

Self-management support and training for patients with chronic and complex conditions improves health-related behaviour and health outcomes

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Abstract

The Sharing Health Care SA chronic disease self-management (CDSM) project in rural South Australia was designed to assist patients with chronic and complex conditions (diabetes, cardiovascular disease and arthritis) to learn how to participate more effectively in the management of their condition and to improve their self-management skills. Participants with chronic and complex conditions were recruited into the Sharing Health Care SA program and offered a range of education and support options (including a 6-week peer-led chronic disease self-management program) as part of the Enhanced Primary Care care planning process. Patient self-reported data were collected at baseline and subsequent 6-month intervals using the Partners in Health (PIH) scale to assess self-management skill and ability for 175 patients across four data collection points. Health providers also scored patient knowledge and self-management skills using the same scale over the same intervals. Patients also completed a modified Stanford 2000 Health Survey for the same time intervals to assess service utilisation and health-related lifestyle factors.

Results show that both mean patient self-reported PIH scores and mean health provider PIH scores for patients improved significantly over time, indicating that patients demonstrated improved understanding of their condition and improved their ability to manage and deal with their symptoms. These results suggest that involvement in peer-led self-management education programs has a positive effect on patient self-management skill, confidence and health-related behaviour.

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THE SHARING HEALTH CARE South Australia chronic disease self-management (CDSM) project in rural SA was designed to assist patients with

What is known about the topic?

Structured behaviour change strategies can lead to improved self-management skills and abilities for patients with chronic illness and have the potential to facilitate long-term behaviour and lifestyle change.

What does this paper add?

This paper describes the Sharing Health Care SA chronic disease self-management (CDSM) project in rural South Australia. Program evaluation found that this program was successful in assisting participants to develop effective self-management of their chronic conditions.

What are the implications for practitioners?

Self-management strategies can be effective for individuals with chronic conditions.

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chronic and complex conditions such as diabetes, cardiovascular disease and arthritis to learn how to participate more effectively in the process of managing their condition and improving their self-management skills. Implicit in the work is the idea that structured behaviour change strategies can lead to improved self-management skills and abilities for patients with chronic illness and have the potential to facilitate long-term behaviour and lifestyle change.^{1,2} These processes in turn may support sustainable health-related behaviour change and lead to improvements in overall patient health and wellbeing.

Results based on an analysis of quantitative patient data, along with qualitative survey data collected during the project, suggest that patient involvement in self-management programs has positive effects on their self-management abilities, confidence and health-related behaviour. The work presented here builds on these preliminary findings by linking improved patient self-management ability to improved health outcomes.

Context

The Sharing Health Care SA (SHC SA) initiative in Whyalla, Port Augusta and Port Lincoln was based on the initial work of the Eyre Peninsula coordinated care trials³⁻⁵ and a chronic illness management pilot program conducted in rural Aboriginal communities in Port Lincoln and Ceduna.⁶ The project was also consistent with developments elsewhere that have shown that chronic disease, much of which can be prevented and/or managed, has become a major burden upon our health systems. In the United States the impact of chronic diseases such as diabetes, coronary heart disease, hypertension and asthma, for example, already accounts for the majority of the nation's health care costs⁷ and this burden is set to rise by 15% by 2010 and by an estimated 60% by 2050⁸ as our population ages.

Effective management of chronic conditions is a major health system challenge, and our health efforts will increasingly need to focus on illness prevention, population health management and community and patient partnerships,⁹ while at the

same time maintaining acute care delivery levels. The challenge is to not only identify and manage emerging chronic illness, but also to intervene at the social, economic and environmental levels to prevent illness at its source⁷ through population-based approaches to the management of community and individual wellbeing.

The SHC SA project therefore developed self-management programs for patients with chronic conditions. Interventions included the use of formal care plans to structure systems of care, education programs based on the Stanford University patient self-management approach¹⁰ and other patient support and empowerment processes such as regular exercise, tai chi, and self-help groups. The Partners in Health (PIH)¹¹ goal setting and care planning process was used to complete "patient-centred" care plans based on lifestyle goals and targets for the management of patient illness.

In this process, the PIH scores, collected at regular 6-month intervals, measured patient skill and ability across a range of self-management categories or domains represented by the 12 questions of the PIH scale. Patients completed self-rated scores, and the health professionals involved in the formulation of care plans also rated patient skills and abilities across the same areas of the PIH scale from a clinical perspective. This dual scoring process provided a mechanism for tracking patient self-management abilities over time and for identifying discrepancies between patient and provider scores for each domain on the scale. The approach served to highlight areas in which patients required further education and information to improve their self-management skills and abilities.

CDSM strategies

Self-management, in the context of this study, refers to a patient's ability to understand the nature of their condition and to manage and organise their access to key elements of their care. A patient who understands their illness, how to recognise early warning signs and take appropriate action, how to manage their lifestyle for

optimal health outcomes and how to work effectively with health care providers and carers is seen to be a good self-manger.

The notion of self-management does not imply that patients need to manage their illness by themselves, in isolation from mainstream services, or have to manage their own treatment plan. Quite the contrary! A good self-manager knows what services to access, how, and when, in order to maximise their potential for wellbeing. This implies an effective partnership between patient, carer and health service provider which ensures that essential elements of care are available when needed and that the various providers involved in a patient's care are informed about key aspects of this care and able to work together to ensure the best possible outcomes for the patient.¹¹

The ideologically burdened proposition that CDSM approaches may be elaborate strategies for instituting demand management rather than effective methods for improving patient health outcomes specifically¹² notwithstanding, there appears to be merit in the process for both Aboriginal and non-Aboriginal people. That is, even though CDSM might well be a construct for shifting demand away from an overtaxed acute system in crisis, it also has potential to contribute to improved health and wellbeing for significant numbers of patients living with chronic illness and to prepare the way for the development of a more integrated preventive approach to health care generally. Whether or not these improved health outcomes can be achieved within the existing cost structures available for the care of patients with chronic illness is yet to be definitively determined.¹³

Whatever may be the outcome of our experiments with coordinated care and chronic disease self-management programs, the Australian health system appears to be no longer able to afford to deliver costly acute health services at the current rate of escalation. Strategies therefore need to be found to reduce demand for acute care services, especially when this demand can be moderated through early intervention programs.¹⁴

Self-management rationale

Lorig, Fries, and others, have demonstrated that major factors in reducing the cost of care for chronic illness sufferers and increasing health outcomes for this group are illness management awareness initiatives and self-management training and support programs.^{9,15-26} In addition, it is widely recognised that where communities and consumers of health services participate meaningfully in the process of accessing and using those services (that is, share in the process of health care) improved health outcomes are more likely than in situations where this sharing does not occur²⁷ — effective public participation in the processes of health care delivery is crucial to improving health outcomes.²⁸ Some organisations are even accepting that self-management processes, as well as being beneficial for patients, can improve patient quality of life and reduce the cost to health systems of providing health care services.²⁹

The SHC SA approach to self-management training and support for patients encouraged and developed patient knowledge of their chronic conditions and empowered them to manage their lives and live more effectively with their illness. At the same time, the formal structures of the demonstration program acted as a stimulus for organisational change in the health system. The project encouraged health care providers to respond more effectively to the needs and demands of the individual patients who, through their more central involvement in their program of care, were empowered and more able to self-manage within the health care system.³⁰

This project was therefore not only designed within a finite timeframe to deliver a modified system of care, encourage self-management and document outcomes through formal research, but to encourage and promote collaboration between providers and patients to ensure that any elements of the program shown to be successful might continue beyond the formal phase of the project.

I Illness groups and relative numbers of patients with these diagnoses

Illness category	Men (n=67)		Women (n=108)	
	Frequency	% of total	Frequency	% of total
Diabetes	26	38.81%	36	33.33%
Arthritis	31	46.27%	70	64.81%
Respiratory	22	32.84%	30	27.78%
Cardiovascular	49	73.13%	68	62.96%
Renal	5	7.46%	2	1.85%
Depression	7	10.45%	14	12.96%
Osteoporosis	4	5.97%	22	20.37%

The patient population

Rural SA was chosen as a site to test a range of chronic condition self-management models because of the adverse impacts of chronic conditions in these communities. Three project sites were selected in which Aboriginal patients of 35 years or over and non-Aboriginal patients of 50 years and older with complex chronic conditions were enrolled in the intervention group. Most patients were recruited through the general practitioner-led Enhanced Primary Care (EPC) and Medicare Benefits Schedule (MBS) care planning process with SHC SA research project staff working in collaboration with practice nurses and allied health staff to prepare care plans, administer standard patient assessment tools and implement patient-centred chronic illness management initiatives. Data for the largest of the project sites are presented in this paper.

Study design

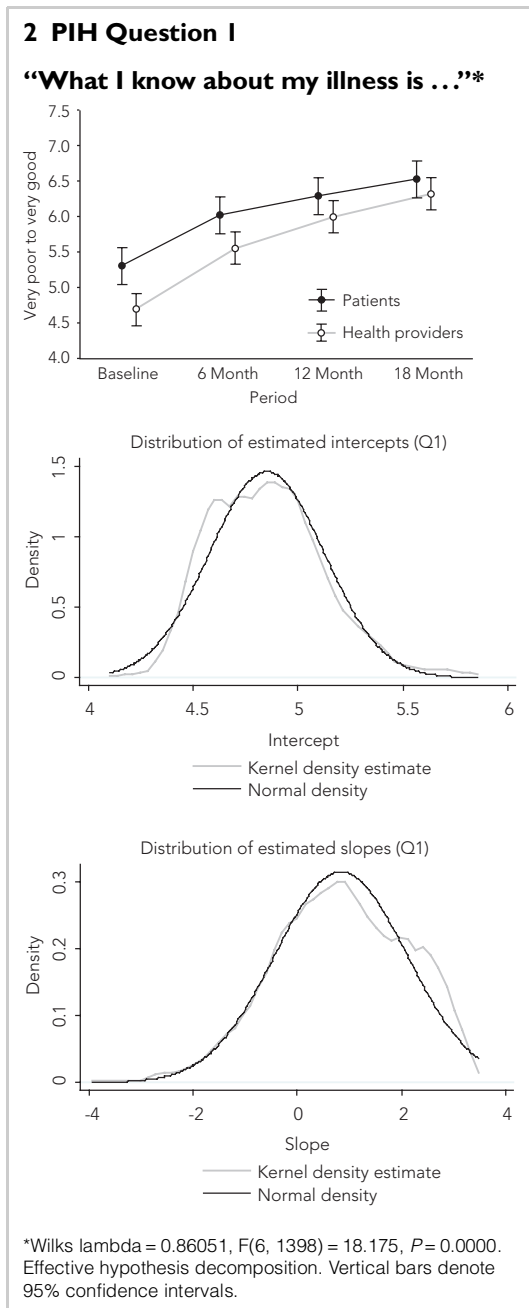
The study was a longitudinal demonstration project designed to explore the effect of improved service access in conjunction with self-management support for patients with chronic and complex health conditions. Enrolled patients were encouraged to participate in the EPC care planning process because all enrolled patients were, by virtue of their diagnosed chronic conditions, eligible for a care plan through the MBS. As part of this care planning process, patients participated in a health status assessment and a review

of their potential as self-managers using a modified Stanford Health Assessment tool and the PIH scale,¹¹ which has been shown to be a valid and consistent measure of patient self-management ability.³¹ Patients were then recommended for appropriate CDSM intervention programs and other relevant services such as participation in information and education sessions related to their specific illnesses.

Data were collected at enrolment and again during care plan review sessions at 6-month intervals in order to assess changes in health status, service access and levels of self-management skill and ability. In addition to clinical and health survey data collected for each participant in accordance with the National Evaluation Framework, local evaluators conducted program reviews and individual surveys to gauge service utilisation and health outcome changes, consumer and provider satisfaction levels, along with the organisational change impacts of the project. The final evaluation of the SHC project consisted, therefore, of a combination of national evaluation and local evaluation reports, which together comprised an assessment of the degree to which the key project aims of improving self-management knowledge and skill and increasing collaboration between patients and providers were achieved.

Stanford 2000 Health Survey

The modified Stanford 2000 Health Assessment, a self-report survey, was administered to partici-



pating patients during regular 6-monthly reviews of progress and at the same time as care plans were reviewed, and the PIH scale scores were recorded in relation to self-management knowledge and skill. Key elements of the modified

Stanford 2000 survey include a general health status assessment; impact of fatigue, shortness of breath and pain on patient wellbeing; physical activity levels; visits to GPs, specialists and other health professionals and attendances at outpatient clinics and hospital admissions in the preceding 6-month period.

PIH scores

Repeated patient self-rated and clinician-rated PIH scores were also collected across four 6-month review periods for a population of 175 patients with a mean age of 68.31 years (SD = 8.02). In this total group, 61.3% were females with a mean age of 68.2 years (SD = 8.18) and 38.7 were males with a mean age of 68.48 years (SD = 7.90). The illness groups and relative numbers of patients with these diagnoses (many had multiple diagnoses) are detailed in Box 1.

The PIH scale and questionnaire, developed for the Australian health care context³¹ was used to assess changes in patient self-management knowledge, skill and ability. In the SHC SA study, the PIH scores provide a longitudinal record of patient and health provider assessments of how effectively patients were living with and managing their chronic conditions. The ratings across twelve domains, or areas of patient knowledge and health-related behaviour, were an assessment of self-management skill and ability from both the patient's own perspective and from the perspective of the treating clinician.

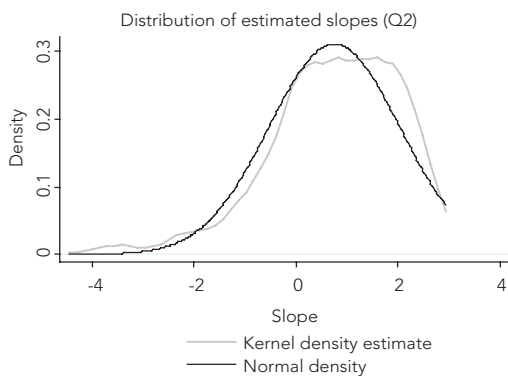
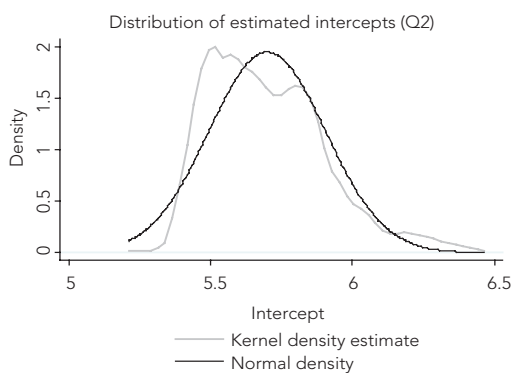
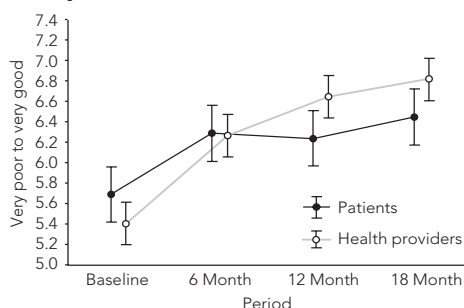
Random coefficient regression analysis, also known as mixed modelling, was used to explore changes over time in the key outcome variables described above. These analyses were carried out with STATA software, Version 9 (StataCorp, College Station, Tex, USA) which has mixed modelling as a powerful feature.

Resultant PIH score analysis

The twelve PIH survey questions look at a patient's progress over an 18-month period. Measurements are taken at baseline, 6 months, 12 months and 18 months. The scale ranges from 0 to 8, with 8 being

3 PIH Question 2

“What I know about the treatment of my illness is ...”*



* Wilks lambda = 0.86119, $F(6, 1398) = 18.077$, $P = 0.0000$. Effective hypothesis decomposition. Vertical bars denote 95% confidence intervals.

the desirable outcome. As a check, the health provider completes the questionnaire as well, with a range of questions measured over time and across two groups — patient and health provider.

For the first question, “What I know about my illness” is reported. (Box 2) The options range from 0 (very little knowledge) to 8 (very good knowledge). The plot shows the trend of the scores over the four time periods for both patients and health providers. The bands represent the 95% confidence intervals. Both patient and health provider showed increasing trends, which indicates that patients were demonstrating an increasing knowledge about and understanding of their condition.

Analysis

The Kernel density estimates shown map the distribution of slope and intercept scores for all individual patients. The random intercepts model showed that the scores are normally distributed and that the majority of scores clustered around a mean of 5, with most scores falling between 4 and 5.5. The estimated slopes graph (rates of change over time) shows that the vast majority of trends were positive, indicating that the majority of scores improved with time and that the distribution was normal, with the main clustering being between a slope of zero (ie, no change) and plus 2 (significant change).

Question 2 was analysed in the same way, showing significant change across mean scores for both patient and provider scores (Box 3). There was a significant result over time in that scores improved substantially. Overall scores (distribution of intercepts) were normally distributed and clustered around a score of 5.5, while trends in slopes (rates of change) were also normally distributed, with the majority of scores clustering in the positive domain; scores for most patients improved significantly with time.

Similar analysis of responses over the four collection points for the 12 domains of the PIH scale for both patients and providers showed statistically significant improvements being made in all domains apart from Question 3. This question deals with how patients reported taking their medication “as directed by their doctor”, and responses suggested that Question 3 was always answered very positively from the begin-

4 Changes in key health indicators (Stanford 2000 Survey)

Service type	Baseline	6 months	12 months	18 months	P value
No. hospital visits (mean)	1.34	1.27	1.23	1.19	0.014
No. general practitioner visits (mean)	4.39	4.15	3.92	3.71	0.012
No. specialist visits (mean)	1.72	1.67	1.60	1.55	0.019
Health indicator	Improved				
General health		Yes			0.021
Fatigue		No			0.520
Pain		Yes (slightly)			0.040
Level of frustration with illness		Yes			0.008
Fear about the future and illness		Yes			0.003
Level of worry		Yes			0.039
Shortness of breath		No			0.121

ning of the project (ie, from baseline), hence there being little or no room for improvement in this domain over time. Clearly there was no decline either. The distribution of rates of change (slopes) indicated little change over time, with the main body of scores having slopes of zero (ie, no change across measurement points) and most intercept scores clustering around 7.2 on the scale, suggesting that most scores for Question 3 lodged consistently between 7.0 and 7.5 across the 8 point scale. In such circumstances it is not possible to conclude that any change has occurred over time in this domain.

Health outcome improvements

Improvements in patient health outcomes over time as measured by the Stanford 2000 Health Questionnaire are demonstrated for the same group of patients over the same period of time as for the analysis of PIH scores. Specifically, health service utilisation (number of visits to GPs, specialists and hospitals), the impact of pain, worry about illness, frustration with illness and fear about the future reduced during the program (Box 4). Frequency of visits was analysed to ascertain if the incidence rate was affected by the time periods over which the intervention applied. A random effects model was applied (646 observations with a mean frequency score of 3.94 visits

per patient and SD = 3.23) across a range of visits from 0 to a maximum of 25.

Summary of results

For the 175 patients in the longitudinal study for whom complete data sets exist we have shown statistically significant improvements in patient self-management knowledge and skill. On a number of key health outcome indicators we have also demonstrated significant improvements in health outcomes for patients involved with a range of Sharing Health Care interventions. Specific improvements have been demonstrated in health service utilisation and in general health and wellbeing, the levels of pain recorded and the overall impact of illness upon daily living where the adverse impacts of chronic illness have been seen to reduce over time. Similar results were reported by PricewaterhouseCoopers in the national evaluation of the combined Sharing Health Care programs across Australia.³²

The fact that the patients involved in the SHC SA program were all people living with complex and chronic conditions, many with multiple disorders, means that the results shown here are even more significant than they might appear at first glance. Not only has patient knowledge and self-management ability improved, but the combination of interventions offered appears, in some

cases at least, to have arrested the expected steady decline in overall patient health status which is normally associated with the natural progress of chronic disease.

An analysis of the national Sharing Health Care Initiative data across patients in all states of Australia for whom complete data exist (in excess of 850)³³ corroborates the results produced through this current analysis of the smaller South Australia-specific cohort of patients involved in the Sharing Health Care SA project:

Small but consistent effect sizes indicating improvement were observed for a number of health status indicators,* health distress, coping with symptoms, psychological distress (Kessler 10) and times in hospital. A trend for improvement was also observed in general health (SF-1), satisfaction with life and self-efficacy, and there was a reduction in the number of GP visits. These observations were confirmed through feedback from the clients and health service providers in focus groups. A longer time period would be needed to fully assess the outcomes of the projects.³² (p. 27)

While these results are encouraging in relation to the potential of self-management programs to improve health status of people with chronic conditions, a more detailed cost–benefits analysis of such programs is needed.

Discussion

The conclusions reported here must be tempered by the fact that the sample is relatively small, especially given the wide range of interventions and outcomes being assessed across the overall SHC SA program. Also, the lack of a matched control group or randomised sample means we cannot conclude absolutely that the health and self-management improvements documented here are due entirely to the SHC SA intervention and not the result of other factors. The Hawthorne effect,³⁴ for example, may contribute to

the outcomes documented; or concurrent changes in system-wide patient management practices, such as new allied health initiatives or changes at a wider system level to outpatient procedures, may also be confounding the results.

Whatever the specific or synergistic causes of these phenomena, the fact that changes have been effected at all in this group of patients with chronic and complex conditions is an important development in the management of the symptoms and impact of chronic and complex illness in the community. The above caveats and considerations notwithstanding, learning, knowledge and health status improvements have been demonstrated for the sample population, but the extent to which these improvements are a function of changes in patient perception or of other system changes must now be tested through more specifically targeted and controlled interventions to eliminate any compounding influences and to enable the application of appropriate corrections for known variables.

Competing interests

Jeffrey Fuller was an external, paid evaluation consultant to the Sharing Health Care program.

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* Details of health status indicators and client questionnaires can be found in the technical report of the National Evaluation.³³

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