

BECOMING ‘HALF A DOCTOR’:  
PARENT-EXPERTS AND THE NORMALISATION OF CHILDHOOD ASTHMA  
IN AOTEAROA/NEW ZEALAND

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ABSTRACT

*In New Zealand, familial responses to childhood asthma largely pivot around the role of the parent-expert who takes primary responsibility for both the management and normalisation of his or her child's condition. Based on a preliminary analysis of cultural texts and interviews with parents, healthcare professionals, and representatives of asthma societies, this paper argues that childhood asthma is largely accepted as being a 'normal' part of life, to the extent that parents and health professionals alike note that the dangerousness of this condition is frequently under-recognized. Strategies for both managing and normalising asthma are heavily reliant upon pharmaceutical therapies, though some attention is also paid to mitigating environmental triggers. Central to these endeavours is the role of the primary caregiver who, with input from General Practitioners, frequently adopts the position of the parent-expert in managing the idiosyncrasies of his or her child's condition. Little emphasis is placed on collective therapeutics or social action, as the primary focus is on individually-tailored familial-based management of children's symptoms.*

INTRODUCTION

New Zealand has the world's second highest rate of asthma, with 22.2% of children currently reported to be suffering from this disease (Mitchell *et al.*, 2009). Rates among Maori and Pacific Island children are even higher, at 28.5% and 25.2% respectively (Ellison-Loschmann *et al.*, 2009). Based on an analysis of cultural texts and interviews with parents of children who have asthma, healthcare professionals, and representatives of asthma societies, this paper argues that familial responses to childhood asthma largely pivot around the role of the parent-expert who takes primary responsibility for both the management and normalisation of their child's condition.

Drawing on their own knowledge of their child's specific triggers, social and healthcare needs, along with input from their General Practitioners, many New Zealand parents readily adopt the role of actively managing their child's condition, sometimes in ways that directly challenge the advice they receive from medical authorities. This is in sharp contrast to countries where asthma care is premised upon long-term relationships requiring regular, frequent contact between patients and either respiratory or allergy specialists, in which the role of the parent is restricted to implementing (or contravening) specialists' instructions, rather than actively 'managing' their child's care (Trnka, 2011a). The more 'managerial' role adopted by Kiwi parents coincides with New Zealand's embrace of neoliberal reforms that induce patients and their families to take increased responsibility for their own healthcare (Newberry, 2001; Barnett, 2000; Fitzgerald, 2004), and, more specifically, the country's leading role in promoting self-management programs for adults with asthma in the late 1980s and early 1990s (see D'Souza *et al.*, 1994). Following a more global healthcare trend that Rose (2006) has referred to as creating a climate of ever-increasing patient 'responsibilization', New Zealand parents are structurally encouraged – and one might even argue *required* – to take up more active roles in determining their child's health needs.

Most of the parents we spoke to relied primarily upon pharmaceuticals to keep their child's asthma under control, though many also paid attention, albeit to a lesser extent, to mitigating environmental triggers. Little emphasis is placed on collective social action to improve health care and environmental conditions, due in part, perhaps, to the overwhelming emphasis placed on both pharmaceuticals and notions of self-reliance and individualized responsibility. Moreover, childhood asthma is, for the most part, accepted as being 'just a normal part of life' to the extent that parents, asthma society representatives, and health professionals alike note that the *dangerousness* of this condition is frequently under-recognized.

## METHODS

This research is part of a larger comparative project examining private and public responses to children's asthma in New Zealand and across Europe. Based on a broad overview of educational materials and public debates, as well as patients', physicians', care-givers' and activists' narratives, the larger project considers how children's asthma is variously framed across a range of medical and non-medical sites, and the consequences of this in terms of public attributions of responsibility for children's health and wellbeing (see Trnka, 2011a, 2011b, 2011c).

Our findings here are based on preliminary research in New Zealand. The first round of research was carried out over the summer of 2009–2010 and consisted of discussions with representatives from the Asthma and Respiratory Foundation and the Auckland Asthma Society, as well as a review of popular representations and social science literature on asthma both in New Zealand and abroad. The second round, during the summer of 2010–2011, was devoted to carrying out more comprehensive interviews. As our aim was to get a broad outline of the variety of approaches to and perspectives on childhood asthma that exist across New Zealand, our approach was to be as inclusive as possible. In total, we interviewed 32 people, among whom there were thirteen parents or caretakers of children with asthma, eight adults who have had asthma since childhood, two respiratory physicians, one allergy specialist, one emergency room doctor, two General Practitioners, one physiotherapist, four nurse educators/asthma society representatives, one representative of the Asthma Foundation, one administrator of respiratory services, one specialist in Buteyko, one leader of an asthma/COPD support group, and one environmental health activist. (The numbers in these categories add up to more than the total of number of interviewees as some people occupied multiple roles). We also searched Parliamentary records and undertook a comprehensive review of articles about asthma on New Zealand-based websites and in the New Zealand popular media. Finally, we undertook a discourse analysis of children's books and educational materials about asthma available in New Zealand libraries or the public school system, or are distributed by the various asthma societies and the Asthma Foundation.

#### NORMALISATION

From our initial comparisons of New Zealand and overseas experiences and representations, we found that New Zealanders tend to frame asthma as a normalised condition. One positive aspect of this normalisation – and, in some cases, even *naturalisation* – is that people with asthma in New Zealand are relatively unstigmatised. This was expressed throughout our New Zealand-based interviews, with many parents expressing surprise that stigma might be possible owing to the commonness of asthma. Even when parents felt their children's asthma was severe and expressed concerns over their ongoing health problems, there was little or no assumption that children with asthma would struggle at school or in sports. This aligns with the dominant perspective in the New Zealand public sphere in which it is generally taken for granted that people with asthma can be successful scholars or athletes. For example, swimmer Danyon Loader, Black Fern captain Casey Williams and All Blacks prop Kees Meewes have not had their fitness publicly questioned on the

basis of their asthma and have not tried to hide their condition. In addition, numerous public figures – whether or not they themselves have asthma – have been happy to endorse the Asthma Foundation’s publicity of this condition, including Warriors rugby player Wairangi Kooopu, politician Rodney Hide and All Blacks rugby player Daniel Carter. In comparison, in 2009, suspicions were raised in the United Kingdom about David Beckham’s fitness when he ‘admitted’ that he had asthma, necessitating the release of press statements reassuring the public that Beckham’s asthma would not affect his football (Daily Mail Reporter, 2009; Hughes, 2009).

The level of acceptance and naturalisation of asthma in New Zealand is further emphasised through our discussions with representatives from the Asthma Foundation who suggested that in New Zealand the challenge in asthma support is not to destigmatise asthma, but rather to try to reinforce that asthma *is* a serious problem. Recent campaigns of the Asthma Foundation, such as the Balloon Day posters, which emphasise that one in four Kiwi kids have a respiratory problem, illustrate such attempts. Another, particularly vivid, example is a brochure from the Asthma Foundation. Titled *Asthma can kill. End of story*, the brochure is set out in the format of Random House’s popular ‘Little Golden Book’ children’s series, complete with its emblematic golden binding. The brochure recounts the story of Lucy, a little girl riding on ‘a giant bunny rabbit named Floppy Ears, the fastest bunny in the Kingdom’. When Lucy buries her face in the rabbit’s fur, she begins to have trouble breathing. The tale ends with Lucy falling to the ground while ‘all poor Floppy Ears could do was just watch’ as she struggles to survive her asthma attack (The Asthma Foundation, 2006).

In our interviews, parents and caregivers largely accepted the high rates of asthma in New Zealand, often commenting that asthma is ‘just a part of life.’ While many remarked upon how high the rates of asthma are in New Zealand in comparison with other parts of the world, there was no sense of urgency as to whether, or how, these rates might need to be addressed. Rather, asthma was largely depicted as a somewhat mysterious but ultimately unsolvable problem. For some, this appeared to be due to their view of asthma as genetically determined, which they seemed to understand as indicating that whilst symptoms can be managed, nothing can be done to decrease the prevalence of this condition.

Beasley and Masoli (2003) have argued that such a high level of acceptance may also be associated with a common complacency about asthma, as seen officially in asthma slipping off the list of priority disorders in the 2000 New Zealand Health Strategy (Ministry of Health, 2000, 2010). This occurred de-

spite New Zealand having the second highest rate of asthma in the world after the United Kingdom, and asthma being the number one cause of hospitalisation of New Zealand children (The Asthma Foundation, 2012). Beasley and Masoli (2003) also note that many New Zealanders' asthma is not under control, with 90% of patients not using long acting beta agonists, and 40% not using sufficient inhaled corticosteroid doses.

Indeed, throughout our interviews, numerous people said that they or their children were not rigorous about using their preventative medication. There was rarely any explicit indication that this may be due to concerns over the potential negative effects of long-term use of high levels of steroids or other medications.<sup>1</sup> Rather, most people explained that once they or their child did not seem to be having a visible breathing problem, they saw no reason to continue using medication on a regular basis. As one mother noted of her son:

R: Well, he sort of does it everyday *if* I have noticed he's been coughing. Then I put him on the Ventolin<sup>2</sup> and the Flixotide<sup>3</sup> straight away and I suppose I would tend to keep him on the Flixotide for a week or two, then. And then if he seems completely better when I drop the Flixotide again – because sometimes he can go 6 months without needing it, up to 6 months.

This was corroborated by doctors who noted that one of the most frequent types of 'noncompliance' was people not taking their preventers:

Dr. K: Preventative inhalers, people use them for a while but they often become non-compliant with it after a while. So, 'this hasn't happened in ages so I can probably stop taking it'.

At the same time, however, our interviews also indicated that many parents were especially aware that, despite being common, asthma can be potentially life-threatening. The most common response was to rely upon daily regimes of inhaled corticosteroids – whether or not they were always entirely successful in sticking to them – to keep their children stable. Secondary forms of prevention and treatment were largely side-lined, or cast aside as being too bothersome. Moreover, when in place, daily corticosteroid regimes often became 'second nature' to that point that 'stepping down' or lowering one's dosage after an acute episode was successfully controlled, became problematic. Parents were unlikely to reduce doses on their own or bring their children back to their General Practitioner for advice on how to do so. As one asthma nurse and asthma society representative explained:

A: All too frequently, once they get to being stepped up [i.e. the amount of their medication goes up], they don't ever get reviewed about dropping it back down again.... a lot of people can be on a lot lower [doses] than what they are.

*What Maui learnt about asthma*

The representation of inhaled corticosteroids as an almost fail-safe panacea for dealing with asthma symptoms is in line with many of the prevalent public health messages addressed to both parents and children. Many of these messages, moreover, go to great lengths to naturalize the use of such medications. In 2009, for instance, Asthma and Respiratory Management Bay of Plenty published the children's book *What Maui learnt about asthma*, by Waka Cookson. Illustrated with brightly coloured pictures, the book is targeted at primary school age children and recounts the story of how the Maori hero Maui first became breathless:

One day, when Maui was walking through the forest, he started to feel quite breathless. He stopped to rest but he could hear a wheezing sound, his chest felt tight and he was finding it hard to get his breath.

'What's happening to me?' he cried. 'I can't enjoy roaming through the forest any more, singing with the birds and playing with the animals' (Cookson, 2009: 4).

Maui's *matua tupuna* (ancestors or grandparents), Papatuanuku and Ranginui, discover Maui wheezing and explain to him that his problem is asthma. They then help Maui to use a spacer, teach him to identify and address his symptoms and start him on a self-management plan. Finally, they tell him that, with his medications, he will be able to stay well.

*What Maui learnt about asthma* is a dramatic instance of not only the normalisation, but also the naturalisation of childhood asthma. Ignoring the recent worldwide escalation of childhood asthma, the story casts asthma into the depths of time immemorial, suggesting that, even in pre-modern Aotearoa, when the land consisted of natural bush populated by legendary figures, asthma was a serious concern. Eliding any suggestion of scientific understandings of the increase in asthma in the past four decades, much less current debates over sharp escalations in asthma rates as being possibly linked to 'Western' modes of life, characterized by increased urbanization, air pollution, and consumption of fast food (Braman, 2006; Beasley *et al.*, 2000; Nagel *et al.*, 2010;

Shi *et al.*, 2012; Sunyer *et al.*, 1997), this tale implies that asthma is, and has always been, a part of New Zealand's landscape and is as natural as the trees, birds and other animals.

Written specifically to appeal to children, and with a particular emphasis on Maori children who, as noted, are over-represented in the asthma statistics, the book conveys the positive message that, even if children have asthma, they too can lead full and satisfactory lives, in which the outdoors and physical activity can be key components. In doing so, however, the book suggests that not only should today's children rest assured that they can easily get control over their asthma, but also that their ancestors have been doing so for millennia – and, surprisingly, by using familiar 20th and 21st Century inhalers and spacers. Indeed, asthma medications are explicitly described as 'precious gifts' being given to Maui by the ancestors, with Papatuanuku specifically telling Maui that the preventer is a 'gift that represents me' while Ranginui is 'represented' by the 'gift' of the reliever (Cookson 2009:10, 12–13).

Maui does get some other instructions, such as that he should eat a balanced diet with fruits and vegetables, and to avoid certain environmental triggers including mould and fungi, stresses, chemicals and smoke. The story's emphasis, however, is on Ranginui and Papatuanuku's unquestioned and unhesitating promotion of pharmaceutical therapies as the primary solution to Maui's asthma. There is, moreover, no suggestion that Maui or his family need to take action to modify their environment. And there is no discussion of the fact that, as a child, and, in particular, a Maori child in New Zealand, he has one of the highest chances in the world of becoming asthmatic. Indeed, rather than questioning why so many children are battling with asthma – i.e. what is happening to make Maui so ill? – Ranginui and Papatuanuku encourage Maui to accept his asthma and get on with managing it himself, primarily by using his medication. Their response, moreover, reflects wider attitudes towards pharmaceuticals as constituting the core, and indeed for many New Zealanders the sole element, of 'self-management' regimes.

#### PHARMACEUTICALS AND OTHER SOLUTIONS

For the most part, when parents and caregivers spoke of getting to grips with asthma it was precisely in terms of finding a comfortable pharmaceutical regime that kept their children's symptoms under control. This approach is in accordance with the emphasis of asthma support groups and other modes of public health outreach, which typically employ the term 'self-management' as a means of discussing how individuals should, under the supervision of their

General Practitioners, self-regulate which and how much medicine they take, 'stepping up' if they experience more symptoms, and 'stepping down' when their breathing improves. Moreover, New Zealand's two national asthma support groups, 'The Asthma Foundation' and 'Asthma New Zealand: The Lung Association', tend to use 'self-management' to specifically refer to patients' compliance with doctors' advice on medicines, rather than in relation to the range of strategies patients might use to cope with asthma,<sup>4</sup> much less the possibility of patients 'self-managing' by defining their own health needs. In line with this emphasis, the self-management plans supplied by these groups focus solely on pharmaceutical management. These brochures, designed for doctors to fill in for their patients, contain various groupings of symptoms, ordered by severity, matched with corresponding medications (or, a recommendation for hospitalisation in the most severe scenario). The role of the 'self' in 'self-management' plans is thus to monitor symptoms and to comply with the recommended (largely pharmaceutical) response.

Although in all of our interviews people identified specific triggers for their own or their children's asthma, much more emphasis was placed on pharmaceuticals than environmental modification. In part this might be because of the direct, and more immediate, returns of taking up an appropriate drug-based regime. However, many people also expressed concern over the importance of maintaining 'normality' and not getting too involved with environmental modification, a concern they did not voice with respect to using medication. In other words, taking a daily regime of drugs was viewed as not only more effective, but also less intrusive and less of an indicator of 'abnormality' than environmental modification. While some people felt that local environmental factors – such as the humidity of Auckland or the smog of Christchurch – were potentially exacerbating, only one family out of the ten we interviewed had relocated on the basis of their asthma. Most people had identified one or more triggers of asthma, with dust, pets and catching a cold being commonly mentioned. While most people tried to avoid these where possible (i.e. by getting family members who do not have asthma to do the dusting, asking neighbours to remove privet, or trying to avoid becoming ill), many people felt that complete avoidance was not necessarily possible or desirable, particularly when it came to avoiding family pets. Similar to the importance of maintaining 'ordinariness' found among English families of people with asthma (Prout *et al.*, 1999), avoidance of triggers among those whom we interviewed was always negotiated alongside the maintenance of normality. One mother said of her family's routine:

P: Just kept it as normal. Because I'm a little you know, I feel like the

more you try to protect and do things the more difficult it gets to try and manage. So just live life as normally as possible and manage it best within the way you're living ..... that's what's...works best for me.

As many of those we spoke with indicated that their General Practitioners often did not give advice about environmental triggers to asthma, management of asthma triggers was typically based on families' own experiences rather than medical professionals' advice. As one mother noted about her child's General Practitioner's advice on non-pharmaceutical matters, it was assumed that the family would already have knowledge about environmental triggers:

F: I think he kind of gave you the benefit of the doubt, figured you'd already looked at those things anyway.

In contrast with Australia, the United States, and Europe, where a range of non-biomedical therapies are often utilized alongside drug-based remedies, with few exceptions, the New Zealanders we spoke with did not express eagerness to engage in organized alternative or complementary modes of prevention or care. None of our New Zealand interviewees spoke of the desirability of attending asthma camps as a way of engaging children in physical exercise and teaching them about asthma care and prevention. While some were conversant with Buteyko – a breathing therapy based on 'breath retraining' – they were in the distinct minority. As far as we are aware, there has been no uptake in New Zealand of complementary therapies such as salt or halotherapy which has become popular in Australia and the United Kingdom over the past two years. Long popular in Eastern and Central Europe, purpose-built salt caves or salt rooms are based on the principle of using dry saline aerosol inhalation as a means of soothing the bronchial passages (Horowitz, 2010; Trnka, 2011a). Similarly, massage, hydrotherapy, or music therapy as a means of both consciously controlling respiration and inducing relaxation were not widely considered desirable treatment or prevention regimes. Except for those with distinct food allergies, we found very little interest in treating asthma through dietary means.

By contrast, one area that was very popular was participating in sport, especially, but not exclusively, swimming (c.f. Davies, 2003). The focus here was largely on children with asthma being encouraged to take part in pre-existing sport activities, as opposed to organizing specialised sports activities specifically for them. This was both as a conscious way of attempting to improve their fitness and lung capacity, as well as part of the larger strategy of normalisation as taking part in sports was widely viewed as a necessary component of everyday activities associated with New Zealand children. Like Maui, who is

encouraged to keep running through the forest, the emphasis was on causing as little disruption to the ‘normal’ Kiwi child’s lifestyle as possible.

However, for most of those we spoke to, pharmaceutical management was seen as by far the most reliable and non-invasive form of accomplishing the maintenance of a ‘normal’ lifestyle. New Zealand parents and caregivers expressed relaxed attitudes about drug intake, as long as activities and surroundings could remain the same as for other children (c.f. Prout *et al.*, 1999). This attitude was exemplified by one mother’s comments about the interventions she is, and is not, willing to undertake to keep her son healthy:

J: [*Laughing*] Oh no, no, no, we don’t like, heat the house all winter or anything. He runs around in the rain, in the cold, like everyone else. He goes swimming whenever he wants to, even if it’s freezing. He does those sorts of things. .... But that’s because we *can* control it with Ventolin and Flixotide.

#### INDIVIDUAL RESPONSIBILITY AND THE ROLE OF THE PARENT-EXPERT

One of the key themes to emerge from our discussions about both treatment and normalisation was the question of who is ultimately responsible for undertaking these measures. References to decision-making over drug choice, frequency and dosage; determining which steps are appropriate or inappropriate for maintaining ‘normality’; as well as drawing up formal or informal plans for coping with asthma episodes all inspired explicit discussions of where responsibilities for taking action, or choosing to be inactive, lie. The theme of responsibility was also implicitly raised in discussions of the environment in terms of how individuals, and wider social groups, view their role in shaping both their immediate surroundings and the broader environment in order to positively impact on children’s health.<sup>5</sup> The most common enactment of responsibility was the parent-expert working in partnership with – although also sometimes contesting – their child’s physician.

It was often through individual experimentation that children with asthma and their families became expert in how to best manage aspects of their condition. Many families described putting in place routines of their own devising which would help them to avoid acute periods, such as having their child placed on antibiotics at the first sign of a cold or trying to keep their children warm. This is in keeping with Dean *et al.* (2008), who found that New Zealanders tend to see health professionals for treatment of acute asthma episodes rather than for assistance with long term management strategies.

Furthermore, while New Zealand patients expressed faith in both doctors and the medications they give them, and showed at least initial adherence to doctors' recommended medication doses, they often tinker with their instructions to find dose levels which suit them. One mother, finding that a spacer didn't suit her son, noted:

J: I think sometimes we would give him two puffs of the Ventolin just to make sure that he got enough.

Carers often became so adept in managing their children's asthma that they would instruct doctors on what their children needed. One mother of a daughter with asthma went out of her way to find a doctor who was happy to prescribe antibiotics whenever she felt her daughter was getting a cold:

R: Initially they were not prescribing antibiotics and I told my doctor look, this is the thing, I want her to have antibiotics. Otherwise I was getting antibiotics from [overseas] and giving them to her. I was not going to take a chance. I was half a doctor by then. *Laughs*. You know, 'cos you kind of know your child.

Another, whose child is now grown, had worked out and demanded what she needed from the hospital system during acute episodes:

J: And we turned up at the children's ward and the matron came out and said...what were we doing there, and we said: 'He needs to be dealt with, we've been here before and we know what you need to do for him.' And she said: 'but you've got to go through A&E first' and we said 'that's really silly', you know, we know he needs to be up here, we know and we can fill the forms in, we've filled them all out before. And they reluctantly took him.

Even initial diagnosis of asthma and suggestions for its treatment are offered by some asthma-experienced family members, as one doctor noted of her patients: 'Sometimes they'll have parents or siblings with asthma and they will sometimes have tried their inhaler and be able to tell you that it works'. At home, the implementation of quite comprehensive, self-styled asthma plans, which included pharmaceutical regimes as well as balancing the negotiation of environmental triggers with the maintenance of family 'normality', was frequently undertaken by carers, particularly mothers.

The gendered nature of this care was especially striking. Reflecting often un-

spoken, but deeply entrenched, cultural attitudes about the gendered nature of domestic care, many of the asthma educators, health professionals, and parents we interviewed explicitly spoke of the role of *mothers* – rather than of *parents* or *mothers and fathers* – in monitoring their child’s health status. Furthermore, some mothers (but not fathers) we spoke with reflected upon their roles as parents, referring to themselves as a ‘slack mother’ or a ‘paranoid mother,’ based upon their responses to their child’s asthma. One mother made the point that, while both she and her husband administer medicine to their son, she makes the decisions about when, how, and how much:

C: Yeah – like my husband will do stuff like hear him coughing in the night and go and give him his Ventolin but in terms of deciding the *policy* [of what he will take] as opposed to the immediate treatment, that’s pretty much me.

In contrast with their readiness to adopt the role of parent-expert, there was little interest in mobilizing collective action in responding to asthma. In part, this may be due to structural shifts in healthcare, requiring patients and/or family members to adopt the new role of self-managing subjects (Rose 2006), but it is likely also to be influenced by broader social and cultural attitudes about the importance of self-reliance.

Although two of our interviewees had asked their neighbours to cut down privet hedges, none of the people with asthma we interviewed saw triggers as community or governmental problems, emphasising instead the importance of privately trying to make the most of one’s situation:

F: But what *can* you do, there’s pollution everywhere now. Look, Auckland, such a lovely green city, even that has pollution now. Then there’s pollen problems here. I mean I believe Auckland is the capital city for asthma now. So how much can you do?

Asthma support groups, such as The Asthma Foundation and Asthma New Zealand: The Lung Association, have also largely not mobilised around environmental causes of asthma, but have rather emphasised the importance of self-management and the support of individuals with asthma.

There are, however, some notable exceptions. These include government and corporate sponsored ‘Healthy Housing’ and ‘Healthy Homes’ initiatives that provide free or subsidized installation of energy-efficient heating in low-income households, as well as donating funding for research into respiratory

illnesses (Housing New Zealand, 2012; Contact Energy, 2006). The Keep New Zealand Beautiful campaign highlights the links between environmental destruction and rising asthma rates as a means of galvanizing volunteers to engage in local clean up campaigns (Keep New Zealand Beautiful, 2012).

The Maori Party, and in particular its co-leader Tariana Turia, has also spoken out about the need for addressing asthma in a more comprehensive way. Turia has actively promoted Buteyko and other complementary medicines as alternatives to biomedical approaches (Berry 2005). In a 2002 presentation to Tu Kotahi (the Maori Asthma Society), Turia advocated for a more comprehensive, collective approach to dealing with asthma. Asserting that the implication of mainstream medical research seems to be 'that if each asthmatic takes more treatment, visits the doctor more, does what they're told and takes more drugs, they could feel better', she went on to argue:

Meanwhile more and more of our mokopuna get caught up in a vicious cycle. I don't think that's good enough. Of course we must manage our asthma as best we can – but we must look beyond individual cases to find a solution for ourselves as peoples. That's when the personal becomes political. Not party political – but groups of people acting together to take control of their own lives (Turia, 2002).

Such explicitly political discussions about asthma are, however, relatively rare in New Zealand and were largely absent from both our overview of representations of asthma in the public sphere (i.e., in the media, health outreach campaigns, Parliamentary and other political debates, etc.) and our interviews with healthcare workers, parents, people with asthma, and asthma society representatives.

In contrast, all of the parents and adults with asthma we spoke with indicated that, for them, asthma prevention and control is a largely familial and private matter. Furthermore, some of our adult sufferers of asthma noted that, although they did not feel any stigma around their asthma, they did not necessarily know which of their friends had asthma:

T: Like there may've been a few but often times you didn't realise someone had asthma until you had asthma and needed an inhaler and they were like I've got an inhaler, here you go, so yeah.

This largely private way of dealing with asthma is not solely a New Zealand phenomenon. In a study of American teenagers' views on asthma, Velsor-Frie-

drich *et al.* (2004:143) quote a teenager as saying ‘Like you don’t really bring it up. Like none of us knew that the other one had asthma. You usually don’t talk about it; you just deal with it on your own’. The authors argue that this approach is due to asthma being seen as not a ‘real serious thing’ (2004:143), rather than due to the teenagers being ashamed.

This contrasts with some of the more visible forms of activism in countries where asthma is widely seen as arising from environmental problems and cast as a collective, public concern. Widespread concerns over air pollution have long been central to environmental health movements in Central Europe, with particular attention paid to highlighting the damaging effects of air pollution on the respiratory health of children (Trnka 2011a, 2011b, 2011c; Vaněk, 1996). There are also pockets of asthma activism in the United States, galvanizing political mobilization in response to environmental degradation, particularly air quality (Keirns, 2009; Brown *et. al.*, 2003; Loh & Sugarman-Brozan, 2002).

## CONCLUSION

In examining the lived experience of childhood asthma and asthma treatments in New Zealand, we discovered a largely individualized and, at times, idiosyncratic approach to the condition within each of the families with whom we spoke. This often included parental monitoring and balancing of ideal or convenient dosages of medications and negotiating of triggers. Parents – most often mothers – readily took on the role of ‘experts’ in managing their child’s asthma, frequently calling on their own experiences of their child’s particular condition to guide their decision-making. Such individual-management was not ostensibly a critique of the efficaciousness of doctors or medications, but appeared to be encouraged by neoliberal reforms towards increasing ‘self-management’, as well as being in line with cultural values of self-reliance.

The parent-expert approach to asthma suggested by our interviews is notably distinct from the self-management strategies envisioned by many physicians. In their analysis of Australian physicians’ understandings of ‘self-management’, Aroni *et al.* (2003:11) have argued that, in clinical discourses, ‘self-management’ has ‘mostly come to signify patient adherence to medically recommended disease management advice’. Instead, we found parent-experts independently involved in tinkering with dosage, adjusting means of drug delivery, and, in some cases, determining treatment strategies (particularly in terms of requesting antibiotics). That said, these steps were always taken within the context of on-going, if at times sporadic, relationships with medical professionals.

With their focus largely upon how to best implement and regulate pharmaceutical regimes, most families did not prioritize other means of therapy or prevention, with the exception of encouraging their child to be involved in sports. Nor did our interviewees express much interest in the possibilities of engaging in collective action for asthma prevention or care. As in the storybook portrayal of Maui's experiences of learning to cope with his asthma, there was very little suggestion that asthma might be considered a collective issue, or that sufferers might attempt to alter their environments, other than by avoiding triggers. The people we spoke with primarily emphasised autonomy and independence, with the overall message being that, if not individual children themselves, then their families, should be self-reliant with respect to managing their child's condition.

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#### NOTES

- 1 This is despite the highly publicized controversy in the late 1980's and early 1990s over the role that Fenoterol played in New Zealand's high asthma morbidity rate (see Pearce 2007). While we had expected more public interest in the question of the safety of long-term pharmaceutical usage, especially of corticosteroids, very few parents raised this issue.
- 2 Ventolin is a popular brand of asthma relievers used to immediately alleviate asthma symptoms. The generic name for this medication is albuterol.
- 3 Flixotide is a corticosteroid preventer, used for long term preventive care.
- 4 Items such as mattress covers are available for purchase at some support groups. These are intended to help people to lessen their contact with dust and, hence,

to help them control their asthma. Such options, however, were not discussed as part of 'self-management' which, as a term, focuses specifically on the pharmaceutical management of symptoms.

- 5 The theme of 'responsibility' in healthcare and more broadly across various emergent technologies of the self is explored in more detail by Rose (2006) and also in Trnka and Trundle (2011); Trnka and Trundle (n.d.)

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