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Chronic disease self-management in Aboriginal communities: Towards a sustainable program of care in rural communities

J. Ah Kit¹, C. Prideaux², P.W. Harvey³, J. Collins⁴, M. Battersby⁴,
P.D. Mills⁵, and S. Dansie⁶

Port Lincoln Aboriginal Health Service¹, Ceduna Koonibba Aboriginal Health Service²
Spencer Gulf Rural Health School (SGRHS) - UniSA³, Flinders University⁴ Adelaide
University Department of General Practice⁵
Eyre Peninsula Division of General Practice⁶

The Chronic Disease Self-Management (CDSM) strategy for Aboriginal patients on Eyre Peninsula, South Australia, was designed to develop and trial new program tools and processes for goal setting, behaviour change and self-management for Aboriginal people with diabetes. The project was established as a one-year demonstration project to test and trial a range of CDSM processes and procedures within Aboriginal communities and not as a formal research project. Over a one-year period, 60 Aboriginal people with type-2 diabetes in two remote regional centres participated in the pilot program. This represents around 25% of the known Aboriginal diabetic population in these sites. The project included training for four Aboriginal Health Workers in goal setting and self-management strategies in preparation for them to run the program. Patients completed a Diabetes Assessment Tool, a Quality of Life Questionnaire (SF12), the Work and Social Adjustment Scale (WASAS) at 0, 6 and 12 months. The evaluation tools were assessed and revised by consumers and health professionals during the trial to determine the most functional and acceptable processes for Aboriginal patients. Some limited biomedical data were also recorded although this was not the principal purpose of the project.

Initial results from the COAG coordinated care trial in Eyre suggest that goal setting and monitoring processes, when modified to be culturally inclusive of Aboriginal people, can be effective strategies for improving self-management skills and health-related behaviours of patients with chronic illness. The CDSM pilot study in Aboriginal communities has led to further refinement of the tools and processes used in chronic illness self-management programs for Aboriginal people and to greater acceptance of these processes in the communities involved. Participation in a diabetes self-management program run by Aboriginal Health Workers assists patients to identify and understand their health problems and develop condition management goals and patient-centred solutions that can lead to improved health and wellbeing for participants. While the development of self-management tools and strategies led to some early indications of improvements in patient participation and resultant health outcomes, the pilot program and the refinement of new assessment tools used to assist this process has been the significant outcome of the project.

The CDSM process described here is a valuable strategy for educating and supporting people with chronic conditions and in gaining their participation in programs designed to improve the way they manage their illness. Such work, and the subsequent health outcome research planned for rural regions, will contribute to the development of more comprehensive CDSM programs for Aboriginal communities generally.

Keywords: Indigenous Communities, Chronic Illness Self-management, Engaging Stakeholders

The Council of Australian Governments (COAG) coordinated care initiative enabled research into more effective management of chronic illness, with the implicit assumption that much of the burden of chronic illness in the community can be prevented or managed to reduce the resultant demand for acute care and improve health

outcomes for patients (Fries, Koop, Sokolov, Carson, & Wright, 1998; Heard, Kalucy, Richardson, Battersby, & McGowan, 2002; McGinnis & Foege, 1993). This work, carried out in all Australian states between 1997 and 2000, was based on funds being pooled for preventive care as a strategy for improving health outcomes for patients, and

reducing unplanned, preventable hospital admissions for this group (Commonwealth of Australia, 2001b). The evaluation of the coordinated care trials for indigenous communities (Commonwealth of Australia, 2001a) also highlights the success of these processes for Aboriginal people and suggests a way forward for chronic disease management programs within Aboriginal communities generally.

As a consequence of the COAG agenda, new item numbers have been introduced to the Medical Benefits Schedule (MBS) for health assessments, care planning and a range of case conferences and service planning for patients with chronic illness (Commonwealth Department of Health and Ageing, 2002a). This is an attempt to fund GPs and health providers in more direct ways to reduce and manage the incidence of chronic disease in the community. The new approach has produced a cautious uptake of the new items in rural South Australia, and a linking of GP care plans more directly to Allied Health service and primary care delivery systems (Lewis et al., 2003). The new Commonwealth Regional Health Service (CRHS) initiative also supports these processes and builds more flexible community-based funding models for preventive health care programs in rural areas. These programs were specifically aimed at improving coordination of service provision for patients with chronic illness in an attempt to reduce the increasing demand for health care services as our patient populations age and develop more complex health care needs (Grey, 1998, p. 907; Mechanic, 2001, p. 38; Podger, 1999).

However, in spite of there being only limited and preliminary evidence of improved health outcomes resulting from coordinated care generally or care planning in particular (Heard et al., 2002), the practice seems set to expand through the agency of the MBS system (Harvey, 2001a, 2001b). What is needed now is more clarity about which strategies within the general framework of coordinated care and primary health care actually achieve improved outcomes for patients. Recent work with Aboriginal communities is making a valuable contribution to this emerging clarity of how best to manage care for patients with chronic conditions in particular.

One outcome of the SA HealthPlus coordinated care trial was the identification of elements of the care planning, Partners in Health (PIH) and

Problem and Goal (P&G) approaches that appeared to improve patient compliance to treatment and lifestyle options and result in improved health outcomes (Battersby, 2000; Commonwealth of Australia, 2001b). The question arose as to which elements of the coordinated care process suited which patients, and, further, which patients were most likely to participate in and benefit from self-management strategies.

Consequently, a number of chronic disease self-management (CDSM) programs have been established to explore more effective ways of introducing patients to better ways to manage their health care and to measure the impact of self-management in particular on patient behaviour change and resultant health outcomes. The Eyre Peninsula CDSM pilot program for Aboriginal people was one such venture, which aimed to develop patient education, behaviour change and management strategies that were culturally appropriate for and applicable to Aboriginal communities, both urban and remote, and to document these approaches as possible models for other communities.

A central hypothesis of the demonstration program was that a modified form of goal setting and initiation into self-management is possible for Aboriginal people and that, when implemented, such approaches can lead to improved quality of life and health outcomes for this patient population. Leaving aside the proposition that CDSM approaches may be elaborate strategies for demand management rather than methods for improving health outcomes per se, there appears to be merit in the process for both Aboriginal and non-Aboriginal people; that is, even though CDSM might be a way of shifting demand away from an overtaxed acute system in crisis, it may also, in the process, actually improve health and wellbeing for a significant number of patients with chronic illness.

The Eyre context

Of the 32,000 people living in Eyre Peninsula, around 15% of these are eligible for health assessments and care plans or both under the new MBS item number system. The basic criteria for health assessment eligibility are Aboriginal people over the age of 55 years and non-Aboriginal people over the age of 75 years (Commonwealth Department of Health and Ageing, 2002b), while all patients with chronic and complex health

conditions are eligible for a formal care plan through the MBS system. The Eyre population includes around 1500 Aboriginal people (Harvey, 1996). Half of these people live in remote and isolated communities in the Far West, while the majority of others live in the Port Lincoln area (Prometheus Information, 2000). An estimated 20% of Aboriginal people in this population suffer from chronic illness or have a high risk of developing a chronic condition under current circumstances.

Timeframe

This project began formally in June 2001. A three-month start-up and planning phase preceded the one-year pilot program with the project being completed in September 2002. In the planning and project development phase, extensive consultations occurred between the training providers, project officers and Aboriginal Health Service staff to ensure that tools and processes used were appropriate for Aboriginal people and Aboriginal Health Organisations.

Project Overview

This Aboriginal CDSM pilot project was designed as a short-term, limited scope project aimed specifically at creating a CDSM model for Aboriginal people that could be scaled up to work in conjunction with other primary health care programs such as the Enhanced Primary Care program (EPC) and the Commonwealth Regional Health Service program (CRHS). It was not a formal research trial or “randomized controlled trial” (RCT) with intervention and control groups, but rather a demonstration project designed to develop locally-managed CDSM programs for Aboriginal people that could be tailored specifically to meet the needs of local communities and families affected by chronic diseases such as diabetes, heart conditions and lung conditions.

Components of the program included:

- development of local CDSM support coordination roles for Aboriginal Health Workers (AHW) in Ceduna and Port Lincoln to work with Aboriginal people with conditions, principally type 2 diabetes and related co-morbidities;
- the extension of previous preventive health programs in the Ceduna area and the development of the coordinated care service

coordination function pioneered by the COAG coordinated care trials as a way of encouraging self-management through education programs;

- development of appropriate self-assessment processes and tools to suit Aboriginal people in their goal setting, behaviour change and self-management approaches;
- documentation of specific family, community and individual health gain resulting from patient participation in a formal CDSM program, in conjunction with the roll out of new item numbers for care planning and additional allied health services being sought under the CRHS agreements;
- development of appropriate staff training that is culturally sensitive and flexible enough to promote the principles of self-management through goal setting, education, access to preventive services and lifestyle changes;
- identifying the allied health services and programs relevant to and effective in achieving health improvements within Aboriginal communities.

Methods and Procedures

Client group

Given the work already carried out in the Far West Communities and in Port Lincoln during the COAG trial and other allied health service initiatives, it is clear that these communities have a need for more allied health and preventive health services and that service provision in some areas is below national average levels for the whole population (Harvey, 1996). There is a high rate of diabetes and cardiovascular disease in the focus population, and a clear need to improve access to services for this group and to enhance the community education and promotion around health and wellbeing generally.

In the community needs analysis for Eyre Region that preceded the COAG trial there:

Members of the Aboriginal community highlighted a lack of basic social infrastructure and an inability for people to participate in meaningful activities as the main causes of public health problems. Basic amenities such as housing, reliable access to good sources of nutrition, family support and purposeful community interaction are lacking in Aboriginal communities and this is contributing to an alarming

early mortality rate and disproportionate occurrences of disease such as diabetes, kidney disorders, illness due to excessive alcohol and tobacco consumption and systemic problems caused by an inadequate diet. (Harvey, 1996, p. 84)

Furthermore, the Wangka Wilurrara Aboriginal Regional Council in its "Regional Plan 1996 - 1999" (Aboriginal Regional Council - Eyre, 1996) highlighted issues such as:

- a life expectancy for Aboriginal people of 15 to 18 years less than the normal for white Australian (males 57 & females 65 years);
- a high incidence of illness such as asthma, ear and hearing problems, and diabetes among Aboriginal people;
- a higher than normal rate of smoking (53.6% of people);
- a consensus that alcohol was a problem in the community (some 78.7% compared with national figures of 58.8% of people indicating that alcohol was a concern);
- a need for greater autonomy for Aboriginal community programs and for the people concerned to be much more involved in framing strategies to deal with health problems;
- a need for more data collection and quantification of health problems in Aboriginal communities as a means of securing funding and new program initiatives;
- a need for funding for specific programs for remote communities in the areas of dialysis support, mental health, aged care, substance abuse, rehabilitation/detox, domestic violence and transport services;
- a need for education and awareness programs for Aboriginal people to begin to address the unacceptably high levels of poor health facing people in the Region;
- a need for improvements in housing and basic family security and comfort;
- a need for increased awareness among mainstream and Aboriginal communities of the degree to which poor housing and living conditions contribute to disease and poor health prospects for indigenous people.

To improve this situation, locally-based CDSM trainers and leaders provided self-management support for patients designed to complement the existing work being done in this area.

Design

The project aimed to develop a local model of CDSM for Aboriginal people through participation of families and community members. Initially, 31 patients were recruited for the program in Ceduna and surrounding areas, with service delivery support provided through the Ceduna Koonibba Aboriginal Health Service (CKAHS) and the Ceduna RHS program. A group of 29 patients was recruited through the Port Lincoln Aboriginal Health Service (PLAHS) in Port Lincoln, making a total population of 60 people involved in the pilot study.

PIH Instruments being developed to capture changes in self-management behaviour during the course of the project, measuring patient readiness to self-manage (Battersby, 2000) were tested at the beginning, middle and end of the project. Other health outcome data, along with longitudinal patient records, were kept during the project. Project data was collected by participating staff in local health units using a combination of data systems that were in place in Aboriginal Health Service Organisations.

Assessment and evaluation tools administered, tested and modified during the active phase included:

- SF12
- Work and Social Adjustment Scale
- diabetes assessment - beginning, middle and end
- Problem and Goal rating (opportunistically and up to three times during the pilot)

Issues in relation to data collection

Most of the assessment tools could not be self-administered by patients. Additionally, many Aboriginal people found the questions confusing and easy to misinterpret due to question complexity rather than to what was actually being asked. This was especially the case with the SF12 and the WASAS.

Aboriginal clients did not like to offend others and would often try to comply with assessments and evaluation materials by responding in a way that they thought would please health workers and create fewer problems for them. There was also some confusion experienced when numerical ratings were used in lieu of text as in the case of the diabetes assessments.

Also, the evaluation and assessment process was not often seen to be as important as other more pressing issues for the community such as housing, food, family, and water supply.

Health teams

As well as developing self-help and support groups to function with the minimum of allied health professional support, a team of local allied health staff recruited through the new CRHS program supported patients and encouraged independent management of their conditions. The new health assessment and care plan item numbers implemented through the EPC program funded GPs to care-plan and manage patient service needs and to schedule participation in group training and self-help programs.

The Eyre Region was fortunate to have the support of the Flinders University Coordinated Care Training Unit (CCTU) during the SA HealthPlus trial. Some of the staff trained as CDSM program leaders now work in the region both in the EPDGP and the ERHS; however, maintaining staff skills and continuity of staffing generally still presents a major difficulty for Aboriginal Health Organisations. These key trainers educated and supported local staff in the management of chronic illness, with particular reference to the importance of education, goal setting and the development of support groups to maintain lifestyle change involving exercise programs and dietary modifications. Staff worked in collaboration with allied health professionals to provide the services necessary to motivate and sustain behaviour change and self-management by patients.

Client recruitment procedures

Local health unit staff, with their knowledge of existing patient need, provided an initial list of potential patients to be recruited into the training program. Patients were asked to volunteer for the program and were recruited through Aboriginal Health Service Organisations in the course of normal health service activities, once having been identified as meeting the general criteria of:

- having a chronic illness and/or co-morbidity (i.e., type 2 diabetes being the principal diagnosis);
- being a person of Aboriginal descent;
- living in and around Ceduna or Port Lincoln districts (the target population areas);
- willing to participate in a CDSM training and education program; and
- willing to cooperate with group leaders and program coordinators over the life of the project and to participate regularly in program activities.

Data Collection and Program Evaluation

In addition to health unit data, local data were kept by project coordinators in both sites to assist the recruitment and management of patients involved in the pilot program. This enabled the aggregation of basic health and wellbeing information, demographic data, and service utilisation information. Other tools were administered and tested during the course of the program to determine the best methods for collecting overall health and wellbeing status information, and to determine patient willingness to participate in behaviour change initiatives. A self-assessment tool developed in the “Partners in Health” component of the South Australian COAG Coordinated Care Trial was adapted to provide direct feedback on patient knowledge of their condition and the degree of success derived from their participation in the program.

CDSM Strategies

Locally trained staff worked with, trained and supported indigenous group leaders in CDSM processes in both sites in relation to the specific conditions outlined. This approach was based on the service coordination model established in the region to develop support groups, education programs and CDSM strategies of particular relevance to Aboriginal communities. Although Aboriginal patients did not participate in organized and formal ‘Lorig style’ CDSM courses (Lorig, Gonzales, & Laurent, 1998; Lorig et al., 2000), one - to - one approaches were used by health teams to educate, support and encourage patients to consider more comprehensive self-management approaches as a consequence of the care planning and goal setting processes used.

Staff training

Training and support for staff and patients was provided through a partnership with the Flinders University Coordinated Care Training Unit, which was responsible for developing the staff training programs for the COAG coordinated care trials in South Australia. This work culminated in the ‘Partners in Health’ program (Battersby, 2000) and other chronic disease self-management initiatives that were modified and adapted for use in local Aboriginal communities. Local mentor and training staff located in the Eyre Peninsula Division of

General Practice (EPDGP) provided the training for allied health workers on behalf of the FUSA Coordinated Care Training Unit.

Some additional training was required through Flinders University (CCTU) to meet the specific demands of running programs in local Aboriginal communities. The major components of the program were based on the CDSM principles developed by Lorig et al. in relation to arthritis management (Holman & Lorig, 2000; Lorig et al., 1998; Lorig, Mazonson, & Holman, 1993; Lorig et al., 1996) but dealt specifically with the management of chronic diabetes, cardiac and respiratory conditions for Aboriginal people.

The program

Patients involved in the project were identified and care planned through the existing item number system already in place in the target areas. The actual care planning process was an effective selection and recruitment process for this group of patients, with the CDSM pilot program being an essential component of the care plan. At the same time, the CDSM process encouraged and reinforced care planning principles and advanced local organisational changes that could lead to improved uptake of the new item numbers for Aboriginal patients.

The patient management program resulting from the care planning process also included medication management, regular reviews, the setting of specific management goals and the modification of lifestyle factors as demonstrated through the 'Partners in Health Program' and the SA HealthPlus Coordinated Care Trial (Battersby, Ask, Reece, Markwick, & Collins, 2001).

In addition to the elements of the care plan mentioned above, the CDSM pilot program, which is a developmental program aimed at determining what elements are most effective for Aboriginal people specifically, involved:

- provision of local support and encouragement with condition management programs already in place (cf. the role of the service coordinators);
- involvement in "rehabilitation programs" through which patients participated in group education sessions about their condition, exercise and diet management programs and self-help groups run by local coordinators;
- participation in community-based, family group and social group meetings and discussion

sessions run by local staff to encourage patients to self-manage;

- participation of carers and other family members in regular sessions designed to encourage groups and family support for patients with chronic conditions;
- participation in consumer group discussion, feedback and promotional sessions designed to expand such programs to include other patients beyond the pilot group;
- participation in formal review, feedback, self-assessment and data reporting activities through which group leaders assessed patient progress over time towards self-management, and determined the most effective CDSM strategies for Aboriginal people.

Tools Tested

Modified SF-12 Quality of life assessment

Not surprisingly, this tool showed no significant change over the course of the trial. Clients largely needed the AHW to physically complete the forms and interpret them. Despite several revisions, and the non-specific nature of this tool, it was cumbersome to use and was unable to differentiate those patients who were able to benefit most from learning self-management strategies.

It is felt that in its initial format, this evaluation tool is still unsuitable for use by Aboriginal people and requires substantial modification. The subsequent modifications made by the AHWs remain to be further tested. Despite the above criticisms, this tool did provide useful information about social functioning that was not otherwise readily evident from the other forms. Ignoring the limitations of having a third party complete the forms, there was an opportunity to identify discrepancies between care and stated need. The comments of the AHWs are noteworthy with regard to clients providing the answers they thought the AHW wanted. The less transparent SF12 may actually have provided much needed clues to overall personal distress.

Modified Work and Social Adjustment Scale (WASAS)

Similarly, this tool also showed no significant change over the course of the trial. This questionnaire represents a revision of the original Work and Social Adjustment Scale used in the first round of the COAG Coordinated Care Trials in South Australia (Commonwealth of Australia, 1999).

Although simple to use, it still created confusion with Aboriginal patients due to the use of a numerical and descriptive options along with an excessive number of choices being available. Substantial support from the AHW to interpret and complete the forms was still required.

Diabetes assessment

This form was generally viewed favourably by health workers as it was simple to administer, not time consuming, and yielded useful information. It is not surprising that large improvements were observed in the fields of knowledge, treatment and lifestyle as a result of this process. It is a locally developed tool that merges the Partners in Health Scale and the Cue and Response Form that were two assessment tools developed through Flinders University Coordinated Care Training Unit to test patient knowledge and self-management ability in preparation for care planning.

This form was developed to simplify the self-management status of patients with diabetes and to provide information that would assist the care planning process. Additionally, it appeared more sensitive to changing patient status compared to other tools tested. General agreement suggested that the use of this form was not confrontational and promoted informal conversation between the health worker and patient about diabetes, while at the same time providing a patient perceived self-management baseline.

Problems and goals assessment

This assessment tool, which rates the impact of patient problems on their lives on a scale of 1-8, was met with a mixed response by the health workers as it was felt that the use of this tool would unearth patient problems that they were not equipped to manage, or problems that were simply too complex to be resolved. Levels of disclosure varied between clients and the quality of Problems and Goals varied considerably. It is clear that some patients did not find this approach useful or motivational, whereas others were able to articulate or disclose issues of significance from a biomedical, social, psychological, or emotional perspective.

The health workers felt that clients could deal effectively with problems associated with their illness but identified issues that could not be resolved. It is noteworthy that despite initial misgivings, problem rating improved over time and

the goal achievement also improved. It is highly likely that as the AHWs developed confidence in using this tool and as the patient relationship evolved, better outcomes were recorded. Further applications of these tools in the programs that are to follow this pilot will enable refinement of the scoring processes to validate the scales and enable the collection of higher quality data for larger numbers of patients.

Results

Limited scale score results are provided here, as the principal task of the pilot program was to develop processes and tools for use in CDSM programs that were both acceptable to indigenous people and useful in identifying changes in self-management ability, knowledge of illness, and changes in behaviour.

Demographics:

Median age: 46 years
Males 28
Females 32
Mean level of education: year 11 secondary

Problems were related to four main domains:

Depression/anxiety/pain
Social/family disharmony
Specific management issues
Diabetes complications

Goals set related almost exclusively to lifestyle change; other areas included self-management strategies in conjunction with other parties such as a dietician, physiotherapist, or AHW.

Problem rating means:

Initial 6.2
Middle 6.0
Final 5.2

Goal rating means

Initial 7.3
Middle 6.1
Final 5.4

SF12; for average scores for questions 1 to 12, the maximum change was 0.27 (12%), the minimum change 0.02 (2%) and the mean 0.07 (5%). WASAS average scores ranged from 0.57 to 1.37 with a mean change of 0.11 (10%). Diabetes assessment average score change ranged from 0.01 to 0.69 with a mean change of 0.26 (47%).

HbA1c overall trended slightly downward; for the Port Lincoln group, the mean HbA1c fell from 7.8 to 7.4. This is a positive outcome as HbA1c tends to trend slightly upwards with time, and HbA1c reductions of 1.8 are associated with reductions in micro-vascular complications of 50%.

Blood pressure measurements for the Port Lincoln group remained unchanged overall. The mean blood pressure was 144/86 at the start of the trial, and 136/84 at the end.

Conclusions

The CDSM program was designed to enhance the evolving integrated allied health service approaches to the management of chronic illness in Aboriginal communities on Eyre Peninsula. It was envisaged that in addition to the care planning and health assessment process, through which patient needs were identified and managed, the CDSM trial would lead to the development of the skills and abilities of local indigenous staff to sustain an ongoing CDSM model of care beyond the short-term demonstration program. Resources available through the MBS system (care planning and GP services) and local allied health services provided through expanding RHS clusters created the potential for sustainability of the CDSM model once the demonstration program was completed.

Outcomes indicated that not only is a CDSM approach a valuable and appropriate approach to take with Aboriginal patients, but that early wellbeing outcomes measured using self-reporting scales showed that patients were satisfied with the process being developed, and that there was some indication of improvements in wellbeing for many patients involved in the program.

More extensive population CDSM research, based on this pilot, is now being undertaken across the Eyre Regional Health Service involving longer-term studies of the actual health outcomes and financial efficiencies resulting from a wider application of CDSM processes. It is expected that these data will indicate, along with providing further pointers for refining this approach to management of care, significant health and wellbeing outcome benefits for the population generally and for Aboriginal patients in particular.

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Jackie Ah Kit
Port Lincoln Aboriginal Health Service
Oxford Terrace
Port Lincoln SA 5606
AUSTRALIA

Colleen Prideaux
Ceduna Koonibba Aboriginal Health Service
Ceduna SA 5690
AUSTRALIA

Jim Collins
Eyre Peninsula Division of General Practice
PO Box 804
Port Lincoln SA 5606
AUSTRALIA

Malcolm Battersby
Flinders Human Behaviour & Health Research Unit
F6 The Flats
Flinders Medical Centre
Bedford Park SA 4052
AUSTRALIA

David Mills
Investigator Clinic
Oxford Terrace
Port Lincoln SA 5606
AUSTRALIA

Sylvia Dansie
Eyre Peninsula Division of General Practice
PO Box 804
Port Lincoln SA 5606
AUSTRALIA
Correspondence to Jackie Ah Kit