The feasibility of assessing the Flinders Program[™] of patient self-management in New Zealand primary care settings

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ABSTRACT

INTRODUCTION: The Flinders ProgramTM has been adopted in New Zealand as a useful and appropriate approach for self-management with primary care clients who have chronic conditions. The Flinders ProgramTM has not been evaluated in New Zealand settings.

AIM: To assess the feasibility of undertaking a substantive long-term trial to gauge the effectiveness of primary care nurses using the Flinders ProgramTM to improve health outcomes for New Zealand populations.

METHODS: A pilot study was undertaken considering four components of feasibility of conducting a long-term trial: practice recruitment, participant recruitment, delivery of the intervention and outcome measures. This included comparing 27 intervention and 30 control patients with long-term health conditions with respect to change in self-management capacity—Partners in Health (PIH) scale—quality of care using the Patient Assessment of Chronic Illness Care (PACIC) scale and self-efficacy across six months. Intervention participants received care planning with practice nurses using the Flinders ProgramTM in general practices, while control participants received usual care in comparable practices.

RESULTS: General practice and participant recruitment was challenging, together with a lack of organisational capacity and resources in general practice for the Flinders ProgramTM. The measures of self-management capacity (PIH), quality of care (PACIC) and self-efficacy were useful and valuable primary outcome measures.

DISCUSSION: The overall findings do not support a substantive trial of the Flinders ProgramTM in primary care. Difficulties associated with participant recruitment and ability of practice nurses to undertake the Flinders ProgramTM within general practice need to be resolved.

KEYWORDS: Self-management; long-term conditions; chronic conditions; chronic illness; primary care; nurses

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Introduction

Increasingly, self-management programmes within primary care are being considered a key strategy for improving chronic care in a number of countries throughout the world. In New Zealand (NZ), long-term or chronic conditions are responsible for approximately 70% of all general practice encounters and 78% of all health care spending. The 2006/7 NZ Health Survey found that two out of three New Zealanders have

a long-term health condition, with Maori and Pacific tending to experience more severe chronic disease than non-Maori, non-Pacific.⁴

The Flinders ProgramTM of Chronic Condition Self-Management, developed by the Flinders Human Behaviour and Health Research Unit (FH-BHRU), Australia, is an evidence-based self-management programme developed from the learnings of the Coordinated Care Trials in Australia.⁵ The programme is based on cognitive behaviour therapy, problem solving and motivational interviewing techniques to support positive behaviour change. This model utilises a number of tools and processes that enable clinicians and clients to collaboratively assess self-management behaviours, barriers, psychosocial issues and client preferences followed by client-identified problems and goal setting leading to individualised client care plans.⁶

The Flinders ProgramTM has been adopted in NZ as a useful and appropriate approach for self-management with primary care clients who have chronic conditions. Since 2005 approximately 500 NZ health professionals have participated in 'Flinders' training. The largest group of health professionals participating in training have been primary care nurses with 298 nurses completing the training in 2007–9 within a postgraduate certificate course which focuses on long-term conditions. The Flinders ProgramTM has not been evaluated in NZ settings.

While the evidence for self-management support is considerable, several authors, consider the evidence base for self-management to be underdeveloped and to have not provided convincing evidence. Australian studies of the Flinders Program have not focussed on practice nurses in primary care settings. Other authors consider that men and ethnic groups are under-represented in studies.

The aim of the 2008/2009 study was to assess the feasibility of undertaking a substantive long-term trial, including the usefulness of primary outcome measures, in order to assess the effectiveness of primary care nurses using the Flinders ProgramTM to improve health outcomes for 'high needs' NZ populations (particularly Maori and Pacific).

The overall challenges of undertaking research which attempts to assess the evidence base for a complex intervention in NZ primary care settings are reported separately.¹⁰

Methods

There were four components that required assessment in terms of the feasibility of a substantive trial: practice recruitment, participant recruit-

WHAT GAP THIS FILLS

What we already know: The Flinders ProgramTM of self-management has been adopted in NZ as a useful and appropriate approach for improving long-term condition management. Over 500 health professionals have been trained in the use of the programme. The evidence for the effectiveness of self-management is, however, inconclusive, and support for the introduction of new and complex interventions in primary care inconsistent.

What this study adds: This paper shows that, despite considerable resources being directed to training primary care nurses in particular in the Flinders Program[™], undertaking a substantive trial to evaluate the effectiveness of the Program[™] is not feasible. Difficulties with introducing a new and complex intervention in primary care with structured support need to be resolved before a trial is undertaken.

ment, delivery of the intervention, and outcome measures. A pilot study was conducted to enable assessment.

Recruitment of general practices

For the pilot study, 100 patients were recruited from 20 general practices with the intention that 50 patients would receive assessment and care planning from nurses using the Flinders ProgramTM (intervention group) in 10 general practices compared with a group of 50 patients who received 'usual care' (control group) in 10 comparable general practices. The intervention practices employed nurses trained in the Flinders ProgramTM whereas the control practices did not have nurses similarly trained. The practices were selected to allow for geographic spread and distribution across socioeconomic areas.

Recruitment of participants

Eligible participants were enrolled general practice patients, aged over 18 years, with one or more long-term conditions such as, but not limited to, asthma, arthritis, gout, diabetes, heart disease, metabolic syndrome, COPD, depression, as well as those with high CVD risk with modifiable risk factors (15% or greater). Participants were required to give informed consent, have sufficient English, Maori, Samoan or Tongan language skills to complete written questionnaires and to be agreeable to follow-up over at least six months. Questionnaires were not translated for

non-English speakers; however, Maori, Samoan and Tongan interpreters were utilised. Exclusion criteria included enrolment in Counties Manukau DHB's Chronic Care Management Programme and having recently moved from a practice where they may have worked with a nurse utilising the Flinders ProgramTM. Previous/concurrent participation in a self-management programme such as the Arthritis NZ 'Living a Healthy Life' programme was not stated as an exclusion criterion. Usual care included enrolment in Care Plus.

Lists of eligible patients were compiled using the patient database for each practice and electronic searching through practice management systems for each disease category. Lists were combined and sorted by surname and ethnicity. In order to achieve the aim of enrolling 10 patients in each practice, a list of 50 potential patients was determined to be necessary. In order to overselect for Maori and Pacific, 20 patients should identify as Maori and 20 as Pacific. Gender mix was not included in the sampling process. When patient lists were combined and duplicate surnames removed, each patient was given a random number and the patient list sorted by randomised number. A list of the first 50 patients from the randomised list was then discussed with the practice and any patient considered inappropriate (e.g. receiving palliative care or having significant cognitive impairment) removed. A letter of invitation to participate in the study was sent from the practice to the first 13-15 patients (of whom five identified as Maori and five Pacific) on the approved list. Patients were invited to opt out of the study by contacting the practice. For those who did not opt out, a research assistant telephoned to confirm their willingness to participate and arrange a time to visit, discuss the study further, complete the consent process and undertake a baseline assessment. Participants had the opportunity to complete this assessment in their own home or to come to the practice. Where the initial letter of invitation did not allow for a sample of 10 clients from a practice, further letters were sent to the next patients on the randomised list.

Delivery of intervention

For patients in the intervention practices the nurses contacted the patient following the base-

line assessment and scheduled an appointment at the practice for a Flinders assessment and development of their client care plan. The Flinders ProgramTM involves the patient first completing the Partners in Health (PIH) questionnaire. The PIH scale utilises 13 questions to assess an individual's self-management skill and capacity on an eight-point scale (very good through to very poor). It is based on the understanding that self-management of chronic conditions requires consideration of the individual, their family, carers and health professionals; requires an holistic approach that acknowledges medical and psychosocial issues and is aimed at empowering the individual through proactive strategies.¹¹ The tool assesses self-reported knowledge of the individual's condition and treatment, ability to share in decision-making with their health professional, engage in activities that promote health, monitor signs and symptoms and manage the impact of their condition on physical functioning, emotions and interpersonal relationships.

The second stage, the Cue and Response questionnaire, involved the health professional going through the same questions and comparing their assessment where the patient is asked what their main life problem is. This problem may not be a 'health' problem. A goal is identified around the problem and transferred to a care plan, which will also include issues identified from the Cue and Response questionnaire as well as other key medical, psychosocial or carer issues.

Follow-up of the intervention patients was as appropriate, for example to discuss progress with specific goals or review medication, but also at three and six months to assess progress and record problem and goal scores in accordance with the Flinders ProgramTM.

Outcome measures

Outcome measures were assessed at baseline and at six months (26 weeks) for all participants (control and intervention) by a research assistant who was blinded as to whether the participant was in the intervention or control group.

The primary outcome measures were:

- Self-management capacity—Partners in Health (PIH) scale. The self-administered rating of a patient's self-management skill and capacity.
- Patient assessment of quality of care—Patient Assessment of Chronic Illness Care (PACIC). The PACIC is a validated patient self-report instrument which assesses the extent to which a patient's care aligns with the principles of chronic care management, i.e. one that is patient-centred, proactive, planned and includes collaborative goal setting, problem solving and follow-up support. 12,13
- Self-Efficacy for Managing Chronic Disease 6-Item Scale. This scale contains items from self-efficacy scales and is validated by the Stanford Patient Education Research Centre for their Chronic Disease Self-Management studies.¹⁴

Secondary outcome measures were collected as part of evaluating the feasibility and usefulness of a broad range of outcome measures. These included the European Quality of Life Scale (EuroQoL), a health-related quality of life outcome measure which assesses outcome in six broad areas (mobility, self-care, activities, pain, psychological functioning, and self-reported overall health-related quality of life);¹⁵ the SF-12 Health Status Questionnaire, a 12-item, self-administered questionnaire that assesses symptoms, functioning and quality of life;¹⁶ and the PHQ^{9,17} a nine-item depression scale used for diagnosing depression.

Clinical outcome measures were not collected, as there was a relatively short follow-up period and changes would not be expected.

Demographic data, current medication, self-reported information on smoking, medication adherence and physical activity levels, together with patient knowledge of their recorded diagnosis, were collected.

Analysis

Data were loaded into the Statistical Package for the Social Sciences (SPSS), version 15.0.1 for Windows, for data analysis. An alpha level of p<.05 was adopted for all of the statistical tests unless otherwise stated. Descriptive analyses

including paired and independent samples t-tests were performed to assess differences at baseline and six months within the groups.

Ethics

Ethical approval for this study was granted by the NZ Northern Y Regional Ethics Committee.

Results

Practice recruitment

A total of 35 general practices in the wider Auckland area were approached to achieve an initial sample of 20 practices which were randomised into 10 intervention practices with a practice nurse trained in the Flinders ProgramTM and 10 control practices where no nurses had completed Flinders training.

Participant recruitment

In order to achieve an initial sample of 100 participants, 331 letters of invitation to participate in the study were sent. Forty-three of the 100 participants did not complete the study (Table 1). Of the 22 control group participants who did not complete, 16 were not followed when it became apparent that the intervention sample would not reach target. Withdrawals from the intervention group included one death, two participants with deteriorating health withdrawn by the practice nurse and 18 who declined to complete the study. Reasons for declining included moving out of the area, deteriorating health and, for one participant, objection to the questioning approach.

A wide spread of patients across disease categories was achieved. The average age of patients was 55 years for the intervention group and 61 years for the control group. No statistically significant difference in the age range between the two groups was demonstrated (Table 2).

Table 1. Participant numbers

Participants	Registered	Completed	Did not complete
Intervention	48	27	21
Control	52	30	22
TOTAL	100	57	43

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Table 2. Participant demographics

	Intervention (n=27)	Control (n=30)		
Age range	25–90 yrs	25–90 yrs		
Average age	61 yrs	55 yrs		
Median age	62 yrs	55 yrs		
Gender				
Male	16	14		
Female	11	16		
Ethnicity				
NZ/Euro	11	17		
Maori	8	6		
Pacific	8	6		
Indian	0	1		
Disease				
CVD/stroke/PVD/HT	13	15		
Asthma/COPD	10	16		
Diabetes	16	10		
Arthritis/gout	14	15		
Other	16	16		
With comorbidities	22	23		

Outcome measures

The sample size was smaller than planned and it was evident from the pilot findings that the study was not powered sufficiently to detect changes in secondary outcome measures and self-reported information on smoking, medication adherence and physical activity levels from baseline to six months. These measures are therefore not reported. Primary outcome measures are reported as part of assessing the feasibility of utilising these measures in a substantive trial.

Partners in Health (PIH)

In Australian studies¹⁸ where sample size has been small (n=31), PIH scores have been amalgamated to allow reporting in six domains: knowledge of condition; treatment adherence; sharing care; measuring symptom progress; impact of illness and progress with adopting healthy lifestyle habits. Utilising this approach a paired samples *t*-test demonstrated no statistically significant difference between baseline and 26 weeks in the intervention group (Table 3). With this scale a lower score at 26 weeks indicates improvement.

Table 3. Paired sample t-test for Partners in Health amalgamated scores

	N	Baseline Mean (SD)	26 weeks Mean (SD)	P-value
Intervention				
Knowledge	24	3.33 (3.06)	2.79 (3.23)	0.345
Sharing	24	0.75 (1.22)	0.38 (0.82)	0.214
Measure symptom	24	6 (4.53)	6.26 (4.26)	0.743
Treatment	22	2.5 (3.98)	1.73 (3.60)	0.392
Impact	24	3.92 (3.79)	3.71 (4.16)	0.805
Lifestyle	23	1.35 (1.74)	1.17 (1.96)	0.701
PIH TOTAL SCORE	21	19.76 (13.50)	16.1 (12.84)	0.126
Control				
Knowledge	30	3 (3.21)	3.03 (3.05)	0.951
Sharing	30	0.96 (1.71)	0.7 (1.8)	0.485
Measure symptom	30	5.93 (4.07)	5.56 (3.09)	0.645
*Treatment	26	3.34 (4.48)	2.19 (4.08)	0.044
*Impact	30	4.26 (4.40)	2.7 (3.29)	0.034
Lifestyle	30	1.6 (2.14)	1.26 (2.09)	0.482
*PIH TOTAL SCORE	26	18.23 (10.88)	14.88 (9.99)	0.048

Paired sample t-test where * denotes significant difference between baseline and six months at p < 0.05

Patient Assessment of Chronic Illness Care (PACIC)

The PACIC scale includes 20 items and assesses on a five-point scale (1=none of the time, 2=a little of the time, 3=some of the time, 4=most of the time, 5=all of the time) the extent to which patients report receiving care that accords with a chronic care model of care, including care that is patient-centred, proactive, planned and includes collaborative goal setting, problem solving and follow-up support.² A higher score at follow-up indicates perceived improvement. The 20 items combine to five sub-scales which relate to different aspects of providing care congruent with chronic care management: patient activation or actions that solicit patient input and involvement in decision-making; delivery system design or actions that organise care and provide information to patients to enhance their understanding of care; goal setting or the patient acquiring information for and setting of specific collaborative goals; and follow-up or coordination of care where clinic treatment is extended and reinforced and proactive contact with patients to assess progress and coordinate care.12 There was a statistically significant improvement (paired samples t-test) at six months from baseline in goal setting (p=0.000), problem solving (p=0.009) and followup (p=0.001) for the intervention group (Table 4).

Self- efficacy

The self-efficacy scale enables individuals to rate their confidence on a 10-point scale (not at all confident through to totally confident) on keeping their physical discomfort or pain, symptoms and emotional distress from interfering with things they want to do; different tasks and activities managed in order to reduce the need to see a doctor; and confidence in doing things other than just taking medication to reduce the effect of illness on their everyday life. A higher score at follow-up indicates improved confidence. For the intervention group there was deterioration in the level of self-reported confidence on all scales, although these scores were not significant (Table 5). For the control group there was improvement on several of the scales from baseline to six months, with improved confidence with managing emotional discomfort and other symptoms statistically significant (p=0.01 and p=0.042) (Table 5).

Discussion

Primary outcome measures

This study was designed to test the feasibility of undertaking a substantive trial and to determine useful outcome measures for such a trial. Despite the small sample size, some findings are of interest and value in determining direction for future studies.

The Partners in Health (PIH) self-ratings by both groups showed positive ratings of self-management skill and capacity on all domains (with one exception, measuring symptom progress). Questions are raised about the care taken by participants in noticing that the PIH scale operates in the opposite direction from other scales used in this study, i.e. from positive responses (a lot, always or very well) scoring low scores to nega-

Figure 1. PACIC sub-scales¹²—goal setting; problem solving; follow-up

The goal setting sub-scale includes the items:

'Over the past six months when I received care for my chronic condition I was:

- Asked to talk about my goals in caring for my condition
- Helped to set specific goals to improve my eating and exercise
- Given a copy of my treatment plan
- Encouraged to go to a specific group or class to help me cope with my chronic illness
- Asked questions either directly or on a survey about my health habits.'

The problem solving sub-scale includes the items :

'Over the past six months when I received care for my chronic condition I was:

- Sure that the doctor or nurse thought about my values, beliefs and traditions when they recommended treatments to me
- Helped to make a treatment plan that I could carry out in my daily life
- Helped to plan ahead so I could take care of my illness even in hard times
- Asked how my chronic illness affects my life.'

The $follow-up\ sub-scale\ includes\ the\ items$:

'Over the past six months when I received care for my chronic condition I was:

- Contacted after a visit to see how things were going
- $\bullet \hspace{0.4cm}$ Encouraged to attend programmes in the community that could help me
- Referred to a dietitian, health educator or counsellor
- Told how my visits with other types of doctors like an eye doctor or surgeon helped my treatment
- · Asked how my visits with other types of doctors were going.'

Table 4. Paired sample t-test—Patient Assessment of Chronic Illness Care (PACIC) at baseline and six months

	N	Baseline Mean (SD)	26 weeks Mean (SD)	P-value
Intervention				
Patient activation	23	2.04 (1.54)	2.63 (1.46)	0.085
*Delivery system	23	2.34 (0.91)	2.92 (1.02)	0.012
*Goal setting	22	1.30 (1.34)	2.40 (1.27)	<0.001
*Problem solving	21	2.16 (1.25)	3.13 (1.32)	0.009
*Follow-up	19	0.93 (1.18)	2.29 (1.36)	0.001
*PACIC summary score	16	1.73 (1.17)	2.65 (0.95)	<0.001
Control				
Patient activation	26	1.65 (1.37)	1.89 (1.39)	0.314
Delivery system	29	2.35 (0.99)	2.52 (1.13)	0.494
Goal setting	29	1.33 (1.14)	1.53 (1.19)	0.383
*Problem solving	27	2.07 (1.11)	2.62 (1.19)	0.043
Follow-up	26	0.99 (1.09)	1.18 (1.21)	0.328
PACIC summary score	22	1.56 (0.83)	1.88 (0.96)	0.068

Paired sample t-test where * denotes significant difference between baseline and six months at p < 0.05.

Table 5. Paired sample t-test for self-efficacy

N	Baseline Mean (SD)	Control Mean (SD)	P-value
24	7.83 (2.61)	7.37 (2.71)	0.319
24	8.33 (2.27)	7.79 (2.78)	0.241
24	8.91 (1.63)	8.04 (2.85)	0.164
23	8.73 (1.76)	7.86 (2.54)	0.132
23	8.13 (2.59)	7.69 (3.02)	0.466
24	7.87 (2.43)	7.79 (3.18)	0.831
30	7.23 (2.69)	7.7 (2.58)	0.291
30	7.43 (2.89)	8.2 (2.20)	0.086
30	6.76 (3.22)	8.3 (1.87)	0.01
30	7.46 (2.41)	8.16 (2.18)	0.042
29	8.10 (2.28)	7.89 (2.46)	0.743
30	7.46 (2.92)	7.93 (2.72)	0.504
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Paired sample t-test where * denotes significant difference between baseline and six months at p < 0.05.

tive (very little, never, not very well) scoring at the high end. While there was no evidence that confusion occurred in this study, discussion with participants suggests that individuals prefer rating from negative (low) to positive (high scores).

The PACIC scale is useful in assessing the perceived quality of care provided. PACIC has been developed from ACIC (Assessment of Chronic Illness Care), an instrument used to enable clinicians and health care teams to assess the extent to which the care they provide aligns with 'best practice' chronic care management.¹² By using similar domains, the PACIC enables an assessment of the quality of care being delivered from the patient's perspective. This study did demonstrate that the Flinders ProgramTM showed a perceived improvement in the overall quality of care and, in particular, evidence-based elements of chronic care management (CCM) such as goal setting, problem solving and follow-up.

The self-efficacy scale provided a useful measure of self-reported confidence in managing chronic disease. The small sample size can account for the finding that the intervention group showed deterioration on their overall self-reported confidence (self-efficacy). A further explanation may be that with the improved opportunity to understand their condition and treatment through participation in the Flinders ProgramTM there is a diminished confidence seen at six months. Improving patient confidence requires ongoing support over a time frame longer than six months and a longer study would be needed to determine this.

A failure to demonstrate difference within and between the 'control' and 'intervention' groups can partially be attributed to the extensive baseline and follow-up data collection process which in itself proved to be an intervention. Completion of the data collection form required approximately one hour and, for both groups of patients, this provided an opportunity to reflect on their illness and the effect this may have on their lives.

Secondary outcome measures

The secondary outcome measures collected, but not reported in this paper, meant that data collection was onerous for patients. These measures added no value. Clinical outcome measures would only be of value in a study of adequate length.

General practice recruitment

The short time frame for completion and the complexity of the general practice environment highlights the difficulties with undertaking studies in primary care with patients who have long-term conditions. Difficulties with practice workloads, staff changes and competing nurse demands resulted in only seven intervention practices completing study requirements within the nine-month time frame of the study. Control practices were also difficult to recruit, as many practices were reluctant to participate in a study where the perceived patient care of the chroni-

Completion of the data collection form required approximately one hour and, for both groups of patients, this provided an opportunity to reflect on their illness and the effect this may have on their lives

cally ill may be shown to be of 'lesser' quality than in the intervention practices. This resulted in the control general practices who 'volunteered' to participate in the study being those practices where chronic care programmes were established. Patients in the control practices, while not completing a Flinders assessment, may have been linked into goal setting and care planning as support for management of their condition.

Patient recruitment

High-needs patients with long-term conditions are frequently a mobile population, and inaccurate addresses and phone numbers combined with difficulties with the accuracy of disease coding in practice management systems resulted in over 300 patients being contacted to recruit a sample of 100. Likewise, follow-up at six months was challenging with many unknown addresses. Data completion required participants to complete

self-reported outcome measures. This resulted in missing values where participants failed to answer some questions.

Intervention

While the nurses in the intervention practices had completed training in the Flinders ProgramTM, none were using the approach in their usual work or were able to use the tools initially with confidence. Additionally, the nurses were not accustomed to the length of structured appointment time required for a patient consultation (up to one hour) using the Flinders ProgramTM, and practice workloads made this difficult. The nurses did not routinely have booked patient case loads and were working to maximal capacity. The need for nurses to be confident and competent with the intervention prior to study commencement is an important part of future studies.

In order to reduce complexity, a narrower disease range may also have facilitated study processes. A United Kingdom study¹⁹ found that nurses were more confident in working with patients in the earlier, less complex, stages of their illness. These issues, alongside a lack of practice organisational capacity and resources for the introduction of the intervention, all contribute to the difficulties of undertaking a substantive trial.

Conclusion

Self-management programmes in primary care will continue to have focus and increasingly this will be a nurse role. However, the overall findings from this study do not support a substantive research trial of the Flinders ProgramTM in primary care at this stage. Further work is first needed to determine how 'new' complex interventions can best be introduced into primary care. This includes considering the report of Finlayson et al.20 on primary care nursing which identifies barriers to nurses expanding their practice. These include heavy nurse workloads, lack of physical resources, lack of support and motivation from general practitioners (GPs), GP attitudes, lack of leadership and poor nurse remuneration. Some nurses in the Finlayson study also reported a lack of self-confidence and a lack of a willingness to embrace change.

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COMPETING INTERESTS

Dr Janine Bycroft is a Flinders accredited trainer.

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