The role of palliative care in non-malignant disease

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Palliative Care

.. is an approach that improves the quality of life of patients and their families facing the problems 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.

W.H.O. 2002
Statistics / SPCS

• In UK / Ireland:
  – cancer diagnosis in 90% – 95% of patients

• In USA:
  – cancer diagnosis in 75% – 80% of patients

• Caution in interpretation
National policy

• Access based on need, and on need alone
  – Not based on pathology, financial status, postal address

• Patients should be enabled and encouraged to express their preferences about where they wish to be cared for, and where they wish to die

• Services should be sufficiently integrated and flexible as to allow easy movement of patients from one care setting to another
Integrated SPCS

In-patient Unit

Hospital

Spec. Palliative Care

Day Care OPD

Community

Education / Training / Research / Resource Centre
Levels of specialisation

• Level one – palliative care approach
  – Basic principles practiced by all HCPs

• Level two – general palliative care
  – Intermediate level care
  – Sub-specialty interest

• Level three- specialist palliative care
Palliative care for all – Integrating palliative care into disease management frameworks

- C.O.P.D
- Cardiac Failure
- Dementia
- Prevalence / mortality data

HSE / IHF, 2008
Problems – actual / perceived

- Knowledge deficit
- Fear of being swamped / overwhelmed
- Funding concerns, including charitable funds
- Fear of being used to bridge gaps in service provision that is the responsibility of others
- Blocking beds
- Less certain prognostication
- Structure / ambience of facilities
## COPD

<table>
<thead>
<tr>
<th>Stage</th>
<th>Severity</th>
<th>Symptoms</th>
<th>PFTs / FEV1</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Mild</td>
<td>Minimal DOE +/- cough</td>
<td>FEV1 &gt; 80%</td>
</tr>
<tr>
<td>2</td>
<td>Moderate</td>
<td>Mod – severe DOE +/- cough</td>
<td>FEV1 = 50% – 80%</td>
</tr>
<tr>
<td>3</td>
<td>Severe</td>
<td>Severe DOE, fatigue Rep. exacerbations</td>
<td>FEV1 = 30% - 50%</td>
</tr>
<tr>
<td>4</td>
<td>Very Severe</td>
<td>Severely impaired Life threatening Resp. failure</td>
<td>FEV1 &lt; 30% or Chr. Resp failure</td>
</tr>
</tbody>
</table>
Triggers for referral

• FEV1 < 30%
• Severely limited and declining function
• Increasing symptoms despite treatment
• Advanced age
• Presence of multiple morbidities
• Complications of COPD
Assess the patient, not the disease

Assess the patient

Reassess the patient

Assess the patient again
Assess the patient

- Disease status & symptom burden (total)
- Disease trajectory
- Current management / compliance
- Functional status
- Quality of life
- Psychosocial / emotional / spiritual wellbeing
- Support framework
- Accommodation
- Patient’s preferences & needs
# NYHA / Heart failure

<table>
<thead>
<tr>
<th>Class</th>
<th>Patient symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>No limitation.</td>
</tr>
<tr>
<td>II</td>
<td>Slight limitation. Comfortable at rest.</td>
</tr>
<tr>
<td>III</td>
<td>Marked limitation. Easily fatigued / breathless</td>
</tr>
<tr>
<td>IV</td>
<td>Unable to carry out any activity with comfort</td>
</tr>
</tbody>
</table>
Disease status

• Remember, two patients with NYHA stage IV cardiac failure share ONLY the same pathology
• They have different Illnesses
• They have different needs
• They have different expectations
• Etc, etc, etc
Differing views

Patient

Family

HCPs
Malignant vs non-malignant

• Futile discussion
• Understand and apply published policy
• Not all cancer patients have SPC needs
• Not all patients with a non-cancer diagnosis have SPC needs
• Not all patients with SPC needs want SPC
• Most SPC patients have multiple pathologies
Case study 1

• 78 year old man
• Carcinoma of oesophagus / stented
• Carcinoma of prostate / bone metastases / hormonally manipulated / radiotherapy
• Multiple myeloma
• Critical aortic stenosis
Case study 2

- 73 year old priest
- Malignant melanoma right foot
- Extensive right inguinal and hemipelvic metastases
- Gross right lower limb lymphoedema
- Right lower limb DVT
- Previous resection of sigmoid carcinoma
- Evolving dementia / night wandering
Case study 3

• 67 year old lady
• Carcinoma of breast / bone metastases
• C.O.P.D. / frequent infective exacerbations
• Diabetes mellitus
• Peripheral vascular disease
• Ischaemic heart disease / Atrial fibrillation
Cultural influences / care settings

- Patient’s home
- Nursing home
- Community hospital
- General medical ward
- General surgical ward
- Paediatric ward
- ICU / CCU
- Specialist palliative care ward
- Psychiatric in-patient unit
Case study 4

• 82 year old man
• Advanced / end-stage dementia
• In patient psychiatric care for 6 months
• Specialist palliative care review for ‘restlessness’
• Diagnosis: actively dying
  Major concerns re food and nutrition
  Reluctance to administer appropriate medications
  Disquiet re discontinuation of antibiotics
Leeds eligibility criteria

1. Active, progressive disease

2. Extraordinary level of need
   - Physical, psychological, social or spiritual

3. All patients satisfying 1 & 2 above, must be referred by a Specialist Palliative care team

Bennett, M. 2000
Discharge policy

1. Change is disease status / no longer has SPC needs
   Response to treatment / very slowly progressive
2. Symptomatic response / no longer has SPC needs
3. No SPC needs identified at initial assessment
4. Patient requests discharge from SPC service
5. Patient / family consistently obstruct SPC service
Proposal

• Access based on need only
• Underlying pathology is irrelevant
• Prognosis is irrelevant
• SPC needs determined by SPC personnel
• Regular review and if needs are reduced, discharge
• Development of joint clinics
  – Oncology, cardiac failure, copd, neurological etc