



## **The acceptability of chronic disease management programmes to patients, general practitioners and practice nurses**

Jocelyn Tracey and Dale Bramley

### **Abstract**

**Aim** To evaluate the perceived effectiveness and acceptability of a disease management programme for patients with congestive heart failure (CHF) in South Auckland.

**Methods** Focus groups were held with patients, and practice nurses (PNs) and general practitioners (GPs) interviewed to develop the questionnaires. Questionnaires were posted to the 150 patients, 14 GPs and 6 PNs involved in the programme.

**Results** The programme was reported as changing patient lifestyle behaviours and patient understanding of medications and CHF. GP management was also seen as having improved. All aspects of the programme were seen as important: clinical review with a GP, educational sessions with a PN, patient-held care plan and educational material. The main issues were lack of time for practice staff to be involved, and payment for their time.

**Conclusions** Disease management programmes such as this are of value and are acceptable to both patients and providers.

As hospitals in New Zealand have struggled to cope with the burden of acute admissions, chronic disease management has become an area of interest. Enhancement of primary care management of chronic diseases may decrease secondary care costs. Audits of the management of patients with chronic diseases do show room for enhancement of primary care management, both in New Zealand and overseas.<sup>1,2</sup>

Four chronic disease management programmes (diabetes, asthma, chronic obstructive pulmonary disease (COPD), congestive heart failure (CHF)) have been implemented in South Auckland between Middlemore Hospital and the Independent Practitioner Associations (IPAs) in an effort to explore ways of making integrated disease management projects work in New Zealand. The model used for disease management has been previously published.<sup>3</sup>

The objective of this study was to evaluate the acceptability of a chronic disease management programme to general practitioners (GPs), practice nurses (PNs) and patients in South Auckland.

### **Methods**

**Nature of the chronic disease management intervention** Congestive heart failure is a major cause of ill health in the South Auckland population. Data from South Auckland showed that there were 610 admissions to Middlemore Hospital with a primary diagnosis of CHF in 1999, and 1968 admissions

with a secondary diagnosis of CHF. The estimated prevalence of CHF in the South Auckland area is 4680.<sup>4</sup>

In response to this, a programme was developed that included: updating general practitioners and practice nurses according to the 2001 Heart Foundation Guidelines of the Management of Congestive Heart failure;<sup>5</sup> payment of \$45 for one free assessment visit by the GP for each patient with CHF identified by the practice; payment for two 30-minute educational sessions with the practice nurse; payment for regular phone calls or home visits by the nurse, as necessary; a free educational booklet; provision to the patient of a personalised patient-held care plan containing details of all their health problems, medications, an action plan for CHF, and a summary of their lifestyle goals;<sup>6</sup> free direct access to echocardiography at Middlemore Hospital; free scales if necessary; and referral to Maori or Pacific nurses as required.

The programme was initially piloted with 14 GPs, 6 PNs and 150 patients from five practices. These five practices covered the range of socioeconomic status found in South Auckland, varied from a one and a half doctor practice to a five doctor practice, all used computerised clinical records (either Next Generation or MedTech 32), and all belonged to either of two IPAs (SouthMed and ProCare). Half of the GPs were already involved in a chronic disease management project for COPD patients. The first education session for GPs and PNs was held in late November 2000, and the patients received the extra services from January through to December 2001, depending on the time of initial enrolment.

**GP questionnaire** A postal questionnaire was used to evaluate the views of the GPs on this chronic disease management programme. The content of the questionnaire was informed by three 30-minute, semi structured, key informant interviews with GPs from three different practices who were known by the project staff to hold varying views on the acceptability of the programme and who came from different socioeconomic areas, practice sizes, and utilised different computer systems. To decrease potential bias, the interviews were carried out by one of the authors, a public health registrar, who was not involved in the development and management of the project. Based on the comments in the recorded interviews and information provided by project staff, the questionnaire was then formulated using Likert scales.

The questionnaire was posted to all GPs with a covering note. There was one follow-up mailing two weeks later.

The questionnaire results were entered onto an Excel spreadsheet and analysis undertaken using the Excel descriptive statistical functions.

**Practice nurse questionnaire** A similar questionnaire was developed for PNs. This was informed by a recorded focus group of six practice nurses. The questionnaire was mailed once to all practice nurses who saw patients in the project, and results analysed in the same way as for the GP questionnaire.

**Patient questionnaire** To inform the patient questionnaire, three focus groups were held. The seven patients in the first group were from a variety of practices, from different sizes and different socioeconomic areas. Six were European/pakeha and one was Samoan, two attended with their wives. A discussion guide was used to ensure all areas of interest to the project were covered, with the discussion allowed to range around these areas.

The second focus group covered the same topics and was attended by eight Maori patients, with the facilitator being Maori. The third focus group had five Samoan participants and was carried out in Samoan.

The draft questionnaire was piloted with the above focus group participants to ensure it was easy to understand and complete. It was translated into Samoan. The questionnaires were posted to patients by their GPs, with a coding system used by the practice to allow a second follow-up mailing, while keeping the questionnaires anonymous to researchers.

## Results

111 of the 150 patients completed a questionnaire, representing 74% of those enrolled in the programme and 79% of those still alive and traceable as at December 2001. Of these, 49% were male, 25% over the age of 80, 41% 71–80 years, 23% 61–70 years, 8% 51–60 years, and 3% younger than 51. Seventy three per cent were NZ European, 9% Maori, 14% Pacific Peoples (including 7% Samoan).

All of the six practice nurses (100%) involved completed the questionnaire. Eleven of the 14 GPs (79%) completed the questionnaire.

**Value of the project for patients** Patients were asked whether the extra services had been helpful to them in making lifestyle behaviour changes (Table 1).

**Table 1. Lifestyle behaviour changes reported by patients following programme**

Potential change	Big change %	Little change %	No change %
Improving diet	22	45	32
Doing more exercise	14	44	38
Taking medications correctly	29	31	40
Understanding purpose of medications	29	29	42
Monitoring own health	24	27	39
Understanding CHF	44	34	22
Understanding harmful lifestyle behaviours	36	25	39

Examples of the importance of these changes is illustrated by comments made in the focus groups:

“No one told me to get weighed. Even my doctor when I visited him. Now if I had been weighed everyday, I would have seen the increase and gone to the doctor and I wouldn’t have ended up in hospital again.”

“Yep. I know what I am taking certain pills for and I didn’t know that before.”

In addition, 61% of patients stated that they understood their medications very well following the programme, compared with 35% beforehand. Ninety five per cent confidence intervals for these percentages are [25,44] and [51,70].

Overall, 39 % of patients felt the programme had been very helpful, 55% helpful, and 6% not at all helpful. Seventy nine per cent were keen or very keen to participate in future similar programmes.

The staff were also asked to assess what value they thought the project was having in terms of affecting patient health, with responses showing a moderate effect (Table 2).

**Table 2. Value of project as perceived by staff**

Effect on patients	GP responses*	PN responses*
Changes to healthier lifestyle	3.4	2.8
More compliant with medication	3.1	3.2
Patients understand their CHF better	3.7	3.7
Improved clinical management	3.4	

\*five-point Likert scale: 1 = not at all useful, 5 = very useful

One GP commented:

“I think that anything that improves the patients’ understanding of their condition and to a certain extent puts a little more responsibility on them is a good thing.”

Another said:

“The patients just love it. That people are interested enough that, one, people will see them for free and that, two, they get that little bit of extra care.”

Patients were asked about the various components of the programme, and asked to rate these as very helpful, helpful, or not at all helpful (Table 3).

**Table 3. Value of programme components to patients**

Programme component	Very helpful %	Helpful %	Not at all helpful %
Session with GP	61	35	4
Sessions with PN	54	41	5
Time getting to know GP and PN better	53	43	4
Patient-held care plan	45	49	6
CHF education booklet	44	47	9

In the focus group one patient commented:

“I had good support from my nurse actually and she gave me a book and everything that’s wrong with me is in it.”

Staff were asked to assess the value of the various components of the project, with most aspects being assessed as moderately helpful (Table 4).

**Table 4. Value of programme components to staff**

Value of project components	GP responses*	PN responses*
Extra time and input to patients	3.8	4.0
Time discussing lifestyle issues	3.8	3.8
Time discussing CHF	3.8	3.7
Time discussing other health issues	3.6	3.8
Getting to know patients better	3.6	4.2
Separate PN sessions with patients	3.3	4.3
Home visits	3.5	3.5
Time for GP management review	3.8	

\*five-point Likert scale: 1 = not at all helpful, 5 = very helpful

**Practice configuration for disease management** A number of questions were asked of GPs and PNs regarding the time required and payment for disease management. When asked if one free assessment visit a year was enough to ensure good management, the majority disagreed (mean of 1.9 on five-point scale, 1= strongly disagree, 5 = strongly agree). The mean number of free visits with the GP thought to be adequate was three, with the same number of PN visits.

One of the difficulties in the project was to find sufficient time for practice nurses to have two half-hour educational sessions with each patient over six months and to ring them monthly for encouragement with any lifestyle changes. As a result, in two of the five practices, a study nurse saw the patients instead of the regular PN. In addition,

there were difficulties gaining the approval of the Health Funding Authority to pay the PNs for their part in the study. A number of questions were therefore asked about practice nurse payments. The option favoured by both GPs and PNs was payment of a bonus to PNs at the end of the project (4.1 and 4.7 respectively on five-point Likert scale). PNs also favoured being paid a fee for each patient seen (4.5). The option of having a locum PN visit the practice to free up the usual PN to see patients was not favoured (GPs 2.3, PNs 2.2), nor was that of having a visiting PN see the CHF patients (GPs 2.4, PNs 2.7). The importance of the patient's own PN supplying the educational component of the programme was illustrated by this comment:

“We lose continuity of care when someone else comes in. Ideally, as we are the practice nurses, it would be better if we saw them.”

A number of other practice issues were raised in the focus group about participation in the disease management programme. The responses to these in the questionnaires are shown in Table 5.

**Table 5. Problems with the disease management programme**

Issues	Size of problem	
	GP responses*	PN responses*
Lack of consultation in regard to PN participation		2.2
Poor selection of practices	2.0	2.3
Poor selection of patients for the project	2.3	2.8
Patients not turning up for their appointments	2.7	3.0
Lack of time to see patients for extra consults	3.5	3.6
Lack of time for GP to review notes before seeing patients	3.2	
Lack of nursing/GP support for the project	2.5	2.8
PNs too busy to see the patients	3.9	
Lack of support from other staff to do home visits		2.0
Lack of time for home visits		4.2
Too little remuneration for the work expected	3.8	4.4
Too many current projects for the practice to cope with	3.6	4.4

\*five-point Likert scale: 1 = no problems at all, 5 = major problems

The difficulty of finding time to do the project was illustrated by this comment from a PN:

“Time is the main problem. We never have enough time.”

There was moderate acceptance of the computerised aspects of the programme, with GPs rating the helpfulness of the electronic templates at 3.7, the electronic checklists at 3.6 (PNs 3.7), and downloading of data for evaluation at 3.9.

When asked how keen they would be to participate in future programmes, the GPs gave an average rating of 3.5 (5 = very keen, 1 = not at all keen), and PNs 3.0. One PN commented:

“It's the way of the future. Being a nurse, we have no time to educate and to sit down and talk to them and support the clients, but with this kind of opportunity to educate and show them a better lifestyle...yes, it's the right way to go.”

In regards to patient views of the structure of the programme, 92% said they had enough time to tell the GP all they wanted to discuss, and 95% had enough time with the PN. Seventeen per cent had transport problems getting to appointments, 17% had difficulties with timing of appointments, and 17% with the costs involved such as transport. This is illustrated by the following comment:

“Transport is a problem. I have to wait for my son to take me to my appointment after work. I have to make my appointments in the afternoon. Sometimes we have to catch a cab and it’s quite expensive.”

**Cultural issues** Eighty three per cent of patients thought having education material available in different languages was either very important or important, and 81% thought that having nurses available who can speak the same language was either very important or important. For example, a patient in the Samoan focus group commented:

“Translating the information in Samoan is important for us old folks. English is a major problem for most of us.”

Ninety one per cent of patients thought the project had been appropriate for someone of their culture. However, in the Maori focus group the following comment was made:

“We would prefer a Maori to talk to us. But in this day and age it doesn’t really matter, as we understand each other. But it would be preferable.”

The burden of CHF on Maori patients and their whanau was also mentioned in the Maori focus group (it was not mentioned in the other focus groups). Maori as well as Pacific participants commented that they wished to be able to keep meeting for support and ongoing education.

“Just being in a group you hear different testimonies. Being by yourself you don’t know what to do. Here you listen to people’s opinions and it helps. I think this is great.” (Maori participant)

Attitudes to cultural aspects of healthcare were collected from project staff (Table 6). When asked about a number of cultural issues in the project, staff responses indicated that any problems were relatively minor (Table 6).

**Table 6. GPs’ and PNs’ views on cultural issues**

<b>Importance of:</b>	<b>GP responses*</b>	<b>PN responses*</b>
Collection of ethnicity data	3.7	2.8
Ability to code for more than one ethnic group in computer system	4.1	4.3
Training to assist in collection of ethnicity information	3.4	3.5
Educational material available in multiple languages	3.4	4.2
Nurses available who can speak same language as patient	3.4	4.2
<b>Potential problems:</b>		
Communication difficulties due to language barriers	2.4	1.5
Lack of practice support to collect ethnicity data	1.9	2.0
Lack of knowledge on how to collect ethnicity data	2.0	1.2
Cultural appropriateness of the project	1.7	1.5

\*five-point Likert scale: 1 = no problem at all, 5 = major problem

## **Discussion**

The methodology used in the study was standard for studies of participant satisfaction in that focus groups were used to inform the questionnaires,<sup>7</sup> and piloting was carried out before administration of the questionnaires. The response rates are adequate to ensure the validity of the results.

Overall, the results show that this disease management programme was perceived to make a difference to patient self care and health status (programme outcomes such as changes in patients on appropriate medications will be published elsewhere). In particular, patients understood their CHF better, had made a moderate number of lifestyle changes and had a much better understanding of their medications. Patient and provider views were similar in regards to these changes.

The acceptability of the programme was also high to both groups, with the majority being prepared to be involved in future disease management programmes.

The components of the programme most highly regarded were those relating to the GP and staff spending extra time with the patient. Patient-held care plans were also seen as being helpful or very helpful by 94% of patients.

Difficulties with disease management centred around both GPs and PNs having sufficient time to be involved because of the pressures of seeing other patients and other projects. However, promoting continuity of care by using existing practice staff rather than bringing in project staff from outside was seen as very important. Sufficient payment of PNs was an issue.

Recording ethnicity, having patient materials available in other languages, and PNs speaking other languages were all seen as important. Almost all patients, regardless of ethnicity, perceived the programme as being appropriate to someone of their culture. This may have been enhanced by the fact that the PN in the practice with the most Pacific patients was of Tongan ethnicity.

Unfortunately, Maori enrolment and participation in this project was low. This will need to be improved in future projects. Information that was collected from the Maori focus group indicated that the burden of CHF in the Maori community was high and had had a dramatic impact on some families/whanau. Both Maori and Pacific participants in the focus groups requested ongoing CHF support groups. This is an area that should be further explored.

## **Conclusions**

This evaluation is important in that it shows that disease management programmes such as the CHF programme are acceptable and valuable to patients and primary care providers in a region such as South Auckland with diverse ethnicities and a low socioeconomic profile. The authors would encourage the development of similar programmes elsewhere and congratulate the Counties Manukau DHB in now allocating funding to incorporate their disease management pilots in CHF, COPD, diabetes and asthma into a generic programme to assist patients with chronic disease across the breadth of their health problems.

**Author information:** Jocelyn Tracey, CHF Programme Director, SouthMed IPA; Dale Bramley, Public Health Medicine Registrar, Counties Manukau District Health Board

**Acknowledgements:** All the general practitioners, practice nurses and patients involved in the project, and South Auckland Health for funding the project.

**Correspondence:** Dr Barry Gribben, Department of General Practice and Primary Health Care, University of Auckland, Private Bag 92019, Auckland. Fax: (09) 373 7006; email: [barry.gribben@cbg.co.nz](mailto:barry.gribben@cbg.co.nz)

### References:

1. Tracey JM, Arroll B. The effectiveness of the RNZCGP Diabetes QA module in changing GP behaviour. *NZ Fam Physician* 1998;25:45–51.
2. Simmons D, Fleming CE, Cutfield R, et al. The Diabetes Care Support Service for general practitioners in Auckland. *NZ Med J* 1997;110:48–50.
3. Tracey JM. Disease management. *NZ Fam Physician* 2000;27:23–6.
4. Internal data. Middlemore Hospital, South Auckland Health.
5. NZ Heart Foundation. A guideline for the management of heart failure. Auckland: NZ Heart Foundation; 2001. Available online. URL: [http://www.heartfoundation.org.nz/downloads/heart\\_health\\_info/heart\\_failure\\_guidelines.pdf](http://www.heartfoundation.org.nz/downloads/heart_health_info/heart_failure_guidelines.pdf)
6. Tracey JM, McAuley S. Patient held care plans for New Zealand. *NZ Fam Physician* 2000;27:31–2.
7. McLeod PJ, Meagher TW, Steinert Y, Boudreau D. Using focus groups to design a valid questionnaire. *Acad Med* 2000;75:671.