Palliative care of people with end-stage heart failure

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Overview

- Definition
- Why heart failure patients?
- Does it make difference?
- What’s so difficult?
- How?
What is palliative care?

• “... an approach that improves the quality of life

• ... relief of suffering by means of ...

• assessment and treatment of pain and other problems; physical, psychosocial and spiritual....”

WHO 2002
What is palliative care?

- aims to help patients live as actively as possible until death;
- uses a team approach
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life

WHO 2002
Overview

Why heart failure patients?
symptomatic

- 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

Overview

Does it make difference?
Does it make a difference? – evidence in cancer

- 3 phase III RCTs
  - N = 322 (lung, breast, colorectal, GU). Those with nurse-led, palliative care-focused intervention alongside oncology care had better QoL (P = 0.2) and mood (P=0.02). *Bakitas et al JAMA 2009*
  - N = 151 (lung). Those with early palliative care had a better QoL (98.0 vs. 91.5; P=0.03); less depressive symptoms (16% vs. 38%, P=0.01); fewer received aggressive end-of-life care (33% vs. 54%, P=0.05); median survival was longer (11.6 vs. 8.9 months, P=0.02) at 12 weeks. *Temel et al NEJM 2010*
  - N = 461 (mixed tumour types). Those randomized to monthly SPC had better QoL at the end of life (2.25 [0.01 to 4.49], p=0.05) and satisfaction with care (3.79 [1.74 to 5.85], p=0.0003) at 3 months. *Zimmernann C et al Lancet 2014*
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

• One RCT
  – participants were housebound and deemed to be terminally ill
  – 33% had HF.
  – outcome measures: satisfaction with care; use of services and healthcare costs; place of death
  – PC arm: increased patient satisfaction; reduced use of services and healthcare costs; more likely to die at home than in hospital.

• At least 4 RCTs of usual care or some kind of PC involvement are ongoing: Usual care vs
  – usual care + interdisciplinary, multi-professional pall care consult
  – usual care + home based palliative care
  – usual care + hospital pall care consult prior to discharge
  – usual care + a symptom management and psychosocial care intervention

• PREFER pilot reported Brannstrom M et al EJHF 2014
A carer’s verdict...

• “..when initially introduced to palliative care..and it is explained to you, the first emotion is one of utter relief that someone is offering a safety net in a time of crisis..”

• “..for the first time in a very long time, that feeling of frustration, helplessness and aloneness is dispelled.”
• “..in (my husband’s) case, it boosted his self-confidence and self-esteem, giving him a better quality of life...he was able to manage his disability without the constant need for hospitalisation, thus cutting out stress of some magnitude.”

• “.. It is difficult to separate his relief from mine, because by making his life more bearable, it made my task easier (even though it was still an ongoing 24 hour job), and because my life was made easier, he began to be more relaxed too.”
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
Overview
NICE Quality Standards

• ...offered personalised information, education, support and opportunities for discussion throughout their care to help them understand their condition and be involved in its management, if they wish.

• ...cared for by a multidisciplinary heart failure team ...with appropriate competencies from primary and secondary care, and are given a single point of contact.

• ...[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.
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
• Communication skills (inc across settings)
• 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
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