

Asthma morbidity 6 yrs after an effective asthma self-management programme in a Maori community

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ABSTRACT: A 6-month Maori community-based asthma self-management programme, involving a "credit card" asthma self-management plan, has previously been shown to be an effective and acceptable system for reducing asthma morbidity.

The effectiveness of the asthma self-management programme and participants' self-management behaviour was assessed 6 yrs after the formal end of the programme.

Participants were surveyed at the time of enrolment, and 1, 2, and 6 yrs after completing the programme. In each survey, participants were questioned on markers of asthma morbidity and use of medical services during the previous 12 months. Self-management behaviour was assessed using a questionnaire at 2 years and 6 yrs.

Of the 69 original participants, 47 (68%) were surveyed after 6 yrs. They generally had reduced severe asthma morbidity and emergency use of health services from baseline. In particular, the proportion who had an emergency visit to a general practitioner had decreased from 41% to 18% ($p=0.02$). However, the percentage of nights woken due to asthma had returned to preintervention levels, and the proportion of participants taking prescribed regular inhaled steroid had decreased from 91% to 53% ($p<0.001$). Compared with 2 yrs after completion of the asthma programme, self-management behaviour had also deteriorated, with 29% *versus* 73% ($p<0.001$) using their peak flow meter daily when their asthma was "getting bad" and 41% *versus* 86% ($p<0.001$) using the "credit card" plan to increase the amount of inhaled steroids in the last year.

Although the programme participants were still experiencing reduced morbidity from their asthma 6 yrs after the end of the self-management programme, the benefits were less than those observed at 2 yrs. These findings suggest that under-recognition and under-treatment of asthma with appropriate amounts of inhaled steroids is a major factor contributing to asthma morbidity in this indigenous rural community. To obtain enduring benefits from a self-management system of care continued reinforcement of self-management skills seems to be an essential component of any follow-up.

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Descriptive asthma mortality surveys of the 1980s reported that the most important factor associated with a fatal outcome was the inability of the patient and doctor to recognise the severity of an asthma attack resulting in delays in seeking appropriate medical treatment and assistance [1, 2]. Other important factors associated with asthma death have been insufficient inhaled prophylactic treatment, limited use of oral steroids during severe exacerbations, poor compliance with treatment and problems with effective medical supervision.

Asthma self-management plans were originally introduced as acute "crisis plans" to address some of these suggested mortality risk factors. By using key symptoms and peak expiratory flow recordings (PEFR) they provide the patient and doctor with specific guidelines for recognizing poorly controlled asthma and instituting early therapy. However, asthma self-management plans have developed into more than just simple crisis plans for use during acute

attacks of asthma. Most plans now involve increasing the amount of inhaled steroids with the early recognition of deteriorating asthma. Although there is no direct evidence that such an increase in treatment can alter the natural course of an exacerbation of asthma, it provides specific criteria by which adequate doses of prophylactic therapy can be titrated by patient and doctor, and encourages appropriate use of inhaled steroid therapy. The monitoring undertaken through use of the plans also reinforces an important long-term therapeutic goal of freedom from symptoms and the attainment of "best" lung function. Thus asthma self-management plans can be used as an integrated teaching aid for both patient and practitioner to acquire effective decision making skills in both acute and chronic asthma management.

A number of randomized controlled clinical trials have now demonstrated that asthma self-management plans can be effective tools in reducing asthma morbidity, requirement

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for acute medical services, and improving lung function and quality of life [3, 4]. However, it is still unclear what components of these programmes are essential to their success or how closely follow-up needs to be carried out to sustain and improve any short-term improvements. Other important issues relate to which is the best setting, and who is the most appropriate health practitioner to optimally introduce and maintain a self-management care package. Efficacy has been documented in a nurse-run general practice [5], and a specialist clinic in both a hospital [6] and community-based setting [7, 8].

The "credit card" self-management plan uses guidelines for the self-assessment of PEF and symptoms, printed onto two sides of a plastic "credit card". The authors have previously shown that this system of self-management can be an effective and acceptable tool for improving asthma morbidity in patients with severe asthma in a programme based in a rural Maori community [7], and in a hospital outpatient-based setting [6]. The authors have demonstrated that these improvements in patient morbidity and health service utilization can be sustained after 2 yrs without further input from the research team [8]. The current paper describes the long-term results of the self-management programme 6 yrs after its formal completion. Once again there was no further input from the research team and the subjects received the "usual care" of their local general practitioners during these 6 yrs. This allowed the authors not only to assess the long-term effectiveness of the programme, but also to assess the self-management skills that the programme participants had developed and had retained.

Methods

The initial Wairarapa asthma programme

The original introduction of the adult "credit card" asthma self-management plan through a community-based programme has been described in detail previously [7, 9]. The study involved introducing the management plan in a series of clinics which were held in marae (the traditional Maori community centre) and other community-based settings in the Wairarapa area, and were organized by Maori community health workers from that area. During the study the Maori community health workers also arranged transport for participants where necessary, maintained contact with the participants, and encouraged participants to complete their diaries. Prior to its commencement, the nature of the programme was also discussed with the general practitioners in the area. The general practitioners were also informed of each participant's involvement in the study and notes were sent regarding their progress and recommended changes in management during and at the conclusion of the intervention period.

The study involved an intervention trial over 6 months comparing markers of asthma morbidity, requirements for acute medical services, and prescribed drug therapy before and after the introduction of the self-management plan. During the initial run-in period of 8 weeks, participants were given a peak flow meter (if they did not already have one) and completed daily diaries on whether they had woken from sleep with asthma or coughing, whether they

had a day "out of action", and the best value from two morning prebronchodilator peak flow recordings.

Every month they also recorded the number of occasions on which nebulized medications were used, courses of oral corticosteroids, hospital emergency department visits, and hospital admissions. Following this initial 8-week period, the self-management plan was introduced at a clinic by one of the four physicians in the study team. The participants were then followed for a further 16 weeks with a second clinic being held after 8 weeks.

The clinics focused on the following key points: the inflammatory basis of asthma, the use of regular inhaled steroids to reduce the frequency and severity of attacks, the use of bronchodilators for relief of symptoms or prior to known aggravating stimuli, (rather than according to a regularly scheduled regime), adequate drug delivery through appropriate inhaler technique or change to dry-powder or spacer delivery systems, and the recognition and appropriate self-management of unstable asthma through use of the "credit card" plan.

Follow-up surveys

Following the enrolment in the initial intervention study ($t=0$ months), participants underwent a run-in period after which the "credit card" plan was introduced ($t=2$ months) and participants followed for a further 4 months ($t=6$ months). Following the 6-month programme the participants were discharged by standardized letter to the care of their usual general practitioner. No further educational or therapeutic involvement was subsequently undertaken with the participants or general practitioners by the research group, but follow-up surveys were conducted 1 yr ($t=18$ months), 2 yrs ($t=30$ months) and 6 yrs ($t=78$ months) after the end of the programme. Each follow-up survey was performed in the month of August.

The questions used to measure markers of asthma morbidity and use of medical services in the enrolment survey were worded identically in each follow-up questionnaire. The only exception was the instructions given to interviewers at the 2 yr survey when asking the question "how many days out of action" have you had in the last year? At two years, the definition of "days out of action" (off work or school or any day when asthma prevented you from doing something you otherwise would have done) was made explicit by interviewers, whereas in all other surveys it had been used only as a guide to enable interviewers to classify participant responses. In addition, at 2 yrs and 6 yrs, self-management behaviour was assessed by questioning participants on how they "usually" used their peak expiratory flow (PEF) meter/plan and how they used these tools if their asthma was "getting worse" or if they had a "bad attack" of asthma.

At 6 yrs the authors gained permission from all those completing the follow-up survey to search their hospital records for any admissions related to asthma. This was performed in an attempt to assess how reliable the questionnaire responses had been regarding previous hospital admissions. This was carried out by sending the only hospital which services the region, a list containing participants full name, date of birth and address. From this list a hospital identification number was generated for each participant by computer search. A research assistant and

two research nurses then performed a manual search of the hospital records for all persons with admissions from 1990–1997. An admission was classified as due to asthma if it was coded as the primary reason for their hospital stay. Concordance (and discordance) were measured by comparing participant's questionnaire responses and whether they had a recorded hospital admission for asthma in the 12 months preceding the administration of the questionnaire. However, it was expected that the hospital admission records would, to some extent, underestimate the true number of asthma hospital admissions in the study participants, since the authors were not able to identify admissions to hospitals outside of the study area. Questionnaire responses were classified as concordant with the hospital records if either both were positive or both were negative (and discordant if one was positive and the other negative). This shows a relatively high concordance (generally >90%) between these two methods for measuring asthma morbidity related to hospital admissions. The concordance is lowest at the initial survey but remains very high throughout the follow-up period. When there is discordance between these two measures it is almost entirely due to an admission being reported in the questionnaire but not identified in hospital records. This is to be expected, since the authors were not able to identify asthma admissions to hospitals outside of the study area.

The adult asthma self-management plan

The self-management plan provided two methods of self-assessment of asthma control: symptoms and PEFr. The method for self-assessment using PEFr was printed on one side and the symptom-based approach on the reverse side of a small plastic card, the size of a standard credit card [7]. For both methods of assessment, there are four general stages in which treatment guidelines are recommended. These guidelines are based on either the development of increasingly severe symptoms or decrease in PEFr from the patients previous "best". For each stage of deterioration clear instructions were written on what self-management steps to take and when to seek help. These were tailored to individual patients and their requirements and were written directly onto the card. Similarly, the patient's individual therapy, inhaled steroid or bronchodilator, and the name and telephone number of emergency help were also written onto the card.

Data analysis

Data were analysed using PC SAS (SAS Institute, Cary, NC, USA) [10]. Each before and after analysis was performed using two different comparison cohorts. Firstly, by comparing all the participants present at each follow-up survey and secondly, by using the same pool of follow-up participants in each/all comparison groups. The before and after comparisons at baseline, at 1 yr, 2 yrs, and 6 yrs following the completion of the 6-month programme were carried out using McNemars test with continuity correction for paired nonparametric data [11]. Continuous measured outcomes (mean dose of inhaled steroids) were compared using t-tests for paired data [11].

Results

Participants

Of the 69 Maori participants who originally took part in the programme interviews were conducted with 47 (68%). Three subjects had died, all in the last 2 yrs (one related to asthma, one due to another cause, and the other occurred outside of New Zealand and therefore it is unclear what the cause of death was). Using national mortality data [12], it can be calculated that it would be expected that 2–3 deaths would "usually" occur in a group with this size and age distribution (selected at random from all Maori, not just those with asthma), followed for this period of time. The other 19 nonparticipants were people that had moved out of the area, or who were still in the area and did not present for interview on at least two occasions. Table 1 shows the baseline characteristics of participants who took part in the four surveys. Although absolute numbers are small, both the 2 and 6 yr surveys include 12/13 who had an emergency department visit for asthma and 9/10 participants who had a hospital admission for asthma in the year prior to enrolment in the original study. This suggests that virtually all those at the severe end of the asthma spectrum from the original study are present in the follow-up surveys. With respect to other characteristics, table 1 shows that the three follow-up surveys involved participants who were similar with respect to demography, use of medical services and asthma morbidity compared to the initial survey. Therefore, despite varying numbers at the follow-up surveys the study participants are reasonably representative of the original study group.

Table 1. – Baseline characteristics* of participants initially enrolled in the Wairarapa asthma programme and those completing the follow-up surveys

	Enrolment (n=69)		1 yr (n=46)		2 yr (n=58)		6 yr (n=47)	
	n	%	n	%	n	%	n	%
Demography								
Mean age yrs	38		36		38		39	
Female	55	80	36	78	48	83	41	87
Smoke	32	46	19	41	27	47	21	45
Use of medical services in previous 12 months								
Nonemergency visit to doctor	54	78	37	80	47	81	41	87
Emergency visit to general practitioner	28	41	18	39	25	43	22	47
Hospital emergency department visit	13	19	8	17	11	19	12	26
Hospital admission	10	14	8	17	10	17	9	19
Asthma morbidity in previous 12 months								
Woken with asthma/coughing most nights**	20	29	14	30	14	24	14	30
>7 days "out of action"	15	22	8	17	10	17	10	21
Asthma self-management								
Peak flow meter	37	54	27	59	32	55	30	64
Written management plan	9	13	7	15	8	14	5	11

*: baseline characteristics—as measured at the time of enrolment;
 **: most nights= ≥ 4 nights on average in the last year.

Table 2. – Before and after comparison of markers of asthma morbidity and health service utilization for participants completing the 6 yr follow-up survey (n=47)

	Enrolment		6 yr		p-value
	n	%	n	%	
Use of medical services in previous 12 months					
Nonemergency visit to doctor	41	87	28	60	0.02
Emergency visit to general practitioner	22	47	9	19	0.009
Hospital emergency department visit	12	26	7	15	0.3
Hospital admission	9	19	5	11	0.6
Asthma morbidity in previous 12 months					
Woken with asthma/coughing most nights**	14	30	13	28	1
>7 days "out of action"	10	21	4	9	0.3

*: most nights= \geq 4 nights on average in the last year.

Asthma morbidity and health service utilization

Table 2 shows a before and after comparison of asthma morbidity and health service utilization for the 47 study participants completing the 6 yr follow-up survey. At 6 yrs study participants had significantly less emergency and nonemergency visits to their general practitioner than at enrolment (n=69). All the other markers of medical service utilization and asthma morbidity at 6 yrs showed no statistical difference to those at enrolment. In particular, the proportion of participants waking most nights with asthma or coughing is virtually identical to that prior to the original programme. The number of participants with a hospital admission or hospital emergency department visit are small and should be interpreted with caution, but are still (nonsignificantly) lower than baseline.

Table 3 shows the trend in markers of asthma morbidity and health service utilization for participants at enrolment, 1 yr, 2 yrs, and 6 yrs after completing the asthma programme. This shows similar findings to table 2 except for the severe markers of asthma morbidity: hospital emergency department visits and hospital admissions. These

Table 3. – Trend in markers of asthma morbidity and health services utilization for participants at enrolment (time (t)=0 months), 1 yr (t=18 months), 2 yrs (t=30 months) and 6 yrs (t=78 months) after completing the asthma programme

	Enrolment		1 yr		2 yr		6 yr	
	(n=69)		(n=46)		(n=58)		(n=47)	
	n	%	n	%	n	%	n	%
Use of medical services in previous 12 months								
Nonemergency visit to doctor	54	78	16	35	23	40	28	60
Emergency visit to general practitioner	28	41	6	13	9	16	9	19
Hospital emergency department visit	13	19	7	15	3	5	7	15
Hospital admission	10	14	4	9	3	5	5	11
Asthma morbidity in previous 12 months								
Woken with asthma/coughing most nights**	20	29	5	11	5	9	13	28
>7 days "out of action"	15	22	3	7	10	17	4	9

*: most nights= \geq 4 nights on average in the last year.

Table 4. – Inhaled steroid use for participants at baseline, end of programme, and 6 yrs later

	Base-line	End of prog.	6 yrs	p-value ⁺⁺	p-value [#]
n	69	66	47		
Prescribed inhaled steroids %	61	93	72	<0.001	0.01
Indicated inhaled steroids prescribed for regular use %	39	91	53	<0.001	<0.001
Mean daily dose of aerosolized inhaled steroids μ g*	484	1016	708	<0.002	<0.01
Mean daily dose of dry powder inhaled steroids μ g*	765	1608	946	0.002	<0.01

Prog.: programme. *: for those participants indicating inhaled steroids prescribed for regular use; ⁺⁺: p-value for baseline *versus* end of programme; [#]: p-value for end of programme *versus* 6 yr survey.

markers now show a proportionally similar level of morbidity to that measured at enrolment, this is probably partly explained by the smaller total numbers participating at 6 yrs (*i.e.* a smaller denominator).

Asthma management and self-management behaviour

Table 4 compares inhaled steroid use for participants at baseline, immediately after completion of the asthma programme and 6 yrs after completion of the programme. Thirty-four participants (72%) reported they were prescribed inhaled steroids, with 25 (53%) reporting that they were prescribed for regular use. For the regular inhaled steroid users the mean total daily dose was 708 mg and 946 mg for aerosol and dry powder preparations respectively. At the 6-yr follow-up, 38 (81%) people still had a peak flow meter with 25 (66%) reporting that they had used it in the last year; 36 (77%) of people reported that they still had their "credit card" self-management plan (table 5).

Table 5 shows the self-management behaviour for participants completing the 2-yr and 6-yr follow-up surveys. Daily monitoring of asthma using a peak flow meter was low when asthma was "not bad". Use of oral steroids for acute asthma was similar at 2 yrs and 6 yrs. However, 42

Table 5. – Self-management behaviour in previous 12 months for participants completing 2 yr and 6 yr follow-up surveys

	2 yr		6 yr		p-value
	(n=58)		(n=47)		
	n	%	n	%	
Used peak flow meter almost daily when asthma "not bad"	14	24	5	11	0.3
Used peak flow meter almost daily when asthma "getting bad"	42	72	11	23	<0.001
Used plan to increase inhaled steroids	50	86	18	38	<0.001
Taken a course of oral steroids	25	43	23	49	0.7
Self-initiated oral steroids	10	40*	9	39 [#]	0.9

*: for participants who had taken a course of oral steroids in the preceding year (n=25); [#]: for participants who had taken a course of oral steroids in the preceding year (n=23).

(72%) participants at 2 yrs used at least daily peak flow recordings to monitor deteriorating asthma but only 11 (23%) did recordings as frequently at 6 yrs. Also, whereas at 2 yrs 50 (86%) participants reported using the self-management plan to increase the amount of inhaled steroids only 18 (38%) of participants did so at 6 yrs.

Discussion

This study further extends the authors' long-term evaluation of participants who completed an effective community-based asthma self-management programme. It shows that, in this community with severe asthma, the health benefits gained following completion of the original self-management programme had been sustained for 2 yrs following the end of the programme, but that much of this improvement had been lost after 6 yrs. Although the authors' previous studies have been based on questionnaires, in the current study they were able to validate the questionnaire information on hospital admissions against local hospital records. There was very good concordance, indicating that the findings of the current study, and of previous studies [7, 8] are unlikely to be significantly affected by inaccuracies in recall or reporting.

Although the number surveyed varied throughout the follow-up period the participation rate still remained relatively high with 71% of the 69 participants initially enrolled in the study taking part in the 6-yr follow-up survey. The participants at 6 yrs include almost all those who either had an emergency department visit for asthma or a hospital admission for asthma in the year prior to enrolment in our asthma programme. These characteristics are known to be hallmarks of asthmatics with an increased risk of severe morbidity [13, 14]. This suggests that nonparticipants at the 6 yr follow-up survey comprise a group of asthmatics who could probably be classified (at least at initial enrolment) as having less severe morbidity. This will tend to inflate the measured proportions of these two variables at 6 yrs but makes it less likely that non-participation is a source of major unaccounted morbidity.

Overall, 6 yrs after the end of the asthma self-management programme, the participants had less asthma morbidity and use of medical services than prior to when the programme started. However, the significant gains and the trend for continued improvement measured at 2 yrs was not completely sustained at 6 yrs. The data would suggest that this community's deterioration in asthma control was due in part to the decreased level of inhaled steroid prescription and use. Immediately after the initial asthma programme the percentage of participants who reported that they were prescribed inhaled steroids had increased by 52% from baseline, and the mean daily dose increased by >100% from baseline. However, at 6 yrs the percentage of participants who reported that they were prescribed inhaled steroids had now decreased by 21% along with a decrease in the mean daily dose by >30% (compared to at completion of the asthma programme respectively). Thus, education and motivation of general practitioners, in addition to the patients themselves, with regard to the value of asthma self-management programmes could have improved the results further.

In some respects whether this deterioration is predominantly due to "inhaled steroid adherence" or, "inhaled

steroid under-treatment" for another reason, may be merely semantics. At 6 yrs the authors found only 38% of participants (compared to 60% in the final 3 months of the initial study, and 86% at 2 yrs) using the self-management plan to increase the amount of inhaled steroids in the preceding year. Anecdotally, at 2 yrs it was also noted that those surveyed would frequently reiterate the therapeutic intervention of the second stage of the "credit card" plan, to "double the dose" of inhaled steroid when waking at night with asthma. It is suggested that self-management plans modify the patient's ability to recognise poorly controlled asthma and this is a key step leading to the appropriate assessment of the level of inhaled steroid treatment. It may be that it is this altered self-management behaviour that is an important element of any indirect improvement in appropriate use of inhaled steroids leading to improved morbidity. This interpretation is consistent with the findings of LAHDENSUO *et al.* [4] who reported that better asthma control was observed in the group using the self-management plan, despite their dose of inhaled steroids being similar to that of the control group, implying that more appropriate use of inhaled steroids, due to the use of the plan, was the crucial factor.

It is interesting to note that acute courses of oral steroids remained infrequent and unchanged during the time of relative better asthma control observed at 2 yrs compared to at 6 yrs when asthma control was not as good. This may indicate that the predominant benefits with self-management plans may in fact be attributable more to their ability to improve chronic asthma control, by adequate long-term inhaled steroid dose adjustment, rather than in their role as a "crisis plan" for oral steroid initiation. If the benefits of self-management plans are indeed behavioural modification of inhaled steroid use, the current findings would suggest that it requires ongoing active reinforcement by the attending health professional. This is probably equally important in periods of stable asthma control and can frequently require more time than a 10–15 min consultation provides. Since the initial programme appeared to be sustained at 2 yrs without any ongoing intervention [8], as long as follow-up is comprehensive, it may not need to be carried out more than annually.

Although the focus of the current paper is on the asthma self-management plan, the community-based approach by which the plan was introduced and used in the current study should also be acknowledged. Maori are disadvantaged in terms of socio-economic status and access to medical care [15], a situation that contributed to the authors' decision to undertake the study in this particular community. This system of delivery, working in partnership with indigenous community health workers and in "traditional" settings is likely to be an approach that may be useful when working with other indigenous populations in other countries. This study also emphasises that health professionals may need to change the setting of their health message if they are to improve the poor participation seen in conventional hospital settings [6, 16] and gain the maximum benefit in other populations with severe asthma morbidity. Whatever the appropriate system of delivery, the long-term benefits of an asthma self-management programme are likely to be greatest, and most sustained, if the recognition of poorly controlled asthma and its adequate early treatment are continually reinforced as part of all patients regular asthma care.

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