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

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Abstract 421 words

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 programmes could be successfully implemented and, if so, whether patient and provider participation in these programmes 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 programme and offered a range of education and support options (including a 6-week peer-led chronic disease self-management programme) as part of the EPC care planning process. Patient self-reported data were collected at baseline and subsequent six-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. The scale therefore assesses, from both provider and patient perspectives, patient knowledge of their condition and the extent to which they have the ability to manage and cope with the impact of their chronic illness on their daily lives.

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 programmes 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 programme is yet to be performed!

Key words: self-management, patient behaviour change, health outcomes
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.

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 programmes 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 trials (2-4) and a chronic illness management pilot programme 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 more population based approaches to the management of community and individual wellbeing.

The SHC SA project therefore developed self-management programmes for patients with chronic conditions. Interventions included the use of formal care plans to structure systems of care, education programmes 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) care planning process was used to complete ‘patient centred’ care plans based on patient lifestyle goals and targets for the management of their 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 whilst 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 organize their access to key elements of their care. A patient who understands their illness, how to recognize 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 having to manage their own treatment plan. Quite the contrary! A good self-manager knows what services to access, how and when in order to maximize 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 coordinated care and chronic disease self-management programmes, the Australian health system appears no longer able to afford to deliver costly acute health services at the current rate of escalation. Strategies need to be found to reduce demand for acute care services, especially when this demand can be moderated through early intervention programmes (13).
Self-management rationale

Lorig and 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 programmes (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 programme 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 programme 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 programme 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 for appropriate CDSM intervention programmes 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 programme 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**

Demographic data (age, country of origin, sex, education, marital status, employment and pension status, illness categories along with alcohol and cigarette consumption rates) were collected using the ‘Client Information Questionnaire – appendix 2). From this data we have compiled an overview of patient characteristics for the target project site and explored demographic groups in which significant changes in health status have been reported over time in the study population.

The modified Stanford 2000 Health Assessment 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 upon which we focus in this self-management correlation include…

- a general health status report
- impact of fatigue, shortness of breath and pain on patient wellbeing
- physical activity levels
- impact of illness upon feelings of wellbeing
- elements of the K10 depression scale
- visits to GPs, specialists and other health professionals (community nurse, physiotherapist) in the previous 6 month period
- attendances at outpatient clinics
- hospital admission rates

**Data details**

Repeated patient self-rated and clinician rated Partners in Health (PIH) scores were collected across 4 evenly spaced, six-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 (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 Table 1.
Table 1

<table>
<thead>
<tr>
<th>Illness Category</th>
<th>Male frequency</th>
<th>% of total</th>
<th>Female frequency</th>
<th>% of total</th>
</tr>
</thead>
<tbody>
<tr>
<td>diabetes</td>
<td>26</td>
<td>38.81%</td>
<td>36</td>
<td>33.33%</td>
</tr>
<tr>
<td>arthritis</td>
<td>31</td>
<td>46.27%</td>
<td>70</td>
<td>64.81%</td>
</tr>
<tr>
<td>respiratory</td>
<td>22</td>
<td>32.84%</td>
<td>30</td>
<td>27.78%</td>
</tr>
<tr>
<td>cardiovascular</td>
<td>49</td>
<td>73.13%</td>
<td>68</td>
<td>62.96%</td>
</tr>
<tr>
<td>renal</td>
<td>5</td>
<td>7.46%</td>
<td>2</td>
<td>1.85%</td>
</tr>
<tr>
<td>depression</td>
<td>7</td>
<td>10.45%</td>
<td>14</td>
<td>12.96%</td>
</tr>
<tr>
<td>osteoporosis</td>
<td>4</td>
<td>5.97%</td>
<td>22</td>
<td>20.37%</td>
</tr>
</tbody>
</table>

The Partners in Health (PIH) scale and questionnaire, validated within the Australian health context (30) was used to assess changes in patient self-management knowledge, skill and ability. In the SHC SA study the PIH provides a longitudinal record of patient and health provider assessments of how effectively patients are living with and managing their chronic conditions. The ratings across twelve domains, or areas of patient knowledge and health related behaviour, provide 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 ANALYSIS

Repeated Measures ANOVA (RMA) has traditionally been the standard treatment for longitudinal data over several points in time. This is a far more powerful approach than ordinary ANOVA since RMA allows the subject to act as his/her own control. As a result, we can look at within-effects as well as between effects. However, RMA has three basic weaknesses:

- RMA needs a balanced data set. Any missing cases for a subject will result in the elimination of that subject in the analysis. While this may not be seen as a big problem in some instances, missing data is a source of serious potential bias. Data imputation may help but great care is needed when tackling such an analysis.

- RMA does not take into account that responses at one time point may well be correlated with responses at the previous time point(s). For example, how a patient reacts to a drug at time $t$ is probably strongly associated with the reaction to that drug at time $t-1$. In effect, this is not taken into account by RMA and it is desirable that these correlations are accounted for in the model.

- While it is important to take individual responses into account, this is a very frequent source of error due to non-uniform error or ‘asphericity’.

Random Coefficient Analysis (RCA), also known as Mixed Modelling, takes care of the above concerns. The analysis maximises likelihood of observed values instead of the ANOVA approach of minimising error variances. As a result we can model fixed effects and random effects. Fixed effects are the changes to the dependent variable that can be attributed to the independent variable or predictor. This is what we usually measure. The values are the same for all subjects in the analysis. The magnitudes are the changes in the means. Random effects, on the other hand, have values that vary randomly within and/or between individual subjects. It is these effects that are often overlooked. They are hidden in ANOVA but are very clear in Mixed Modelling. The magnitudes are represented by standard deviations. Asphericity is taken care of since it can be modelled as random effects. Confidence intervals for the standard deviations for individual responses are easily calculated. The major disadvantage of
Mixed Modelling is that it is not well understood and not many statistical packages have this feature. The analyses in this paper are carried out with STATA (Version 9), which has Mixed Modelling as a powerful feature.

The covariance structure can be specified at the start. It can be independent (this defeats the purpose of the exercise since we are trying to model the correlations between successive observations). It can be exchangeable (we only look at time 1 and 2 and assume no change after that). It can be autoregressive (this assumes that the correlations will be decreasing) and, finally it can be unstructured. This imposes no conditions at all—this may seem to be the method we should always use, but for a large number of time points many parameters may have to be estimated.
**PIH SCORES**

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. We thus have a range of questions measured over time and across two groups—patient and health provider.

As previously stated, the Random Effects model allows for analysis within and between subjects. In effect, the total variance can be broken down into variance explained by the predictors at stage 1. At stage 2, the remaining unexplained variance is broken down into variance explained by the random intercepts (starting values). At stage 3, the rest of the unexplained variance is broken down into the variance explained by the random slopes (rate of change) and the remaining unexplained variance is the error. The model has an excellent advantage in that we can look at the correlations between intercepts and slopes and thus easily establish whether subjects with initial low scores are changing at the same rate as subjects with initial high scores. The random effects model is shown below:

If we designate the scores as $Y$ and time as $t$ then, for an ordinary least squares regression we have:

$$ Y_i = \beta_0 + \beta_1 t + \epsilon_i $$

where $\epsilon$ designates the error term.

By allowing random intercepts and slopes then the subject acts as their own control and we have:

$$ Y_{it} = \beta_{0i} + \beta_{1i} t + \epsilon_{it} $$

We simply then incorporate a binary variable, $X$, which takes on values of 0 (Health Provider) or 1 (Patient) to complete the model.

$$ Y_{it} = \beta_{0i} + \beta_{1i} t + \beta_{2i} X_{it} + \epsilon_{it} $$
As an example, if we take the first question “What I know about my illness is:" 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 bands represent the 95% confidence intervals. Both patient and health provider are showing increasing trends, which indicates the patients are showing an overall increasing knowledge of their illnesses.

<table>
<thead>
<tr>
<th>Question</th>
<th>Time Effect</th>
<th>Patient Mean overall</th>
<th>Health Provider Mean overall</th>
<th>Correlation between Intercept and Slope</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. What I know about my illness is:</td>
<td>0.843 (p=0.000)</td>
<td>6.04</td>
<td>5.64</td>
<td>-0.693 (p=0.000)</td>
</tr>
<tr>
<td>2. What I know about the treatment of my illness is:</td>
<td>0.750 (p=0.000)</td>
<td>6.17</td>
<td>6.28</td>
<td>-0.761 (p=0.000)</td>
</tr>
<tr>
<td>3. I take my medication as asked by my doctor</td>
<td>-0.018 (p=0.429)</td>
<td>7.87</td>
<td>7.12</td>
<td>-0.586 (p=0.000)</td>
</tr>
<tr>
<td>4. How I share in decisions made about my illness is:</td>
<td>0.098 (p=0.008)</td>
<td>6.53</td>
<td>6.97</td>
<td>-0.615 (p=0.000)</td>
</tr>
<tr>
<td>5. I arrange and attend appointments as asked by my health provider</td>
<td>0.016 (p=0.406)</td>
<td>7.50</td>
<td>7.68</td>
<td>-0.474 (p=0.000)</td>
</tr>
<tr>
<td>6. My understanding of why I need to check and write down my symptoms:</td>
<td>0.285 (p=0.000)</td>
<td>6.22</td>
<td>6.37</td>
<td>-0.881 (p=0.000)</td>
</tr>
<tr>
<td>7. I check and write down my symptoms</td>
<td>0.549 (p=0.000)</td>
<td>4.41</td>
<td>5.58</td>
<td>-0.705 (p=0.000)</td>
</tr>
<tr>
<td>8. My understanding of what to do when my symptoms get worse:</td>
<td>0.271 (p=0.000)</td>
<td>6.40</td>
<td>6.33</td>
<td>-0.830 (p=0.000)</td>
</tr>
<tr>
<td>9. I do the right things when my symptoms get worse</td>
<td>0.242 (p=0.000)</td>
<td>6.80</td>
<td>6.52</td>
<td>-0.896 (p=0.000)</td>
</tr>
<tr>
<td>10. How I deal with the effects of my illness on my physical activities:</td>
<td>0.233 (p=0.000)</td>
<td>5.65</td>
<td>6.15</td>
<td>-0.599 (p=0.000)</td>
</tr>
<tr>
<td>11. How I deal with the effect of my illness on the way I feel and how I mix with others is:</td>
<td>0.141 (p=0.000)</td>
<td>5.89</td>
<td>6.43</td>
<td>-0.528 (p=0.000)</td>
</tr>
<tr>
<td>12. My progress toward living a healthy life is:</td>
<td>0.119 (p=0.001)</td>
<td>6.02</td>
<td>6.36</td>
<td>-0.614 (p=0.000)</td>
</tr>
</tbody>
</table>
A possible way to treat the data analysis is the ANOVA approach. Repeated Measures Anova does not, however, model the covariance among the repeated observations. Efficiency is lost (31, p 114-125). The approach cannot address the treatment effects, which are related to the mean response over a longitudinal framework. It must be kept in mind that the responses are not independent over this time frame but are related. Repeated Measures Anova can only be used efficiently for a balanced data set (no missing values over the 4 time frames) and, while this data set is balanced, it is believed that a method that allows for the correlation between the time points is to be preferred.

A Random Effects model allows for analysis within and between subjects. In effect, the total variance can be broken down into variance explained by the predictors at stage 1. At stage 2, the remaining unexplained variance is broken down into variance explained by the random intercepts (starting values). At stage 3, the rest of the unexplained variance is broken down into the variance explained by the random slopes (rate of change) and the remaining unexplained variance is the error. The model has an excellent advantage in that we can look at the correlations between intercepts and slopes and thus easily establish whether subjects with initial low scores are changing at the same rate as subjects with initial high scores. The random effects model is shown below:

The simplest of these is the random intercept (between subjects)

\[ Y_{it} = \beta_{0i} + \beta_1 t + \varepsilon_{it} \]

This assumes a constant rate of growth. We can combine a random intercept and a random slope with time.

\[ Y_{it} = \beta_{0i} + \beta_1 t + \varepsilon_{it} \]

By incorporating the group type (health provider or patient) the model here is extended to:

\[ Y_{it} = \beta_{0i} + \beta_1 t + \beta_2 X_{it} + \varepsilon_{it} \]

In this analysis \( t \) takes values from 0 (baseline) to 3 (18 months). \( X \) is either 0 (health provider) or 1 (patient). The \( Y \) values are the assessment scores.
PIH Question 1

WHAT I KNOW ABOUT MY ILLNESS IS:
Wilcoxon test: -38.651, 1df, 1399 = 16.17%, p = 0.000
Effective hypothesis decomposition
Vertical bars denote 0.95 confidence intervals

Distribution of estimated intercepts (Q1)

Distribution of estimated slopes (Q1)
Analysis

From the graphical representations above for question 1 on the PIH scale it can be seen that the mean scores for both patient and provider have increased over time. These mean scores, however, could be masking significant distribution anomalies, outliers or even consistent middle ground scoring. Until we examine the distribution of intercepts and slopes (rate in which each patient’s score is changing or trending) it is not possible to conclude much from the data.

The random intercepts model shows that the scores are normally distributed and that majority of scores cluster 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 are positive indicating that the majority of scores have improved with time and that the distribution is normal with the main clustering being between a slope of zero (i.e. no change) and and plus 2 (significant change).

Question 2 is analysed in the same way showing significant change across mean scores for both patient and provider scores ($p=0.000$). There is a significant result over time in that scores have improved substantially. Overall scores (distribution of intercepts) are normally distributed and cluster around a score of 5.5 whilst trends in slopes (rates of change) are also normally distributed with the majority of scores clustering in the positive domain; scores for most patients are improving significantly with time.
PIH Question 2

WHAT I KNOW ABOUT THE TREATMENT OF MY ILLNESS IS:
Wilks lambda=0.8119, F(16, 1399)=10.077, p<0.0001
Effective hypothesis decomposition
Vertical bars denote 0.95 confidence intervals

Distribution of estimated intercepts (Q2)

Distribution of estimated slopes (Q2)
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 except for question 3. This question deals with how patients report taking their medication ‘as directed by their doctor’. Responses suggest, however, that question 3 was always answered very positively from the beginning of the project (i.e., 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) shown below indicate little change over time with the main body of scores having slopes of zero (i.e., no change across measurement points) and most intercept scores clustering around 7.2 on the scale suggesting that most scores for question 3 lodge 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!

![Distribution of estimated slopes (Q3)](image1)

![Distribution of estimated intercepts (Q3)](image2)
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), pain, worry about illness, frustration with illness and fear about the future are shown to have reduced during the programme (see table 2).

Frequency of visits (count data) was analysed to ascertain if the incidence rate is affected by the time period (0,1,2,3) over which the SHC intervention was run. 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. The variance of 10.43 showed over-dispersion indicating that the data set is not suitable for a Poisson model.

Random Effects models were unsuitable due to lack of convergence (the method is iterative). Generalised Estimating Equations were used instead with success. Like Random Effects models, the correction for dependency for responses, within each subject, is made. A correlation structure can be specified (32, p62-66). The model is shown below:

$$Y_{it} = \beta_0 + \beta_1 X_{it} + \beta_2 t + \rho_{it} + \epsilon_{it}$$

It can be seen that the within-subject correlation, \( \rho \), is treated as “nuisance” variable (covariate). Due to the dispersion noted above, a Negative Binomial model with a Negative Binomial link was used.

xtgee t time, family(nbinomial) link(nbinomial) corr(unstructured) robust scale(x2) nolog

GEE population-averaged model
Number of obs = 642
Group and time vars: subject time
Number of groups = 174
Link: negative binomial
Obs per group: min = 1
Family: negative binomial (k=1)
max = 4
avg = 3.7
Correlation: unstructured
Wald chi2(1) = 7.05
Prob > chi2 = 0.0079
(Std. Err. adjusted for clustering on subject)

<table>
<thead>
<tr>
<th>Semi-robust</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>t</td>
<td>Coef.</td>
</tr>
<tr>
<td>time</td>
<td>-0.0113641</td>
</tr>
<tr>
<td>_cons</td>
<td>-0.204605</td>
</tr>
</tbody>
</table>

The coefficient of time is negative and significant. The incidence of GP visits is decreasing over time. The standard errors are robust and small compared to the coefficients. There is some evidence of under-dispersion (scale parameter is less than 1). The incidence ratio is less than unity, which again suggests that the frequency of visits to the GP is decreasing.

----------------------------------------------------------------------------
The median visits to the GP for each time frame are...0; 4.39, 1; 4.15, 2; 3.92, 3; 3.71

<table>
<thead>
<tr>
<th>time</th>
<th>Visits</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>4.38636</td>
</tr>
<tr>
<td>1</td>
<td>4.1477</td>
</tr>
<tr>
<td>2</td>
<td>3.92203</td>
</tr>
<tr>
<td>3</td>
<td>3.70863</td>
</tr>
</tbody>
</table>
Number of times patient visited specialist.

A Poisson model showed evidence of over-dispersion. A Negative Binomial model was used instead. A Generalised Estimating Equation with a Negative Binomial link was used. There is evidence that the number of visits has altered over time.

The coefficient of time is negative and significant indicating a drop in visits to the specialist. The robust standard errors are acceptably small compared to the coefficients. There is a little over-dispersion but this is not significant.

The incidence ratio is less than unity, which again suggests that visits to the specialist are decreasing whilst the median number of predicted visits to specialist is 0; 1.72, 1; 1.67, 2; 1.60, 3; 1.55.

Number of times patients have visited hospital.

One extreme case was removed. This patient had visited the hospital 10 times. There has been some change over time. A Negative Binomial Generalised Estimating Equation with a Negative Binomial link was applied. The coefficient of time is negative and significant, indicating a general fall in visits to the hospital. The robust standard errors are acceptably small. There is some evidence of over-dispersion but not as great as Poisson (the scale parameter was 3)

Table 2 – changes in key health indicators (Stanford 2000 Survey)

<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>median predicted hospital visits</td>
<td>1.34</td>
<td>1.27</td>
<td>1.23</td>
<td>1.19</td>
<td>0.014</td>
</tr>
<tr>
<td>median predicted GP visits</td>
<td>4.39</td>
<td>4.15</td>
<td>3.92</td>
<td>3.71</td>
<td>0.012</td>
</tr>
<tr>
<td>median predicted specialist visits</td>
<td>1.72</td>
<td>1.67</td>
<td>1.60</td>
<td>1.55</td>
<td>0.019</td>
</tr>
</tbody>
</table>

Random effects – unstructured covariance model for analysis of change over time

<table>
<thead>
<tr>
<th>Health Indicator</th>
<th>improved</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td>general health</td>
<td>yes</td>
<td>0.021</td>
</tr>
<tr>
<td>fatigue</td>
<td>no</td>
<td>0.520</td>
</tr>
<tr>
<td>pain</td>
<td>yes (slightly)</td>
<td>0.040</td>
</tr>
<tr>
<td>level of frustration with illness</td>
<td>yes</td>
<td>0.008</td>
</tr>
<tr>
<td>fear about the future and illness</td>
<td>yes</td>
<td>0.003</td>
</tr>
<tr>
<td>level of worry</td>
<td>yes</td>
<td>0.039</td>
</tr>
<tr>
<td>shortness of breath</td>
<td>no</td>
<td>0.121</td>
</tr>
</tbody>
</table>
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 PWC in the national evaluation of the combined Sharing Health Care programmes across Australia (33).

The fact that the patients involved in the SHC SA programme 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 it been possible to improve patient knowledge and self-management ability, but the combination of interventions offered appear, 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 exists (in excess of 850) (34) 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, as reported below…

‘Small but consistent effect sizes indicating improvement were observed for a number of health status indicators\(^1\), 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.’ (33, p27)

Whilst these results are encouraging in relation to the potential of self-management programmes to improve health status of people with chronic conditions, a more detailed cost/benefits analysis of such programmes 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 programme SHC SA programme. 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 (35), for example, may contribute to the effects noticed 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.

\(^1\) Details of health status indicators and client questionnaires can be found in the technical report of the National Evaluation
Whatever the specific or inter-related synergistic causes of these phenomena, the fact that changes have been effected at all 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 elimination any compounding influences and to enable the application of appropriate corrections for known variables.
Appendix 1

Modified Stanford 2000 Health Survey
Appendix 2

Client Information Questionnaire
Appendix 3

PIH scale and questions???
References


Self management support .doc


