International Observatory on End of Life Care

Palliative Care in Stroke and Heart Failure

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Overview

- Background – facing the end of life with heart failure and stroke
- Research studies on palliative care needs in heart failure
- Research on palliative care needs in stroke
- Comparsions and implications

Background – chronic illness

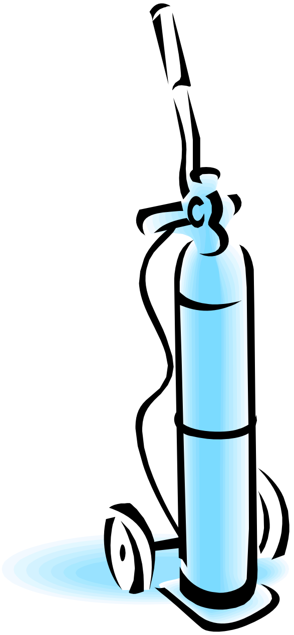
- Demographic changes mean that 83% of people in the UK die over 65 years
- Most die with chronic diseases
- Approximately two thirds of older people will have 2 or more co-morbidities.
- 60% of all deaths could benefit from palliative care (Davies and Higginson 2004)
- First and second main predicted causes of death in 2020 are ischaemic heart disease and cerebrovascular disease including stroke (Murray and Lopez 1997).

Heart failure

- HF is the cause of at least 4% of all deaths in the UK per year (British Heart Foundation).
- Over 100,000 hospital admissions due to HF annually (Adams & Zannad, 1998).
- HF has been called a ‘disease of older people’, affecting approximately 7% of those aged 75-84 years and 15% of those aged 85 years and older.
- HF has a poor prognosis and has high level of unmet palliative care needs.

Heart failure - characteristics

- Breathlessness
- Oedema
- Fatigue
- Mobility problems
- Anxiety
- Depression
- Sleep disturbance



Stroke

- Stroke is the third most common cause of death in the UK, with 26,400 people dying annually.
- About 20% of patients die in the acute phase of stroke (first 28 days).
- 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.

Stroke characteristics

- Hemi-paresis
- Speech and language problems
- Swallowing and eating difficulties
- Mobility problems
- Pain
- Emotional and social difficulties
- Fatigue

Access to specialist palliative care

Evidence that access to specialist palliative care is less likely for:

- People with conditions other than cancer
- Older people
- Black and ethnic minority groups
- Where prognosis is uncertain
- Where professionals do not recognise that the person is dying or do not recognise palliative care needs and make referrals.

(Ahmed et al *Palliative Medicine*, 2004, 18 (6), 525-542)

Dilemmas in providing specialist palliative care for all

Summary of debate:

- ‘flood-gates’ argument – services will be overwhelmed
- Skills of specialist palliative care practitioners
- Do patients with other conditions have needs and levels of symptom burden that merit palliative care?
- Do palliative care interventions benefit those with other conditions?
- When should patients be referred when prognostication is uncertain?
- Are hospice and specialist palliative care services acceptable to those with other conditions?
- Funding and resources

(Field and Addington-Hall 1991; Addington-Hall 2004)

Important questions about palliative care in heart failure and stroke

- What are the palliative care needs of patients?
- What are the patterns of physical and psychological symptoms?
- How are patients recognised to be dying and what referrals are made?
- What is the impact on family caregivers caring for patients near the end of life?
- What are the views of health care professionals about end of life care in heart failure and stroke?

Initial qualitative study

- Interviews with 20 older people (60-83 years) with end-stage heart failure.
  - – Psychological – sadness, depression.
  - – Preparation for life closure and dying process.
  - – Social/practical – aids for daily living required.
  - – Physical – mobility, fatigue, breathlessness.
  - – Spiritual – existential concerns.
- 5 focus groups with 59 staff from a variety of backgrounds and experience.

(Horne and Payne, *Palliative Medicine*, 2004, 18 (4), 291-296)

Sheffield Palliative Care in Heart Failure Project Team

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4 School of Health Studies, University of Bradford

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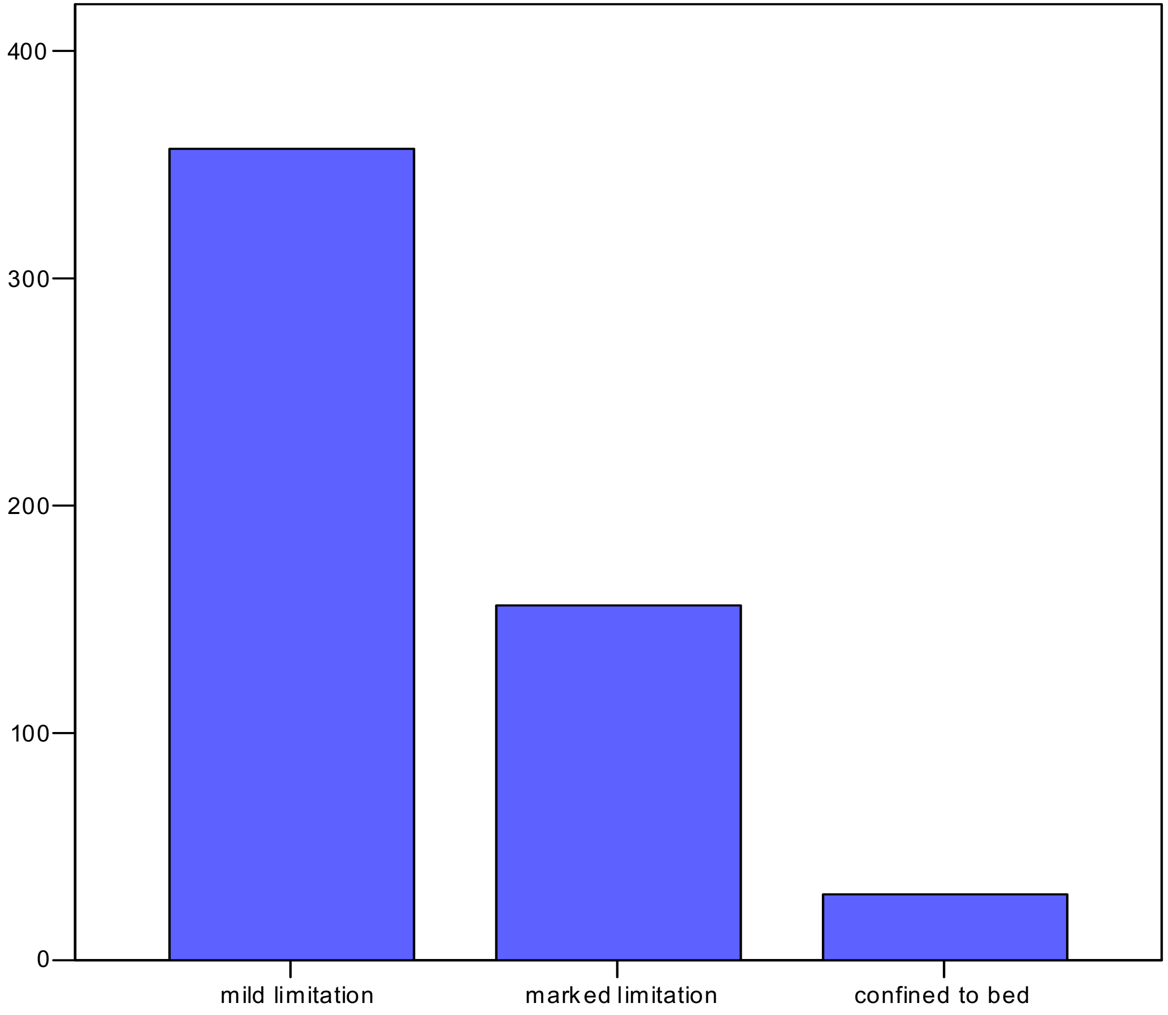
Methods

- Baseline data from a 3-year longitudinal study exploring the palliative care needs of 542 people with HF aged >60 years and 213 nominated informal carers.
- Completing quality of life and service use questionnaires every 3 months for 24 months, 53% still participated at 24 months, 14% died.
- Qualitative data gathered via 40 patient interviews, 15 carer post-bereavement interviews and 9 focus groups with primary care professionals

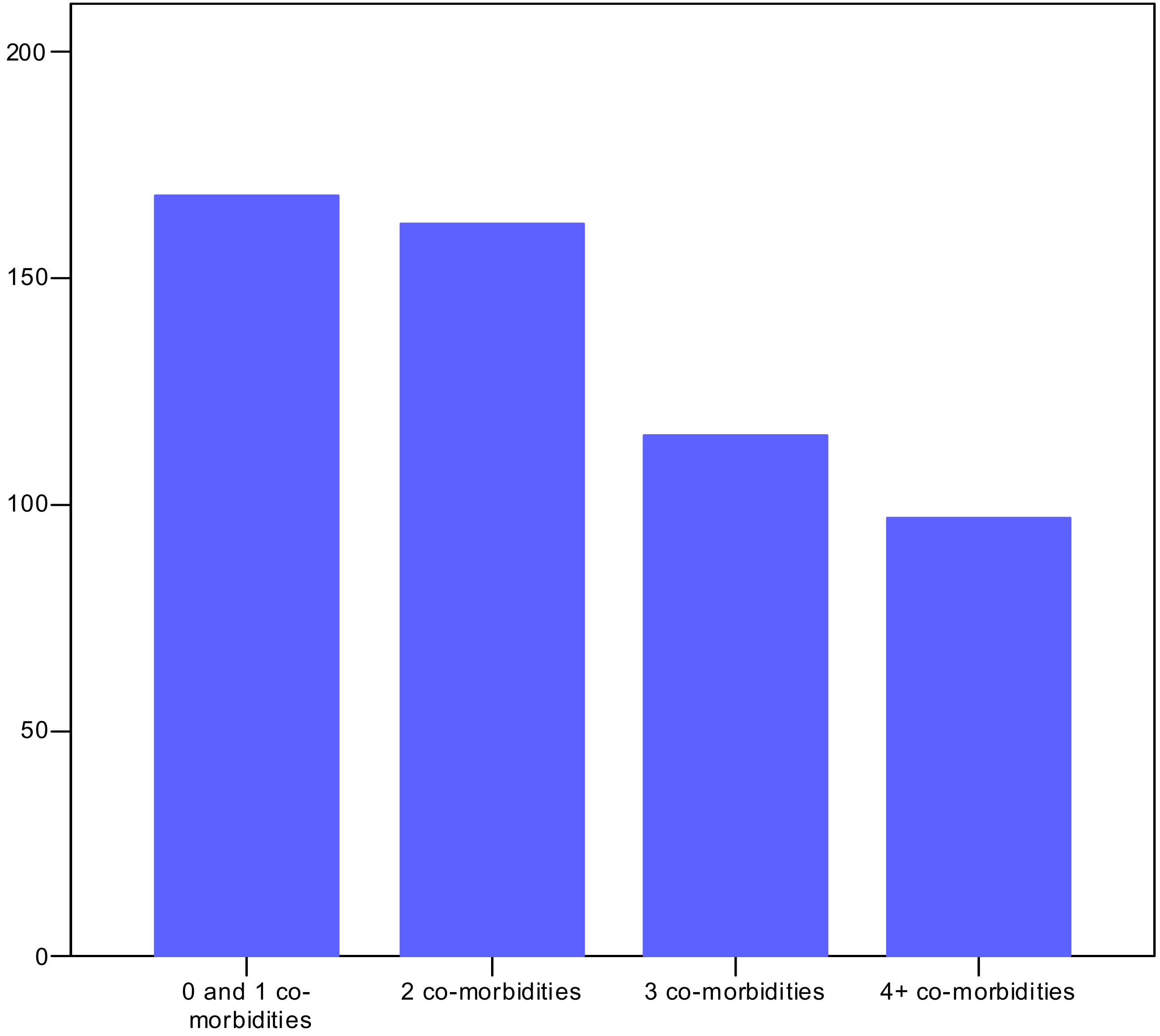
Recruitment of patient sample

- Patients recruited from 16 GP surgeries in four areas of the UK: Bradford, Barnsley, East Devon and Hampshire. These areas were selected to maximise demographic variability on key factors (rural/urban; presence/absence of heavy industry; socio-economic status).
- Pragmatic means of identifying HF patients from GP records (Seamark et al, 2002)
- Focus on patients with NYHA stages II-IV

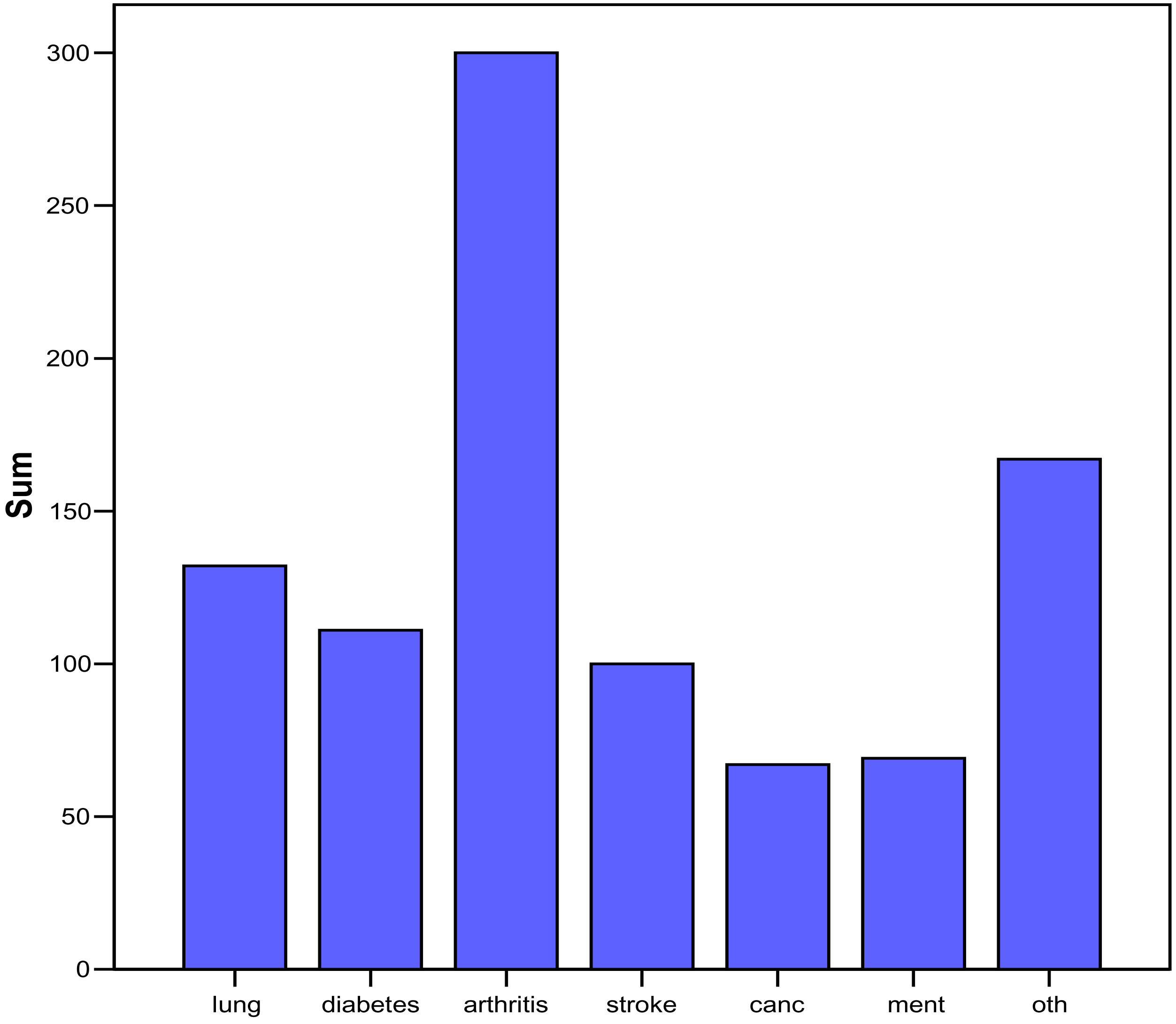
Functional status at baseline



Number of co-morbidities



Nature of co-morbidities



Main findings - symptoms

- High prevalence of symptom burden

- Over 50% daily high levels of breathlessness and/or fatigue.
- Symptoms severely restricted daily life.

"it's the tiredness that affects me most." (Female, 85 years)

- **Quality of Life** – difficult or challenging
- **Survival time** – 74 deaths (14%) – more likely to die if male, NYHA IV, over 85 years, co-morbidity of cancer.
- **Trajectory of illness** – no typical pattern.
- **Co-morbidities**

"Apart from the angina, the diabetes and me giddiness I'm as fit as a fiddle!" (male, age 85)

"but I'm, you get worried not, er, I'm not afraid of being dead but I'm worried about dying. I don't want to die and I don't want to know that I'm dying, I want to die in my sleep"

(Heart failure patient, 16)

Main findings – communication

- **Communication** - patients report inadequate information and few discussions of prognosis.
- **Advance care planning** – little evidence identified.
- **Patient and carer education** – none.

“Is it going to be painful? I’m frightened of pain, I’m no hero, so it’s just not knowing what’s going to happen… so that’s about the only concern I have, not am I going to die, but how am I going to die [laughs].”

(female, 83 years)

“many a time he’ll sleep and all at once he’ll stop, he’ll stop breathing and I’m stood and watched, he doesn’t know like cause I’m watching but…I’ve counted 30 before he’s (sigh). I’ve thought O God he’s alright, you know, it just stops”

(Wife of heart failure patient 5)

Main findings – service utilisation

- Most care provided by primary care.
- Continuity of care valued but less likely to be received in urban population.
- 25% reported social services input.
- Overall high levels of patient and family satisfaction with health care.

“Someone offered to cook my meals, but some days I’m not really hungry…so it is no good having anybody coming in if you don’t feel like eating…I couldn’t eat a big meal.”

(female, 88 years)

Main findings – family carers

- 76% carers were female, 70% aged over 60 years, 73% spouse of patient.
- High levels of carer strain

“He is suppose to be my main carer but at the moment I think its me looking after him more than the other way round.”

(female patient, 71 years, spouse carer, 79 years)

- Bereavement support – very little provided.

“I never heard another word from the practice at all…I got nothing from his GP. Not even a phone call or anything.” (daughter, 54 years)


A BIT OF HEAVEN FOR THE FEW?

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Palliative care in acute stroke

Research Team

- Sheila Payne, Lancaster University
- Professor Julia Addington Hall, University of Southampton
- Dr Chris Burton, University of Bangor
- Dr Tony Stevens, Lancaster University
- Amanda Jones, Stroke Nurse Consultant, Sheffield

The STROKE Association

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Aim and Objectives of Research

- 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.

Study design

- Critical appraisal of the literature

  (Stevens et al *Palliative Medicine*, 2007, 21, 323-331)

Phase 1

Assessment of palliative care needs in prospective cohort of acute stroke patients and their families (n=191) recruited from 2 general hospitals. Measures:

- 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

Phase 2

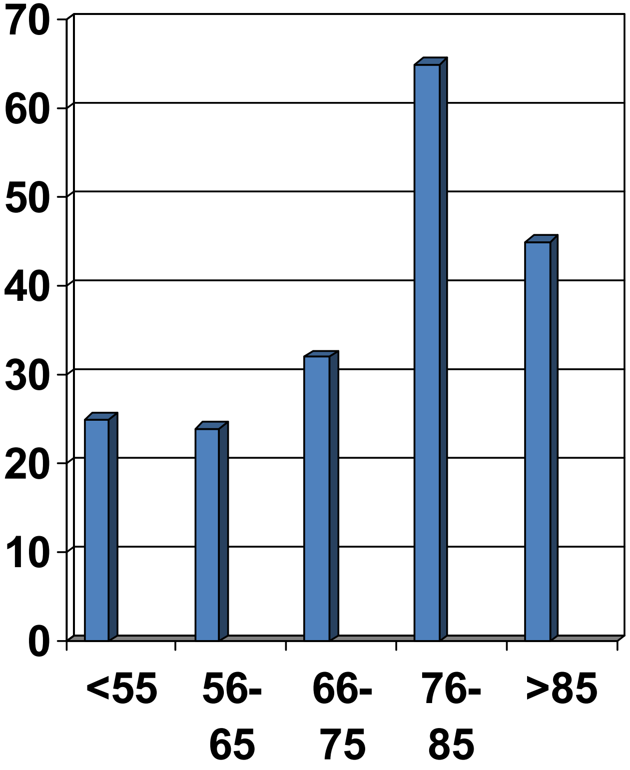
Health professionals working with stroke patients

- Focus groups with 30 stroke unit staff

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%)
- 59% relatives wanted more information, while 69% patients did not.
- Specialist palliative care team referral – none.

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Focus groups with stroke service staff

- Concerns about withdrawal of active treatment and rehabilitation.
- Difficulty in identifying and communicating poor prognosis.
- Difficulty in communicating with families about loss.
- Difficulty in recognising and acknowledging dying until very late.
- Lack of understanding of specialist palliative care.

More questions than answers

- Do specialist palliative care providers have the capacity and skills to supply these needs?
- Is there a role of a general palliative care leader/advocate amongst heart failure and stroke specialist staff?
- What are the educational needs for heart failure and stroke team members to increase their knowledge, skills and confidence in general palliative care?

Thank you for listening.