The role of heart failure specialist nurses in palliative care

The view from the UK

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Disclosure

No conflicts of interest
The problem

- Unpredictable trajectory
- Complex management regimes
- High rates of unmet needs:
  - symptom management,
  - communication,
  - decision-making,
  - emotional support,
- Co-ordination of care
- Quality of end of life care
Service configuration change

• From designed to react to acute problems to

• Pro-actively address individuals’ concerns in the context of:
  – Wider community
  – Systems of health and social care
  – Overarching national policies

• “micro”, “meso”, “macro” chronic care model

The heart failure nurse as key worker

• L Blue et al BMJ 2001
  – RCT reduced readmissions (any cause or HF) and days in hospital
• Home/phone visits
  – Educate about the condition
  – Optimise cardiac treatment (drugs/diet/exercise)
  – Teach self-management
  – Liaise with other health/social care
  – Psychological support
• Widespread investment in heart failure liaison nurses initially through the British Heart Foundation
• Primary role: optimising heart failure management
• Evolving role
• Therefore – what is the HFNs role in palliative care?
Evolving role: NICE Quality standards: people with CHF are -

- offered personalised information, education, support and opportunities for discussion throughout their care

- cared for by a multidisciplinary heart failure team .......consisting of professionals .....from primary and secondary care, and are given a single point of contact for the team.

- [following HF admission]have a personalised management plan that is shared with them, their carer(s) and their GP.

- people with moderate to severe chronic heart failure, and their carer(s), have access to a specialist in heart failure and a palliative care service.
Audit Feb- July 2006  (Millerick)

- Highly symptomatic with many care needs
- 73 patients generated 887 patient contacts over 6 months
  - average 12 per patient
    - home visits, hospital admission, clinic and telephone contacts,
- 482 home visits (6.6 per patient, range 1 – 18)

Maximum tolerated evidence based therapy
  - NYHA class III or IV
  - Combined diuretic therapy
  - Multiple contacts (hospital admission/home visit and telephone contact)
  - Renal impairment
  - Opioid prescription
Glasgow and Clyde palliative care project report 2006 - 2009 (Millerick 2010)

- Can supportive and palliative care role be encompassed within the HFNS’s role?
  - Most “yes” but some said “no”
  - Time-consuming
    - 1.5 hours average consultation to include S&PC issues
    - 20 – 30mins for “usual” home visit
    - 15 mins for “usual” clinic visit
- Education and training needs, including communication skills
- Important to work with specialist palliative care colleagues
- Earlier identification improved with the criteria, but still patients being missed

National picture: national survey
Johnson MJ et al EJCN 2011

- Do you provide general palliative care?
  - 2010: 83%

- Does specialist palliative care has a role in providing care for patients with advanced HF?
  - 2005: 151/152 (99%)
  - 2010: 163/168 (97%)

- Referral criteria for specialist palliative care?
  - 2005: 53%
  - 2010: 68%

- Never referred to SPC?
  - 2005: 29%
  - 2010: 14%

Back to the problem of patient identification again .... Some are better than others.
What helps?

- Local agreed pathways and protocols between heart failure and palliative care
  - Increased referral to specialist palliative care
- Named contacts in palliative care team
- Education and training
- Advanced communication skills
- Integrated working
“They are experts in symptom control and also can access some services much quicker and easier for dying patients. I have found their input invaluable to provide seamless care for dying patients.”

“It seems psychological support of the family and patient are better dealt with, however if I had the manpower and time I feel I could offer the same.”
Different solutions

• “hand over” to the palliative care nurse specialist?
• “hand over “ to a palliative heart failure nurse specialist?
• If so when?
• A pragmatic response
  • Individual team dynamics and skills
  • Individual team balance with heart failure and palliative care expertise
Advance planning – can it work?
Two centre audit

- prospective data on all patients known to the HFNSs, who died during one year (n=126)
- length of HFNS involvement
- planning for end-of-life care
- preferred and actual place of death
- services accessed

Planning for end-of-life care

- “surprise question” documented
- DNA-CPR
- ICD de-activated
- referral to SPC services
- preferred place of care/death
- actual place of death
- anticipatory end of life medication was dispensed

Preferred Place of Death Compared with Actual Place of Death

Preferred known for:
78% S
55% B/A
Heart failure nurses have a very clear and effective role in palliative care
BUT

- Not an explicit part of the role
- And
  - Time consuming
  - Emotionally costly
- And
  - HF with preserved ejection fraction
  - Co-morbidities and frail elderly
The way ahead?

- Explicit part of role
- Training/education in palliative care
- Support (clinically and personally) from palliative care services
- Support from cardiology team (e.g. ceiling of care decisions; communication)
- Clear integrated clinical teams, pathways and referral criteria between palliative care and cardiology
- Resource the teams
  - Workforce issue
EAPC taskforce

- Supportive and palliative care for people with heart disease
- Steering group
  - Palliative care/cardiology or geriatric representation from 6 member states
- Launch at the EAPC world congress in Lleida, Spain in June 2014
- 5 workstreams: needs assessment; symptoms and management; ethics; education/training; research
- Anyone interested: contact miriam.johnson@hymns.ac.uk
Thank you

- On behalf of:

Scarborough heart failure-palliative care MDT
- Sharon Parsons
- Janet Raw
- Annette Docherty