Management of breathlessness

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Cambridge Breathlessness Intervention Service
Overview

1) What?
   - The size of the problem

2) Why?
   - Management challenges

3) How?
   - Management approaches
Prevalent...

Percentage of participants (age >70) reporting restricting breathlessness at each month during their last year of life, by condition leading to death

Johnson et al 2016
Poor quality of life
Psychological morbidity
Social isolation

‘Invisible’
Carer distress and exhaustion
Long trajectory of suffering

“It’s like being strangled while you have a big weight pushing down on your chest”
“It’s terrible to see it......and you feel so helpless, so useless, so useless, I don’t know how you can help really.
“He says he can’t breathe but he has enough air to yell at me”
Dyspnea Is a Better Predictor of 5-Year Survival Than Airway Obstruction in Patients With COPD*  
(CHEST 2002; 121:1434–1440)

5-year survival according to FEV1

5-year survival according to MRC dyspnea scale

Nishimura et al 2002
Breathlessness: the challenges

1. Breathlessness has little relationship to lung function

2. Little evidence for pharmacological palliation
### Current evidence: drug approaches

<table>
<thead>
<tr>
<th>Intervention</th>
<th>Evidence</th>
<th>Clinical recommendations</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Opioids</strong></td>
<td>• 5-8mm improvement in 100mm VAS</td>
<td>• Use if maximised non-drug approaches, or near the end of life.</td>
</tr>
<tr>
<td><strong>Ekstrom 2015</strong></td>
<td>• 4.7, 3.0, 2.9 times more N+V, constipation, drowsy</td>
<td>• Start with low dose eg morphine 1mg bd and 1mg PRN.</td>
</tr>
<tr>
<td><strong>Barnes 2016</strong></td>
<td>• Steady state opioids slightly more effective</td>
<td></td>
</tr>
<tr>
<td><strong>Benzodiazepines</strong></td>
<td>No significant benefit</td>
<td>• Avoid; occasional short term role for acute symptoms eg lorazepam 0.5mg s/l, and in the terminal phase.</td>
</tr>
<tr>
<td><strong>Simon 2016</strong></td>
<td></td>
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<tr>
<td><strong>Oxygen (SBOT)</strong></td>
<td>When pO2&gt;7.3kPa:</td>
<td>• Encourage use of fan instead of oxygen.</td>
</tr>
<tr>
<td><strong>Uronis 2008</strong></td>
<td>• Only benefit in COPD during exercise; 7mm in 100mm VAS</td>
<td>• Individual clinical assessments.</td>
</tr>
<tr>
<td><strong>Abernethy 2010</strong></td>
<td>• No benefit in cancer or ILD</td>
<td>• BTS Home Oxygen guideline 2015: ambulatory oxygen if saturations fall by &gt;4% to &lt;90% during exercise.</td>
</tr>
<tr>
<td><strong>Ekstrom 2016</strong></td>
<td></td>
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<tr>
<td><strong>Bell 2017</strong></td>
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</table>
Breathlessness: the challenges

1. Breathlessness has little relationship to lung function

2. Little evidence for pharmacological palliation

3. Large number non-pharmacological approaches
### Current evidence: non-drug approaches

<table>
<thead>
<tr>
<th>Intervention</th>
<th>Evidence strength</th>
<th>References</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pulmonary rehabilitation</td>
<td>++++</td>
<td>McCarthy 2015</td>
</tr>
<tr>
<td>Neuromuscular electrical stimulation</td>
<td>+++</td>
<td>Bausewein 2008, Pan 2014</td>
</tr>
<tr>
<td>Chest wall vibration</td>
<td>+++</td>
<td>Bausewein 2008</td>
</tr>
<tr>
<td>CBT</td>
<td>++</td>
<td>Howard 2014, Livermore 2015</td>
</tr>
<tr>
<td>Fan</td>
<td>++</td>
<td>Galbraith 2010, Luckett 2017, Kako 2018</td>
</tr>
<tr>
<td>Breathing techniques</td>
<td>++</td>
<td>Borge 2014</td>
</tr>
<tr>
<td>Mindfulness</td>
<td>++</td>
<td>Chan 2015, Malpass 2018</td>
</tr>
<tr>
<td>Relaxation</td>
<td>++</td>
<td>Hyland 2016, Yilmaz 2017</td>
</tr>
<tr>
<td>Walking aids</td>
<td>++</td>
<td>Buasewein 2008</td>
</tr>
<tr>
<td>Acupuncture</td>
<td>+</td>
<td>Lau 2008, Feng 2016</td>
</tr>
</tbody>
</table>
# Evidence: breathlessness services

<table>
<thead>
<tr>
<th>Complex intervention</th>
<th>Description</th>
<th>Outcome</th>
<th>Ref</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kings’ Breathlessness Support Service (AHP/medical OP/home)</td>
<td>105 patients Mixed RCT</td>
<td>Improved breathlessness mastery, and survival</td>
<td>Higginson 2014</td>
</tr>
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<td>Cambridge Breathlessness Intervention Service (AHP/medical OP/home)</td>
<td>53 patients Cancer RCT, phase 3</td>
<td>94% benefited, reduction in distress from breathlessness; cost-effective</td>
<td>Farquhar 2014</td>
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<td>Cambridge Breathlessness Intervention Service (AHP/medical OP/home)</td>
<td>87 patients Non-cancer RCT, phase 3</td>
<td>92% benefited, non-significant trend in reduction in distress from breathlessness</td>
<td>Farquhar 2016</td>
</tr>
<tr>
<td>Three or one sessions of a breathlessness service</td>
<td>156 patients Cancer RCT, phase 4</td>
<td>No difference between one and three sessions; single session cost-effective</td>
<td>Johnson 2015</td>
</tr>
</tbody>
</table>
Acute threat

Threat to survival

Emotional response

Avoidance behaviour
Chronic threat

Breathlessness

Emotional response

Avoidance behaviour
Chronic threat

Breathlessness

Emotional response

Avoidance behaviour
Chronic threat

Breathlessness

Emotional response

Avoidance behaviour
Chronic threat

Breathlessness

Emotional response

Avoidance behaviour
Breathlessness

Thinking

Attention to the sensation
Memories of past experiences
Misconceptions and thoughts about dying

Anxiety, feelings of panic
Frustration, anger, low mood
Breathlessness

Thinking
- Attention to the sensation
- Memories of past experiences
- Misconceptions and thoughts about dying

Anxiety, feelings of panic
- Frustration, anger, low mood

Functioning
- Cardiovascular and muscular deconditioning

- Reduced activity
- Social isolation
- Reliance on help

Clinician version
May 17
Breathlessness

- Inefficient breathing
- Increased work of breathing
- Increased respiratory rate
- Inappropriate accessory muscle use
- Dynamic hyperinflation

Thinking

- Attention to the sensation
- Memories of past experiences
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- Cardiovascular and muscular deconditioning
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Clinician version
May 17
Dynamic hyperinflation

Strong correlation between exertional dyspnoea and end-expiratory lung volume  

*O’Donnell 2006*
Breathing

- Inefficient breathing
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- Increased respiratory rate
- Inappropriate accessory muscle use
- Dynamic hyperinflation

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Clinician version
May 17

Spathis et al. 2017
BTF model role

1. Making sense
   - Explains breathlessness perpetuation, potential role trigger
   - Understand symptom out of keeping with disease severity

2. Motivation and mastery
   - Explains symptom relief when maximal disease management
   - Provides rationale: small change causing ‘cycle of improvement’

3. Management focus
   - Allows initial focus on predominant vicious cycle(s)
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<tbody>
<tr>
<td>Breathing techniques</td>
<td>Relaxation techniques</td>
<td>Pulmonary rehabilitation</td>
</tr>
<tr>
<td>Handheld fan</td>
<td>CBT techniques</td>
<td>Exercise/activity</td>
</tr>
<tr>
<td>Airway clearance techniques</td>
<td>Mindfulness</td>
<td>Walking aids</td>
</tr>
<tr>
<td>Singing therapy</td>
<td>Self-hypnosis</td>
<td>Pacing</td>
</tr>
<tr>
<td>Inspiratory muscle training</td>
<td>Acupuncture</td>
<td>Nutritional supplements</td>
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<tr>
<td>Chest wall vibration</td>
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<td>NMES</td>
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<td>Non-invasive ventilation</td>
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</table>
Mr James (1)

- COPD, stage 3
- Had to retire early from building trade
- Hip/knee pain from osteoarthritis
- ‘Panic’, thought he was dying
- Increasingly housebound since then
- ‘Agoraphobic’, IAPT referral
- Angry, ‘people think I’m loony’
- Excessive use of SBOT
- Initially uncertain about meeting breathlessness service...

“I don’t really like talking about my breathing – it makes it feel worse…”
Mr James (2)

- ‘Thinking’ and ‘functioning’ vicious cycles particularly apparent
- Mr and Mrs James engaged by logic of explanation
- Realised trigger panic episode had made things much worse as could not bear thought of it happening again
- Relieved and briefly tearful, ‘I’m not going mad’
Assessment meeting

1) Gather information
   - Existing coping strategies
   - Expectations and priorities
   - Trigger event
   - Assess Breathing
   - Assess Thinking
   - Assess Functioning
   - Predominant cycle

2) Initiate management
   - Reinforce existing successful self-management
   - Actively manage expectations
   - Use BTF model to help engage
   - Use BTF model and patient priorities to focus management
   - Aim for ‘quick wins’ at first meeting
## Addressing misconceptions

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<tr>
<th>Breathing</th>
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<tbody>
<tr>
<td>“It is natural to think when you are feeling breathless that you need more air in. In fact this isn’t the case - we know that there is plenty of air in your lungs. Try instead to lengthen your out breath, which can make your breathing more efficient and create space for your next breath.”</td>
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<table>
<thead>
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<tr>
<td>“Some people say that they’re terrified that they are going to die gasping for breath. Although this is an understandable feeling, this almost never happens” (Then give a relevant explanation for a particular patient, for example “At that time, waste gases tend to build up in the blood, making people feel calm and sleepy.”)</td>
</tr>
</tbody>
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<table>
<thead>
<tr>
<th>Functioning</th>
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<tbody>
<tr>
<td>“Choosing to make yourself moderately breathless by being active is not harming you. In fact it builds up fitness in your muscles again and can improve your breathing and general health over weeks and months.”</td>
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</tbody>
</table>
‘Breathing’ – example

Recovery breathing

- Fan
- Forward lean
- Focus on the out breath

Practical tips:
- Proactively explain: ‘you don’t need more air in, you need to empty your lungs, which will make space for the next breath’
- ‘Lengthen’ out breath in hyperinflation or hyperventilation, ‘relaxed’ out breath in restrictive lung conditions and lung cancer
- Use: very breathless, panic, extreme hyperinflation
## The fan

<table>
<thead>
<tr>
<th>Study</th>
<th>Outcome</th>
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<tr>
<td><em>Liss and Grant 1988</em></td>
<td>Increase in breathlessness after nasal anaesthesia in COPD patients receiving air or oxygen via nasal cannulae</td>
</tr>
<tr>
<td><em>Booth et al 1996</em></td>
<td>Oxygen and air both reduced breathlessness at rest in advanced cancer, but no difference between air and oxygen</td>
</tr>
<tr>
<td><em>Galbraith et al 2010</em></td>
<td>Crossover RCT showing reduction in breathlessness with fan in 50 patients with advanced disease</td>
</tr>
<tr>
<td><em>Luckett et al 2017</em></td>
<td>Mixed methods analysis of pooled data; 82% benefit, particularly shortening recovery time after activity</td>
</tr>
</tbody>
</table>

“...tiny but so effective... brilliant... definitely it does seem to work”
Action plan for breathlessness

I have had this feeling before – I know it will go away soon

1. I am going to lean forward and use my fan

2. I am focusing on breathing out for longer, gradually longer and longer with each breath out

3. I am gently relaxing and softening my shoulders a little more each time I breathe out

I can do this – I am doing it now
‘Thinking’ – examples

- Address misconceptions about ‘dying gasping for breath’
- Progressive muscular relaxation
- Guided imagery...
Make yourself comfortable
Think about the colour green
Concentrate on green all around you
The green of spring turf on cliff tops
The damp green of misty hillsides
Cricket on a lazy village green
Close your eyes and feel the freshness of green
‘Functioning’ – example

Pedometer and walking programme

- Record daily and/or weekly steps in a diary
- First week baseline activity
- Aim to increase stepwise each week by 10%
- Continue for 6 weeks
Mr James (3)

- Reinforce existing self-management strategies
- Focus on T and F cycles, and goal of walking dog around field

Initial management
- Explicitly address misconception about dying in a panic attack
- Laminated action plan in case feels panic
- Explain that making himself breathless by being moderately active is not harming him
- Turn to fan before oxygen (SBOT)

Next visit
- Start walking programme
- CD with narrative of short relaxation technique for daily practise
Final points

- BTF model: helps make sense of breathlessness, supports motivation and mastery, and provides management focus

- Support patients to practise non-pharmacological techniques, like a ‘daily pill’

- Enhance resilience, actively manage expectations and know when not to talk about breathlessness

Cambridge Breathlessness Intervention Service
www.cuh.org.uk/breathlessness
Key references

- Barnes et al. Opioids for the palliation of refractory breathlessness in adults with advanced disease and terminal illness. Cochrane Database of Systematic Reviews 2016;(3):CD011008


Cambridge Breathlessness Intervention Service

Referral criteria
- Diagnosed cause of intractable breathlessness
- Optimal medical management
- Would benefit from self-management programme

The team
- 1 WTE Occupational Therapist
- 1.2 WTE Physiotherapists
- 0.2 WTE Consultant in Palliative Medicine
- 0.6 WTE Medical PA
- Access to Clinical Psychologist