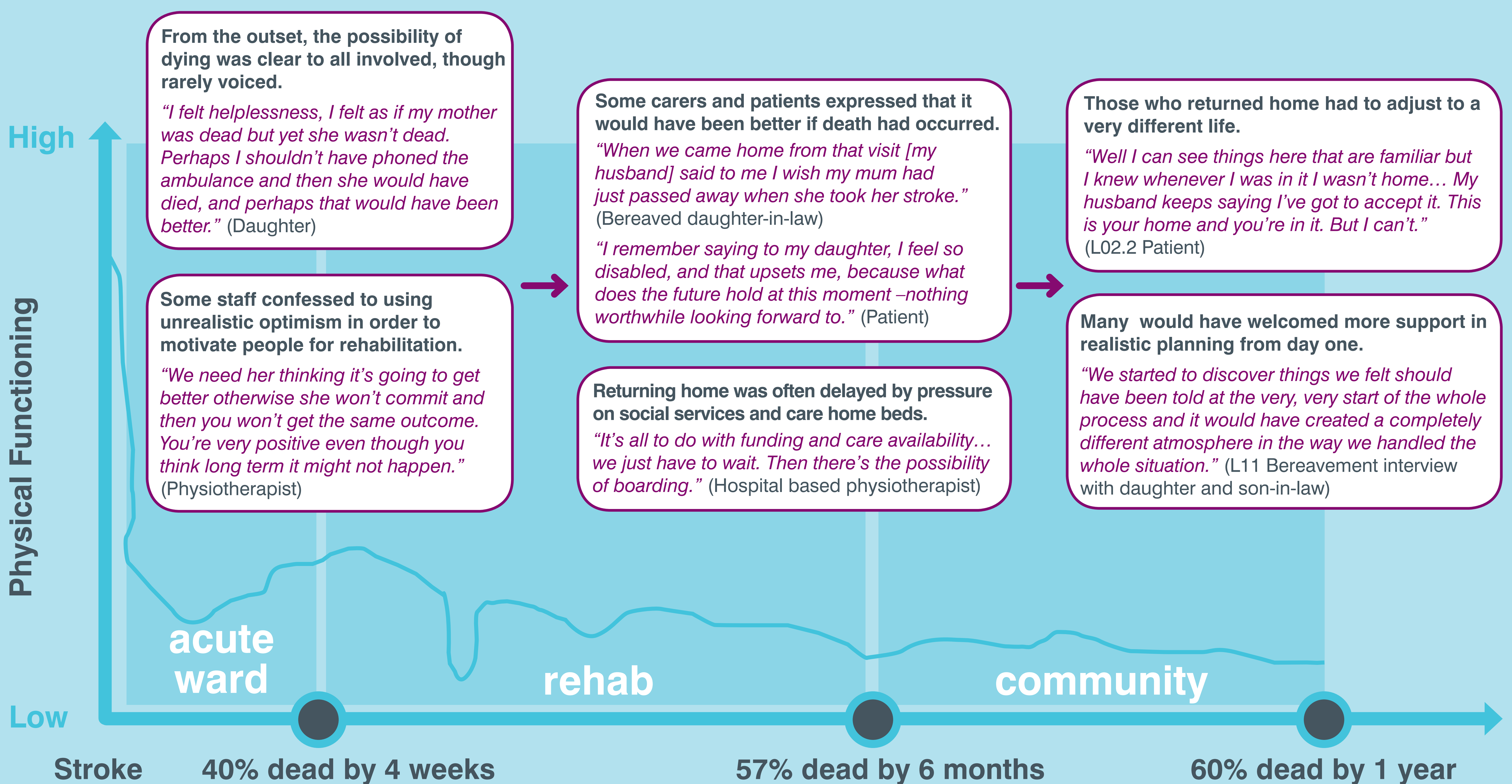
## Background

- 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, Euroqol5D-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



### 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