Palliative care for patients with non-malignant end stage respiratory disease

Dr Sabrina Bajwah
King’s College NHS Foundation Trust
Cicely Saunders Institute
Aims

• Need for palliative care for non-malignant diseases
• Trajectory of diseases and poor prognostic signs
• Managing symptoms
• Managing psychosocial and end of life planning needs
• How to work most effectively with your palliative care team
Background

• Non-malignant lung disease patients experience pre-terminal disease

• High symptom burden comparable to cancer

• End of life Care Strategy and NICE guidance advocate extension of palliative care services

• Poor access to palliative care services
Background

• COPD
  • 4th commonest cause of death worldwide
  • Gore et al 2000
    • COPD patients scored significantly worse than lung Ca for activities of daily living, physical, emotional and social functioning
    • Less likely to have accepted their illness and more likely to be depressed
  • Edmonds et al 2001
    • No difference in number of symptoms
    • Groups differed in which symptom was most troublesome and their access to palliative care services
Background

• ILD
  • 5,000 deaths in England and Wales each year
  • Bajwah et al 2012 (LUNG)
    • A high symptom burden in last year of life
    • Non-pharmacological treatments rarely used
    • Limited palliative care involvement
    • Limited documentation of EOL preferences

• Bajwah et al 2012 (BMJ Supportive and Palliative Care), Bajwah et al 2013
  • Understanding of disease
  • Symptoms and associated distress- Bajwah et al 2012 (THORAX)
  • Impact of disease
  • Information needs
  • End of life planning
Background

• CF
  • 100 deaths in England and Wales each year

• Stenekes et al 2009
  • 84% had pain, 83% cough and 64% breathlessness

• Braithwaite et 2011
  • Lack of information
  • Challenge of maintaining hope while planning for death
  • Lack of belief that symptoms could be controlled
Table 5 Prevalence of palliative care needs of both hospitals compared to cancer, AIDS, HD, and RD as found by Solano et al. [18]

<table>
<thead>
<tr>
<th></th>
<th>Combined RBH + KCH</th>
<th>Cancer</th>
<th>AIDS</th>
<th>HD</th>
<th>COPD</th>
<th>RD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Shortness of breath</td>
<td>98</td>
<td>10–70</td>
<td>11–62</td>
<td>60–88</td>
<td>90–95</td>
<td>11–62</td>
</tr>
<tr>
<td>Fatigue</td>
<td>29</td>
<td>32–90</td>
<td>54–85</td>
<td>69–82</td>
<td>68–80</td>
<td>73–87</td>
</tr>
<tr>
<td>Insomnia</td>
<td>7</td>
<td>9–69</td>
<td>74</td>
<td>36–48</td>
<td>55–65</td>
<td>31–71</td>
</tr>
<tr>
<td>Anorexia/weight loss</td>
<td>18</td>
<td>30–92</td>
<td>51</td>
<td>21–41</td>
<td>35–67</td>
<td>25–64</td>
</tr>
<tr>
<td>Pain</td>
<td>36</td>
<td>35–96</td>
<td>63–80</td>
<td>41–77</td>
<td>34–77</td>
<td>47–50</td>
</tr>
</tbody>
</table>

Data presented as %
The graph shows a decline in function over time, with markers indicating 'Could die' and 'Death'. The arrows indicate 'Disease modifying' and 'Palliative care'.
Poor Prognostic signs

• COPD
  • At least two of the indicators below:
    • Disease assessed to be severe (e.g. FEV1 <30% predicted)
    • Recurrent hospital admissions (at least 3 in last 12 months due to COPD)
    • Fulfils long term oxygen therapy criteria
    • MRC grade 4/5 – shortness of breath after 100 metres on the level or confined to house
    • Signs and symptoms of right heart failure
    • Combination of other factors – i.e. anorexia, previous ITU/NIV, resistant organisms
    • More than 6 weeks of systemic steroids for COPD in preceding 6 months

• ILD
  • 6 month decline in FVC (10%) and/or DLCO (15%)

• CF
  • Pseudomonas aeruginosa and Burkholderia cepacia
  • Cystic fibrosis related diabetes
Needs assessment

• Triggered by exacerbation
• Use of appropriate needs assessment tool
  • Palliative Care Outcome Scale
  • NAT-ILD
• Holistic assessment
  • Physical - cough, pain, fatigue and secretions
  • Psychosocial - emotional impact of symptoms, coping strategies, fears and concerns for the future
• Advance care planning
<table>
<thead>
<tr>
<th>Symptom</th>
<th>Drug treatment</th>
<th>Additional measures</th>
</tr>
</thead>
</table>
| Breathlessness | Codeine phosphate 15 mg 6-hourly as needed PO  
Morphine IR 2.5 mg 4-hourly as needed PO  
Morphine MR 10 mg daily PO  
Lorazepam 500 µg SL 6-hourly  
*End of life*: morphine 2.5–5 mg SC as needed or CSCl  
Midazolam 2.5–5 mg SC as needed or CSCl | Oxygen if hypoxic  
Pulmonary rehabilitation  
Supportive equipment (e.g. wheelchair or stair-lift).  
Distraction  
Reassurance  
Cool air fan  
Cognitive behavioural therapy |
| Cough        | Codeine linctus 15 mg 6-hourly PO  
Morphine IR 2.5 mg 6-hourly PO  
Methadone linctus 2 mg (in 5 ml) 12 hourly PO |                                             |
| Secretions   | *Clearance*:  
Nebulized 0.9–7 % saline 6-hourly  
Carbocisteine 750 mg 8-hourly PO  
*Suppression*:  
Hyoscine hydrobromide patch 1 mg 72-hourly TD | Sputum clearance physiotherapy  
Cough assist devices  
Oropharyngeal suctioning |
|              | *End of life*: Death rattle  
Hyoscine hydrobromide 400 µg SC 4-hourly as needed or 1.2–2.4 mg CSCl |                                             |
| Anxiety      | Lorazepam 500 µg SL 6-hourly as needed | Reassurance  
Distraction  
Cognitive behavioural therapy |
| Haemoptysis  | Tranexamic acid 1G 8-hourly PO | Bronchial artery embolisation |

CSCI – continuous subcutaneous infusion; IR – immediate release; MR – modified release; PO – orally; SC – subcutaneously; SL – sublingually; TD – transdermal. Although every effort has been made to ensure dosages are correct at the time of printing, please refer to the most recent summary of product characteristics document available before using any of the drugs mentioned clinically. Although every effort has been made to ensure dosages are correct at the time of printing, please refer to the most recent summary of product characteristics document available before using any of the drugs mentioned clinically.
Psychosocial

• “Do you ever feel anxious or depressed?”

• “How do you feel about the future?”

• “What support network do you have?”

• “How is your loved one coping?”
Advance care planning

• Detailed conversations about most appropriate treatment options
  • “What do you understand about your disease?”

• Detailed conversations about end of life preferences
  • “Have you had any thoughts about how and where you would like to be looked after?”

• Documentation of preferences

• Distribution to MDT
Role of palliative care

• The division of care into “active” or “palliative” is inappropriate
• All general palliative care may be delivered by the chest team
• Encourage application of palliative care principles
  “Palliative care is an approach that 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.”- WHO

• Referral to specialist team if needed
• Palliative Care teams may facilitate treatment discussions and advance care planning
• Different models of joint working
Developing and evaluating a Hospital2Home Palliative Care service for patients with severe Progressive Idiopathic Fibrotic ILD phase 0-II

Dr Sabrina Bajwah
Dr Surinder Birring
Prof Irene Higginson
Dr Julia Riley
Dr Joy Ross
Prof Athol Wells
Key components

(1) Poor prognostic signs and limited disease modifying treatment available

(2) Transfer of care from acute to community setting

(3) Medical, nursing, OT/physio, social, spiritual, cultural, end of life care planning needs are considered and met
Case conference

• H2H nurse leads conference where a care plan is developed
• The document is agreed among patient, nurse, and GP/other community staff
• Each stakeholder knows their specific role in the patient’s end-of-life journey
• Advance care planning needs, information needs
• More likely patients will achieve PPC +PPD and symptom control

Illustrative care plan

<table>
<thead>
<tr>
<th>Current issues</th>
<th>What to do</th>
<th>Who to contact</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dyspnoea</td>
<td>Give X medication of X dose kept in X location</td>
<td>Could be GP, district nurse, out-of-hours GPs or ambulance</td>
</tr>
<tr>
<td>Anticipated problems</td>
<td></td>
<td>Where to re-route patient (e.g. hospice) should they deteriorate further beyond home care facilities</td>
</tr>
<tr>
<td>Chest pain</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cough</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anxiety</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Constipation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fatigue</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Care Needs</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Catheter</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Results

• 53 patients were recruited (26 fast-track, 27 control).
• Mean (SD) POS scores at 4 weeks were -5.7 (7.5) fast-track vs -0.4 (8.0) control, (mean change difference between the two arms was -5.3 (95% CI: -9.8 : -0.7) Independent t test p=0.02);
• Effect size (95%CI) -0.7 (-1.2 to -0.1).
• The secondary outcomes of quality of life, anxiety and depression were superior in the fast-track arm
• Qualitative findings corroborated these data.

Summary/Conclusion

• Clear need
• Be aware of poor prognostic signs and facilitate conversations
• Early consideration of what palliative care needs are
• Holistic assessment
• Role of palliative care changes throughout disease journey
• More research needed into different models of care at the end of life
References


- Bajwah S, Higginson IJ, Ross JR, Wells AU, Birring SS, Patel A, Riley J. Specialist palliative care is more than drugs: a retrospective study of ILD patients. Lung 2012;190(2):215-20


