

Sustaining Chronic Disease Management in Primary Care: Lessons from a Demonstration Project

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Chronic disease self-management (CDSM) programs have been found effective in improving clinical, behavioural, and self-efficacy outcomes associated with a range of chronic illnesses, and evidence suggests that CDSM is effective in reducing health care costs and health service utilisation. As the setting where most chronic disease is managed, primary health care is an ideal setting for supporting CDSM. This study aimed to explore the uptake and sustainability of CDSM within routine activities of primary health care clinicians involved in the implementation of a demonstration project within an Area Health Service in Sydney NSW. Interviews and focus groups were conducted with managers and clinicians involved in the project. Findings included (1) widespread support from participants for CDSM (2) participating clinicians thought that CDSM was valuable to themselves, their clients and the health system (3) the program required clients to be able to speak and understand English and so presented many barriers for implementation in CALD communities, and (4) the program was not effective in engaging some key members of the primary care team; in particular, general practitioners. The study highlights system design issues including communication and continuity of care between service providers, workforce supply and demands of acute care delivery in the community that will need to be addressed for sustainable and effective CDSM to be achieved.

Key words: Primary health care, Chronic disease self-management, Primary health nurses, Integration, Sustainability, Evaluation

As the population ages, chronic disease management (CDM) becomes an increasing part of the work of the health system. Support for chronic disease self-management (CDSM) is a recognised part of CDM. This involves professionals supporting clients to develop skills in managing long-term health conditions (Lorig, Holman, & Sobel, 1994). CDSM programs have been found effective in improving clinical, behavioural and self-efficacy outcomes associated with asthma, arthritis, and chronic pain (Foster et al., 2003), and diabetes and hypertension (Jordan & Osborne, 2007). Patients with effective self-management skills have enhanced self-care (Jordan & Osborne). CDSM programs can reduce health care costs (Weeks et al., 2003; Foster et al., 2003), health service utilisation (Foster et al.), and have been found effective in both rural, urban, and a number of different cultural settings (Feyer, Francis, Quiqley, Jessop, & Walsh, 2003). A recent systematic review of CDM found that patient self-management support was the most commonly used and most effective intervention for chronic disease care (Zwar et al., 2006).

A review of 145 studies related to self-management approaches for people with chronic conditions (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002), found that the majority of self-management approaches have been undertaken related to asthma, diabetes, and arthritis. The initiatives were delivered usually by health professionals and in a variety of settings (clinical, community, home) utilising group sessions, individualised approaches or a combination of both; the format and content of the approaches varied considerably but most approaches used lectures and a manual.

Most self-management initiatives have been built on theories including social, cognitive, behavioural, and self-efficacy, and have focused on the management of specific conditions (Chodosh et al., 2005). Self-management initiatives have been found to use multiple components such as drug management, symptom management, psychosocial management, lifestyle changes, social support, goal setting, and the provision of information on how to access support services (Barlow et al., 2002). The

CDSM program developed by Lorig and Colleagues in the US is widely accepted (Dongbo et al., 2003), because it provides a generic chronic disease self-management program that can be implemented by lay leaders. This model was developed based on self-efficacy theory and incorporates components such as weekly action plans, behaviour modeling, different management techniques, group problem solving, and individual decision-making through goal setting and support (Dongbo et al.). The Expert Patient Program is a chronic disease self-management program used widely in the UK.

The literature reports only a few CDSM programs modified for use in different cultures. There has been some work in adapting the Lorig Program, which has been found to be effective in improving health behaviours, health status, and self-efficacy (Lorig, Ritter, & Jacquez, 2005) in Spanish-speaking populations, and culturally acceptable in Chinese populations (Dongbo et al., 2003). The Arthritis Self-management Program (ASMP) originally developed in the UK (Wilson, 2001), has been used in many countries (the Netherlands, Australia, Canada) and adapted for Spanish-speaking populations, where it has led to similar improvements in outcomes for pain, self-efficacy and exercise compared to studies undertaken in the other countries (Barlow et al., 2002).

A number of success factors for CDSM support programs implemented in countries where English is the main language spoken have been identified. These include a collaborative approach between clients and clinicians (Norris, Engelgav, Venkat Narayan, 2001), self-management education, clients making behavioural and lifestyle changes, motivation interviewing (Zwar et al., 2006), and engagement of local community networks, particularly for disadvantaged clients (McDonald, 2004). Barriers reported by Australian studies include: cessation of the program if the coordinator leaves, insufficient resources, implementation of the program in the wrong area, insufficient program content, lack of recruitment of patients (Weeks et al., 2003), unclear criteria for patient eligibility, inconvenient schedules for education sessions (Foster, 2003), and lack of affordable transport (Murphy, Saunders, Campbell, Jackson, & Berlowitz, 2003). Harris, Harris, and Roland (2004), also suggest that programs which do not reflect the social attitudes and cultural beliefs of participants

(especially from minority populations) can make initiatives such as CDSM less effective.

Primary health care is an ideal setting for supporting CDSM. It is the setting where most chronic disease is managed. The holistic approach to health care taken by primary health nurses (PHNs) is congruent with the principles of CDSM and their work across multiple settings allows them to recruit, manage, and provide follow-up support to clients (Weeks et al., 2003). General practitioners (GPs) are also highly accessible to patients, and involving them promotes continuity of care (Halcomb & Davidson, 2006).

Consistent support for CDSM in primary health care requires that it be integrated into the work of primary health care and seen by clinicians as part of their normal work (Jordon & Osbourne, 2007). However, this is hard to achieve in fragmented primary health care services that have workforce shortages, staff limitations in their roles and organisation, problems with communication and continuity of care, and use multiple payment systems and inefficient financing arrangements (Swerissen, 2006). Very little research has been undertaken on factors that will support uptake and sustainability of CDSM initiatives within area health services, or their integration into health services (Weeks et al., 2003).

In 2002–03 the Australian Government Department of Health and Ageing implemented the “Sharing Health Care Initiative”, which funded 12 CDSM projects. These projects had discrete funding and were developed and supported locally by an Area Health Service, Division of General Practice, Aboriginal Organisations or the Arthritis Foundation. Each reflected local needs, but all were required by the funding body to include the Stanford University CDSM Program (Lorig Program), the Stages of Change Model and telephone follow-up.

The project that formed the basis of this study had a focus on the interface between patients, PHNs, and GPs and was implemented by an Area Health Service characterised by a diverse ethnic and cultural population. Key elements of this project included patient assessment by PHNs, joint development of a care plan by the patient, their PHN and GPs, referral to locally organised education programs, and telephone follow-up by the PHN. The study aimed to explore the uptake and sustainability of CDSM within routine activities

of primary health care clinicians, to review some of the system challenges facing primary health care in supporting and sustaining CDM.

Method

Qualitative methods were chosen to document the processes and arrangements impacting on the uptake and sustainability of CDSM activities. Data were collected through semi-structured face-to-face (and one phone) interviews and focus groups.

Prior to the interviews and focus groups, participants were given an information sheet and signed a consent form, including consent for sessions to be audio-taped. Ethics approval was gained from the UNSW Ethics Secretariat and the Ethics Committee of the participating Area Health Service.

Participant sampling and recruitment

The project targeted three groups. PHN teams across the local area and selective clinicians working at the local hospital (cardiac rehabilitation) were trained in undertaking patient assessments, care plan development, and the processes around referral of clients to the group education sessions, and follow-up procedures. Four local PHNs were trained in conjunction with a number of community lay persons in implementing the group education sessions based on the Lorig Program.

Hospital clinicians and PHNs who participated in the delivery of the program either through involvement in client assessment, care planning, referral to or implementing the group education sessions were invited to participate in the follow-up study by email, with a follow-up phone call. Those who were not employees of the Area Health Service were excluded as the study was concerned with factors associated with the integration of the CDSM activities into usual (health service) clinical practice. Following recruitment, a member of the research team telephoned each participant and allocated them to either an interview or focus group. It was considered important to include only clinicians in the focus groups and to interview managers separately, to avoid clinicians' censoring their comments in the presence of their manager.

Interviews

Face-to-face interviews were conducted at a time and location convenient to participants. The pro forma consisted of 14 open-ended questions and

the interview took approximately 45 minutes to complete.

Focus groups

The focus groups were conducted at a central location for participants. They were conducted by an experienced facilitator using a pro forma with six open-ended questions. An observer was present to record discussions and group processes. Each focus group ran for approximately 1.5 hours.

Analysis

Audio-tapes were transcribed verbatim and checked by one of the researchers against the notes recorded during the sessions. A line-by-line content analysis was performed, generating a summary of recurring themes and issues. These initial summaries were coded into categories and sub-categories whose names reflected phrases in the data or pre-existing literature. During the coding process, no information was deleted or regarded as irrelevant. The coding framework was reviewed by a second researcher for consistency and divergence of codes. All participants in the study were given a final draft report for comment.

Results

The sample

Four face-to-face interviews were undertaken with managers and a further two (one face-to-face and one telephone) with clinicians who were unable to take part in the focus groups due to work commitments. Two focus groups were held with clinicians—one with 5 PHNs and 2 nurses employed at the hospital (from aged care and cardiac rehabilitation), and one with 3 PHNs, 1 ethnic health worker, 1 aged care nurse and a clinical nurse consultant in pain management.

Two of the original local CDSM coordinators also attended the focus groups.

Most participants had taken part in the in-service education for CDSM and had been involved in client assessment, care plan development and referring patients/clients to the CDSM group education sessions. Most of the clinicians had subsequently moved on to different roles.

The information that emerged from the interviews (largely managers) and the focus groups (clinicians) was broadly congruent across the questions asked.

Three main themes emerged from the study:

- Acceptability and uptake of the CDSM project
- Integration of CDSM into the routine activities of clinicians
- Sustainability.

Acceptability and uptake of the CDSM project

Participants were generally positive about their involvement in the CDSM project. Much of this discussion focused on running the group education sessions based on the Lorig Program.

Factors that were helpful for the education sessions included good internal team support for the project and clinician acceptance of the format and content of the Lorig Program. The group education sessions were well received when the clinicians perceived that they, their clients, and the health service benefited from the group education sessions.

Participants commented that there was a high degree of team support for the CDSM project:

And the team supported, when we ran the groups, we'd pick up our workload for the morning, you'd only have an afternoon workload and that was seen as very appropriate because it was part and parcel of the workload. You were either doing the work or you were doing your clinical load or whatever and the rest of the team supported those of us that were doing it. (Clinician, Focus Group 1)

The structured format of the Lorig Program was found too prescriptive by some clinicians, but most found it useful and helped them deliver the education within a timeframe: "We were supposed to just follow the Program we had to be strict about it, but in a lot of times it actually wasn't appropriate some of the concepts in it" (Clinician, Focus Group 1); "I think the structure was quite good, from our point of view" (Clinician, Focus Group 2).

Clinicians considered that clients gained both health and social benefits from taking part, and reported that they gained confidence and job satisfaction from their involvement. Both managers and clinicians considered that among the main benefits of the education sessions were reduced hospital admissions and reduced number of visits by PHNs:

You find that they manage their symptoms better, they stay out of hospital for longer, they are not bouncing back into hospital because of that big fear

because they have actually have control, they know what to do and they're able to contact their service providers, they're able to make their way through this incredible network that we've created in our hospitals, you know, they know who to phone, they know what steps to take, they've actually got written action plans to follow. (Manager, Interview 1)

One barrier was the narrow selection criteria for clients, which included being able to speak and understand English well. This was a major obstacle to recruiting clients, given the diverse ethnic and cultural mix in the area. Other barriers included a lack of affordable public transport to the education sessions and lack of funding to support activities such as hiring venues, providing transport and acquiring additional client education resources.

Integration of CDSM into the routine activities of clinicians

Overall, participants saw activities associated with the program (e.g., client assessment, care planning, and implementation of group education sessions) as congruent with their roles and with the types of clients they saw, most of whom were elderly, with existing chronic diseases. CDSM was seen as enabling clinicians—in particular PHNs—to provide holistic care to their clients and validating the early intervention and education they provided:

We were able to spend that bit more time in educating them and looking at those aspects of the management holistically, which is basically what we should be doing in primary health care but unfortunately a lot of it tends to go to just an acute kind of service. (Clinician, Focus Group 1)

The main barriers identified for incorporating CDSM into routine work were workforce issues, competing priorities for service delivery, and difficulties with linkages between hospital/community clinicians and GPs. Other barriers included client/clinician acceptability of the philosophy of self-management, difficulty in identifying improved patient health outcomes as a result of participating in the group education sessions, and a sense that health service managers saw CDSM activities as a discrete project rather than as a core component of routine work.

Workforce problems included a high turnover of community health staff and workforce shortages, coupled with difficulties in recruiting nurses. This was seen to increase the workload of community health clinicians, and also to reduce the number of

staff in the health service that had undergone CDSM training, including client assessment/care planning, and running the group education sessions:

It's their knowledge and that goes to the knowledge basis you have to educate people again and try to do that while you're trying to give them a workload and say "come on you've got to get out and see whatever number of clients you have or the day". (Manager, Interview 3).

At the moment we're so short staffed so it's not a good question to ask, we, they wouldn't have the time for, for anyone to be doing it. (Clinician, Interview 4)

Some participants felt that providing acute care was now a higher priority in community health and that this reduced their capacity to support CDSM: "The roles are changing as well, like our role in the community is changing. I've got a lot of acute clients now so therefore you concentrate on acute clients but what about the chronic, you know" (Clinician, Focus Group 2).

Some participants saw poor linkages between hospital/community clinicians and local GPs as reducing continuity of care, increasing the workload for clinicians in finalising care arrangements for patients, and, ultimately, less time for supporting self-management.

One of the [difficulties] of the project is that they didn't manage to link with hospitals as well, continuum care is something that we really, we talk about a lot but we don't actually seem to kind of do too much about... um...our care plans went to GPs but they didn't necessarily go with the clients back into hospital so it wasn't that formalised link. (Clinician, Focus Group 2)

Many participants reported that links with GPs were informal and centred around the development of a care plan for CDSM, with varying opinions on how engaged the GPs were in this. It was noted that GPs have their own care planning systems for which they can receive reimbursement, and that the CDSM care planning was seen as a separate and additional activity. GPs were also seen to be reluctant to become involved in new initiatives that might not be sustained in the longer term.

...like with the GPs are getting frustrated when we say we want you to get involved in this and...they get really wary about working with us and you get really wary about selling something because you turn around and it's changed or pulled completely and you look like a.....and yeah it's just really frustrating. (Clinician, Focus Group 2)

Sustainability of CDSM

Factors identified as making it easier to sustain CDSM as part of routine work included the appointment of a CDSM coordinator, ongoing staff education (particularly including CDSM in staff orientation and in-service education), training for PHNs in running group education sessions (in this project PHNs were trained only in undertaking client assessments and care plans), and feedback to clinicians on the impact the CDSM activities on patient outcomes: "You do require somebody to keep it in the face and keep it going and that, and because we have such a changeover of staff ...um... the girls who were all trained are gone..." (Clinician, Focus Group 2).

One participant suggested that providing comprehensive training to PHNs would enable them to run the group education sessions in their local areas. Other suggestions included broadening the client eligibility criteria, addressing workforce and referral service issues, and finding ways to involve GPs more uniformly in CDSM.

Most participants identified two main barriers to the long-term sustainability of this project. The first related to problems with the license to use the Lorig Program, which led to the ending of patient group education programs. The second concerned the selection criteria for participating in the group education sessions.

These criteria require clients to speak and have an understanding of English. Within such a multi-cultural area, this left a relatively small proportion of clients eligible to take part. After the project had been running for a period of time some participants reported that all their eligible clients had already completed the program. In addition, it was noted that CDSM was yet to be accepted in some cultures and that the content of the education sessions was not always appropriate, even where an interpreter was available: "The concept of self-management is not always received, it's not received in the same manner by different cultures, so obviously there are cultures where self-management is quite alien and a lot of acceptance is needed" (Manager, Interview 2).

Other factors included the lack of local referral services related to CDM and the time-consuming assessment and care planning processes that were often seen to duplicate routine assessments and planning: "One thing that...did highlight about the care plans are the lack of services because we were

doing a whole list of assessments of clients.....” (Clinician, Focus Group 2).

Discussion

This study found widespread clinician support for CDSM among the participants involved in the study and general agreement that components of CDSM including assessment, care planning, follow-up and group education sessions were congruent with the role of clinicians; in particular, PHNs. The results of this study also indicate that: (1) participating clinicians thought that CDSM was valuable to themselves, their clients, and the health system (2) the design of the Lorig Program, which focuses on clients’ ability to speak and understand English, presents many barriers for implementation in culturally and linguistically diverse (CALD) communities, and (3) the program was not effective in engaging key members of the primary care team; in particular, general practitioners.

The CDSM Demonstration Project incorporated many of the components identified in the literature as necessary for such a program, but it also found similar barriers as reported in other Australian studies in insufficient resources and lack of affordable transport. These need to be addressed during the planning stages of future projects. Furthermore, future work needs to investigate the facilitators and barriers to implementing CDSM programs in CALD communities.

The primary health care workers indicated that CDSM education was able to continue informally after the end of the formal program through one-to-one education, provision of information resources, and referral to local services where available. However, there were no further client group education sessions. This is likely to be less effective, as previous research suggests that group education sessions are more effective than individual education (Garrett et al., 2005).

This study provides a case study of the difficulties in transferring a mainstream program into an ethnic and culturally diverse community, and, in particular, the shortcomings of the Lorig Program’s client selection criteria for these populations. The findings suggest that a single mainstream CDSM program may not be appropriate under these circumstances.

Workforce shortages and fragmented care undermined continued implementation of this

CDSM project, and participants reported that post-acute care was increasingly competing for their time. The strategy of using lay peer leaders to run the client education groups has been implemented in the UK (Tyreman, 2005). This would reduce the reliance on the already overtaxed existing PHC workforce and would be especially appropriate for the development of more culturally sensitive CDSM programs (Griffiths et al., 2005). However, the development of such models has been quite limited in Australia, and may be worth further investigation.

An alternate approach might be to deliver comprehensive training to PHNs that includes leader training to implement the group education sessions. This could enable the program to be delivered more locally, reducing transport problems and difficulties with venue hire. Most importantly, further training would strengthen the role and contribution of PHNs to CDM. Provision of a local CDSM facilitator to provide ongoing support would be important for both uptake and sustainability.

There was little evidence of widespread engagement of GPs in the CDSM activities to date; this appeared to lead to some duplication in areas such as care planning and a lost opportunity to enlist the resources of general practice in support of CDSM. Lack of confidence about how long the project would continue was seen as undermining GP commitment. Thus, sustaining CDSM programs is important to engaging GPs in them. It may also be possible to build stakeholder commitment by engaging Divisions and non-government organisations (NGOs) in the program, from planning through to evaluation, and tapping resources from a number of sources to ensure coordinated care and comprehensive chronic disease management.

This study was a qualitative evaluation of the views of clinician participants of one CDSM project implemented within an Area Health Service in Sydney NSW. As such it is unable to demonstrate the impact of the project on the health outcomes or health service use of patients who were recipients of the project activities, including the group education sessions. As a qualitative study, it provides insights into the range of views of staff and the reasons behind these. However, it does not provide quantitative information about how commonly such views were held. Further research

evaluating the impact on health outcomes is needed along with continued monitoring of routine implementation of CDSM by health services.

Conclusion

This study confirms that CDSM is acceptable to primary health care workers and congruent with their values and clinical roles. The most important barrier to uptake by patients was the inflexibility of the program to deal with the needs of different cultural and linguistic groups in the local

population. The study highlights system design issues including communication and continuity of care between service providers, workforce supply and demands of acute care delivery in the community, which will need to be addressed for sustainable and effective CDSM to be achieved. Innovative models with greater involvement of GPs and volunteers should be explored. Future evaluations of such models should aim to assess the impact of the programs on service design and delivery and patient health outcomes.

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