Pathways to pulmonary rehabilitation: It works, so how do we get people to go?

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Acknowledgements

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- Health Research Council
- Asthma Foundation NZ
## Burden of COPD

<table>
<thead>
<tr>
<th></th>
<th>NZ</th>
<th>AUS</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Prevalence</strong></td>
<td>130,000-330,000</td>
<td>1.45 million</td>
</tr>
<tr>
<td><strong>Rank: cause of death</strong></td>
<td>4&lt;sup&gt;th&lt;/sup&gt;</td>
<td>6th</td>
</tr>
<tr>
<td><strong>Health cost per year</strong></td>
<td>$100-$200 million NZD</td>
<td>$1 billion AUD</td>
</tr>
<tr>
<td><strong>Total financial cost per year (including loss of productivity)</strong></td>
<td>-</td>
<td>$8.8 billion AUD</td>
</tr>
<tr>
<td><strong>Indigenous peoples</strong></td>
<td>Prev. 2.2X higher</td>
<td>Death rate 5X higher</td>
</tr>
</tbody>
</table>

(Shirtcliffe et al., 2007, McKenzie et al., 2010, Town et al., 2003; Broad & Jackson, 2003)
Māori and COPD

- Māori are affected by COPD up to 20 years earlier than non-Māori
- Māori are significantly more likely to be admitted to hospital for COPD than people in other ethnic groups in New Zealand
- Māori (50–64yrs) are 5x more likely to die from COPD-related causes
- Smoking rates are higher for Māori (males 40.2%, females 49.3%) compared with 21% overall (15–64yrs) [MOH, 2009]

‘Diagnosis and management of COPD in Māori and Pacific peoples’, BPAC 2012
Pulmonary Rehabilitation

- One of few interventions shown to significantly ↓ COPD burden
- Usually consisting of 6-12 weeks exercise +/- education
- Delivered in hospital or community
Evidence


N.B. The Cochrane Library is freely available to all NZers via the Ministry of Health Website: http://www.health.govt.nz/cochrane-library
Effect on QOL (Fatigue)

(Lacasse et al., 2006)

Figure 1. Forest plot of comparison: Rehabilitation versus usual care, outcome: QoL - Change in CRQ (Fatigue).

<table>
<thead>
<tr>
<th>Study or Subgroup</th>
<th>Rehab</th>
<th>Usual care</th>
<th>Mean Difference IV, Random, 95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Behnke 2000a</td>
<td>1.63</td>
<td>-0.2</td>
<td>1.83 [1.00, 2.66]</td>
</tr>
<tr>
<td>Cambach 1997</td>
<td>1.25</td>
<td>1</td>
<td>1.25 [0.39, 2.11]</td>
</tr>
<tr>
<td>Goldstein 1994</td>
<td>0.1</td>
<td>-0.28</td>
<td>0.38 [-0.18, 0.94]</td>
</tr>
<tr>
<td>Gosselink 2000</td>
<td>0.63</td>
<td>-0.1</td>
<td>0.73 [0.07, 1.39]</td>
</tr>
<tr>
<td>Griffiths 2000</td>
<td>0.98</td>
<td>-0.13</td>
<td>1.11 [0.75, 1.47]</td>
</tr>
<tr>
<td>Güell 1995</td>
<td>0.8</td>
<td>-0.3</td>
<td>1.10 [0.47, 1.73]</td>
</tr>
<tr>
<td>Güell 1998</td>
<td>0.2</td>
<td>-0.5</td>
<td>0.70 [-0.10, 1.50]</td>
</tr>
<tr>
<td>Hernandez 2000</td>
<td>0.93</td>
<td>0.02</td>
<td>0.91 [0.09, 1.73]</td>
</tr>
<tr>
<td>Simpson 1992</td>
<td>1.18</td>
<td>0.25</td>
<td>0.75 [-0.14, 1.64]</td>
</tr>
<tr>
<td>Singh 2003</td>
<td>0.9</td>
<td>0.06</td>
<td>0.84 [0.29, 1.39]</td>
</tr>
<tr>
<td>Wijkstra 1994</td>
<td>0.88</td>
<td>0.25</td>
<td>0.63 [-0.10, 1.36]</td>
</tr>
<tr>
<td><strong>Total (95% CI)</strong></td>
<td><strong>326</strong></td>
<td><strong>292</strong></td>
<td><strong>0.92 [0.71, 1.13]</strong></td>
</tr>
</tbody>
</table>

Heterogeneity: $\tau^2 = 0.02; \chi^2 = 11.53, df = 10 (P = 0.32); I^2 = 13$

Test for overall effect: $Z = 8.59 (P < 0.000001)$
Effect on functional exercise capacity

**Analysis 1.10. Comparison 1 Rehabilitation versus usual care, Outcome 10 Functional exercise capacity.**

Review: Pulmonary rehabilitation for chronic obstructive pulmonary disease

Comparison: 1 Rehabilitation versus usual care

Outcome: 10 Functional exercise capacity

<table>
<thead>
<tr>
<th>Study or subgroup</th>
<th>Rehab</th>
<th>Usual care</th>
<th>Mean Difference</th>
<th>Weight</th>
<th>Mean Difference</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>Mean(SD)</td>
<td>N</td>
<td>Mean(SD)</td>
<td></td>
</tr>
<tr>
<td>Behnke 2000a</td>
<td>15</td>
<td>0 (103.4)</td>
<td>15</td>
<td>0 (65.1)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>5.7 %</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>0.0 [-61.83, 61.83]</td>
</tr>
<tr>
<td>Booker 1984</td>
<td>32</td>
<td>21 (85)</td>
<td>37</td>
<td>5 (90)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>10.0 %</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>16.00 [-25.33, 57.33]</td>
</tr>
<tr>
<td>Wijkstra 1994</td>
<td>28</td>
<td>9 (87)</td>
<td>15</td>
<td>-28 (141)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>3.9 %</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>37.00 [-41.29, 115.29]</td>
</tr>
<tr>
<td>Total (95% CI)</td>
<td>346</td>
<td>323</td>
<td></td>
<td></td>
<td>100.0 %</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>48.46 [31.64, 65.28]</td>
</tr>
</tbody>
</table>

Heterogeneity: Tau² = 295.31; Ch² = 20.36, df = 15 (P = 0.16); I² = 26%

(Lacasse et al., 2006)
Effect on exacerbations of COPD resulting in hospitalisation

Effect on readmission rates

Figure 2. Forest plot of comparison: 1 Rehabilitation versus control, outcome: 1.1 Hospital admission (to end of follow-up).

<table>
<thead>
<tr>
<th>Study or Subgroup</th>
<th>Experimental Events</th>
<th>Total</th>
<th>Control Events</th>
<th>Total</th>
<th>Weight</th>
<th>Odds Ratio M-H, Random, 95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Behnke 2000</td>
<td>3</td>
<td>14</td>
<td>9</td>
<td>12</td>
<td>16.7%</td>
<td>0.09 [0.01, 0.56]</td>
</tr>
<tr>
<td>Eaton 2009</td>
<td>11</td>
<td>47</td>
<td>15</td>
<td>50</td>
<td>29.9%</td>
<td>0.71 [0.29, 1.77]</td>
</tr>
<tr>
<td>Man 2004</td>
<td>2</td>
<td>20</td>
<td>12</td>
<td>21</td>
<td>18.1%</td>
<td>0.08 [0.02, 0.45]</td>
</tr>
<tr>
<td>Murphy 2005</td>
<td>2</td>
<td>13</td>
<td>5</td>
<td>13</td>
<td>16.2%</td>
<td>0.29 [0.04, 1.90]</td>
</tr>
<tr>
<td>Seymour 2010</td>
<td>2</td>
<td>30</td>
<td>10</td>
<td>30</td>
<td>19.0%</td>
<td>0.14 [0.03, 0.72]</td>
</tr>
<tr>
<td><strong>Total (95% CI)</strong></td>
<td></td>
<td>124</td>
<td>126</td>
<td></td>
<td>100.0%</td>
<td>0.22 [0.08, 0.58]</td>
</tr>
</tbody>
</table>

Total events: 20 (in control) vs 51 (in control)

Heterogeneity: Tau² = 0.61; Chi² = 8.15, df = 4 (P = 0.09); I² = 51%
Test for overall effect: Z = 3.06 (P = 0.002)

(Puhan et al., 2009)
Effect on readmission rates

NNT = 4; 25wks

(Puhan et al., 2009)
Figure 4. Forest plot of comparison: 1 Rehabilitation versus control, outcome: 1.2 Mortality.

- **Troosters 2000**:
  - Experimental: 6 events, 24 total
  - Control: 12 events, 19 total
  - Weight: 67.3%
  - Odds Ratio: 0.19 [0.05, 0.72]

- **Man 2004**: 1 event, 20 total
  - Control: 2 events, 21 total
  - Odds Ratio: 0.50 [0.04, 5.99]

- **Behnke 2000**: 1 event, 14 total
  - Control: 1 event, 12 total
  - Odds Ratio: 0.85 [0.05, 15.16]

**Total (95% CI)**
- Experimental: 58 events, 52 total
- Control: 15 total
- Odds Ratio: 0.28 [0.10, 0.84]

Heterogeneity: $\tau^2 = 0.00; \chi^2 = 1.07, df = 2 (P = 0.59); I^2 = 0\%$

Test for overall effect: $Z = 2.29 (P = 0.02)$

(Puhan et al., 2009)
Effect on COPD mortality

NNT = 6; 107wks

(Puhan et al., 2009)
Pulmonary Rehabilitation

• High quality evidence:
  \( \uparrow \) exercise capacity
  \( \uparrow \) Improved QoL
  (Lacasse et al. 2006)

• For people in hospital with exacerbation of COPD
  \( \downarrow \) mortality rate
  \( \downarrow \) rehospitalisation rate
  (Puhan et al. 2009)
Number of people with COPD in NZ

No. with COPD by GOLD standard

275,480

(Shirtcliffe et al., 2007)
Number of people going to pulmonary rehabilitation each year

- No. with COPD by GOLD standard: 275,480
- No. with COPD participating in PR: 1786 (0.6%)

(Levack et al., 2012)
Māori and Pulm Rehab

- Maori comprise 11% of attendees at Pulmonary Rehabilitation sessions nationally (despite having 34% of all COPD hospitalisations)

Connolly et al. (2008)
Discussion of uptake

- Marked shortfall between number of people with COPD and number of people in PR
- Consistent with figures in UK & Canada
  (Brooks et al., 2007; Yohannes & Connolly, 2004)
- Audit of respiratory services in NZ:
  - Problem with access to PR consistent with lack of investment in respiratory services, in general, nationally (Garrett et al. 2009)
Of those referred for Pulmonary Rehabilitation in 2009, 2569 people were referred, 1786 entered, and 1378 completed (Levack et al., 2012).
So why the poor uptake?
Two populations of interest

• Non-attenders
  – Referred but don’t attend any sessions

• Non-completers
  – Commence PR, but don’t complete required number of sessions.

(Keating et al. 2011)
Non-attendance

- Disruption to established routines
- Travel, transport and location
- Influence of the participant’s doctor
- Lack of perceived benefit
- Inconvenient timing of programme

... plus some minor themes

(Keating et al. 2011)
Non-completion

• Illness and comorbidities
• Travel and transport (again)
• Smoking (odds ratio 0.17)
• Depression (odds ratio 0.55)
• Lack of social support
• Lack of perceived benefit
... plus some minor themes

(Keating et al. 2011)
What about illness perceptions?

- The cognitions (ideas, view, and beliefs) that patient have about their symptoms and illness.

- Formed from
  - Personal & observed illness events
  - Medical sources
  - ‘Popular’ media
  - Friends, parents, the Internet, strangers... etc...
What about illness perceptions?

Systematic literature search:
• 323 paper on IP in cardiovascular med.
• 376 papers on IP in oncology
• 16 published studies on IP and COPD

(Kaptein et al. 2008)
Leventhal’s Common Sense Model

- **Identity** - what do I have?
- **Cause** - how did I get this?
- **Timeline** - how long will I have this?
- **Control** – can this be controlled or cured?
- **Consequences** - what does this mean for the future?
- **Affect** – perceptions of anxiety, depression etc. induced by the illness
Atkins et al. (1984)

• 71 people with COPD prescribed an exercise regime
• Cognitive-behaviour modification versus no additional input
• Intervention resulted in significant improvements in exercise adherence & QOL

... so what was the intervention
The intervention

- Identification of maladaptive illness perceptions
  *I can’t walk very far without getting short of breath, so what’s the use*
- Addressing and changing these beliefs
  *This walking is uncomfortable, but I can handle it. Soon I’ll be able to walk further.*
Investigating barriers and facilitators of access to PR for Maori: a qualitative study

- Dr Tristram Ingham
- Dr William Levack
- Bernadette Jones RN
- Ms Cheryl Davies
- Dr Rebecca Grainger
Methods

- Kaupapa Māori Methodology
- Interviews & focus groups with 14 Māori attending either mainstream or marae-based COPD pulmonary rehabilitation sessions
- Comparative interviews with 7 Pākehā & 1 Samoan
- Grounded theory analysis
- NVivo used for data management
Accessing Pulmonary Rehabilitation:

Two things of interest -

- Getting there for the first time
- Wanting to continue
Accessing Pulmonary Rehab

Before deciding to attend...

After going....
Accessing Pulmonary Rehab

- Past Experiences
  - Of health care services
  - Of exercise
- Attitudes & Expectations
- Practical Things
- Pulm Rehab Experience
Accessing Pulmonary Rehab

Past Experiences

Attitudes & Expectations
- Expected difficulty
- Expected enjoyment
- Expected benefit
- Understanding of COPD
- Views on providers motives
- Mood
- Views on taking charge

Practical Things

Pulm Rehab Experience
Accessing Pulmonary Rehab

Other influences
- Family
- Health care workers
- Information sheets
- Invitation letters
- Initial visits

Past Experiences

Attitudes & Expectations

Practical Things

Pulm Rehab Experience
Accessing Pulmonary Rehab

Past Experiences

Attitudes & Expectations

Practical Things

• Transport
• Timing
• Duration
• Location/venue
• Cost
• Competing commitments (e.g. work)

Pulm Rehab Experience
Accessing Pulmonary Rehab

- Past Experiences
- Attitudes & Expectations
- Practical Things
- Pulm Rehab Experience

- Group environment
- Relationship with Pulm Rehab staff
- Experience of initial benefits
- Being in charge
- Sense of safety
Accessing Pulmonary Rehab

Past Experiences
Attitudes & Expectations
Practical Things

Māori Context

- Experience of Western cultural health services
“Yeah, I went to that department, ah, where you blow these things in the tube. What do you call it, what do call those... Yeah. Yeah. I chucked in too, that one. Pissed me off. They told me to blow, blow, blow, blow, keep blowing. And that was- I had a severe- ah, breathing. So I chucked it in.”
Accessing Pulmonary Rehab

- Past Experiences
- Attitudes & Expectations
- Practical Things
- Pulm Rehab Experience

Māori Context

Attention/inattention to things Māori:
- Whānau
- Whakawhanaungatanga
- Wairua
- Tikanga
- Whakapapa
- Kaupapa of pulm rehab
Community-based:
“I didn’t know these groups existed... Until she came to my place, or actually it was my partner they’d rung, because my doctor said that there’s a Māori hauora [at the local marae]. So she rung them and they came round.”

Credibility:
“I’m looking - ‘who are these two jungle bunnies come here?’ And they told me. They’d read up on what I had you know. I said ‘jees, these people came straight off the street, they know what I got.’ So they ended up dragging me along - not dragging me, but getting me to come here, you know, and I knew I had a problem...”
Follow-up support:

“...Then when I came in, I realised these people had the same problem. You know, and I thought whoa, I’m not that bad, then denial kicks in in straight away. Oh, I’m not coming back here, these people - When I got home, and I started coughing, she gets on the phone... she got reinforcements, she sent [the respiratory nurse] around too.”

[MARAE-BASED]
“I felt like you know, being a Māori, you know... I stuck out like a sore thumb, being the only Māori there. I said to her ‘am I the only Māori coming?’ And she said ‘well there’s meant to be others, but they’re not coming.’”

[HOSPITAL-BASED]
Whakawhanaungatanga

Building Relationships/Cultural Connection:

“Whanaungatanga time is very important, how everyone feels. It’s something personal to yourself... it’s a kind of down to our level, and it’s good bringing the tikanga aspect side of things, tikanga Maori. Our waiata. How we do things, who with, and in a place that we feel good in being.”

[MARAE-BASED]
“The fact that I wanted, and... my friend, wanted some support to meet our needs....we got maybe a cuppa and a bikkie at the end. That’s all I remember.”

[HOSPITAL-BASED]
Accessing Pulmonary Rehab

- Past Experiences
- Attitudes & Expectations
- Practical Things
- Pulm Rehab Experience

Māori Context

• Marketing of Pulm Rehab
  - What’s in it for Maori?
  - Options that exist
Promoting the benefits:

“The doctor in charge, right, [should] say to you before you left: ‘I’ve got this brochure, we found it really works for people,’ a good soft sell. Yeah. Like it’s ‘get this, you get this, you get this. Interested? How about you-’ And I think that might be a much better- yeah, much more professional.”

[HOSPITAL-BASED]
Using a health literacy approach:

“I mean I’ve had letters from you people about signing different things, they sent out all these letters that I had fill in, I didn’t bother with that...”

Culturally tailored marketing of pulm. rehab:

“There’s nothing that says ‘if you are Maori, this is what you need.’ It says you take part. And I was looking for the Maori side... Lot of the questions, didn’t even refer to the kaupapa.”

[HOSPITAL-BASED]
Discussion

- Need for culturally responsive mainstream pulm. rehab options, AND
- Need for by Maori/for Maori pulm. rehab services.
- Need to address social inequities when delivering pulm. rehab (e.g. transport issues, costs, sense of entitlement)
Conclusions

• PR is one of the best interventions we can offer people with COPD
• Services need to be adequately resourced to provide PR to all people requiring it
• PR needs to be appropriately marketed and provided to maximise uptake
• Cultural issues merit particular attention in PR, with the aim of reducing inequalities in health outcomes
References

References


