Heart Failure
Vital steps for palliative care

Dr Karen J Hogg
Glasgow Royal Infirmary
Overview

• Why is heart failure a problem?

• Why do we need integrated cardiology and palliative care services?

• Cardiology barriers

• The Glasgow service & the core components of care

• Next steps and challenges
Why is heart failure a problem?

**Poor Prognosis**
- 30-40% patients diagnosed with heart failure are dead within 1 year

**Ongoing symptoms despite treatment**
- High symptom burden

**Complexity of care**
- Elderly
  - Multiple co-morbidities
- Rx options increasing in complexity
- Variety of social care issues
- Social & family care burden is high

**Poor understanding about heart failure & its implications**
- Many patients are not told they have “heart failure” or don’t understand what that means
- “Expectation gap”
Why is heart failure a problem?

- Poor Prognosis
- Ongoing symptoms despite treatment
- Complexity of care
- Poor understanding

Uncoordinated care
Why is heart failure a problem?

- Poor Prognosis
- Ongoing symptoms despite treatment
- Complexity of care
- Poor understanding about heart failure

Uncoordinated care

- Aspects of care left unmanaged
- Hospital admissions (prolonged) ↔ readmissions

Poor QoL

Death in hospital
Why is heart failure a problem?

• Patients with heart failure
  – Inequity of access to palliative care services
    • UK survey of patients receiving palliative care (1997-98)
      – 1094 patients had cardiac disease
      – 62499 patients had a cancer diagnosis
    • The National Council for Palliative Care (2005)
      – “Patients dying of advanced heart failure remain disadvantaged compared to peers with cancer in terms of symptom control, management, communication and access to palliative care support networks”
  – Less likely
    • Involved in health care planning & end of life discussions
    • Access to social and financial supports
    • Placed on palliative care register

Allen et al. JAMA 2008;299:2533-42
Murray et al. BMJ 2002; 325: 929-932
Why do we need palliative care for patients with heart failure?

- **YC (68yr old female)**
  - Ischaemic cardiomyopathy with severe LVSD
    - Late presentation MI complicated by VF arrest aged 50
  - Multiple comorbidities
    - Poorly controlled Type 1 DM
    - Hypertension
    - Mild renal impairment
    - COPD (Smoked 40-60 cigarettes per day)
  - Management
    - Shared care local cardiology team, Tx team, HFLN & 1° care team
    - Optimal doses of evidence based medical therapy
    - CRT-D
    - Not for cardiac Tx
Why do we need palliative care for patients with heart failure?

- 8yrs after index event before she had 1st HF admission
- Over the next 3 years
  - 12 admissions with HF (300 bed days)
  - 4 admissions with shocks from device
    - Single shocks deteriorated to multiple shocks
  - Worsening symptoms
    - Struggling with ADL
    - Housebound unkempt and depressed
    - Leg ulcers with recurrent cellulitis
    - Cachectic
  - Symptomatic hypotension & renal impairment
    - Medical therapy reduced
- CP had raised concern about her active device and no management plan but her concerns were not shared by the medical team
Why do we need palliative care for patients with heart failure?

- **Final admission**
  - Pulmonary oedema and shocks from CRT-D
  - Multiple attempts at central line access
  - IV Frusemide & IV Amiodarone
  - 21 shocks from CRT-D & external defib prior to death
  - Failed attempts at overdrive pacing
  - Anaesthetist was called to discuss admission to ITU
  - Family were not present
  - Died in CCU in the procedures room

- **Discussion with the family**
  - “shocked” – didn’t realise how unwell she was
  - “hospital admissions & shocks from device were signs that this would happen so soon?”
  - “were the shocks prior to death painful?”
Why do we need palliative care for patients with heart failure?

• Despite technically good “cardiology” care
  – Poor QoL
  – No early identification and planning despite being at a ceiling of treatment
    • Uncoordinated care including EoL care
    • Uncomfortable & undignified death in hospital
    • Discharges from device hours prior to death
    • Family viewed her predictable death as a “sudden death”
      – Unsupported
      – Many unresolved issues mainly related to
        » Poor planning & communication
Definitive cardiology decisions

Frequent hospital admissions

Frequent discharges from CRT-D

Increasing symptom burden despite optimal treatment

Worsening renal function

Anorexia, Wt Loss, Cachexia

Support for patient or carers

Advanced care planning

Consideration of appropriateness of device Rx

Realistic choice for care and EOL care

Death in hospital
“Sometimes cardiology intervention is the right approach”

• 59yr old male
  – Severe heart failure
    • Secondary prevention ICD
    • Ischaemic aetiology – previous MI, CABG
  – Severe aortic stenosis
    • Not candidate for surgical intervention
  – Multiple hospital admissions with heart failure
    • SOB, nausea, pain from oedematous ulcerated cellulitic legs, exhaustion, chest pain, exacerbations COPD
Sometimes cardiology intervention is the right approach

• Further admission to hospital
  – Managed on general medical ward
  – Discharged home with no cardiology follow up
  – Medical discharge letter
    • “Terminal heart failure”
  – 10 days after discharge patient admitted to local hospice for symptom management by GP
    • Leg pain
    • Nausea, vomiting and anorexia
Sometimes cardiology intervention is the right approach

• **During hospice admission**
  – Leg pain and nausea were managed well
    • Felt much better, started eating and drinking more
  – Developed abdominal distension, chest clear, no peripheral oedema.
  – Renal function deteriorated eGFR 40 - 20 and creat 168 – 357
    • Diuretics stopped
  – **Chest pain**
    • Morphine
    • ISMN was added
      – Result was acutely hypotensive in the context of severe AS and severe HF
        » Cardiogenic shock
        » Active ICD
        » Family were not prepared for him to die
  – **Discussed with cardiology** – “how can we deactivate patients device?”
    • Transferred to the cardiology unit
Sometimes cardiology intervention is the right approach

- **Cardiology**
  - Nitrate stopped, IV frusemide, IV dobutamine, increased oral thiazide
  - Off-loaded and stabilised
    - BAV procedure to open the Aortic valve
  - Next 3 months was worked up for TAVI
  - TAVI procedure
    - Doing well
    - Heart failure has improved – now moderate LVSD
    - Still has painful weeping legs but he is able to mobilise more and gradually the legs are improving as is his nausea with mobility, improved heart failure and medical therapy
Sometimes cardiology intervention is the right approach

• **Problem**
  – No appropriate cardiology follow up
  – No early identification
  – No anticipatory care planning for
    • Medical care
    • Symptom management
    • Device therapy
    • No identification of priorities and preferences of care
    • No ceiling of therapy
  – Fell under a banner of “*terminal heart failure*”
What is missing?

• Provision of integrated cardiology and palliative care

“Palliative care should be integrated in all settings and by all hospital specialties”

WHO 2014
Why does providing palliative care in advanced HF seem so difficult?

“Discomfort was not necessarily greatest in those dying from cancer; patients dying of heart failure, or renal failure, or both, had the most physical distress”

_Hinton JM The physical and mental distress of the dying. QJM 1963;32: 1- 21_
Why does providing palliative care in advanced HF seem so difficult?

Cardiology perspective:
• Only appropriate for patients
  – Cancer
  – Facing imminent death where the time lines are clear
    • We have to know when patients are going to die

• Impact on HF treatments
  – De-escalation of medical Rx
  – Deactivation of device therapy
  – Not for any further escalation of Rx

• Focus is very much about death

• Difficulty with prognostication
  – “When is the right time?”
Why does providing palliative care in advanced HF seem so difficult?

Increased need for palliative care services

Adapted from Murray, S. A et al. BMJ 2005;330:1007-1011
Why does providing palliative care in advanced HF seem so difficult?

“The physician who can foretell the course of the illness is the most highly esteemed”

Hippocrates

D = clinical decompensation

Sudden cardiac death

Intervention: CRT

Death

Adapted from Murray, S. A et al. BMJ 2005;330:1007-1011
Caring Together Programme
Better end of life care for patients with heart failure

National cardiac palliative care clinical education programme
Core components of care

Understanding what palliative care means & early identification

Cardiology, holistic assessment & management

Coordination, Communication & MDT working

Education & peer support

Patient centered care
WHO Definition of Palliative Care

- Palliative care is an approach
  - improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual
- provides relief from pain and other distressing symptoms
- intends neither to hasten or postpone death
- offers a support system to help patients live as actively as possible until death
- offers a support system to help the family cope during the patient’s illness and in their own bereavement
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- will enhance quality of life, and may also positively influence the course of illness
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, and includes those investigations needed to better understand and manage distressing clinical complications.
Understanding palliative care & Identification of patients with palliative needs

Cardiology

Palliative Care

Cardiology

Palliative Care

Bereavement Care
Understanding palliative care & Identification of patients with palliative needs

- Palliative Care
- Symptom triggers & Hospitalisations
- Heart Failure Treatment
- Death

Functional Status vs. Time
HEART FUNCTION & SUPPORTIVE CARE SERVICE

EARLY IDENTIFICATION

Cardiologist

HF & PC
specialist
nurse

GP    HFLN    GIM    COTE    CARD    AHFU    ACHD

Additional supports

- Long term conditions & finance
- Spiritual care
- Clinical psychology
- SPC
- Day services hospice
  - Breathless
  - Fatigue
  - Anxiety
  - Depression
  - Physio & OT
  - Alternative therapies
  - Patient & support grps

ASSESSMENT

- HF management optimised
  - Medical Rx: ACE-I/ARB, BB, MRA
  - Rhythm management and device therapy
  - Consideration of cardiac Tx
- Fluid balance: diuretic adjustment
- Symptom management:
  - Cardiac and non-cardiac
- Holistic assessment for patient and carer
HEART FUNCTION & SUPPORTIVE CARE SERVICE

IDENTIFICATION

GP    HFLN    GIM    COTE    CARD    AHFU    ACHD

ASSESSMENT

Cardiologist

HF & SC specialist nurse

Finance & Benefits

INTEGRATED & COORDINATED CARE

Integrated HF&SC approach

COMMUNICATION & PLANNING

Case Manager

Care Plans

Network of care
An approach to care
“Coordination & communication

• Following assessment all patients will have:
  – *Tailored care plan*
    • HF Management plan
    • Medical Anticipatory care plan (MACP)
  – *Case manager*
    • HFLN for LVSD
    • HF&PC specialist nurse for non-LVSD
  – *Network of care “communication hub”*
    • Primary & secondary care teams
  – *Pathways of care*
    • Managing inevitable decline
    • Defibrillator deactivation
Medical Anticipatory Care Plan

Patient ACP
- Patient held & led document
- Documents patients’ priorities of care

Medical ACP
- Led by healthcare professional in conjunction with patient
- Designed to guide patient care in different care settings in context of patients’ priorities of care
Summary medical history

Current & anticipated Medical, Device & Symptom management plan

Ceiling of therapy

Priorities of care

Palliative care register

Care manager & emergency contact details
Medical Anticipatory Care plans match preferred place of care & reduce hospital admissions

K Hogg & SMM Jenkins
Medical Anticipatory Care Plans prevent hospital admissions
European Heart Journal (2012) 33 (Abstract supplement) 483-484
The provision of palliative care for patients with heart failure is not difficult

“but changing practice and mind sets is”
Next steps & challenges

• Public Health “close the expectation gap”
  – Development of understanding & education
    • Public, patients, HCPs to understand what a diagnosis of HF means and the implications for patient and families
      – Prognosis, QoL, symptom burden, morbidity

  – Non-palliative care physicians (in particular cardiologists)
    • Understand what palliative care means
    • How early identification and an integrated approach can benefit patients and families rather than an “all or nothing” approach
Next steps & challenges

• Prioritising & ensuring that the provision of palliative care is accessible to all
  – Promote early identification
    • Based on “needs” rather than on prognosis
    • Move the focus from death to quality of life, care & death
Next steps & challenges

• **Service redesign**
  – Sustainable integrated care pattern
    • Most patients do not require direct SPC
    • Delivering the “core components” of cardiac palliative care
    • Within models to suit the locality
    • Pathways of care

• **Training, education and peer support**
  – Core knowledge and skills

• **Collaborative research**
Heart failure vital next steps for palliative care