Breathlessness services?

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Outline

• Acknowledgements: work that informed services
• Models: integrated palliative care
• Evidence of effectiveness & cost-effectiveness
• How does it work and what do patients prefer?
Acknowledgements

• Corner: Randomised trial of nurse led clinic in lung cancer
• Booth: Developed understanding and service
• Gysels, Bausewein, Malik, Simon, Reilly, Johnson, Wilcock, Currow, Moxham, Jolley, Farquhar & many more
• Cicely Saunders International – pivotal – allowed us to support bringing together a individuals with interest in breathlessness from different disciplines, respiratory & palliative
Why think of services?

• Numerous interventions to relieve breathlessness\(^4\) but rarely combined & symptom still not managed satisfactorily
• Cuts across conditions: cancer, COPD, heart, neurology
• King’s College Hospital London: 1400 hospital admissions for breathlessness (3700 bed days) per year
• Patients isolated & missed by existing services
• Breathlessness patients - complex: average 14 symptoms, plus psychological, social problems
• Need new services combining respiratory, physiotherapy and palliative care and treatments\(^5,6\)

Need to think about breathlessness differently.

What were you doing last time you got breathless?
Services

Breathlessness Intervention Service
- Cambridge based
- Palliative care led
- Team members incl physiotherapy and occupational therapy
- Primarily home visiting

Breathlessness Support Service
- London based
- Integrated palliative care, respiratory, physiotherapy and occupational therapy
- 2 clinic attendances & home visit to assess environment
- Specific discharge plan

Both
- Similar leaflets, support, fan, walking aids, muscle strengthening, pacing (BSS – ‘pack’, poem & water spray)
- Write to patient regarding meeting, and copy GP/others
Breathlessness Support Service (BSS)

- **Holistic intervention focused on patients & carers**
  Evidenced based interventions

- **Non – pharmacological interventions**
  Anxiety management, emergency planning, fan, walking aids, physiotherapy, occupational therapy, positions to relieve breathlessness, education and support, modification techniques for ADLs, family support

- **Pharmacological interventions**
  optimisation of drugs (e.g. low dose opioids), referral for long term oxygen therapy or short burst oxygen therapy if applicable

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<th>Components of the BSS</th>
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<td><strong>Time</strong></td>
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| Week 1                 | Contact with respiratory medicine  
Assessment of the symptom of breathlessness and its triggers and optimise disease - orientated management  
Contact with palliative medicine  
Explores both the patients and carers experience of breathlessness, leading to the development of holistic breathlessness management intervention (patient tool kit)  
Social worker input  
Patient and/or carer assessment including understanding of disease, symptoms, information needs and coping strategies |
| 1st Outpatient clinic visit |  |
| Week 2-3               | Based on the patients’ needs as assessed during the home visit:  
Physiotherapy & Occupational therapy interventions includes;  
Breathing control techniques, anxiety management, positions to relieve breathlessness, airway clearance, home exercise programmes, education on planning, pacing and energy conservation techniques to patients and carers, optimisation of ADL’s and referral to other community services (local / out of area) as appropriate |
| Home visit             |  |
| Week 4 - 5             | Contact with palliative medicine  
Re-evaluation of breathlessness and other symptoms, reinforcing BSS interventions, referral to medical and / or palliative care services if appropriate and discharging from the service |
| 2nd Outpatient clinic visit |  |
BSS – Patient tool kit

- Hand held fan / water spray
- Information sheets
  - Breathlessness commonly asked questions
  - Managing breathlessness
  - Pacing
  - Hand held fan
  - Distraction techniques
  - Positions to ease breathlessness
- Relaxation CD
- Crisis plan
- Breathlessness poem (Jenny Taylor)
- Home visit by physiotherapy/occupational therapy provides walking aids, home adaptations, exercise DVD or equivalent & reinforces clinic advice

http://www.kcl.ac.uk/ism/research/divisions/cicelysaunders/research/symptom/breathlessness.aspx
Is a specialist breathlessness service more effective and cost-effective for patients with advanced cancer and their carers than standard care? Findings of a mixed-method randomised controlled trial

Morag C Farquhar1,2*, A Toby Prevost3, Paul McCrone4, Barbara Brafman-Price5, Allison Bentley5, Irene J Higginson6, Chris Todd2 and Sara Booth7

Results: BIS reduced patient distress due to breathlessness (primary outcome: \(-1.29; 95\% \text{ CI } -2.57 \text{ to } -0.005; P = 0.049\)) significantly more than the control group; 94% of respondents reported a positive impact (51/53). BIS reduced fear and worry, and increased confidence in managing breathlessness. Patients and carers consistently identified specific and repeatable aspects of the BIS model and interventions that helped. How interventions were delivered was important. BIS legitimised breathlessness and increased knowledge whilst making patients and carers feel ‘not alone’. BIS had a 66% likelihood of better outcomes in terms of reduced distress due to breathlessness at lower health/social care costs than standard care (81% with informal care costs included).

Methods: A single-centre Phase III fast-track single-blind mixed-method randomised controlled trial (RCT) of BIS versus standard care was conducted. Participants were randomised to one of two groups (randomly permuted blocks). A total of 67 patients referred to BIS were randomised (intervention arm n = 35; control arm n = 32 received BIS after a two-week wait); 54 completed to the key outcome measurement. The primary outcome measure was a 0 to 10 numerical rating scale for patient distress due to breathlessness at two-weeks. Secondary outcomes were evaluated using the Chronic Respiratory Questionnaire, Hospital Anxiety and Depression Scale, Client Services Receipt Inventory, EQ-5D and topic-guided interviews.
Effectiveness of early integration of palliative care: in breathlessness support service - randomised trial evidence, UK evidence, NIHR funded

- **105 patients** randomised to early palliative care integrated with respiratory services
- Cancer, COPD, ILD

- **Significant benefit in primary outcome**, a component of quality of life, 16% better in early palliative care group

- **Significant survival benefit**
- **No difference in costs**

Higginson et al Lancet Respiratory Medicine, Dec 2014; 2(12): 979-987
DOI:10.1016/S2213-2600(14)70226-7
Mechanisms of impact

• Gain knowledge
• Reduce isolation and break cycle of ‘invisibility’
• Gain confidence
• Exercise, muscle strengthening
• Tools to help with crisis of breathlessness: fan, walking aids, ‘poem’, plan, positions
• Caregivers learn & accept them doing things
• Pacing
• ‘Breathlessness won’t kill you’
Dedicated service addresses:

Invisibility

• Metaphor capturing breathlessness:
  – nature of symptom of breathlessness / cough
  – interactions with social environment
  – Stigma (e.g. smoking)
  – Insidious onset
  – Non-response from services

• This combination shapes the experience of breathlessness: lack of support

Inclusion of guides for walking etc, addresses
Spiral of Disability

Cardiorespiratory Diseases

Breathlessness

Excess Lactate / CO₂ Production

Muscle Deconditioning

Inactivity

Leg Fatigue

Leg Weakness

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Illustrative quotes: Confidence and how to do things

- … giving you tips on how to do things (physiotherapist and occupational therapist home visit), you know sort of little things like when you’re using the vacuum cleaner, to breathe out when you push it out. Little things like that, you don’t think of. Um, there were quite a few things and they’re logged in the memory bank, but I remember them as I do them it’s become automatic now.’ (patient with cancer)

Gysels et al, submitted, confidential
Discussion & listening to address emotional, social & spiritual response to breathlessness

- Psychological situation
- Personality
- Perception of breathlessness
- Perception of illness
- Cultural background
- Coping mechanisms
- Earlier experiences with breathlessness
- Impact of illness and breathlessness
- Expectations
Tenor of care and integrated approach

• … they both stood up, shook your hand and said ‘hello nice to meet you’, you know? […] How many doctors do you know that […], say ‘take a seat’ […] people don’t even look at you… (patient with cancer)

• I was a bit surprised that they went outside the particular problem […] they talked about my general health and that sort of thing… I suppose it’s interconnected. You can’t have it in isolation. (patient with ILD)

Gysels et al, submitted, confidential
Illustrative quotes about valued interventions and mechanisms by which the BSS improved individual patient’s quality of life and mastery over their breathlessness

‘It’s improved my ability to cope with it better; my breathlessness has improved [...]. Going to the clinic has done that because before I would get into a panic when I was breathless, but now I can sit down use my fan, wet my face, read my laminate (breathlessness poem) and I calm down pretty quick so, that’s is um, it’s funny how a laminate (breathlessness poem) could be so helpful (laughs). It’s embarrassing to know that just that, that writing, to be able to read it it calms me down so well.’ (Female, COPD)

“The advice they gave me which improved me mentally and my walking stick that helped me physically. It’s overall, its good overall, I’m happy. I’m glad. I’m glad I did come.’ (Male, Cancer)
Take home messages

- Breathlessness requires a more integrated approach and is complex
- Not only related to disease within the lung but any deconditioning /weakness
- Breathlessness support services which comprise early integration of skilled palliative care, therapies, and treatments in combination are effective and cost-effective
- Home v clinical attendance and role of respiratory medicine needs further consideration
- Such services should now be rolled out, with exploration of different models of care, and should be funded by health care services
Useful resources

• Breathlessness Support Service resources:
  http://www.kcl.ac.uk/lsm/research/divisions/cicelysaunder/research/symptom/breathlessness.aspx

• Breathlessness Intervention Service resources:
  http://www.cuh.org.uk/breathlessness-intervention-service-bis
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• Project Advisory Board

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