Self-management training for people with chronic conditions

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Abstract

Background
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. 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. These processes, in turn may also support sustainable health-related behaviour change and improve overall health and wellbeing for the patients.

Aims
The project was designed to determine whether community-based patient education and support programs could be successfully implemented and, if so, whether patient and provider participation in these programs might lead to improved patient self-management skills and abilities and improved quality of life for people with chronic and complex conditions such as diabetes and arthritis.

Methods
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 EPC care planning process. All patients were given a care plan via the Partners in Health process and then provided with a range of materials and information about their condition. This was reinforced during review sessions and re-care planning.

In addition to completing the PIH at six-month intervals, patients also completed a modified ‘Stanford 2000 Health Survey’ for the same time intervals and through which overall patient health status was assessed along with service utilisation and other health related lifestyle factors such as smoking and alcohol consumption.

Results
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. It may also lead to participants enjoying improved overall health and wellbeing and improved quality of life. Cost/benefit analysis of the program is very promising with significant savings shown.
Background

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 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). These processes, in turn may support sustainable health-related behaviour change and lead to improvements in overall patient health and wellbeing.

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 co-ordinated care trials (2–4) and a chronic illness management pilot program conducted in rural Aboriginal communities in Port Lincoln and Ceduna (5). 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 US the impact of chronic diseases such as diabetes, coronary heart disease, hypertension and asthma, for example, already account for the majority of the nation’s health care costs (6, p579) and this burden is set to rise by 15% by 2010 and by an estimated 60% by 2050 (7) as our population ages.

It is now becoming clear that effective management of chronic conditions is a major health system challenge and that our health efforts will increasingly need to focus increasingly on illness prevention, population health management and community and patient partnerships (8) while at the same time maintaining acute care delivery levels. The challenge is to identify, and manage, not only emerging chronic illness, but also to intervene at the social, economic and environmental levels to prevent illness at its source (6, p586) 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 approach (9) and other patient support and empowerment processes such as regular exercise, Tai Chi, and self-help groups. The Partners in Health (PIH) (10) 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-manager.

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 patients (10).

The ideologically burdened proposition that CDSM approaches may be elaborate strategies for instituting demand management rather than effective methods for improving patient health outcomes specifically (11) 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 (12).

Whatever may be the outcome of our experiments with co-ordinated care and chronic disease self-management programs, the Australian health system appears 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 (13).

**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 (8, 14–25). 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 occur (26, p155)—effective public participation in the processes of health care delivery is crucial to improving health outcomes (27, p37). 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 (28, p117).

The Sharing Health Care 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 (29).

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.

**The patient population**

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 GP led EPC and Medical 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, as all enrolled patients were, by virtue of their diagnosed chronic conditions, eligible for a care plan through the Medical Benefits Schedule (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 ‘Partners in Health’ scale (PIH) (10) which has been shown to be a valid and consistent measure of patient self-management ability (30). Patients were then recommended by their health providers for appropriate CDSM intervention programs and other relevant services such as participation in information and education sessions in relation to their specific illnesses.

Data were collected at enrolment and again during care plan review sessions at six-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-reported survey, was administered to participating patients during regular six-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, attendances at outpatient clinics hospital admissions in the preceding six month period.

**Partners in Health scores**

Repeated patient self-rated and clinician rated Partners in Health (PIH) scores were also collected across four six-month review periods for a population of 238 patients with a mean age of 68.48 (SD = 8.25). In this total group 59.8% were females with a mean age of 67.8 (SD = 8.17) and 40.2% were males with mean age 69.5 (SD = 8.37). The illness groups and relative numbers of patients with these diagnoses (many had multiple diagnoses) are detailed in Table 1.
Table 1

<table>
<thead>
<tr>
<th>Illness category</th>
<th>Male frequency</th>
<th>95% of total</th>
<th>Female frequency</th>
<th>% of total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diabetes</td>
<td>36</td>
<td>37.9%</td>
<td>51</td>
<td>37.9%</td>
</tr>
<tr>
<td>Arthritis</td>
<td>47</td>
<td>49.5%</td>
<td>89</td>
<td>63.1%</td>
</tr>
<tr>
<td>Respiratory</td>
<td>30</td>
<td>31.6%</td>
<td>40</td>
<td>28.4%</td>
</tr>
<tr>
<td>Cardiovascular</td>
<td>65</td>
<td>68.4%</td>
<td>88</td>
<td>62.1%</td>
</tr>
<tr>
<td>Renal</td>
<td>6</td>
<td>6.3%</td>
<td>4</td>
<td>2.8%</td>
</tr>
<tr>
<td>Depression</td>
<td>11</td>
<td>11.6%</td>
<td>23</td>
<td>16.3%</td>
</tr>
<tr>
<td>Osteoporosis</td>
<td>5</td>
<td>5.3%</td>
<td>26</td>
<td>18.4%</td>
</tr>
</tbody>
</table>

The Partners in Health (PIH) scale and questionnaire, developed for the Australian health care context (30) 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 behaviours, were an assessment of self-management skill and ability from both the patient’s own perspective and from the perspective of the treating clinician.

Method of analysis

The data is longitudinal across four time frames. As a result Mixed Modelling was used. This method has many advantages over the more usual methods such as Repeated Measures Analysis of Variance (RMAanova). Both RMAanova and Mixed Modelling allow subjects to be treated as a random effect. This is useful since the primary interest is all subjects not just these 238. Subjects are therefore their own control. The power of Mixed Modelling comes from the recognition that responses at any point in time are almost certainly correlated with the response at the previous time point and even with responses before that. Furthermore, these correlations need not be equal as assumed by RMAanova. The correlations often decrease over time. This correlation structure can be specified and becomes part of the model. The starting points (intercepts) and rates of growth (slopes) can be designated as random. Thus each respondent has their own intercept and slope. The analysis thus becomes subject-specific not population-averaged as is the case with fixed effects models. The modelling was carried out using STATA (version 9), which has powerful mixed modelling features. In essence the random effects model is given by:

\[ Y_{ij} = (\alpha + a_i) + (\beta + b_j)t + \epsilon_{ij} \]

for subject \( i \) at time \( j \).

The \( \alpha \) and \( \beta \) are the usual fixed effects parameters (intercept and slope) associated with ordinary least squares regression. The \( a \) and \( b \) parameters are the random effects of the intercept and slope respectively.

Resultant PIH score analysis

The twelve Partners in Health 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 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. The options range from 0 = very little knowledge to 8 = very good knowledge. The plot below shows the trend of the scores over the 4 time
periods for both patients and health providers. The patients may be over-rating a little but there is a common trend for both patient and health provider.

The mixed model estimates random intercepts and slopes. Ideally these should have a Normal distribution. The density plots below show quite a reasonable Normal distribution for both the intercepts and slopes.

The distribution of the intercepts (starting points) shows that most of these fall between 4.5 and 5.5. The distribution of the slopes shows that most of these lie in positive territory, which indicates that the majority of scores are improving over time. Some of these lie in negative territory, indicating that some respondents have decreasing scores over time. The mean intercept was 4.85 (SD = 0.27) and the mean slope was 0.84 (SD = 1.26)
It is informative to look at a scatterplot of slopes versus intercepts.

![Relationship between slopes and intercepts](image)

The correlation is -0.82, which is very significant. Subjects who start at a low score (intercept) improve at a faster rate (higher slope) than those who begin at a high score.

Similar analysis of responses over the four collection points for the 12 domains of the PIH scale for both patients and providers shows statistically significant improvements being made in all domains apart from question 3. This particular question deals with how patients report taking their medication ‘as directed by their doctor’ and responses suggest that question 3 was always answered very positively from the beginning of the project (from baseline) hence there being little or no room for improvement in this domain over time. Clearly there was no decline either! The mean slope is -0.02 (SD = 0.58). The mean intercept is 7.14 (SD = 0.14).

**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 are shown to have reduced during the program (see Table 2). Frequency of visits was analysed to ascertain if the incidence rate is affected by the time periods over which the intervention applied. The significance of the health indicators was established using a mixed model. The service use involves count data and so a Generalised Linear Mixed model with a Poisson distribution and log link was used.

<table>
<thead>
<tr>
<th>Service type</th>
<th>Baseline</th>
<th>6 months</th>
<th>12 months</th>
<th>18 months</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean hospital visits</td>
<td>0.43</td>
<td>0.27</td>
<td>0.26</td>
<td>0.21</td>
<td>0.000</td>
</tr>
<tr>
<td>Mean GP visits</td>
<td>5.39</td>
<td>4.71</td>
<td>4.09</td>
<td>4.13</td>
<td>0.000</td>
</tr>
<tr>
<td>Mean specialist visits</td>
<td>1.25</td>
<td>1.04</td>
<td>0.88</td>
<td>0.90</td>
<td>0.001</td>
</tr>
<tr>
<td>Health indicator...</td>
<td>Improved</td>
<td>( p ) value</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>-------------------------------------</td>
<td>----------</td>
<td>----------------</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>General health</td>
<td>yes</td>
<td>0.020</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fatigue</td>
<td>no</td>
<td>0.620</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pain</td>
<td>yes</td>
<td>0.006</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Level of frustration with illness</td>
<td>yes</td>
<td>0.008</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fear about the future and illness</td>
<td>yes</td>
<td>0.003</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Level of worry</td>
<td>yes</td>
<td>0.019</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Shortness of breath</td>
<td>no</td>
<td>0.121</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Cost benefit analysis of improved service use**

With respect to service use, it is clear that this has improved (i.e. reduced) over the four time frames. The savings associated with decreased general practitioner and specialist use while statistically significantly lower are not of practical significance and may only amount to between $35 and $50 dollars per patient; a helpful but hardly an opportunity for achieving major savings. The hospital use figures are different however. It can be seen from the plot below that the model is very accurate.

The application of Monte-Carlo simulation on the differences (10 000 samples) shows a mean saving of 66.3\% on hospital costs.

It can be seen that almost all the differences (savings) lie in positive territory. Given the cost of a hospital stay, this is a very significant result, both statistically and clinically.
Summary of results

For the 238 patients in the longitudinal study 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 (PWC) in the national evaluation of the combined Sharing Health Care programs across Australia (31).

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 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.

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 program 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. In this study however, a subgroup of these 238 patients undertook an intensive 6-week course comprising of training for three hours per week. This was in addition to the training/support received by others. In our study, this group did better in many facets of the program. The differences were not statistically significant but they were consistent and are the focus of a future study.

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.

References


**Presenter**

**John Petkov** is the Director of the Applied Statistics Unit at the Centre for Regional Engagement based at the Whyalla campus of the University of South Australia. John has a particular interest in biostatistics and has worked with the Spencer Gulf Rural Health School as well as providing support for Honours and Masters health science students in Adelaide. The Applied Statistics Unit also provides statistical support to companies such as OneSteel as well as local government and private businesses. John is completing a PhD on the self-management of chronic diseases concentrating on beneficial health outcomes and associated cost savings.