Palliative care of people with end-stage heart failure

Miriam Johnson
Overview

Definition
Why heart failure patients?
Does it make difference?
What’s so difficult?
How?
terminology

- End of life care
- Terminal care
- Care of the dying
- Palliative care
- Supportive care
- Patient-centred care
Patient centred care

• NICE, ESC and AHA have recommended a patient-centred approach for CHF.
• An agreed global definition is lacking but include
  – respect for patients’ needs, values, preferences,
  – patient-healthcare professional collaboration,
  – shared decision making

Kane et al Heart Fail Rev 2015 DOI 10.1007/s10741-015-9508-5
Patient centred care

Supportive/palliative care

End of life care

Care of the dying
Overview

Why heart failure patients?
### symptomatic

<table>
<thead>
<tr>
<th>symptom</th>
<th>cancer</th>
<th>CHF</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain</td>
<td>35-96%</td>
<td>41-78%</td>
</tr>
<tr>
<td>Fatigue</td>
<td>32-90%</td>
<td>69-82%</td>
</tr>
<tr>
<td>Breathlessness</td>
<td>10-70%</td>
<td>60-88%</td>
</tr>
<tr>
<td>Insomnia</td>
<td>9-69%</td>
<td>36-48%</td>
</tr>
<tr>
<td>Anxiety/depression</td>
<td>3-79%</td>
<td>9-49%</td>
</tr>
</tbody>
</table>

- Pantilat et al. *J Card Failure* 2010;16:S88
- Ng and von Gunten *J Pain Sympt Man* 1998;16:307-16
- Solano et al. *J Pain Sympt Man* 2006;31:58-69
Knowledge and communication difficulties

A Rogers et al BMJ 2000 321: 605 - 607

- Little lay understanding of disease
- Didn’t understand importance of symptoms and when to call GP
- >50% talked about death and dying
- Socially isolation
- Confusion or short term memory loss
- Difficulties getting to appointments
- Perception that doctors didn’t want to give information

“...they don’t take you into their confidence...either they think you’re stupid..or else not interested..”
Dying of lung cancer or cardiac failure:....
S Murray et al BMJ 2002; 325: 929 - 932

• Heart failure patients have:
  – a different illness trajectory
  – different concerns,
  – a poorer understanding of illness and prognosis,
  – less opportunity to address end of life issues
  – health, social and palliative care services are less readily available

• Care should be pro-active and designed to meet specific needs
GP research database records for deaths in 2009: 27,689 evaluable decedents

<table>
<thead>
<tr>
<th>Number on the palliative care register at time of death</th>
<th>Heart failure only</th>
<th>Cancer only</th>
<th>Heart failure and cancer</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Total N (%)</td>
<td>Palliative care register N (%)</td>
<td>Total N (%)</td>
</tr>
<tr>
<td>Total</td>
<td>3,122 (100)</td>
<td>234 (7)</td>
<td>7,608 (100)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Time between palliative care register and death</th>
<th>Heart failure only</th>
<th>Cancer only</th>
<th>Heart failure and cancer</th>
</tr>
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<tbody>
<tr>
<td></td>
<td>N (%)</td>
<td>N (%)</td>
<td>N (%)</td>
</tr>
<tr>
<td>≤ 1 week</td>
<td>69 (29)</td>
<td>294 (8)</td>
<td>30 (12)</td>
</tr>
<tr>
<td>&gt; 1 week to 6 weeks</td>
<td>40 (17)</td>
<td>755 (21)</td>
<td>61 (24)</td>
</tr>
</tbody>
</table>

Overview

Does it make difference?
Evidence in non-malignant conditions

- Phase III RCT
- N = 105 (COPD [54%], ILD [20%], cancer [18%], heart failure [5%], other [3%]).
- Intervention: a palliative respiratory service for refractory breathlessness integrating palliative care, respiratory medicine, physiotherapy, and occupational therapy.
- Those receiving the intervention instead of usual care had improved mastery over breathlessness. Subgroup with ILD and COPD had better survival at 6 months.
- Higginson et al Lancet Respiratory 2015
Does it make a difference? – evidence in heart failure

- RCT (Brumley R et al JAGS. 2007)
  - housebound/deemed to be terminally ill; 33% had HF.
  - PC arm: increased patient satisfaction; reduced use of services and costs; die at home > hospital.

- PREFER RCT pilot, N=72 Brannstrom M et al EJHF 2014
  - MDT – specialists in heart failure, pall care, OT, physio
  - Improved KCCQ QoL p=0.047; Reduction in total symptom burden p=0.035
  - Increased self-efficacy p=0.041; NYHA improved p=0.015; Fewer rehospitalisations p= 0.009; No difference in mortality
Does it make a difference? – evidence in heart failure

- Phase 3 RCT.
  - IPs with acute HF (single site; N = 232)
  - PC consult and follow-up vs standard care
  - Primary outcomes
    - symptom burden (ESAS), depressive symptoms (PHQ9), and QOL (MLWH) measured at baseline, 1, and 3 months.
  - Secondary outcomes
    - ACP, inpatient 30-day readmission, hospice use or death within 6 months.

Sidebottom A et al JPM 2015; 8: 134 - 141
Findings

• Primary outcome adjusted for age, gender, and marital status.
• Improved symptom burden = 8.39 (PC) vs 4.7 (control) at 1 month (p < 0.001).
• QOL score +12.92 points (PC) vs +8 (control) at 1 month (p < 0.001).
• ACP = only secondary outcome associated with PC (HR 2.87, p = 0.033).

NB – no increased risk of inpatient 30-day readmission, hospice use, and death
Overview

What’s so difficult?
Policy – identifying those in the last year of life

Haga et al. Heart 2012

- 138 consecutive NYHA III/IV community dwelling patients
- Seattle Heart Failure Model:
  - 12% sensitivity; 99% specific
- GSF prognostic indicator:
  - 83% sensitivity; 22% specific
  - 86% met criteria for end of life care
  - 82% difficult refractory symptoms
  - 24% ≥2 admissions in last year for heart failure symptoms
‘Clinical Indicators: Heart Failure’

• NYHA functional class III or IV.
• Recurrent hospital admission for symptomatic / decompensated heart failure despite maximum or optimal tolerated therapy
• Deteriorating renal function
• Persistent hypotension
• Persistent hyponatraemia
• Progressing hypoalbuminaemia
• Difficult physical or psychosocial issues despite optimal tolerated therapy
Prognosis – the “holy grail”

• If we wait until
  – incontrovertible,
  – completely obvious,
  – irreversible,
  – no chance of stabilisation or improvement
  – deterioration

• The patient will be dead
Needs based care

• Systematic and regular holistic assessment
• Identify and triage needs of patient and carer
• Training and support for cardiology and primary care staff

• Service configuration
• MDT cardiology and palliative care
Difficult conversations

- Uncertainty
- Misconceptions
  - 85% patients with ICDs believed that re-programming meant that the heart would stop (Stromberg 2014)
- The elephant in the room (Barclay et al 2011)
- Emerging evidence
  - Allows support for preferred place of care (Johnson et al BJC 2012)
  - “the way that its done”
  - Allows access to services and joined up care
  - Reframing hope

Communication skills needed!!!
(including across settings)
When to involve specialist palliative care?

- Persistent, complex symptoms
- Other support needed, including for family
- Difficult things to talk through
- Preference in place of care
- Local service configuration

- Problem based, *not* prognosis based
- Extended team based, *not* “either/or”

Integrated care
Example 1- palliative heart failure service

- Est 2000 Scarborough, district general hospital; urban/rural
- Palliative consultant led
  - Consultant cardiologist
  - Heart failure nurse specialists
  - Palliative care nurse specialists
  - Communication with primary care (written, nurse liaison)
- Cross setting (hospice, hospital, community); multiple funders
- Multi-disciplinary team meeting
  - Referrals (access to all palliative care services)
  - Education & training
  - Local protocols (ICD reprogramming; subcutaneous furosemide)

Core component 1: cardiology and palliative care
Core component 2: nursing and medical – with opportunities for joint consultation
Core component 3: communication with primary care
Core component 4: key role for heart failure nurse specialist
Core component 5: education and training
Core component 6: audit & evaluation
Example 2 - Caring Together Project

- **Est 2011 Glasgow. Major regional tertiary hospital.**
- **Cardiology consultant led**
  - Consultant palliative physician
  - Heart failure nurse specialists
  - Palliative care nurse specialists
  - Communication with primary care (written, nurse liaison)
- **Cross setting (hospice, hospital, community); multiple funders**
- **Multi-disciplinary team meeting monthly**
- **Reconfigured cardiology service with dedicated palliative cardiology clinic, and medical ACP**
- **Evaluation**
  - Qualitative study
  - Cohort: Palliative care needs of people admitted due to HF
  - Two cohort study (palliative cardiology clinic; usual care clinic): symptoms, QoL, service use, documentation of care plan

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**Core component 1:** Cardiology and palliative care

**Core component 2:** Nursing and medical – with opportunities for joint consultation

**Core component 3:** Communication with primary care

**Core component 4:** Key role for heart failure nurse specialist

**Core component 5:** Education and training

**Core component 6:** Audit & evaluation
**dissemination**

- **Education & training**
  - National
    - Elements of both models being taken up across the UK (exception re configuration of cardiology services) in a responsive manner
    - Sharing of protocols (SCF, ICD)
    - Caring Together: Scottish government funding for team training from each Health Board region using blended learning. Core components rather than specified model

- **Access to palliative care services is a NICE Quality Standard**

- **Despite crucial role of HFNS, but still no clarification in job description, or in training**

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%
What helps?

• Local agreed pathways and protocols between heart failure and palliative care
  – Increased referral to specialist palliative care
• Named contacts
• Education and training
• Communication skills
• Integrated working
Full of practical, evidence-based advice, Heart Failure and Palliative Care: a team approach encourages a multidisciplinary team-based approach. It stimulates joint working between primary care, cardiology and palliative care teams—raising awareness of the problems associated with supportive and palliative care for heart failure patients.

Heart Failure and Palliative Care: a team approach offers invaluable advice for primary care, cardiology and other healthcare professionals including heart failure nurse specialists, consultants, and ward nurses.

This second edition of Heart Failure and Palliative Care: a team approach is an asset for all teams involved in the care for patients with heart failure, and it can be seen as the basis for optimal care. The first edition of this book was received very positively by healthcare providers as one of the first heart failure-specific books about palliative care that addressed theoretical and practical knowledge. Its pragmatic approach opened the eyes of many 'cardiology people' and clarified the importance and relevance of palliative care for their heart failure patients. It also opened the eyes of many 'palliative care people' to see the complexity of heart failure and the need for an interdisciplinary team approach. This second edition of Heart Failure and Palliative Care: a team approach has the same pragmatic and realistic approach and is updated with the latest evidence and insights. In this edition palliative care for heart failure patients is placed in a wider international context and elaborates more on patient experiences and advance care planning.'

From the Foreword by Tiny Jaarsma,
Professor in Nursing Science, Linköping University, Sweden