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Implementing the Flinders Model of Self-management Support with Aboriginal People who have Diabetes: Findings from a Pilot Study

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A pilot program for Aboriginal people with diabetes on Eyre Peninsula, South Australia, aimed to test the acceptability and impact of using the Flinders model of self-management care planning to improve patient self-management. A community development approach was used to conduct a twelve-month demonstration project. Aboriginal health workers (AHWs) conducted patient-centred, self-management assessment and care planning. Impacts were measured by patient-completed diabetes self-management assessment tool, goal achievement, quality of life and clinical measures at baseline and 12 months. Impact and acceptability were also assessed by semi-structured interviews and focus groups of AHWs. Sixty Aboriginal people with type 2 diabetes stated their main problems as family and social dysfunction, access to services, nutrition and exercise. Problems improved by 12% and goals by 26%, while quality of life scores showed no significant change. Self-management scores improved in five of six domains. Mean HbA1c reduced from 8.74–8.09 and mean blood pressure was unchanged. AHWs found the process acceptable and appropriate for them and their patients. It was concluded that a diabetes self-management program provided by AHWs is acceptable, improves self-management and is seen to be useful by Aboriginal communities. Barriers include lack of preventative health services, social problems and time pressure on staff. Enablers include community concern regarding the prevalence and mortality associated with diabetes.

Key words: *Aboriginal health, Diabetes, Chronic-condition self-management, Rural health, Care planning*

Evaluation of the SA HealthPlus Coordinated Care trial identified that the Problem and Goal (P&G) approach was a key element in improving quality of life for intervention patients with a wide range of chronic conditions, including Aboriginal people with diabetes on Eyre Peninsula (Battersby et al., 2007) While the P&G approach assisted patient self-management, self-management had not been operationalised. Therefore, a pilot study was conducted towards the end of the trial to develop a generic (not disease-specific) assessment, which would lead to targeted self-management interventions to supplement the P&G approach. This resulted in the Partners in Health program, which enabled self-management issues and interventions to be combined with medical management on a single care plan (Battersby et al.,

2002). This program was further refined when the Flinders (University) Human Behaviour and Health Research Unit (FHBHRU) was contracted by the Australian Government Department of Health and Ageing to provide a clinician education program for the National Sharing Health Care Initiative demonstration projects (Australian Government Department of Health and Ageing, 2004).

In 2001, the South Australian Department of Human Services (DHS) funded four projects to test the effectiveness of various models of chronic condition self-management (CCSM). This paper reports on the outcomes of the Aboriginal diabetes CCSM pilot project on Eyre Peninsula. The core partners in the project were the Port Lincoln Aboriginal Health Service (PLAHS), the Ceduna Koonibba Aboriginal Health Service (CKAHS)

and the Eyre Peninsula Division of General Practice (EPDGP). FHBHRU provided training, ongoing supervision of Aboriginal health workers (AHWs) and project support. Ethical approval to conduct the study was obtained through the Ethics Committee of the Aboriginal Health Council of South Australia.

This pilot program aimed to explore the acceptability and impact of introducing AHWs and patients to more structured systems of care and to measure the impact of such systems on patient behaviour and the delivery of services. The project aimed to adapt the Partners in Health program to develop patient education, behaviour change and self-management strategies that were culturally appropriate for Aboriginal communities.

The main aim of the project was to test whether a modified form of self-management assessment, goal setting and care planning delivered by AHWs—in partnership with the patient and their general practitioner—is acceptable to an Aboriginal community. Second, whether such an approach can lead to improved patient self-management behaviours. A third aim was to test the psychometric properties of the revised self-management assessment scale to see whether changes in self-management are associated with changes in clinical and quality of life measures. It was not anticipated that improvements in quality of life and health outcomes for this patient population would occur in a short timeframe and the project design (without a control group) did not permit a formal evaluation of this.

The Eyre Peninsula context

The Eyre Peninsula population includes around 1500–2000 Aboriginal people (some transient [Harvey, 1996]). Half 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, particularly diabetes and cardiovascular disease. These communities are underserved by allied health and preventive health services (Harvey, 1996).

The Wangka Wilurrara Aboriginal Regional Council in its “Regional Plan 1996–1999” (Aboriginal Regional Council–Eyre, 1996) highlighted issues such as (a) a life expectancy for Aboriginal people of 15 to 18 years less

than white Australians (males 57 and females 65 years); (b) a high incidence of illness such as asthma, ear and hearing problems and diabetes; (c) a higher than normal rate of smoking (53.6% of people); (d) 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.

Methodology

The project began in June 2001 with community consultation over a three-month period to seek input into the developmental process. This preceded the one-year pilot program, with the project being completed in September 2002.

The development phase

Consultation with tribal elders in the Aboriginal community identified that there was widespread concern about the health of the Aboriginal community, and about diabetes specifically. The concept of patients being encouraged to engage in self-management was strongly supported by the community. The elders identified four central issues that were important in understanding and directing care in their community:

- A better understanding of what diabetes was
- Better support of families and the community
- More education of young people about diabetes
- Improved availability of better and more appropriate nutrition.

Collaboration in the development phase also focused on adapting the Partners in Health program to ensure that tools and processes were appropriate for Aboriginal people and Aboriginal health services (AHS). Some allied health services were available in local communities as part of the newly-established Commonwealth Regional Health Services (RHS). This project was designed to create a diabetes CCSM model for Aboriginal people, that, if successful, could be used for all chronic conditions to access the Medical Benefits Schedule (MBS) Enhanced Primary Care program (EPC) item numbers (Commonwealth Department of Health and Ageing, 2002) and the Commonwealth Regional Health Service program (CRHS).

Evaluation measures

The instruments described below were adapted to reflect language and literacy levels of the Aboriginal population to enhance the acceptability and utility of the instruments for use beyond the project. The adaptation of the Partners in Health (PIH), SF-12 and Work and Social Adjustment Scale (WSAS) was seen as the first step, of testing acceptability in the process of establishing psychometric properties of reliability and validity of the tools for future clinical or research use. In addition, the project aimed to determine whether the instruments were able to detect change over time.

Diabetes Assessment Form (DAF)

The Partners in Health (PIH) scale is a twelve-item, self-administered tool for patients with chronic conditions to assess their current self-management knowledge, attitudes, behaviours and impacts of their condition. It has been tested in people with a range of chronic conditions and reliability and preliminary validity established (Battersby, Ask, Reece, Markwick, & Collins, 2003). The project adapted the PIH scale by adding questions from the Cue and Response interview, developed as a clinician validation of the PIH scale. These interviewer-administered questions aim to elicit strengths and barriers to self-management in the same 12 areas as the PIH (Battersby et al., 2003). This resulted in 27 questions in the six core domains of self-management (knowledge of condition, knowledge of treatment, sharing decisions, monitoring, physical/social/emotional impact, and lifestyle) derived from a literature review and focus groups as part of the development of the PIH scale. Each item is rated 0, 1 or 2 with "0" good and "2" poor. Patients were asked to rate themselves on each of the items, sometimes assisted by the Aboriginal health worker where literacy or comprehension was a problem. Scores were calculated as a sum of the items for each of the six sub-scales and a sum total of the sub-scales. Higher scores indicate deficits in self-management. Within this project the modified PIH was titled "Diabetes Assessment Form".

Problems and goals (P&G)

This semi-structured interview conducted by the Aboriginal health worker enables the individual to define a key problem impacting on their life and a realistic medium-term goal described in behavioural terms, which, if achieved, will reduce the impact of the problem (Battersby et al., 2001).

The problem is rated on a 0-8 Likert scale by the individual in terms of severity, with "8" indicating the highest severity. The goal is rated by the individual on a 0-8 Likert scale, with "8" indicating no progress towards achieving the goal.

SF-12

The SF-12, a derivation of the widely used SF-36 measure of quality of life (Ware & Sherbourne, 1992), was adapted by modifying the wording of some items. The SF-36 has been validated in Australian populations (Sanson-Fisher & Perkins, 1998). The SF-12 has been used in the National Mental Health and Well Being Study (Andrews, Hall, Teesson, & Henderson, 1999) and validated in Australian non-Aboriginal (Sanderson & Andrews, 2002), but not Aboriginal populations. In addition to providing scores for each of the 12 items, a mental and physical summary score can be calculated (Gandek et al., 1998).

Work and Social Adjustment Scale (WSAS)

The WSAS is a five-item self-rated scale with each item rated on a 0-8 Likert scale. The scale measures disability and handicap in areas of work, home management, social leisure, private leisure and family relationships, and was originally developed for mental health populations (Marks, 1985) with established reliability and validity (Mundt, Marks, Shear, & Greist, 2002). It was used in 4603 intervention and control patients with a broad range of chronic illnesses in the SA HealthPlus Coordinated Care trial, including Aboriginal populations with diabetes, and was shown to be able to measure change over time (Centre for Health Care Evaluation, 2000).

Medical measures

Glycated Haemoglobin (HbA1c), a serum measure of blood sugar control, and blood pressure were collected at baseline, six and 12 months.

Qualitative evaluation

At the end of the study, a focus group of AHWs was held to determine acceptability of the program to them and their patients. In addition, they were asked to nominate the barriers and enablers to completing the care planning assessment and providing support to the patients to achieve their care planning goals and access to services. Aboriginal health workers completed a second task of reviewing the adapted tools used in the study for their acceptability and relevance to Aboriginal patients.

Data collection

Data was collected by staff of participating health units using a combination of resident data systems and the evaluation tools. This data was to be owned by local communities and linked where possible to the EPDGP “Eyre Care” care planning software, in an effort to encourage ongoing data sharing and cooperation across service provider groups and general practitioners. SF-12 and WSAS were administered at baseline and 12 months and DAF at baseline, six and 12 months. P&G were rated at baseline and follow-up appointments as part of the review and motivational process and at 12 months. Data was analysed by comparing group pre- and post-scores for each measure and correlations between measures using SPSS (SPSS Inc., 1997).

Recruitment

Aboriginal health workers

AHWs were responsible for the administration of this project at each site, with support provided by their employing organisation, the EPDGP and FHBHRU. Workers engaged for this project were current employees, with project responsibilities being incorporated into their existing role to support sustainability of the model of care. The AHWs were well known within the Aboriginal community, with significant levels of trust and rapport already established. However, it was evident that they required professional support to implement new programs.

Patients

Patients with diabetes were recruited either opportunistically by the AHS, general practitioner or AHW at a non-related appointment, or were invited to participate verbally or in writing from a list of patients with a diagnosis of diabetes on the patient registry. Eligibility criteria were that patients were Aboriginal, living in and around Ceduna or Port Lincoln, had type-2 diabetes with or without co-morbid medical or psychiatric diagnoses and aged 40 or above. Patients were excluded if they were unable to give informed consent or were significantly distressed or cognitively impaired so as to prevent active participation in the project.

Training

Aboriginal health workers contributed to the content and structure of training modules to ensure

that training would be culturally and educationally appropriate. Training was provided by the FHBHRU. Module One consisted of definitions of chronic condition and self-management, patient and project outcome objectives, skill training in how to conduct a self-management assessment interview using the DAF. Client recruitment, consent and administrative responsibilities, along with data collection requirements, were described.

Module Two training was conducted several weeks after Module One, providing skills training in patient-defined P&G settings with a focus on behavioural change strategies. Training included the use of measurement of problem severity and goal achievement as both as a motivational process and an outcome measure. A care planning module, developed by the EPDGP as part of the Enhanced Primary Care initiative, was also used.

The model of care

At the assessment interview, the AHW assisted the patient to identify self-management strengths and barriers using the DAF. Evaluation tools were administered. The Aboriginal health worker then arranged an appointment for the patient to see the general practitioner for a care planning consultation. Prior to this appointment, the AHW and general practitioner analysed the DAF and P&G to identify service, education or intervention needs. The AHW liaised with other current providers of care; for example, podiatrist, dietician or registered nurse, to identify current services and future service needs. A draft care plan was created from this information.

At the care planning meeting, the patient and general practitioner negotiated an agreed twelve-month plan of care that included medical monitoring (HbA1c, blood pressure, lipids), preventative appointments (podiatry, retinal examination), self-management education, and self-management goals (weight, nutrition, exercise). The Aboriginal health worker explained how a care plan is used and encouraged the patient to use it as part of their health management. Copies were distributed to relevant providers. The AHW assisted the patient to access the recommended services and self-management education programs over subsequent weeks or months. Follow-up appointments for monitoring progress were arranged. A more complete description of the training modules, model of care and evaluation tools is available from

the report to the South Australian Department of Human Services (Collins, 2003).

Results

Demographic data

Sixty patients were enrolled in the study; 31 from Ceduna and surrounding areas and 29 from the Port Lincoln area. There were 28 males and 32 females with a median age of 46 years. Three female and one male AHW participated in the project. One female and one male AHW, one from each site, resigned or were redeployed in the last six months of the project. All 60 patients received assessment and care planning. There were no withdrawals, although not all patients completed all measures.

Medical measures

There was a significant reduction in mean HbA1c levels from baseline (8.74) to 12 months after treatment (8.09) $p < .01$. There were no significant changes in mean blood pressure before and 12 months after treatment (Diastolic: before 84.64, after 83.76, ns; Systolic: before 139.48 after 136.68, ns).

Diabetes Assessment Form

The DAF item scores are summed into six sub-scales and a total score. Lower scores indicate better self-management. Significant differences at 12 months are found across most of the dimensions of the DAF and the total score for the DAF (see Table 1).

DAF and HbA1c levels

At initial assessment, there was no significant association between DAF total score and HbA1c levels ($r[51] = -.07$), but there was a significant positive association between DAF impact sub-scale and HbA1c levels ($r[51] = .40$, $p < .01$). At twelve-month assessment, there was no significant association between DAF total score and HbA1c levels ($r[51] = -.26$) and there were no other

significant relationships for sub-scales. Changes in DAF scores over 12 months were correlated with changes in HbA1c levels over the same period (see Table 2). There was only a significant positive relationship between DAF item 8 and HbA1c ($r[33] = .34$, $p = .05$), "Do you always have enough money to buy your medication?"

Table 2: Correlations for 12-month changes in DAF scores and HbA1c levels

12-month change	_HbA1c	p	N
Knowledge	0.175	0.29	39
Treatment	0.168	0.31	39
Sharing care	-0.110	0.50	39
Measure	-0.149	0.37	39
Impact	-0.110	0.51	39
Lifestyle	0.118	0.48	39
Total	0.093	0.58	39

SF-12

There were difficulties in comprehension and appropriateness of some items. Mean SF-12 values are well below the American population norm of 50 (SF-12 norms have not been developed for an Australian Aboriginal population). There were no significant changes in physical or mental health summary scores over 12 months (Gandek et al., 1998; see Table 4) and no individual dimensions of the SF-12 showed significant differences over the 12 months.

Problems and Goals Assessment

The initial problem ratings ($M = 6.22$, $SD = 2.23$) and the six-month problem ratings ($M = 6.00$, $SD = 2.03$) were significantly higher than the one-year problem ratings, indicating a significant improvement in problem severity over the 12 months ($M = 5.28$, $SD = 2.20$; $F(2,70) = 8.72$, $p < .01$). Similarly, the initial goal ratings ($M = 7.26$, $SD = 1.57$) were significantly higher than the six-month goal ratings ($M = 6.16$, $SD = 1.94$), both of which were significantly higher than the one-year goal ratings ($M = 5.42$, $SD = 2.18$; $F(2,74) = 20.37$, $p < .001$), indicating significant

Table 1: DAF mean (SD) at initial assessment and 12-month follow up

Sub-scales	Initial (n=46) (SD)		12-Month Follow-up (n=46) (SD)		Paired Differences (SD)		t[45]	p
Knowledge	0.57	(0.64)	0.28	(0.51)	0.29	(0.62)	3.22	0.002
Treatment	0.40	(0.50)	0.20	(0.34)	0.20	(0.36)	3.82	0.000
Sharing care	0.24	(0.43)	0.10	(0.27)	0.14	(0.38)	2.55	0.014
Measure	0.68	(0.52)	0.58	(0.50)	0.11	(0.46)	1.54	0.130
Impact	0.39	(0.44)	0.14	(0.29)	0.25	(0.37)	4.67	0.000
Lifestyle	0.54	(0.58)	0.15	(0.37)	0.39	(0.50)	5.31	0.000
Total	13.48	(9.19)	7.28	(6.69)	6.20	(6.79)	6.19	0.000

goal achievement. Correlations indicated no significant linear relationships between problem and goal ratings. The problems and goals that were identified related to four main areas: day to day living conditions such as food, money and transport; overwhelming family problems (e.g., social obligations/conflict, overcrowding, alcohol and the absence of effective support structures); personal psychological problems including post-traumatic stress disorder; and low levels of health education and understanding.

Work and Social Adjustment Scale

The work sub-scale was not completed for most patients because of the high unemployment rate. Other patients found the wording of some items difficult to comprehend. There were no significant changes in the WSAS scales over 12 months.

Qualitative evaluation

A workshop was held at the end of the project to review the evaluation tools and obtain feedback from the Aboriginal health workers, medical and nursing staff about the strengths and weaknesses of the program. The predominant workload rested with the AHWs. They carry the burden of expectation of their community and were approached at work and at home to provide advice and support. AHWs are in a unique position to assess the needs of individual patients and their families. This was one of the first opportunities for some Aboriginal people to describe their health needs and to seek solutions. It also revealed a large range of psychosocial needs that impacted on their health. AHWs were confronted with the problems of overcrowding, inadequate housing, finances, drug and alcohol misuse, domestic violence and unemployment. The successful negotiation of these central issues by project staff was critical in maintaining the patients' confidence in AHWs; however, their inability to provide solutions also caused some patients to lose confidence in the system.

Some patients were able to formulate goals beyond those described above. Often the issues were extremely confidential, such as childhood sex abuse, marital conflict or grief related to recent family loss. Only modest services were available to deal with these complex issues; generally there was a reluctance to use non-Aboriginal or mainstream services, which ultimately left the AHW to deal

with the problems as best they could.

The most difficult problem for AHWs was lack of time because of the competing demands of clinical crises. There were delays in getting clients to services and in filling in forms, which many Aboriginal people could not read or understand. The time required to complete the clinical process was often double the expected time. There was no shortcut to this process, which generated important rapport, particularly if sensitive areas were to be covered. Ultimately the relationship between client and provider was one of the most successful aspects of the project.

Medical provider experience was similar to that of the AHWs. Acute medical problems invariably shortened doctor-patient contact. Inadequate preparation time for care plans was common. In most cases, disease-specific goal setting was against the background of social problems that were perceived to be more important.

During the workshop, the wording of the WSAS and SF-12 was revised to be more relevant and appropriate. The DAF was deemed to be useful, understandable and relevant, and not revised. All tools are available from Malcolm Battersby upon request.

Patients' experience of the program was not formally evaluated, although a parallel program focusing on the involvement of the Aboriginal elders in a diabetes support program has been described elsewhere (Weetra et al., 2002). However, AHWs reported that the program was acceptable to most patients and for those patients who did not benefit, the fear of complications from diabetes was overtaken by more immediate daily crises. That diabetes often produces no easily discernible symptoms reinforced this line of thinking.

Discussion

This pilot project demonstrated that chronic condition self-management assessment and goal setting delivered by AHWs in partnership with the patient and their general practitioner is acceptable to an Aboriginal community. The project design (without a control group) did not permit a formal evaluation of the efficacy of the intervention; however, results provided preliminary evidence of improved patient self-management and clinical outcomes. No improvements in quality of life and disability were found, although this may

be a reflection of the relevance of the measures used and would not be expected for this patient population in a short timeframe.

The mean HbA1c scores fell from 8.74 to 8.09 over 12 months. This is against the usual trend of gradually increasing HbA1c, over time, of 0.1% per year. HbA1c reductions of 0.9% are associated with significantly lower risks of complications (UK Prospective Diabetes Study [UKPDS] Group, 1998a) in intensively treated populations. Mean blood pressure values remained close to National Guideline targets (140/80) and fell from 140/85 to 137/84. Blood pressure reduction to 140/82 is associated with significant reductions in stroke (44%), cardiovascular deaths (34%) and microvascular complications (37%) in diabetic populations (UKPDS Group, 1998b).

Changes in DAF scores over 12 months were weakly correlated with changes in HbA1c levels and blood pressure over the same period. Patient-defined problems and goals improved significantly. In many cases the main problem was of a social or psychological nature. These problems are barriers to effective self-management so that a reduction in the severity of the problem may have assisted self-management. Patients achieved goals with the support of the AHW. It seems that a combination of targeted self-management support and addressing a main life problem and goal may lead to significant change in self-management behaviour, and, possibly, clinical measures. This is a necessary intermediate step towards achieving reductions in complications of diabetes and improved wellbeing.

Community issues

Chronic condition programs in Australia are at an early stage of evolution. Their application in Aboriginal communities is an enormous challenge in the context of numerous health and social problems. Factors known to promote good quality management of chronic conditions in primary care have been summarised in the chronic care model (Wagner et al., 2001). The six elements of the chronic care model include the wider health system, community resources, and four elements of service delivery including self-management support (Von Korff, Gruman, Schaefer, Curry, & Wagner, 1997). Failure of any element may impact on the ability of the program to succeed. The two communities had limited connection with

the wider health system and minimal community resources but were able to build on the existing clinical information systems to create, through design of a delivery system, self-management support. Decision support regarding evidence-based guidelines for diabetes was also part of the clinical information system.

In determining these prerequisites, it is assumed that patients have access to housing, electricity, food, clothing, transport and money to buy medications. Their families are also assumed to play a positive role in their ongoing care. Patients are assumed to perceive their own condition as important. Unfortunately, few of these conditions are met in many Aboriginal communities. Services may be fragmented and discontinuous, with retention of staff an ongoing problem, as occurred in this study. Additional barriers to providing chronic illness care in Aboriginal communities are the high levels of morbidity, which reduce personal and community resources and increase the pressure on medical services to provide acute rather than planned, preventative care.

An advantage is that the communities are small and can mobilise towards a common purpose. They have a shared language and culture, and, from an organisational point of view, have salaried as compared to fee-for-service employment arrangements. This means that staff have one employer and a board comprised of community members who can set strategic goals and provide system and leadership support. This project demonstrated that an individual approach engaged health workers and the community in identifying preventative behaviours and social determinants of health as key issues in the management of diabetes in their community.

Limitations of the study

Patient selection may have been biased to include those more likely to be motivated to manage their diabetes. We do not know which patients did not choose to participate and whether they represented the more complex cases. However, the complexity of the subjects' problems and baseline HbA1c levels reflect a broad spectrum of patient complexity and severity. The study design does not permit conclusions regarding the efficacy of the Partners in Health model but provides indicators of acceptability to Aboriginal people and their health workers. The SF-12 and WSAS caused

difficulties in comprehension and relevance. This led to a revised WSAS and a revised and shortened SF-12 (SF-11).

Future research

The use of a comparison group (a randomised control group with Aboriginal people from the same community who do not receive the intervention would not be acceptable) in a matched community which does not receive the intervention, would test whether this model of self-management support initiated by a AHW leads to improved self-management, clinical or health outcomes. The timeframe would need to be longer (two to three years) so that the benefits of improved self-management have time to impact on clinical indicators, health outcomes and service use. The Partners in Health program is designed to be generic and further research could test its efficacy in a range of chronic conditions, acknowledging that most chronic conditions co-exist with mental

or physical co-morbidities. Future studies could trial the revised WSAS and SF-12 to determine their reliability and validity in an Aboriginal setting.

Conclusions

The study found that an AHW-led program of self-management support for Aboriginal patients with diabetes is acceptable. Time pressures on staff, social problems and available services are factors that need to be considered in planning the implementation of such programs so that patient and staff expectations are met. There were indicators that this approach may lead to improved self-management capacity along with improvements in clinical outcomes. Evaluation instruments for quality of life and disability and handicap need further development and trial to be acceptable to Aboriginal patients with diabetes.

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