A palliative care approach for people with advanced heart failure

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Background
Equity in the Provision of Palliative Care in the UK: Review of Evidence

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“More malignant than cancer”

Stewart et al. EJHF. 2001:3(3):315-22
• National and international consensus guidelines recommend a palliative care approach in heart failure

• Current UK policy recommends identification of those requiring palliative care based on prognosis (last year of life)

Heart failure has an unpredictable course and clinicians may not discuss a palliative care approach for fear of causing alarm and destroying hope “prognostic paralysis”

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Prognostic variables associated with last year of life

- Study methods
- Findings

Recognition compared with cancer patients

- Study methods
- Findings

Perceptions of patients, carers and clinicians

- Study methods
- Findings

Synthesis

Clinical recommendations
Explore aspects of a **palliative care approach** for people with advanced heart failure: recognition of need, **transitions** in care and impact on patients, family carers and clinicians
Prognostic markers of the last year of life

- Systematic literature review
- 32 articles included
- Predictors were explored in a single or only a few studies, often in restricted populations
- Gold Standards Framework Prognostic Indicator Guide
- Clinical usefulness?
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• Secondary analysis of contemporaneously collected UK primary care records using Clinical Practice Research Datalink

• Used Quality and Outcomes Framework codes for palliative care registration as a proxy of recognition of the need for a palliative care approach
Heart failure decedents in 2009 were poorly represented on the palliative care register; 7% (234/3122), compared to 48% (3669/7608) of cancer patients.

Palliative-registered heart failure patients were more likely to be entered close to death.
Time from first time coded as on a palliative care register to date of death for each disease group
• First use of CPRD, worlds largest primary care database to explore palliative care
• Able to link to other databases e.g. Hospital Episode Statistics (HES)
• Potential to look at other conditions
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Study methods

Findings
• Explore perceptions of patients, carers and health care professionals regarding the transition to a palliative care approach in heart failure

• Qualitative semi-structured interviews with 19 patients receiving a palliative approach to care, with their carers, and with clinicians
**Patient and carer**

- Symptoms and coping

**Clinicians**

- Communication and understanding
- Recognition of palliative phase
- Decision making and consequences

**Team Roles**
Coping and symptoms

- Coping e.g. humour, stoicism, counting blessing, family support, life experiences, belief systems
- Symptoms variety and distress
- Social isolation and reducing social world
- Not so evident in clinician interviews, symptom (need based recognition), literature on hope humour maintain person hood, services such as day hospice for social isolation
Communication and understanding

- Patient and carers quickly and readily talked about their deteriorating health dying and death and in detail
- Clinicians very concerned to bring up conversation
- Key finding: looked at deviant cases (“duty of doctor”)

Recognition of palliative phase

- Variable disease trajectory discussed by both groups
- Patient often “palliative” for long periods (sampling strategy)
- Clinicians concerned about getting timing right (when irreversibly physically deteriorating)
- Patients more accepting of uncertainty and positive at times “got to see my grandson”
Decision making and consequences

- Explored each dyad/triad recognition could be patient initiated

- Just needs decision to be made, no dissent in team

- Leads to consequences such as access to services
The noise started in the hospital at half past six on a morning, early morning shift of nurses coming in and doing those who had messed the beds, you know. But it was the noise that they made doing it and the lights are all on, and that was still happening at half past eleven at night. I said “When do I get any sleep?” So eventually I grabbed the doctor and said “I must go out. If I’m going to die I’ll die in bed at home, not here. It’s too noisy, wouldn’t be able to die for people making a noise.”(Patient 7)
Patient: I’m planning ahead for the future because I know what’s going to happen and I want to be prepared for it. I don’t want to leave [wife] with a lot of odds and ends to tie up. They’ll all be ready and in place.

Wife: He still hasn’t got, shown me how to do the television yet [laughs] so he can’t go yet.

Patient: Well SON will show you how to do that.

(Patient 13)
Team roles

- More from clinicians than patients
- Fluidity of teams, different roles in each patient
- May never meet, communication often on need/task basis
- Seem to respect each others input
- No clear responsibility, who initiates conversations
- Different approach proactive v reactive; regular visits v patient initiated
- Also comorbidity, specialism and complex balance of treatments
• Clinicians’ fears about initiation of difficult conversations were unfounded in this group

• The approach to care was felt to be beneficial even in those who stabilised or improved

• Uncertainty should not prevent exploration of patients’ wishes about the focus of their care
Synthesis
• A palliative care approach before the very end of life is beneficial in this group

• A problem based flexible approach to recognising the need for palliative care rather than prognosis is recommended

• Focus less on predicting when patients will die but more on palliative care assessment of needs and future aims of care
Future research
Rollout and monitor results of wide implementation

If successful

Evaluation-with comparison- use randomised trial or appropriate alternative. Assess outcomes and intervention processes

If successful

Feasibility of intervention AND study design and mechanism/active ingredients

If successful

Theory, development and modelling – try to understand mechanism of intervention

Consider implementation implications at each step
An integrated palliative and respiratory care service for patients with advanced disease and refractory breathlessness: a randomised controlled trial

Prof Irene J Higginson, PhD, Prof Claudia Bausewein, PhD, Charles C Reilly, PhD, Wei Gao, PhD, Marjolein Gysels, PhD, Mendwas Dzingina, MSc, Prof Paul McCrone, PhD, Sara Booth, MD, Caroline J Jolley, PhD, Prof John Moxham, MD

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Antoine de Saint-Exupery: ‘if you want to build a ship, don’t drum up people together to collect wood and don’t assign them tasks and work, but rather teach them to long for the endless immensity of the sea’
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References


Thank you

Any questions or comments?