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NEW ZEALAND

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Rehabilitation Teaching & Research Unit



Tu Kotahi Māori Asthma Trust

Making pulmonary rehabilitation engaging for Māori

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The central question of this presentation

How do we make pulmonary rehabilitation meaningful, accessible and engaging for Māori whānau with COPD?

The key 'take home' message

- Building **long-term, trustworthy relationships** with Māori whānau and Māori communities is a key building block in making pulmonary rehabilitation successful



Content

- Why is special attention to Māori involvement in pulmonary rehabilitation needed?
- What can we learn from the experiences of Māori attending pulmonary rehabilitation?
- How can we make “mainstream” pulmonary rehabilitation classes more engaging for Māori?
- What can we learn from Māori-led pulmonary rehabilitation classes?

Part 1

Why is special attention to Māori involvement in pulmonary rehabilitation needed?

Burden of COPD in NZ

- COPD is the 4th leading cause of death in NZ (6% of all deaths in 2009)
- COPD affects 15% of NZers over 45 years, and is **undiagnosed**
- In 2003, COPD was estimated to cost \$100-200 million/year

(Town et al., 2003)

- In 2012, COPD cost **\$60 million** in hospital admissions alone
- For individuals, COPD results in:
 - reduced household income
 - difficulties with planning for the future
 - reduced socialisation and community engagement
 - poorer quality of life

(Miravittles & Ribera, 2017)

Burden of COPD for Māori

- Māori 5 X more likely to die from COPD than non-Māori.
- Māori affected by COPD up to 20 years earlier than non-Māori

(TMG Associates Ltd, 2009)

- Māori 4.4 times more likely to be admitted to hospital for COPD
- Māori in hospital for COPD are ~ 9 years younger than non-Māori

(Milne & Beasley, 2015)

- Smoking rates at twice as high for Māori compared to non-Māori, with tobacco accounting for 85% of COPD (note: not all COPD is caused by smoking)

(Harwood et al, 2012)

Burden of COPD for Māori: hospitalisations

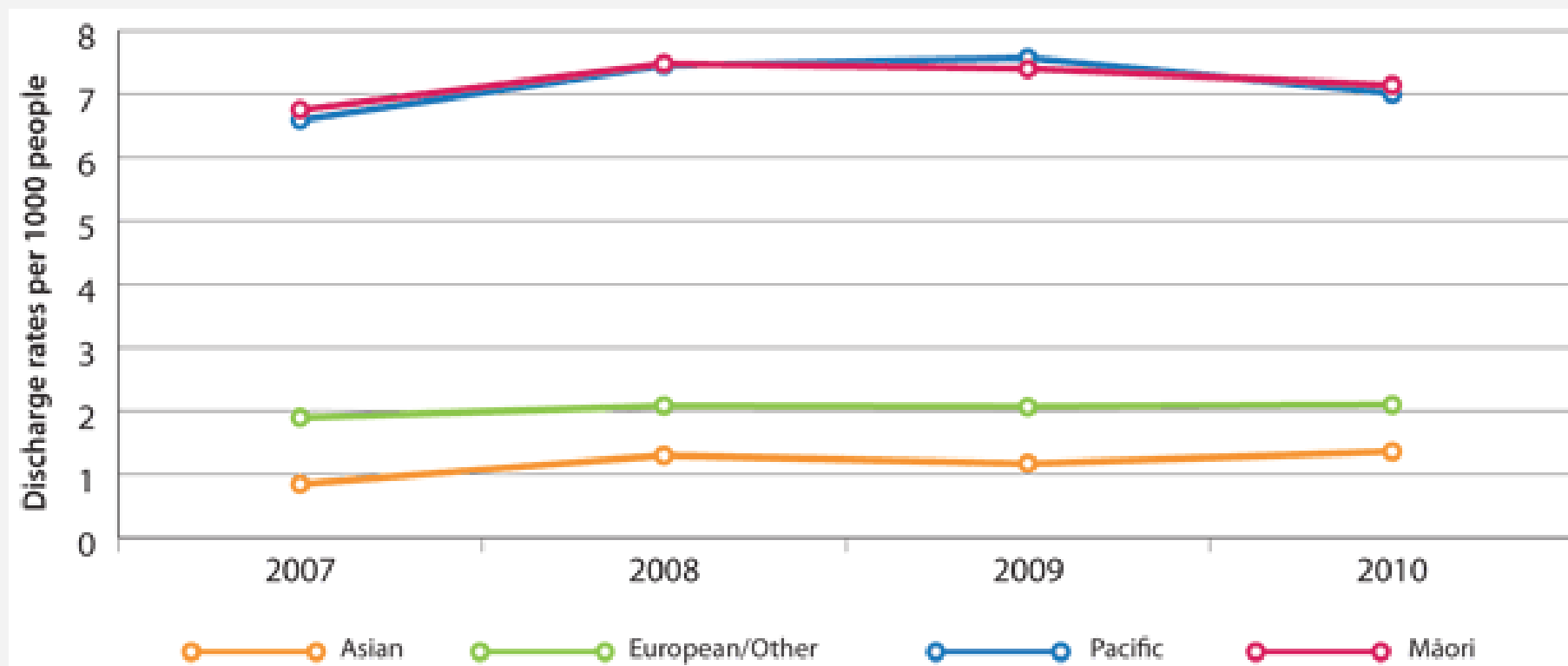


Figure 1: Age-standardised hospital discharge rates in New Zealand with a primary diagnosis of COPD, per 1000 enrolled patients by ethnicity*

* Data source: Ministry of Health, National Minimum Data Set (NMDS). Hospital Discharges Population source: DHB
Estimated Resident Population 1996-2006 (Prioritised)

(Harwood et al., 2012)

Part 2

What can we learning from the experiences of
Māori attending pulmonary rehabilitation?

Levack et al. Int. J. COPD. 2016. 11: 489-501.

International Journal of COPD

Dovepress

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ORIGINAL RESEARCH

Whakawhanaungatanga: the importance of culturally meaningful connections to improve uptake of pulmonary rehabilitation by Māori with COPD – a qualitative study

This article was published in the following Dove Press journal:
International Journal of COPD
9 March 2016

Number of times this article has been viewed

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Background: Pulmonary rehabilitation is known to improve function and quality of life for people with chronic obstructive pulmonary disease (COPD). However, little research has been conducted on the influence of culture on experiences of pulmonary rehabilitation. This study examined factors influencing uptake of pulmonary rehabilitation by Māori with COPD in New Zealand.

Method: Grounded theory nested within kaupapa Māori methodology. Transcripts were analyzed from interviews and focus groups with 15 Māori and ten New Zealand non-Māori invited to attend pulmonary rehabilitation for COPD. Māori participants had either attended

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Past research on cultural issues in PR?

- “In practice, details of program construction and setting will vary with different cultures and health care systems”

[ATS/ERS statement on PR]

- But almost no research has ever been conducted on this.
- Keating et al. (2011) – 11 studies on barriers and facilitators to PR, but **no data on ethnic variability in uptake**

Three questions for this study...

1. What makes it **easier or harder** for people to get to pulmonary rehabilitation?
2. Can we **make it easier** for people to do pulmonary rehabilitation
3. Can we make things **work better** for Māori?

Method

- Grounded theory
- N=25 (15 Māori; 10 non-Māori)
- Interviews with 11 people with COPD referred to mainstream pulm rehab (3 Māori, 7 Pakeha, 1 Samoan)
- Focus group meetings with 11 Māori attending Marae-based COPD classes
- NVivo used for data management



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Getting to Pulmonary Rehabilitation

Two things of
interest -

Getting there for the first time

Wanting to continue

Getting to Pulmonary Rehab

Past Experiences

Attitudes & Expectations

Before deciding to attend...

Access Issues

Pulm Rehab Experience

After going....

Getting to Pulmonary Rehab

Past Experiences

Attitudes & Expectations

Access Issues

Pulm Rehab Experience

Getting to Pulmonary Rehab

Past Experiences

- Of health care services
- Of exercise

Attitudes & Expectations

Access Issues

Pulm Rehab Experience

Past experiences: exercise

- Oh, that was the main thing that actually in a way almost put me off, "be active", I thought 'oh, God.'... I'm not- I'm not a sports person... And no, I've never been particularly into exercising of any kind.

[F2, female, NZ European, hospital-based PR]

Past experience: exercise

- The course it really like a circuit training thing – which I could relate to that, because I - I have been absolutely super fit in my time.

[M3, male, NZ European, hospital-based PR]

Past experiences: health services

- I had a hospitalization, went to see [the] doctor, and he told me basically I had less than five years to live. See you later. And that's how it was put to me... We still [had] a few questions for the surgeon, but it turned into "oh, it's a very busy clinic today." You know, I'm supposed to trust this man to open me up and take my lung out, and it's money, it all comes back to money...

[M11, male, Māori, marae-based PR]

Getting to Pulmonary Rehab

Past Experiences

Attitudes & Expectations

Access Issues

Pulm Rehab Experience

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

Attitude

- *What was your initial reaction when you heard about the class? Can you remember?*
- Oh at first I was really had a bit of a negative attitude to it. Cause I have negative attitude to everything. And I'm like 'nah, I don't want to go to that.' You know, I lose interest in things quick. Real quick

[F5, female, Māori, hospital-based PR]

Mood

- I wasn't there at the end of last year, cause I was still in that dark place, and I was finding excuses every week, why I'm not coming. Even though [the respiratory nurse] and them are trying to push me here, and push me here. Because I wasn't in the right head space for myself, I didn't want to bring anyone else down.

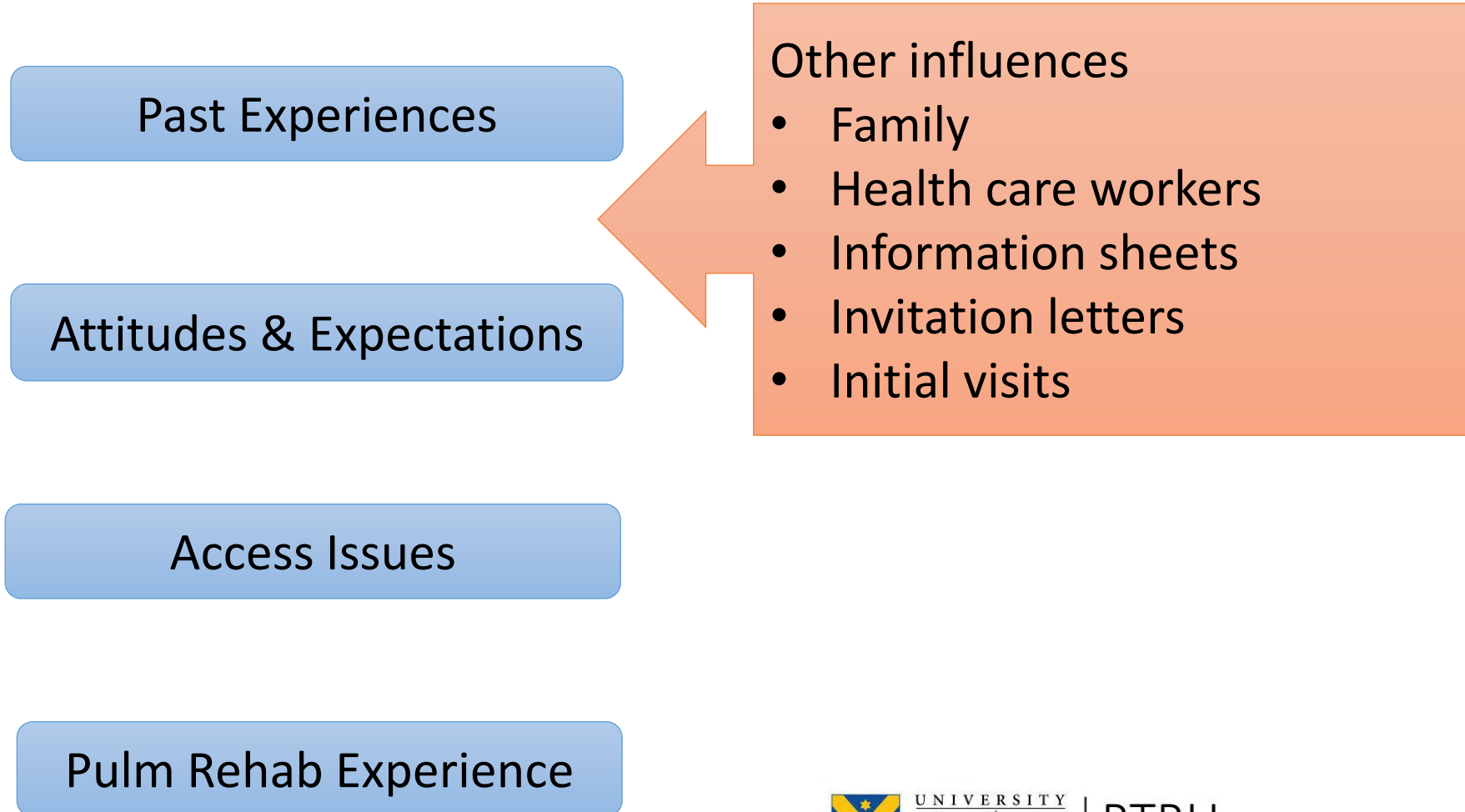
[M16, male, Māori, marae-based PR]

Treatment expectations

- I used to have a bad attitude, I used to think ‘oh, exercise ain’t going to help me.’ You know... I just thought ‘oh, what we’re going to get out of it?’ ... But then I said to them, when I’d been for it for a few times, ‘oh, I must admit, it has been doing me good.’ I said- I- before I used to think oh, exercise was just a load of- it’s not going to help you, you know, with all the breathlessness and all that. It’s not going to help you.

[F5, female, Māori, hospital-based PR]

Getting to Pulmonary Rehab



Influence of health professionals

- I didn't know these groups existed. I didn't even know [the marae] had a hauora. Until she [the marae nurse] came to my place, or actually it was my partner they'd rung... and they came round. I'm looking – “Who are these two jungle bunnies come here?” And they told me – they read up on what I had you know. I said “Jesus, 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.

[M17, male, Māori, marae-based PR]

Getting to Pulmonary Rehab

Past Experiences

Attitudes & Expectations

Access Issues

Pulm Rehab Experience

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

Getting to Pulmonary Rehab

Past Experiences

Attitudes & Expectations

Access Issues

Pulm Rehab Experience

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

Getting to Pulmonary Rehab

Māori Context

Past Experiences

Attitudes & Expectations

Access Issues

Pulm Rehab Experience

Attention to things Māori:

- Whānau
- Whakawhanaungatanga
- Wairua
- Tikanga
- Whakapapa
- Kaupapa of pulm rehab

Lack of group membership

- I said to her 'am I the only Maori coming?' And she said 'well there's meant to be others, but they're not coming.'

[F14, female, Māori, talking about hospital-based PR]

Whakawhanaungatanga

- And it just that 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 to 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. Knowledge-wise, I mean I've learnt a lot, just by working here, and management plans, and all the rest of it.

[F15, female, Māori, marae-based PR]

Whakawhanaungatanga

The lady [a Māori nurse] who picks us up... She asked me the question when she saw it [a NIV machine for sleep apnea in the participant's home], and she said "do you use that?" And – and I looked at her. And she goes "no, you don't aye?" I went "no."... She happened to see it sitting there, and she asked me...

So you hadn't told anyone else you weren't using it?

No, I just kept quiet about it. I didn't know you had to come to the hospital after, and they check your machine, you see... So now I just felt relaxed with her. And yeah, I just – every question she asked I just answered it to my best knowledge.

[F4, female, Māori, hospital-based program]

Part 3

How can we make “mainstream” pulmonary rehabilitation classes more engaging for Māori?

Strategies for 'mainstream' pulmonary rehab

- **Put time into building relationships** with Māori patients & whānau, local community groups, local Māori health provider groups
 - ✓ Find out who the Māori providers and community groups are in your region
 - ✓ Look for opportunities to connect, network, and/or partner
 - ✓ Offer a public presentation in Māori community spaces (e.g. marae) on COPD, pulm rehab, what is offered, what people can do for themselves
 - ✓ Invite Māori groups to join in with training/teaching activities in your space
 - ✓ Meet and ask 'what would make things work better for you?'
 - ✓ Make it a service objective to build these meaningful relationships
- **Reciprocate**
- Be prepared to **listen** and try new things
- **Trust** needs to be earned not assumed

Strategies for 'mainstream' pulmonary rehab

- Address problems with **transport**
(a shuttle to pulm rehab for 12 weeks is heaps cheaper than 1 hospital admission for COPD)
- Consider working in partnership with a local Maori health provider
- **Develop information sheets** on your pulmonary rehab service for Māori people specifically: what's in it for Māori?
- Make the **pulm rehab space** Māori-friendly
 - ✓ Add some Te Reo posters, info sheets, conversation
 - ✓ Make sure there is a good welcome and introduction when people first start
 - ✓ Encourage participants (and staff) time to connect before and after pulm rehabilitation sessions (whakawhanungatanga)
 - ✓ Ask Whānau about their experiences and what could be done better/differently

Strategies for ‘mainstream’ pulmonary rehab

- Check your Māori patients’ understanding of COPD and the potential value of pulmonary rehab.

“When your whānau asks what advice I gave you, what will you say?” (Harwood et al., 2012)
- Consider the venue – would a community venue, e.g. the marae be more appropriate
- Reassure people that pulmonary rehab wont be to hard for them

Part 4

What can we learn from Māori-led pulmonary rehabilitation classes?

Teaching from a 'for Māori, by Māori' programme

- **Work in partnership** to design the programme: mainstream and Maori health provider
 - Culturally appropriate programme name: e.g. **Te Ha Oranga** (healthy breathing)
 - Importance of **whakawhanaungatanga**: connecting with whānau, building the trust
 - Venue: Safe & welcoming environment (not clinical), Māori artwork/te reo posters
 - **Manaakitanga** (hospitality): shared kai, other whānau invited and included in group
 - Providing a safe space for Maori **tikanga** practices (karakia, waiata)
 - **Tino Rangatiratanga**: self-empowering: supporting whānau to identify their priorities and set the agenda
 - Education approach: use health literacy strategies e.g. 'teach back method'
 - Resources: 'keep it simple' style (in plain English and **te reo**)
 - Transport provision essential



Conclusions

- Māori communities face greater burden from COPD than non-Māori.
- Pulmonary rehabilitation is an important service people with COPD, so attention ought to be paid to facilitating Māori engagement with it.
- Many strategies for improving access to pulm rehab for Māori are also beneficial for non-Māori.
- Services for Māori can be improved by building stronger, more meaningful relationships with Māori individuals and Māori community groups.
- Attention to Māori experiences of pulm rehab can be helpful for identifying and addressing barriers.

Conclusions

“Breathing properly is everyone right”
- Dame Tariana Turia.



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