Chronic condition management and self-management in Aboriginal communities in South Australia: outcomes of a longitudinal study

Peter W. Harvey1,5 DipT, BEd, PhD, Director Flinders Centre for Gambling Research
John Petkov2 MSc, Director Applied Statistics Unit
Inge Kowanko3 BSc, PhD, Project Leader
Yvonne Helps4 BA, Project Officer
Malcolm Battersby1 PhD, FRANZCP, FACHAM, MBBS, Director Flinders Human Behaviour and Health Research Unit

1Margaret Tobin Centre, Flinders University, Flinders Drive, Bedford Park, SA 5042, Australia. Email: Malcolm.battersby@flinders.edu.au
2University of South Australia, Mount Gambier, SA 5290, Australia. Email: john.petkov@unisa.edu.au
3Flinders University, Flinders Drive, Bedford Park, SA 5042, Australia. Email: inge.kowanko@flinders.edu.au
4Aboriginal Health Council of SA, King William Road, Adelaide, SA 5000, Australia. Email: yvonne.helps@ahcsa.org.au
5Corresponding author. Email: peter.harvey@flinders.edu.au

Abstract

Objectives. This paper describes the longitudinal component of a larger mixed methods study into the processes and outcomes of chronic condition management and self-management strategies implemented in three Aboriginal communities in South Australia. The study was designed to document the connection between the application of structured systems of care for Aboriginal people and their longer-term health status.

Methods. The study concentrated on three diverse Aboriginal communities in South Australia; the Port Lincoln Aboriginal Health Service, the Riverland community, and Nunkuwarrin Yunti Aboriginal Health Service in the Adelaide metropolitan area. Repeated-measure clinical data were collected for individual participants using a range of clinical indicators for diabetes (type 1 and 2) and related chronic conditions. Clinical data were analysed using random effects modelling techniques with changes in key clinical indicators being modelled at both the individual and group levels.

Results. Where care planning has been in place longer than in other sites overall improvements were noted in BMI, cholesterol (high density and low density lipids) and HbA1c. These results indicate that for Aboriginal patients with complex chronic conditions, participation in and adherence to structured care planning and self-management strategies can contribute to improved overall health status and health outcomes.

Conclusions. The outcomes reported here represent an initial and important step in quantifying the health benefits that can accrue for Aboriginal people living with complex chronic conditions such as diabetes, heart disease and respiratory disease. The study highlights the benefits of developing long-term working relationships with Aboriginal communities as a basis for conducting effective collaborative health research programs.

What is known about the topic? Chronic condition management and self-management programs have been available to Aboriginal people in a range of forms for some time. We know that some groups of patients are keen to engage with care planning and self-management protocols and we have anecdotal evidence of this engagement leading to improved quality of life and health outcomes for Aboriginal people.

What does this paper add? This paper provides early evidence of sustained improvement over time for a cohort of Aboriginal people who are learning to deal with a range of chronic illnesses through accessing structured systems of support and care.

What are the implications for practitioners? This longitudinal evidence of improved outcomes for Aboriginal people is encouraging and should lead on to more definitive studies of outcomes accruing for people engaged in structured systems of care. Not only does this finding have implications for the overall management of chronic illness in Aboriginal communities, but it points the way to how health services might best invest their resources and efforts to improve the health status of people.
Background

Several major chronic illness management research and implementation strategies involving Aboriginal communities in South Australia provided the context for the current Cooperative Research Centre in Aboriginal Health (CRCAH) project. The Council of Australian Governments (COAG) National Coordinated Care Trials were established in 1996–1998 to test the effect of integrated care systems for people with chronic and complex conditions as a strategy for integrating care, reducing hospital admissions and improving health outcomes. Aboriginal people in South Australia, as a result of Regional Health Service initiatives, were involved in this early coordinated care work with some communities initiating and sustaining ground-breaking programs of care.

In 2001, the National Sharing Health Care Demonstration initiative followed the COAG National Coordinated Care Trials as a specific strategy for implementing self-management approaches to improving the management of chronic and complex conditions in a range of communities. Through this process both the Stanford University and the Flinders University approaches to self-management were implemented in Aboriginal communities in South Australia. The culmination of much of this work was the establishment in South Australia in 2003 of the National Health and Medical Research Council (NHMRC)-funded Centre of Clinical Research Excellence (CCRE) in Aboriginal and Torres Strait Islander Health. This was the first Centre of its type to be established in Australia, providing capacity building and research training opportunities for Aboriginal people, overcoming historical impediments to research in Aboriginal communities and building evidence-based service provision models.

The processes of care management, care planning and chronic condition self-management have been evolving in Aboriginal communities over time and this current project builds on extensive community collaboration and the evolving skills and expertise of Aboriginal people involved in health services management across South Australia. Chronic illness management programs now exist to varying degrees in different communities and this current research program was designed to examine the processes of establishing and maintaining these systems in Aboriginal communities and to document the effects of different approaches to and strategies for illness management and prevention on the health and quality of life of the people involved.

The participating communities had a range of chronic illness management strategies in place, providing a rich context in which to examine the evolution of these approaches and interventions over time as well as to document the outcomes of some of the longer-term strategies being used to encourage more effective management of chronic illness. One community, for example, had well-established processes for preparing and monitoring formal chronic condition management care plans along with other self-management initiatives based on a modified Stanford University self-management model. Other initiatives underway in these communities included the introduction of formal care planning processes and community education and support programs to encourage people with chronic conditions to make lifestyle and dietary changes.

The study was approved by the Aboriginal Health Research Ethics Committee and the Flinders Clinical Research Ethics Committee in accordance with the principles of the NHMRC guidelines on research in Aboriginal communities.

Study aims

The primary aim of the CRCAH Chronic Condition Management study was to examine the longer term effects of structured care planning and chronic condition management and self-management programs on the health of Aboriginal people in three participating communities. A secondary aim was to explore the enablers and inhibitors of the provision of effective chronic condition care in Aboriginal communities in order to create a model for effective organisation of care based on the experiences of patients and health care providers in the participating communities. This component of the larger project is being reported elsewhere and published separately.

Methods

In two of the three participating communities, extensive longitudinal patient records were in place and researchers negotiated with these services to release clinical data for consenting patients for longitudinal analysis and in order for the research team to work with these patients to understand their journey through illness diagnosis, treatment and ongoing self-management. The third community provided no quantitative data.

A composite group of 36 clients with ages ranging from 35 to 81 years (63.9% female) and with a mean age of 60.8 years (s.d. = 10.3) from two separate health services gave consent to access clinical data from electronic patient record systems, some spanning periods of up to 10 years with repeated-measures for lipids and HbA1c, for example, exceeding 20 time points. Key clinical indicators of health (HbA1c, lipids, BMI) were measured at most client visits and these data were extracted along with the date of the tests. The combined dataset provides a longitudinal record of health status for this group and enables the exploration of changes in these indicators over time that may be associated with the implementation of structured chronic condition management systems (CCMS).

Statistical analysis of group trends in clinical indicators (log-transformed where not normally distributed) over time was conducted using random effects modelling and STATA version 12. This method allows for the ‘messiness’ in the available data. That is, the clients have different, often multiple chronic conditions and treatments with widely varying lengths of clinical records. Clients also differ in the number of measures available and the time sequences of their clinical measurements.
The random effects modelling approach therefore recognises that subjects have different baseline measurements and also that clinical measures change over time in different ways and at different rates. The process involves developing individual client profiles based on the most common quantitative chronic condition indicators (HbA1c, BMI, cholesterol, lipid profile) followed by a group analysis to determine the significance of trends over time.

The random effects modelling method is a robust statistical technique that requires reasonably normally distributed data. These models use all available data over the follow up, handle differences in length of follow up, and take into account the fact that repeated-measures on the same individual are correlated.29

All health activities and interventions were recorded for clients over an extended period with some patients returning data for around 10 years. Due to the nature of the data; different health conditions and combinations of health conditions, different starting points and different data collection time frames, standard repeated-measures analysis of these data was not possible.22

<table>
<thead>
<tr>
<th>Clinical indicator</th>
<th>Statistical significance of change</th>
<th>Effect size (Cohen’s d, clinical importance)</th>
<th>Intra-cluster correlation</th>
<th>Change over time (time parameter, 95% confidence interval)</th>
</tr>
</thead>
<tbody>
<tr>
<td>HbA1c</td>
<td>Significant ($P=0.000$)</td>
<td>0.22 (small)</td>
<td>75%</td>
<td>$-0.005$ ($-0.007$, $-0.003$)</td>
</tr>
<tr>
<td>BMI</td>
<td>Significant ($P=0.000$)</td>
<td>0.21 (small)</td>
<td>82%</td>
<td>$-0.115$ ($-0.175$, $-0.055$)</td>
</tr>
<tr>
<td>Triglyceride</td>
<td>Significant ($P=0.043$)</td>
<td>0.15 (very small)</td>
<td>65%</td>
<td>$-0.114$ ($-0.22$, $0.000$)</td>
</tr>
<tr>
<td>Total cholesterol</td>
<td>Significant ($P=0.000$)</td>
<td>0.32 (small)</td>
<td>45%</td>
<td>$-0.076$ ($-0.103$, $-0.049$)</td>
</tr>
<tr>
<td>LDL</td>
<td>Significant ($P=0.001$)</td>
<td>0.34 (small)</td>
<td>53%</td>
<td>$-0.074$ ($-0.105$, $-0.043$)</td>
</tr>
<tr>
<td>HDL</td>
<td>Not significant ($P=0.473$)</td>
<td>0.02 (negligible)</td>
<td>62%</td>
<td>$0.002$ ($0.004$, $0.009$)</td>
</tr>
</tbody>
</table>

Fig. 1. Individual client cholesterol profiles; actual values and trends (from random intercept model with time as a continuous variable).
Two different approaches were taken to the analysis of the data; profiling of individual patients for key outcome measures such as HbA1c, lipids, BMI and cholesterol along with modelling over time for the whole group using random effects modelling with time as a continuous variable. Instead of taking definitive time points and checking for changes over time at these regular time points using repeated-measure processes, generalised models of trends were produced for individuals as well as for the whole group of subjects using random effects modelling. This type of modelling has the advantage of not relying on regular data points and being able to accommodate missing data if it is generally missing at random.

Only HbA1c and triglyceride scores required log-transformation as their frequency distributions were right skewed. Data from clients with less than four time points were excluded from analysis. Individual client profiles were visually checked to see how well the model of predicted values fitted the actual data recorded for each patient. A group analysis was then performed to determine if the trends were statistically significant and clinically important. Results are summarised in Table 1.

Results

Figure 1 shows the cholesterol profiles and the trend lines predicted from the model for each client. The horizontal axis represents measurement time points. It can be seen that individual cholesterol profiles vary in how well they fit the model, but that the trend lines are mostly going in similar directions, indicating improvement over time. Similar profiles were developed for other clinical indicators (HbA1c, BMI, HDL, LDL, triglycerides).

The analysis for the combined group of 36 clients shows that the overall time parameters are negative where a drop is the desired health outcome (HbA1c, BMI, triglycerides, total cholesterol, LDL) and positive where an increase is the desired outcome (HDL). These changes were all statistically significant ($P < 0.05$), except for HDL which did not change significantly overall. Furthermore the effect sizes for HbA1c, BMI, total cholesterol and LDL, although small, were all in the range for the Cohen’s $d$ adjustment accepted as clinically meaningful (0.15 $\leq d < 0.40$) as discussed by Hojat and Kraemer. All the clients in the group were involved in some form of structured CCMS, ranging from effective self-management with clinical support at one extreme to simple diagnosis and medication support at the other during the data collection period. These early results support the hypothesis that structured systems of chronic condition care may be associated with improved health status of participants.

The smaller group of 24 clients from one service was analysed separately in order to provide relevant local information to that health service. Summary results are shown in Table 2. The results broadly mirror those of the larger group. Trends in the clinical indicators decreased significantly, indicating improving health status. Since this service operates a well-established model of structured care with most clients involved in self-management, this is strong evidence of an association between this structured CCMS and positive health outcomes of clients.

The model using a log-transformation of the data to obtain a more normal distribution of scores, shows cholesterol changes, using time as a continuous variable beginning at time point one for each patient. It is evident from the modelling that some individuals are showing reducing cholesterol levels over time and when this model is applied to the total population, a significant reduction in cholesterol levels for this group is observed. A similar profile is shown for triglyceride levels, although a significant improvement for the group over time on this measure is not demonstrated.

In addition to the modelling outlined above, individual plots were developed and graphically summarised for each patient in order for clinicians to demonstrate to them, during treatment and regular review sessions, how changes in clinical markers can be influenced by other life factors or changes in lifestyle. In these plots, significant changes were marked on the profiles so patients were able to visualise and observe their progress over time and understand how life events may affect their health status.

Discussion and conclusion

This pilot study conducted in three Aboriginal communities in South Australia is an initial and important step in quantifying the health benefits that can accrue for Aboriginal people living with and managing, with the support of coordinated self-management approaches, complex chronic conditions such as diabetes, heart disease and respiratory illness. The study is limited by its lack of a control group and it is acknowledged that a range of factors may have influenced the longitudinal outcome documented here. A controlled study would now be required to test the main hypothesis in a more structured study environment, although the process of randomising participants to a wait list control group, for example, when the benefits of coordinated chronic illness management are becoming more generally accepted, may be problematic.
In addition to documenting health improvements for Aboriginal people over time, the study highlights the importance of working collaboratively with individuals and communities and emphasises the development and implementation of innovative patient monitoring and feedback mechanisms such as the use of individual patient profiling and health risk rating charts in the provision of evidence-based models of chronic illness care.

**Competing interests**

The authors declare there are no competing interests.

**Acknowledgements**

This study was funded by the Cooperative Research Centre for Aboriginal Health (CRC AH) and would not have been possible without the support of the Aboriginal Health Council of South Australia (AHC CSA), the communities AHC SA represents and the numerous community leaders acknowledged in the final project report for the Lowitja Institute (22).

**References**

4. Harvey PW. Eye regional health service needs analysis report. Port Lincoln, SA: ERHS Board, Eyre Peninsula South Australia; 1996.

www.publish.csiro.au/journals/ahr