

Challenges and Benefits of Implementing a Chronic Disease Self-management Program in an Aboriginal Community Controlled Health Setting

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The experience of Aboriginal health workers and general medical practitioners at the Aboriginal Medical Service Western Sydney in using patient-centred health measures as a part of chronic disease self-management program is discussed. Challenges encountered were lack of confidence in using these tools, adaptation of the tools without full understanding of their background and adequate testing, and lack of take-up of the care planning component by GPs. Benefits included improved communication between Aboriginal health workers, GPs and patients. The major benefit noted was that Aboriginal health workers felt the tools helped them to understand the barriers their most challenging patients faced to changing their health behaviour. This was motivating and encouraging for Aboriginal health workers, who often provide extensive support—both emotional and practical—to patients with high burdens of chronic disease and self-management difficulties.

Key words: Patient-centred health measures, Aboriginal health worker, General practitioner, Chronic disease self-management

Patient-centred health measures are increasingly used in a research setting to measure health program outcomes. They also have considerable clinical uses in improving communication between patients and health care providers, facilitating shared health management, and identifying hidden health problems (Higginson & Carr, 2001; O'Connor, 2004, pp. 1-22).

In 2003-2004, the Aboriginal Medical Service (AMSWS), formerly known as Daruk AMS, undertook a trial of the Partners in Health scale and the linked Cue & Response scale, -patient-centred health measures designed to both assess and to enhance chronic disease self-management (CDSM). These continue to be widely disseminated and used in multiple settings nationally.

Background

This paper describes the process of a trial of these tools undertaken by Aboriginal health workers (AHWs) and general practitioners (GPs), discusses the challenges and benefits of their use in an Aboriginal medical service, and highlights the lessons learnt from this process.

The Partners in Health scale (PIH) and the Cue & Response (C&R) scale were developed by the Flinders Coordinated Care Training Unit as part of the SA HealthPlus Coordinated Care Trials. They were designed to facilitate communication

and identify health issues in order to improve patient CDSM, as well as to evaluate CDSM programs (Battersby, Ask, Reece, Markwick, & Collins, 2003).

The Flinders team runs an extensive national program of training and dissemination of their model (Flinders Human Behaviour and Health Research Unit, 2006) and the NSW Department of Health has promoted use of the tools as part of their chronic care initiatives (NSW Department of Health, 2004). They have been used in several Aboriginal health services nationally (Ah Kit et al., 2003; Giles, 2006) and continue to be evaluated in this setting. There is currently a national focus on increased CDSM training and initiatives (Council of Australian Governments, 2006), thus making our feedback relevant.

In the PIH scale, patients complete 11 health statements using a visual analogue rating scale from 0 ("very good") to 8 ("very poor"). The C&R scale is administered by a health care provider in the form of a semi-structured interview, using the same items and scales plus prompting questions that allow the patient to expand on the items. Examples of the statements are "My knowledge of my condition is...", "My ability to take my medication as directed by my doctor is..." and a more global question at the end: "My progress towards adopting habits that improve my health

is...". Discrepancies between item scores from the PIH self-report and the C&R provider-based report may highlight self-management areas that need further exploration.

The scales were developed as part of a set that includes a "Problem and Goals assessment", and a link into a GP care plan for multidisciplinary management. The Problem and Goals tool allows the health care provider and the patient to set patient-centred health goals. The linkage to the care plan aims to make sure the health assessment is holistic and involves GPs, and that the program is sustainable in the primary care setting through the availability of Enhanced Primary Care Medicare reimbursement.

Patient-centred health measures are increasingly important in the evaluation of health programs, and potential users should have a good knowledge of what tests are available and best for their purpose before choosing which to use or deciding to develop new ones (Garratt, Schmidt, MacKintosh, & Fitzpatrick, 2002). The Partners in Health scale is a generic CDSM scale, developed because existing self-management scales were all disease-specific (Battersby et al., 2003). A large proportion of people have more than one chronic disease at a time (Druss et al., 2001; Australian Institute of Health and Welfare, 2006), and all are likely to impact on their wellbeing and self-management.

Due to the high burden of multiple chronic illnesses in Aboriginal people (Australian Institute of Health and Welfare, 2005) people attending CDSM programs in Aboriginal health settings are very likely to have several co-morbidities. Generic CDSM programs and measures may also be more practical in an Aboriginal health setting due to the difficulty of engaging a sufficient number of participants in a self-management program at any one time. Furthermore, generic tools place less emphasis on symptoms than disease-specific tools, and allow more room to pick up unexpected issues (O'Connor 2004, pp. 16-17). It could be argued that they are more culturally appropriate as they look at the whole person in their context, in keeping with the Aboriginal definition of health (National Health and Medical Research Council, 1996). Disease-specific tools may be more useful at picking up small changes in health outcomes that may be more important in the research setting.

The process and outcomes of using the tools at AMSWS

In 2003, a group of AHWs and GPs received training in the Flinders CDSM model, through a two-day training program. This focused on core principles of CDSM and behaviour change, and how to administer the tools. We were encouraged to go on to adapt and use all or any of the tools with the support of the Flinders Coordinated Care Unit. It was our first experience of using a patient-centred health scale as part of our delivery of primary health care and health promotion programs.

The PIH and C&R scales were originally designed to improve communication between people with chronic disease and their health care providers, as well as to provide evidence of changes in self-management resulting from the Partners in Health program. This in turn was to provide evidence of the efficacy and cost-effectiveness of a model of health care provision in chronic disease. However, in our setting, within an Aboriginal community controlled medical service, the purpose of using the scales would necessarily be different. We wanted to use the tools to improve communication between patients and health care workers, and, hopefully, to uncover hidden barriers that were preventing patients taking control of their own health. We targeted patients we felt needed extra support to achieve health behaviour changes. We also planned to use the tools for evaluation of our programs, hoping to demonstrate improved self-management scores by re-administering the scales 12 months after engaging the patients in our programs. These programs included exercise and nutrition health promotion groups as well as AHW case management and education.

Initially, the tools were trialled on several staff and community members with chronic disease. As a result of this we made some changes to the tools, including dropping two items from the scales and making minor wording changes. More prompts were added to the C&R tool as the AHWs were inexperienced with semi-structured interviews and wanted a clear "script" to follow. We chose not to use the Problems and Goals assessment after struggling with it briefly, again a choice by the AHWs who reported feeling overwhelmed by paperwork as well as the responsibility of helping patients to set achievable health goals when it was hard to know where to start.

Although four AHWs and six GPs undertook the training, two AHWs and four GPs subsequently used the tools. The PIH and C&R tools were administered by the AHWs, who used the insights gained for their own case management of the clients and referred clients to relevant health promotion programs. The completed tools and any AHW advice were passed on to the GP, who then used the information in a care plan or consultation as they saw fit. A total of 25 clients were involved, with the majority having the PIH and C&R scale administered twice, 12 months apart. All had AHW management, but only 13 had care plans. At the time of our trial, Medicare requirements for care plans were more complex than the new Medicare GP management plans.

Feedback interviews with participating AHWs, GPs and clients were undertaken 6-12 months after the trial. AHWs reported that the C&R tool in particular was useful, helping them to understand better the barriers to effective CDSM their clients were facing, which in turn helped motivate the AHWs in their ongoing efforts to assist their clients. The AHWs found learning to use the measures and conduct semi-structured interviews a steep but rewarding learning curve, although they lacked confidence in structured health goal-setting. GP feedback indicated that the care plan component was only sometimes helpful and was not always appropriate as it did not link directly with the information being gathered from the C&R tool. Results from the patient survey supported these impressions, with the vast majority of patients reporting that the AHW interview (C&R tool) was useful, but they did not remember having done the PIH scale or the GP care plan.

Challenges encountered

Our program was not successful in terms of providing systematic data back to the developers on the effectiveness of the tools in enhancing and evaluating CDSM. One of the main reasons for this was our team's general lack of understanding of the principles behind these tools. A potential problem was that the measures were adapted without much thought or testing. Although adapting measures to suit your own setting and purpose is considered good practice, understanding the theoretical background and original process of development and testing of the measures is important (O'Connor, 2004, pp. 66-68). The Flinders team first defined

CDSM and its core attributes through a literature review. They then used expert opinion and reference group input to devise the PIH health statements to reflect these attributes. The wording of these PIH items was refined after testing on consumers for readability, comprehension, relevance and acceptability of the questions. The scales were then field tested and shown to have high internal consistency and inter-rater reliability (Battersby et al., 2003). At this point we became involved as one of several groups trialling the tools in an Aboriginal setting.

Validity is a matter of degree and is dependent on the population in which the test has been used. A test developed, tested and felt to be valid in one population cannot be assumed to be valid in a different population without being tested again (O'Connor 2004, pp. 52-55). At AMSWS we agreed to trial the PIH and C&R scales, but it was not really clear to us what testing the tool really meant—as we saw in retrospect. This was not discussed by the Flinders' trainers, who took care to support but not direct us, in a very culturally sensitive manner. However, it is possible the changes we made may have inadvertently led to the instrument becoming less valid. We decided to discard two of the items because we felt they were repetitive. The concept that we could be affecting the content validity by changing the relative emphasis being given to core attributes, by deleting and therefore not scoring certain items, did not occur to us. The AHWs assisted the clients in filling the PIH out when requested, so there was not a clear divide between patient-derived and provider-derived scores, so information on the usefulness of the PIH tool in this group, is not reliable. Similarly, the decision not to use the Problems and Goals tool and to rely instead on the care plan may have also had a negative impact.

Service benefits

The trial of the Flinders tools was successful in terms of educating both AHWs and GPs in the principles of CDSM, and in developing the skills of the AHWs in the use of semi-structured interviews and patient-centred health measures for clinical management. The new skills will also be useful in future program evaluation.

Despite the challenges, we discovered that patient-centred health measures were more useful

in the clinical setting than we had realised. The major benefits were in facilitating communication and patient-centred health goals and thus motivating both workers and patients.

Much of the literature focuses exclusively on the use of patient-centred measures for program evaluation and research (Muldoon, Barger, Flory, & Manuck, 1998), though clinically their greatest advantage is in improving communication between health care providers and patients. This is potentially even more valuable when AHWs are administering the measures. People may give more honest disclosure about their problems with a peer than a doctor (Chew-Graham, May, & Perry, 2002), and we also noted in this trial that many patients disclosed valuable information to the AHWs in the C&R interview that they had not disclosed previously to their GPs.

Patient-centred measures can be empowering, giving patients an opportunity to express their feelings about their health care and take the consultation beyond the medical model of symptoms and treatments. Multiple seemingly overwhelming social and medical problems can paralyse both patients and health workers and make it unclear where to start; very relevant in our setting. The C&R scales were useful to both GPs and AHWs in developing management plans based on the patient's own priorities.

The AHWs reported the tools gave them a deeper understanding of the patient's problems and barriers to self-care. This in turn made it easier for AHWs to understand why they were doing so much support work, such as home visits and

facilitating patient appointments, and strengthened relationships between AHWs, patients and doctors. We consider this to have been the most helpful aspect of the program, and the learning experience that has stayed with us.

Conclusion

The trial of the PIH and C&R chronic disease self-management tools in our Aboriginal community controlled medical service was a useful way to learn about the principles of chronic disease self-management and how that can be improved and evaluated through the use of patient-centred health measures. A potential problem was our adaptation of the tools without testing, which may have decreased the content validity of the tools. Lack of experience in structured health goal setting was a barrier for AHWs in use of this potentially valuable part of the program; concern about excessive paperwork was another barrier. Benefits noted were improved confidence by AHWs in the use of semi-structured interviews and patient-centred health measures, as well as improved communication and teamwork between AHWs, GPs and patients. The major benefit noted was that AHWs felt the tools helped them to understand the barriers their most challenging patients faced in changing their health behaviour and therefore taking control of their health. This was motivating and encouraging for AHWs, who often provide extensive support—both emotional and practical—to patients with high burdens of chronic disease and self-management difficulties.

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Items in the PIH and C&R scales:

1. My knowledge of my condition is:
2. My knowledge of the treatment of my condition is:
3. My ability to share in decisions about the management of my condition is:
4. My ability to arrange appointments as recommended by my doctor or health service provider is:
5. My attendance at appointments is:
6. My ability to take my medication as directed by my doctor is:
7. My understanding of why I need to observe, measure and record my symptoms is:
8. My ability to observe, measure and record my symptoms is:
9. My understanding of what to do when my symptoms get worse is:
10. My ability to take the right action when my symptoms get worse is:
11. My progress towards adopting habits which improve my health is:

Lessons learnt:

1. Adaptation of patient-centred measures to suit local needs is good practice, but should be done with knowledge of the theoretical background of the measure and with adequate testing.
2. The semi-structured interview style of the C&R tool was a valuable way for Aboriginal health workers to explore and gain understanding of their more challenging clients' barriers to chronic disease self-management.
3. Training in use of patient-centred health measures and structured health goal-setting should be available to AHWs.
4. Over-emphasis on the GP care plan component was a major contributor to the derailment of this program. The Problems and Goals tool may better complement the PIH and C&R tools, or the more recent Medicare "GP management plans" with team care plans when appropriate may also be more successful.

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