The Sharing HealthCare Initiative: An Evaluation of the Chronic Disease Self-Management

Centre for Work Leisure & Community Research

Arthritis Queensland

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The Queensland team worked within a national framework. Thanks must go to the National Evaluation Team, especially Caitlin Francis, and to the members of project and local evaluation teams across the country. At each meeting, it was so important to share our experiences, build linkages between our projects and learn from each other.

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Beth Hunter & Elizabeth Kendall
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Key Points: Recruitment and Participation
Key Points: Satisfaction

- Satisfaction with the course expressed at the final session was extremely high in all areas. The simplicity and relevance of the course were its most valued characteristics.

- A common point of dissatisfaction was the lack of follow-up.

- Leaders were respected for their kindness, openness, generosity and personality. However, it was noted that leaders were not available beyond the course. Leaders also acknowledged that providing such ongoing support was not possible.

- When participants were dissatisfied with leaders, it was usually in relation to the delivery of the content. In these instances, participants complained of ill-prepared leaders, unprofessional materials, lack of presentation skills and difficulties hearing Leaders or seeing their charts.

- For inexperienced leaders, participants were more satisfied if they were in a larger course, whereas in those with at least one experienced leader, larger course size was dissatisfying. Perhaps the inexperience of the leader was offset by the enhanced interaction in a large group.

- The group process was confronting for some participants and required strong facilitation. When group dynamics were negative or even just unmotivated, the participants were dissatisfied that their own achievements were jeopardized.

- Shared learning emerged as an important factor – although skill training was valued, it was the learning that occurred as a result of mixing with others and sharing their experiences that was crucial.

- Lay leaders were crucial to the success of the groups – many participants noted that leaders did not need to be professionals to be good leaders, but that lay leaders also provided empathy and sound suggestions based in experience.

- The ability of leaders to model the self-management processes, even if only in maintaining their goals during the delivery of the course, was seen as important to the credibility of the course.

- A strong message was the need to remove the American flavour of the course and the materials, as this was distracting.
### Key Points: Outcomes

- Few health outcomes changed significantly over time as a result of the CDSM.

- Positive changes were found in level of aerobic activity, concern about symptoms and coping. Participants’ lives became less stressful, more meaningful and more organized and they perceived themselves as being more supported.

- The CDSM appeared to influence health outcomes and behaviours through cognitive variables such as perceived stress, organization and coping.

- Health service utilisation declined over the duration of the course, but also appeared to be associated with improvements in cognitive variables, such as perceived stress, organization and coping.

- There was evidence that the rate of usage may not be the most important change. Participants’ ability to make more efficient use of their healthcare provider was seen as a valuable outcome.

- Intrusiveness of illness increased after the course, perhaps as a result of the awareness of symptoms and the acceptance of illness that accompanied the course.

- Few outcomes were sustained beyond the 6-month follow-up period other than for those participants who engaged in an ongoing support group. The support group participants reported better health, less concern about symptoms, better coping, more confidence and more progress at 12-month follow-up.

- There was evidence that rural participants were already more independent in their healthcare and well supported in their community. This may suggest that the course should focus on different factors for this group but further investigation is necessary.

- There was also some evidence that men differed systematically from women in terms of their self-report ratings of health status. Given the low levels of participation for men, there is clearly a need to modify the CDSM for this population. More investigation is needed.
Key Points: Sustainability

- Most participants saw a place for the CDSM in the current health continuum but also believed that self-management also needed to be integrated into the education system.

- The greatest barrier to sustainability was thought to be the rigidity of ingrained beliefs about healthcare, in particular the domination of the medical model.

- The General Practitioner was seen as a gatekeeper to the success of the course, both in terms of its credibility and referrals. Given this vital role, they were considered to be lacking in information about self-management and CDSM.

- Apprehension among health providers was seen as a subtle yet pervasive barrier – the concept of lay leaders and expert patients was considered threatening for some health professionals.

- For some consumers, self-management was a foreign notion, leading to lack of interest unless referred by a GP and/or creating uneasiness about the changing nature of relationships with health care providers.

- There was also some cynicism about the motives of the CDSM, namely as a cost-reduction tool that would not really benefit people with chronic conditions, or that these benefits were serendipitous.

- The current level of enthusiasm and support for CDSM (for whatever reason) was seen as a positive feature of the system on which sustainability could be built.

- There was a critical need to strengthen the referral base and educate health professionals about self-management.

- The powerful role of funding was acknowledged – the likelihood of the course being adopted was dependent on the financial incentives for organisations and professionals.

- Without consistent follow-up for course participants, there was a risk that the course would be seen as a temporary solution and eventually not supported.

- Recruiting, maintaining and accrediting a quality network of leaders was a significant difficulty encountered in this study.

- Sustainability in rural and indigenous communities emerged as a special issue that requires further investigation.
Research Questions

In accordance with the National Evaluation Framework, the following hypotheses and research questions were addressed. Each of these questions has been examined separately in this report, using both quantitative and qualitative data.

Hypotheses

1. That the CDSM program will improve:
   (a) health-related quality of life for people with chronic diseases, particularly those with co-morbidities;
   (b) carer/family/significant other’s perceptions and experiences of the health-related quality of life for people with chronic diseases and,
2. That the CDSM program will help facilitate improvements in awareness and understanding about the benefits of self-management among health service providers and, consequently, behaviour changes as well as improving communication between GPs, people with chronic conditions and their families, and other health professionals.
3. That the CDSM program will result in more appropriate use of health services.

Specific Evaluation Questions addressed by the Queensland Project

1. Recruitment and Participation:
   (a) Which recruitment strategies are most successful in recruiting which groups of clients to the CDSM?
   (b) Which clients/groups of clients are most likely to participate in the CDSM?
   (c) What other factors influence participation rates and in which direction?

2. Outcomes for Clients:
   (a) How and by how much does the CDSM influence the health behaviours and health outcomes of clients?
   (b) What are the issues associated with client support and follow-up?

3. Satisfaction
   (a) What is the level of client satisfaction associated with the CDSM?
   (b) What factors influence satisfaction with the CDSM?

4. Sustainability of the Program:
   (a) What factors affect the sustainability of the CDSM?
Overview and Background

The prevalence of chronic diseases and the associated burgeoning health care expenditure is a significant public health concern globally (WHO, 2000; AIHW, 2002). In Australia, around 80% of the burden of disease is attributable to chronic conditions (AIHW, 2002). Although conditions such as arthritis, asthma, diabetes, stroke and depression contribute significantly to this burden, there are wide disparities across socio-economic and cultural groups, with the majority of the burden being felt in lower socio-economic groups and indigenous populations (AIHW, 2002). While chronic diseases occur across all ages, a major factor escalating the current burden in most developed countries is an aging population (Michaels Miller & Iris, 2002). A rapidly aging population combined with greater life expectancies in most developed countries has resulted in chronic disease among older adults becoming a focus of health promotion and prevention strategies (Bonomi, Wagner, Glasgow, & Von Korff, 2002). As in other countries, the ageing population contributes substantially to the increase in chronic diseases. With the population aged 65 years and over expected to increase to 16% by the year 2016 (AIHW, 1999), chronic disease among older adults is now a national health priority.

The CDSM was developed in response to the demand for viable, cost-effective solutions to the growing public health threat posed by chronic illnesses in the USA (Lorig, 1996). Research conducted in Australia has shown that the CDSM course may represent an appropriate method of addressing gaps in the healthcare and rehabilitation process and encouraging self-management of chronic conditions (Catalano et al., 2003). Self-management involves a shift in the traditional role of clients, from one of passivity and compliance with professional treatment regimes, to one of active partnership with their healthcare team and daily management of their own condition (Lorig, Sobel, et al., 2001). The basic premise of the CDSM is the facilitation of personal resources such as enhanced confidence and self-efficacy, goal-setting, problem-solving and decision-making skills, delivered within a milieu of peer support (Lorig, Ritter, et al., 2001). According to the CDSM framework, as individuals gain mastery over the skills to manage their life with a chronic condition, their sense of control and self-efficacy increases, and hence quality of life is improved (Lorig, Sobel, et al., 1999; Lorig, Sobel, et al., 2001; Nodhturft, et al., 2000).

For older people facing the challenge of chronic conditions, self-management education programs have become an integral part of secondary prevention measures. Self-management is argued to be the basis for improving well-being, strengthening self-determination and participation in health care (Bodenheimer, Lorig, Holman, & Grumbach, 2002; Lorig, Sobel, Ritter, Laurent, & Hobbs, 2001) and maintaining quality of life among older people with chronic disease (Michaels Miller & Iris, 2002; Wagner et al. 1996). Thus, encouraging self-management of chronic conditions among older adults has become a key component of the Enhanced Primary Care (EPC) initiative announced by the Australian Government in 1999.

The Enhanced Primary Care (EPC) initiative allocated funds for the development and evaluation of chronic disease service delivery models throughout Australia. The demonstration project in Queensland sought primarily to enhance self-management skills among older adults with chronic conditions by engaging them in the chronic disease self-management (CDSM) course (Lorig et al., 1996). This course involves a small group education process (usually 10-15 participants), conducted for two hours each week for six weeks. Programs are delivered in community settings and facilitated by two trained leaders, one of whom is often a lay leader who has experienced a chronic disease.
The Evaluation

The main purpose of the demonstration projects was to add to the evidence-base for the CDSM. Thus, this project is an evaluation of the outcomes of CDSM as well as an investigation of relevant process variables (i.e., marketing, methods of delivery, participation and so forth) that contribute to or influence these outcomes. In relation to outcomes, the CDSM was expected to be associated with positive health outcomes, health behaviours and service utilisation patterns for older people with chronic conditions. However, in terms of process variables, the project aimed to elucidate the factors that contributed to or hindered the accessibility of the program and the best methods for recruiting people with chronic conditions. In Queensland, the project also aimed to investigate the different outcomes and processes across urban and rural regions. Finally, the project aimed to comment on the sustainability of the CDSM approach within the current health and rehabilitation system in Queensland.

The Role of the Local Evaluators

1) Review current methodology to ensure that the designated evaluation questions can be answered effectively and meaningfully through the proposed methodology;
2) Liaise with the National Evaluator in relation to data requirements;
3) Refine the data collection tools, particularly the qualitative interview questions;
4) Ensure the validity and reliability of the quantitative measures;
5) Overview the process of data collection to ensure that data is clean and appropriate;
6) Ensure sampling process is unbiased and attrition can be minimized and analyzed;
7) Guide analysis and interpretation of qualitative data in response to research questions;
8) Guide the statistical analyses of quantitative data in response to research questions;
9) Contribute to the preparation of reports and publications.

The Context of the Local Evaluation

The Centre for Work Leisure and Community Research at Griffith University was established to consolidate knowledge about change and human needs within and across each of three key life domains - work, leisure and community. The Centre unites over 50 researchers who espouse similar underlying philosophies, such as the promotion of social justice and quality of life and the meaningful transfer of knowledge to policy and practice. The Centre also brings together multi-disciplinary expertise to address social and health issues. Most importantly, the Centre represents a synergy of research frameworks and domains that impact on our knowledge and its application to health and social services. Within this broader Centre, the Health, Safety and Well-being Research Program focuses on the continuum of health and well-being, across the work, leisure and community contexts. The purpose of the research stream is to design, examine and evaluate strategies that promote well-being and prevent injury, illness or disadvantage.
Project Design

The Queensland project was a longitudinal examination of the CDSM, conducted as part of the National evaluation of the EPC Initiative. Demonstration projects were established in each State, and each differed at several critical design points. The critical decision points at which projects could differ included the selection of a target group, the methods used to raise awareness and recruit participants, the type of intervention or service delivery, the nature of support and follow-up provided. In terms of defining, manipulating or holding constant these critical design variables, the following decisions were made in relation to the Queensland demonstration project.

Target population

Following the comprehensive media and awareness-raising campaign, participants were recruited through one of four possible referral pathways: (1) self-referral; (2) referral by a health professional; (3) referral by another advocate (e.g. relative or friend) or (4) recommendation by an existing course participant. When participants made first contact with the project team, they were asked to nominate their referral source or where they had heard of the course.

The eligibility criteria that was widely advertised included:
- Aged 50 years and over (35 years for Indigenous Australians)
- Residence in, or attendance at a general medical practitioner in the designated geographical areas (Brisbane North District or Southern Downs District).
- Diagnosed with one or more of the following conditions: arthritis, diabetes, cardiovascular disease (including stroke and hypertension), respiratory disorders, osteoporosis, or depression.

The target group was recruited from two regions, one metropolitan and one rural. The rural district, Southern Downs, included a number of small towns, Warwick, Killarney, Pittsworth, Inglewood, Texas, Stanthorpe, Milmerran and Goondiwindi. The district contains 6 small hospitals, an aged care facility and 5 nursing homes. The estimated population of the region is 58389, with 31.1% being over 50 years of age. Indigenous people constitute 3.1% of the population and 7.1% are non-English speaking. In 2003, 682 inpatient episodes of care at the District hospitals involved age-related conditions (1.16 % of the population).
The metropolitan district covered the area from inner north Brisbane city and western suburbs to the outer northern areas of Pine Rivers. This region was extremely well resourced, with several major hospitals, multiple rehabilitation units, community health and community services. The estimated population of the district was 552,204, with 27.2% being over 50 years of age. Indigenous people constituted only 1.2% of the population and 7.5% were non-English speaking. As a comparison, 2,559 inpatient episodes during 2003 involved age-related conditions (only 0.46% of the population).

**Awareness, and marketing**

Focus groups and piloting were used to develop the most effective materials to promote the CDSM and an intensive marketing campaign was implemented prior to the conduct of the project. The marketing materials were developed in conjunction with an external marketing agency. The photographic material and logo were designed to represent the principles of partnerships, warmth and growth. Project letterhead, brochure, and website were produced, together with an 8 and 2.5 minute video (including footage of participants’ testimonials, courses in progress, exercise information and general course details) was produced to market the course to a variety of audiences. As would be expected, the video incurred the greatest production cost (approximately $25000). The poster and brochure cost approximately $11000. Additional materials such as referral pads, folders and fax-back referral sheets cost approximately $10000. Mass media was not considered to be an appropriate method of marketing given the inability to contain its impact to the project regions.

After the materials were developed, the course was widely marketed in the two target districts using a range of strategies to reach as many participants as possible. The campaign targeted both health professionals and the public and comprised two key components.

- A social marketing campaign targeting existing social, health and education groups frequented by older adults, service clubs, aged care facilities and city councils, using a range of print media and presentations. Purpose: to cultivate a social milieu in which self-management of chronic illness was more acceptable.
- Dissemination of evidence about the efficacy of self-management to health professionals including GPs, community care providers, allied health professionals and other private practitioners, largely through presentations and workshops. Purpose: to ensure that health professionals and organizations supported and understood self-management.

Intensive marketing occurred during the pilot period (November, 2001 to June, 2002), beginning with the official launch, but continued throughout the project until December, 2003. Both marketing campaigns involved a comprehensive range of strategies. These strategies all relied on the range of marketing materials, but could be classified broadly into:

- **Organisational networks** (e.g., forming strong supportive links with other health-related agencies and health providers to promote/support the course, develop infrastructure for the future, and facilitate referrals);
- **Health provider promotions** (e.g., advertising in professional newsletters, mail outs to GPs and health providers to attract referrals and leaders);
- **General community awareness** (e.g., presentations, newsletters/magazines, GP surgeries to attract referrals);
- **Group marketing** (e.g., presentations designed for members of relevant community groups, nursing homes, leisure groups to attract self-referrals and/or carer referrals).
During the project, 5156 people were contacted by mailouts (1479 GPs or Health professionals and the remainder consumers), 58 newspaper or magazine articles were produced, approximately 1470 consumers and 730 health professionals attended presentations. Organisational networks were maintained with 17 major organizations, including Department of Veterans Affairs, CRS, Diabetes Queensland, Heart Foundation, Wesley Healthwise, MBF, University treatment hospitals, St. Lukes, Blue Care and Ozcare, Community Health, Divisions of General Practice and Arthritis Queensland. These organizations contributed to referrals, recruitment of leaders, public awareness, and health provider awareness to varying levels.

The ongoing cost of major marketing strategies (i.e., excluding the initial cost of developing the marketing materials) can be estimated by calculating expenses such as staff time, postage, reproduction of materials and travel. Although only guidelines, these estimates provided a reasonably reliable indication of the cost according to project records. The table below shows the costs of mailouts, advertisements and presentations, as these activities formed the basis of most marketing strategies used in this project.

<table>
<thead>
<tr>
<th>Mailouts to memberships</th>
<th>Newsletters/ Newpapers</th>
<th>Presentations to Referrers</th>
<th>Presentations to Consumers</th>
</tr>
</thead>
<tbody>
<tr>
<td>$45 per letter incl. Postage – NB. Size of most mailouts exceeded 100</td>
<td>$450 per advertisement (variable cost - glossy advertisements most expensive, editorials least)</td>
<td>$180 per group of 10</td>
<td>$90 per group of 10</td>
</tr>
</tbody>
</table>

Using these costings, the total estimated cost for mailouts during the course of the project was approximately $232,000. Newspapers and magazine advertisements cost a total estimated amount of $26,000. Presentations to consumers cost an estimated amount of $13,000 and presentations to health professionals, organizations and community groups also cost an estimated amount of $13,000.

**Recruitment**

Following the comprehensive media and awareness-raising campaign, participants were recruited through one of four possible referral pathways: (1) self-referral; (2) referral by a health professional; (3) referral by another advocate (e.g. relative or friend) or (4) recommendation by an existing course participant. At the time of first enquiry, participants were asked to nominate how they heard about the CDSM or how they came to make the enquiry.

**Intervention**

Although there are many methods of facilitating self-management, the Queensland project selected the Stanford CDSM course delivered in a group format over a six-week period, run by both professional and lay leaders. Seventeen CDSM courses (14 in Brisbane North and 3 in Southern Downs) were conducted during the pilot period (January to June 2002) prior to the beginning of a National evaluation of the Sharing Healthcare initiative. Data for the National Evaluation were collected during the project period from July 2002 to December, 2003. During this period, 52 courses were conducted and completed (44 in Brisbane North and 8 in Southern Downs). The courses from which data were gathered were conducted with
between 5 and 15 participants, averaging 8.9 (SD=2.46). Median attendance was 9 participants. Rural courses tended to be slightly larger (X=10.6, SD=2.42) than urban courses (X=9.3, SD=2.52; t(378) = -3.31, p<.001). If asked by participants, nominated companions could also participate in the course. Seventy-two companions attended.

In most courses, a health professional and lay leader combination was used. However, 14 courses were delivered by two health professionals and the primary leader was usually a health professional (45 courses). Although an attempt was made to ensure that less experienced leaders were teamed with experienced leaders, this was not always possible. In seven courses, less experienced leaders ran a course together.

Arthritis Queensland is the only organization in Queensland licensed to train Stanford CDSM leaders and, in the last 18 months, has trained 233 leaders throughout the State. Given the importance of CDSM leaders to the success of the course, it was necessary to establish a large leader pool prior to the beginning of the project and during the pilot phase. This recruitment campaign followed four major steps.

- Existing leaders who had been trained in the delivery of similar courses were contacted and, after undertaking a bridging course, were engaged in the project;
- Health professionals were approached through Community Health and other organizations. Leaders were also targeted during general project activities;
- Leaders were asked to identify course participants who could be approached to become Lay Leaders – each course usually produced 1 to 2 potential leaders;
- Leadership was promoted directly in courses during the later part of the project.

In Queensland, all leaders were required to attend a four-day workshop. The workshop was standardized according to a leaders’ manual. On completion, leaders were rated by the Master Trainers and as either a) ready to conduct a course, b) require further training and practice or c) not suitable to be a course leader. Leaders are expected to attend an update session after their second course, but no other requirements are placed on them to engage in ongoing training. During the project, 77 leaders were trained through 8 workshops (50 health professionals and 27 lay leaders). Of these leaders, 20 health professionals and 6 lay leaders were located in Southern Downs.
Support and follow-up

There are also many ways of supporting clients after the completion of the CDSM course but the Queensland project elected to simply observe and document the natural development of support groups without providing deliberate project input. However, project staff assisted groups once they identified a need by providing advice and support and developing a framework for the establishment and growth of groups over time. Of those who participated in a CDSM course, 44 were involved in some form of long-term follow-up after their course. Two support groups emerged among suburban participants. One inner suburban group consisted of 22 members who met regularly and produced a newsletter. Another 16 participants met regularly, but retained an informal structure. Finally, six participants from a rural area met on three occasions following their course and considered these meetings to constitute a support group.

Although other support networks may have emerged undetected, this was unlikely given the ongoing contact between participants and the project team. Only 26 of these 44 participants were also in the research study. For this group, statistical comparisons were conducted to determine whether or not they differed from the general participants in terms of outcomes.
Data Collection Procedure

To investigate participation patterns, an attempt was made to access five groups of older adults with chronic conditions.
1. Non-Contactors: Those who were eligible for the CDSM and had been exposed to marketing in some form, but had elected not to make contact.
2. Non-Enrollers: Those who inquired about the CDSM or expressed an interest but did not enroll in a course.
3. Non-Attendees: Those who enrolled in a CDSM course but did not attend;
4. Non-Completers: Those who attended less than four of the six CDSM sessions;
5. Completers: Those who attended four or more of the six sessions.

At the time of enquiry, demographic information was collected for all potential participants via telephone. If participants failed to express any further interest in CDSM (non-enrollers), they were asked to respond to a telephone non-participation survey or at least offer reasons for their non-interest. Those who expressed interest in the course were sent information and details of course locations/times and were regularly sent updated information about available courses if they failed to enroll. If participants subsequently decided to enroll in a CDSM course, they were mailed the initial survey, together with details of courses and a course confirmation form. Participants enrolled in and attended the next-available and convenient six-week CDSM course according to their time and location preferences. Those who consented to be involved in the research completed a survey prior to the CDSM course, and again at 6, 12 and 15 months post-completion of the course, providing four data collection intervals. The battery consisted of standard demographic data and illness descriptions, the Stanford Scales measuring Health Status, Self Efficacy, Services Usage and the Kessler 10 measure of psychosocial distress.

In addition to this battery of outcome measures, research participants completed the Personal Projects Survey (PPS) at the beginning of three course sessions (first, third and sixth sessions). By collecting this short five-item data at each course session, it was possible to tap the subtle changes that occur as the course developed. The survey was also administered at the 6 month and 12 month follow-up period. The PPS is based on theory about the dimensions with which people explain their lives and the activities or issues they are managing within that life. The five dimensions include meaningfulness, structure, community, progress and stress.

At completion of the course, participants completed a feedback and satisfaction survey. The questions in the survey addressed three areas of evaluation: the participants’ experience of the course, their perceptions of the course leader’s suitability and their experience of the course administration and management. These questions were answered in the format of a five-point likert scale ranging from ‘Strongly agree’ to ‘Strongly disagree’, and were supplemented by an open-ended comment section if participants wished to offer further information.

For each course, process data was collected, including attendance records for each session, details regarding the location of each course, the names of leaders, their status (i.e., health professional or lay leader), their level of experience and number of courses they had previously run. Any unusual circumstances that affected that course were noted, including any changes of leaders, venue changes or cancellations.
Those who enrolled in a course but did not attend (non-attendees) and those who did not complete their course (non-completers) were contacted by telephone after completion of the course in which they were enrolled. At this time, they were asked to complete the telephone non-participation survey. During this survey, respondents were asked to comment generally about their reasons for not participating in the CDSM course at this time. They were able to nominate more than one reason. Non-participation comments were recorded verbatim.

Finally, six focus groups were conducted to examine attitudes, perceptions, knowledge and behaviours in relation to the CDSM following participation (or non-participation) in the CDSM course. Four groups were conducted with people who had participated in the CDSM program (three rural and three urban). The rural focus groups were conducted with the same participants at three different times (following completion of their course (September, 2002), six months later (April, 2003) and twelve months later (October, 2003). The urban focus groups consisted of a mix of participants at different stages post-course, but were conducted at the same time intervals. The remaining three focus groups were conducted with members of community or health organizations, lay leaders and people with chronic conditions who had attended a project presentation, but had not enrolled in the CDSM.

The focus groups were audio-recorded, transcribed verbatim and coded by two researchers who had also run the groups. Initially, units of text were coded into four broad categories that corresponded to the research questions, namely participation/recruitment, outcomes, satisfaction and sustainability issues. Each category was then re-coded in terms of the major ideas that were present in the data. The ideas in each category were then re-examined by an independent coder to determine the extent to which the same coding structure was apparent to another person. In reporting the themes in the data, direct quotes have been replicated using a coding system to enable identification of the source.

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**Initial Data Collection from all Inquiries and Referrals**
Demographics, source of referral/awareness, information on course

- **Enroll**
  - Non-Enrollers
    - Non-participation Survey
  - Non-Attendees
    - Non-participation Survey

- **Non-Contactors**
  - Focus Group

- **SIX WEEK CDSM COURSE**
  - Baseline, 6, 12 & 15 mth: Questionnaire; PPS (+ Wks 1, 3, 6); Wks 1-6: Attendance register, Wk 6: Satisfaction/feedback survey

- **Non-Completers (<4 sessions)**
  - Questionnaire; PPS; Non-participation

- **Completers (4-6 sessions)**
  - Questionnaire; PPS at 6, 12 and 15 mths post course

- **Focus Group**

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Methodological Comments

Of the participants who enrolled in a CDSM course, only 406 provided outcome data at baseline (prior to the CDSM). Attrition in the research was significant, with only 186 participants (23.6% male) remaining in the study at time 2 (6 months follow-up). At time 3 (12 months), only 72 participants remained (19.4% male), and by time 4, 45 participants remained (17.8% male). The size of this attrition is misleading, however, given that participants who completed the course after June, 2002 or beyond were recorded as missing for times 2, 3 and 4. This data continues to be collected. Nevertheless, the loss of participants from times 1 to 2 was high and could not be attributed to anything other than attrition. Only 46% of participants remained in the study between these two time points.

None of the outcome or demographic variables predicted later missing data. However, a derivative variable was constructed by counting the number of items coded “not applicable” in the Illness Intrusiveness scale. This measure predicted later attrition in the research (OR=1.171, 95% CI=1.032 to 1.330, p=.05 with 53.3% concordance and 13.9% ties), a finding that indicates participants who perceived the questionnaire items to be irrelevant to their lives were less likely to continue in the study.

During the study, many comments were made regarding satisfaction with the research process that could account for this attrition rate. Several participants nominated their unwillingness to participate in the research as their reason for dropping out of the course. Although participants were advised that their participation in the research was voluntary and would not affect their involvement in the course, the prospect of research was too daunting.

There were significant difficulties associated with engaging particular people in the CDSM. Unfortunately, participation in the research was influenced by the same factors that influenced participation in the CDSM. Accordingly, the study was unable to shed any light on the outcomes for those who did not enquire about or enroll in the CDSM. As a result, only limited conclusions can be drawn about the impact of the CDSM. A small group (n=24) elected not to participate in the CDSM course, but continued their involvement in the research and, therefore, provided some opportunity for a useful comparison. Full datasets were only available for 15 of these participants at baseline and only 8 provided data at the six-month follow-up. None participated beyond that point in time. A pseudo-experimental design was constructed, using 15 non-attendees and 30 completers who were matched to the non-enrollers on basic demographic variables. This analysis failed to show any significant differences between the groups on the outcome variables, suggesting no detectable effect of the CDSM. It was possible that a small effect was present but was not detected due either to low power, non-random attrition or some combination of both factors.

The absence of a true control group limited the findings of the current study (i.e., a sample that was matched to the participants, but was not offered the opportunity to enroll in the course). Without this control sample, it was difficult to conclude whether or not the CDSM accounted for any change that was observed, or whether the absence of change on some variables could actually represent the prevention of a deterioration that would be expected without the intervention.
### Themes in the Qualitative Data about the Questionnaire

<table>
<thead>
<tr>
<th><strong>Enlightening</strong></th>
<th>For several participants, and possibly many who elected not to be involved in the study, the questionnaire was seen as a threat to their well-being and a source of stress.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>“I hated that first questionnaire that we had to answer. I nearly didn’t come back after that” (U1, p. 4). One participant clearly articulated how distressing it was to answer the study’s survey questions pertaining to her abilities and her health.</td>
</tr>
<tr>
<td></td>
<td>“I didn’t know how sick I was until I filled in that stupid questionnaire. And I found that all the things that I couldn’t do and I hated acknowledging them. Whereas I was always concentrating on what I could do and having to write down what I couldn’t do, it was dreadful, it was dreadful. I mean the lady over the road, she said ‘Oh yes how you are going, how was that course you were going to do?’, and I burst into tears, I was so distressed over the stupid questionnaire” (U1, p.5).</td>
</tr>
<tr>
<td><strong>Useful</strong></td>
<td>In contrast, some participants found the process of responding to the survey useful as it helped them to identify areas that required improvement.</td>
</tr>
<tr>
<td></td>
<td>“I thought it was quite good because it made you aware of, it made me realise what things you had difficulty with….I thought it was quite good…[that process] Helps you to improve” (U1, p. 5).</td>
</tr>
<tr>
<td></td>
<td>“Actually filling in forms which came through the mail and posting them back, that’s a type of support as well. Somebody is still interested” (U2, p. 24).</td>
</tr>
<tr>
<td><strong>Benign</strong></td>
<td>A number of participants in the group stated that they had no problem with the questionnaire but understood how it could be a difficult process for individuals who may not have faced up to their problems.</td>
</tr>
<tr>
<td></td>
<td>“I think it is just a matter of whether you have ever faced up to the problem and if you truly went under the carpet, you really don’t want to get it out and analyse it” (U1, p. 7).</td>
</tr>
<tr>
<td><strong>Limiting</strong></td>
<td>Many participants felt that the questionnaires missed a lot of information and that more information could be gathered from other types of measures.</td>
</tr>
<tr>
<td></td>
<td>“Cause I quite often find with various surveys, they’re so narrow. And because they are so narrow, they miss out on so much other information that could be valuable”. (U2, p.2)</td>
</tr>
<tr>
<td></td>
<td>“I know we do with the questionnaire but I feel that face to face is, I’d think you’d find that there’s a lot of difference. I can tick off there what I feel is for myself, but also when you come around the table and you’re discussing I think you need to be a little broader about it” (R3, p. 9).</td>
</tr>
</tbody>
</table>

Interestingly, the focus groups received no criticism and were seen as a positive activity. Indeed, for many participants, the focus groups highlighted the need for follow-up and support groups after the CDSM. Focus group participants were selected randomly by the project team.
During the project period, 1038 official enquiries were received about the course (224 males and 814 females). The enquiries came from a range of age groups, with 18% aged younger than 50 years, 22.6% aged between 50 and 60 years, 24.9% aged between 60 and 70 years and 34.5% aged over 70 years. The primary condition in 45% of these cases was arthritis, with 9.1% reporting osteoporosis. Only 10% reported a cardiovascular condition (i.e., heart condition or stroke), 7.9% respiratory and 7% diabetes. Depression was reported as the primary condition for only 1.5% of the population. Primary condition was unknown for 20% of the enquiries, but this group represented a combination of those for whom the enquiry was inappropriate, they were not contactable after making the initial enquiry or wanted no further information and did not wish to provide their details. In a small number of cases, this data was missing as a result of inaccurate data collection.

Data gathered at the time of first enquiry indicated that while 9.3% (n=58) could not nominate the source of their knowledge about the CDSM, 37.9% percent of those who enquired had been actively referred by a health professional or health organization (n= 239). The most common source of referral was community health (16.3%), with GPs and Health Professionals referring 10% and 11.6% respectively. Word of mouth encouraged 49 people to enquire about the CDSM (7.8%), with higher numbers (6.2% versus 1.6%) reporting friends as the source. Referrals from mailouts constituted 23.5% of the sample. Magazines and newspapers brought 6.5% of enquiries and brochures, posters or video displays were associated with 5.1% of enquiries. The website was negligible in terms of influence on the frequency of enquiries.

<table>
<thead>
<tr>
<th>Source of Referral</th>
<th>Percentage of Enquiries</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unknown or missing</td>
<td>9.3%</td>
</tr>
<tr>
<td>Website</td>
<td>.3%</td>
</tr>
<tr>
<td>Brochure, Poster or Video display</td>
<td>5.1%</td>
</tr>
<tr>
<td>Magazine and Newspaper</td>
<td>6.5%</td>
</tr>
<tr>
<td>Organizational referral</td>
<td>7.5%</td>
</tr>
<tr>
<td>Family and Friends</td>
<td>7.8%</td>
</tr>
<tr>
<td>Presentation to Consumers</td>
<td>9.7%</td>
</tr>
<tr>
<td>Referred by General Practitioners including specialists</td>
<td>10%</td>
</tr>
<tr>
<td>Referred by other Health Professional</td>
<td>11.6%</td>
</tr>
<tr>
<td>Referred by Community Nurse</td>
<td>16.3%</td>
</tr>
<tr>
<td>Mail outs</td>
<td>23.5%</td>
</tr>
</tbody>
</table>

These figures may be slightly misleading in that many people were exposed to several aspects of the marketing campaign. Although they nominated a particular source of awareness, this material may only have come to their attention through another aspect of the overall strategy (e.g., a brochure received in a mailout, a poster that was displayed as a result of a presentation, a newspaper advertisement that prompted a friend to advise the consumer about CDSM). With consideration to this qualification, rough estimates can be made about the relative effectiveness of each strategy if activity levels and costs are plotted against enquiries.
The number of mailouts, newsletters and presentations conducted in each quarter, the cost of marketing activity each quarter and the total enquiries received during the same period are plotted against each other in the figures below. Giving consideration to the fact that there would be a time lag between activity and response, the enquiries received during each quarter are plotted below against mailout activity, presentation activity, news advertisements and the total cost of marketing activities. These figures show that there were slight trends for mailout activity to correspond with enquiries as would be expected. There was also a trend for the pattern of health professional seminars to correspond with enquiries and for the overall expenditure on marketing to yield returns.

![Enquiries and Mailout Activity per Quarter](image1)

![Enquiries and Presentations per Quarter](image2)
When the enquiries received were categorized according to referral source, there was concordance between the activities and the source of referral. Details of enquiry by quarter?

The return rate for each type of marketing activity per quarter is shown in the table below. This table shows that the greatest details.
<table>
<thead>
<tr>
<th>Marketing Method</th>
<th>Enquiries Attracted</th>
<th>Total Cost</th>
<th>Effectiveness Ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td>Posters, video and/or brochure presumably seen in a GP surgery, community group or organization as a result of a mailout to these providers OR Referred directly by providers either as a result of mailout to provider or following a presentation to providers.</td>
<td>32 saw a brochure/poster 73 referred by a health professional 63 referred by GPs or specialists 103 referred by community health 47 referred by a community group or organization TOTAL: 318</td>
<td>Cost IF materials mailed to GP, HP, community group or organization @ $45/person – estimated total cost for project $102,000 Cost IF delivered by presentation $180 per group – total estimated cost during project $13,000</td>
<td>$320.75 per enquiry</td>
</tr>
<tr>
<td>Mailouts to consumers</td>
<td>178 received a letter 62 heard from another consumer or friend/family</td>
<td>Cost of $45/person – total estimated cost during project - 70% of $340000 = $238,000)</td>
<td>$40.88 per enquiry</td>
</tr>
<tr>
<td>Newspaper articles and Magazines ($450/article maximum – total cost over course of project $26000)</td>
<td>47 saw a newsletter or magazine article</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Website</td>
<td>2 people found the website</td>
<td></td>
<td>0.7</td>
</tr>
</tbody>
</table>

This finding suggests that even though they resulted in the largest absolute number of enquiries, mailouts to consumers were the most expensive form of marketing. However, it is important to note that early mailouts conducted during this project were not as useful as they could have been. Following experience, mailouts became more targeted and associated with local districts and specific courses. Thus, the true success of this method may be obscured. Further, in future, mailouts about courses may become routine aspects of community group or GP practice activity, thus dispersing the cost beyond any single organisation.

The cost-to-response ratio for newspaper advertisements was $553.19 per enquiry, although this cost would reduce considerably over time because materials and stories are readily available and marketing campaigns are likely to become more localized. Similar to the mailouts, early newspaper and magazine activity was less targeted than it could have been.
Mailouts or presentations to health providers, health organizations and community groups yielded a cost-to-response rate ranging from $52.16 to $67.04 per enquiry, assuming that the mailout resulted in a display of brochures or posters that attracted consumers. However, it is likely that this activity also contributed to the 314 enquiries that were direct referrals from health professionals, increasing the response rate considerably. Consequently, this activity (i.e., mailouts and presentations to health professionals, organizations and community groups) appeared to be the most cost effective method of recruitment. Website lead to negligible enquiries.

Importantly, enrollers and non-enrollers did not differ in terms of referral type (i.e., whether they heard about the course or were directly referred) and referral source (i.e., how they heard about the course or by whom they referred). Referral source and type were also unrelated to eventual completion of the course and did not differ across non-attendees, non-completers and completers. Thus, the method by which an individual entered the course did not affect their eventual status, suggesting that a less expensive method may result in similar recruitment levels.
## Qualitative Themes on Recruitment and Enquiry

<table>
<thead>
<tr>
<th>General Lack of Knowledge about CDSM</th>
<th>Qualitative data gathered during the focus groups suggested that most participants knew very little about the CDSM prior to undertaking the program and that more effective advertising strategies were required. Many participants stated that they did not know what to expect from the CDSM prior to their attendance. There was consensus from the rural focus group on all three occasions that they “didn’t have a clue” what the CDSM was all about (R3, p. 3) despite intensive marketing in the district. Poor understanding about the objectives and process of the course lead to negative conclusions in some cases.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Importance of Word of Mouth</td>
<td>For all groups, the benefit of word of mouth exposure was a major point of discussion. A number of participants indicated that they had already spread the word about the CDSM to people in their social networks. Stakeholders and community leaders alike agreed that it was an important marketing strategy to tap into the resource of those individuals who have completed the course and encourage them to share their positive experiences with others—including their healthcare professionals. There was a consensus that it “takes time for word of mouth to work” and that the strategy was incremental, increasing over time as information entered the community.</td>
</tr>
<tr>
<td>Strength of GP Referral</td>
<td>According to participants, the greatest faith was placed in advice received from GPs. Despite little knowledge or expectation of the CDSM, many people attended simply because their doctor had referred them. “I didn’t know nothing - my doctor just said ‘I want you to do it so do it’” (U3, p. 13); “Well my GP put me onto it because I got to that stage where I just didn’t know what to do with myself. I was just in so much pain” (R3, p. 3). Most comments supported the crucial role of the GP. Some comments indicated, however, that GPs often failed to play this crucial role and that many GPs ‘only focus on the medical aspect’ (R3, p. 30) and could be less ‘informed’ and ‘enthusiastic’ than participants would have liked (R3, p. 29).</td>
</tr>
<tr>
<td>Need to Clarify the CDSM Process and Purpose</td>
<td>Some participants thought that it was important to clarify the fact that the course involved such an interactive group process. Some individuals may dislike sharing their experiences in this forum, while others this would be an attraction. The reason for non-attendance for a small number of people (5%) was that groups or courses were not their preferred service. Indeed, some individuals were dissuaded from attending the CDSM “if they knew they have got to talk” (U3, p. 9).</td>
</tr>
<tr>
<td>Terminology as a Barrier</td>
<td>The language used in advertisements was an important consideration, particularly in relation to terminology such as chronic disease and self-management. “I think a lot of people are unaware that they actually have what is classed as a chronic illness. When you see the list of different diseases that you can have, … a lot of people don’t realise that they come under the banner…. People don’t like the word disease - I’ve never felt I have a disease (CLL2, p. 3). Lay leaders explained that there was a distinction between living with symptoms and accepting that they had a disease. The self-management terminology was also confusing. When asked to expand on the term ‘self-management’, members of the non-enroller focus group offered explanations far different from those of a medical or health perspective. “We would do that [self-manage] before we went into something else wouldn’t we just to see how far we could go”; “I don’t really know what it means. I am looking after myself and I have done for the last 20 years. I am managing really well” (NA3, p. 4).</td>
</tr>
</tbody>
</table>
Participation

Of those who enquired about the CDSM, 608 enrolled in a course and 427 expressed no further interest (non-enrollers). Those who enrolled in a course were mostly located in the inner suburbs of Brisbane (n=356), with 144 located in the outer suburbs and 105 in the rural region.

Enrollers and non-enrollers did not differ on gender, age or primary condition.

<table>
<thead>
<tr>
<th>Group</th>
<th>Number</th>
<th>Gender</th>
<th>Age Group</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>M</td>
<td>F</td>
</tr>
<tr>
<td>Enrollers</td>
<td>608*</td>
<td>128 (21%)</td>
<td>480 (79%)</td>
</tr>
<tr>
<td>Non-Enrollers</td>
<td>427*</td>
<td>93 (22%)</td>
<td>334 (78%)</td>
</tr>
</tbody>
</table>

*NB: missing data on some variables accounts for different totals

Reasons for non-enrolment were provided by 93 non-enrollers. A common reason for non-enrolment was a loss of interest (n=26) in the course. Another large group continued to indicate their interest in the course, but did not enroll for the duration of the project and could not provide a reason for this discrepancy (n=28). A large group of non-enrollers had moved during the project and were no longer contactable (n=14). Simple barriers such as transport difficulties, timing of the course, and location were stated by 4 non-enrollers. Other commitments such as caring responsibilities, appointments, work or study prevented 5 enquirers from enrolling in a course and another 5 stated that the course was not right for them or that they did not enjoy a group atmosphere. For 11 participants, health was the major reason for not enrolling – either because they were too healthy to consider a course about chronic conditions or too unwell to attend.

Of those enrollers who also participated in the research (n=406), the majority reported two or three chronic conditions (n=245 or 60.35%). Only 17.24% had one condition, and 21.92% had four or more. The average number of conditions at baseline was 2.65 (SD=1.25) and the average duration for conditions was 31.20 years (SD=30.74). At follow-up, the average number of conditions was 2.51 (SD=1.40), and the duration was 28.17 years (SD=26.21). The most frequent combination of conditions was Arthritis and Diabetes, occurring in 14.32% of participants. Cardiovascular disease co-occurred with Diabetes and Arthritis in 10.86% of cases. Although Arthritis was the most common primary condition in absolute numbers, diabetes was the most common co-morbid condition (occurring in 74% of cases).
Qualitative Themes on Participation

<table>
<thead>
<tr>
<th>Theme</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>Although participants in the CDSM were mostly over 60 years of age, the number of enrolments from younger people was surprising. However, there was evidence that the CDSM did not meet their needs. “I was amazed at seeing a number of young people in their early forties with osteoporosis. That really startled me” (U3, p. 22). “The younger ones were the ones that I found they dropped out” (U3, p. 9).</td>
</tr>
<tr>
<td>Males</td>
<td>Male participation was lacking in most CDSM courses unless organized by a female companion. The bias towards women in the groups was noticed by most participants. “Actually I find one thing of concern looking around the group, … [Participant’s name] is the only male. Surely there must be just as many men out there with chronic health conditions … I think it is a very serious health issue. [chorus of agreement]” (C, p2).</td>
</tr>
<tr>
<td>Sickness Bias</td>
<td>Qualitative data indicated that people made judgements about their level of disability or health and used these as a basis for determining whether or not they would participate in the course. Reasons for non-enrollment supported this conclusion. Fifteen percent of those who gave reasons for not participating in a course were too sick or disabled by their condition to attend (n=9) or were managing too many other commitments, including caring responsibilities or medical appointments (n=7). In contrast, another 5% reported being too well to attend (n=6) and did not associate with the idea of a chronic disease.</td>
</tr>
<tr>
<td>Preaching to the Converted</td>
<td>In many cases, people who had a chronic illness were not aware of the opportunities presented by the program unless they were already searching for help. It was noted that, “unless you are wanting something from the community you are not going to really hear about it unless it is advertised” (CS1, p.4). It was concluded that people may have to be “in the market for a chronic disease management course” before they could be recruited.</td>
</tr>
<tr>
<td>Open to New Experiences</td>
<td>Individuals who participated in the CDSM expressed a common desire to learn something new that might help them to manage their chronic illness. “I just thought I might learn something” (U2, p. 15). Many participants highlighted the importance of an open mind. “If you don’t try you don’t know do you? You are not going to find out, it might not be any good for some people. Everyone is different but I would say to anyone go along and have a go and see what you can get out of it because if you do not get anything out of it at least you meet other people” (R1, p. 7).</td>
</tr>
<tr>
<td>Self-Motivated</td>
<td>There was evidence that the participants for whom the benefits of the CDSM were likely to be greatest were those who were motivated to change. “People who are attending courses are self-referees, so the completion rates are high and the long term sustainability is high” (CS1, p.17). Participants confirmed that motivation was crucial as was the willingness to take personal responsibility. “No one can do it for you, you have got to do it for yourself” (R3, p.10). These participants had difficulty understanding others who lacked drive. “I get angry when there are opportunities out there for people to help themselves and they don’t take the chance…. the opportunity is out there for everybody but they have to get off their backsides”. (R3, p. 10)</td>
</tr>
<tr>
<td>Acceptance of the Need</td>
<td>Participants believed that a major motivator for their choice to embrace the CDSM approach was their acceptance of the fact that they might never be symptom-free, but that they could learn to manage symptoms and continue living despite them. “I think a big part of the problem is that people want their pain taken away - they have tried to do that and it hasn’t worked and so they have said ‘Here I am’.…. the idea of managing the pain to live with it - you have got to cross [into that way of thinking].” (R3, p. 11)</td>
</tr>
</tbody>
</table>
Attendance

Of the 608 who enrolled in a course, only 470 actually attended and completed. A further 10 eventually completed a course after more than one attempt (completed at least 4 sessions of the course). Attendance data were collected each week. Of the 605 enrollers, only 40.8% (n=250) completed all six sessions. The median attendance was five sessions (n=165), with 66 participants attending 4 sessions. However, 32.2% (n=128) of the sample attended 3 or fewer sessions, 20 of whom completed no sessions at all. Five of these non-attendees were serial non-completers, enrolling in 2 or 3 courses and failing to complete any. Attendance rates (as a percentage of those who enrolled in a course) from weeks 1 through 6 were respectively, 91.0%, 84.1%, 79.1%, 73.2%, 72.5% and 74.4%.

Logistic regression failed to demonstrate any effect of gender, age or primary condition on completion status, indicating that other factors contributed to whether or not those who enrolled in a course eventually completed.

<table>
<thead>
<tr>
<th>Group</th>
<th>Number</th>
<th>Gender</th>
<th>Age Group</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>M</td>
<td>F</td>
</tr>
<tr>
<td>Completers</td>
<td>480*</td>
<td>99 (21%)</td>
<td>381 (79%)</td>
</tr>
<tr>
<td></td>
<td>50s</td>
<td>185 (39%)</td>
<td>125 (26%)</td>
</tr>
<tr>
<td></td>
<td>60s</td>
<td>168 (35%)</td>
<td></td>
</tr>
<tr>
<td>Non-Completers</td>
<td>108*</td>
<td>24 (22%)</td>
<td>84 (77%)</td>
</tr>
<tr>
<td></td>
<td>50s</td>
<td>50 (46%)</td>
<td>24 (22%)</td>
</tr>
<tr>
<td></td>
<td>60s</td>
<td>32 (29%)</td>
<td></td>
</tr>
<tr>
<td>Non-Attendees</td>
<td>20*</td>
<td>5 (25%)</td>
<td>15 (75%)</td>
</tr>
<tr>
<td></td>
<td>50s</td>
<td>11 (55%)</td>
<td>3 (15%)</td>
</tr>
<tr>
<td></td>
<td>60s</td>
<td>6 (30%)</td>
<td></td>
</tr>
</tbody>
</table>

*NB: missing data on some variables accounts for different totals

Interestingly, month of inquiry was associated with completion status (χ²=22.8, p<.018, with exp<5 in 2 cells; confirmed via Fisher’s Exact test p<.011). Enquiries made during March, 2003 were most likely to result in eventual course completions. However, the month in which the course started was also associated with completion (χ²=18.6, p<.03, Fisher’s Exact Test p<.036). Courses started in May and August were likely to be poorly completed, whereas courses started in March and April were most likely to be completed. This finding was not attributable to the delay in starting a course, as delays from enquiry to the start of course did not differ across the months (Kruskal-Wallis χ²=12.103(9), p>.20).
An interesting and intuitively sensible finding was the fact that courses held on Tuesdays were completed at a rate higher than would be expected, whereas courses held on Thursdays were poorly completed.

Completers differed from non-completers in terms of the delay between time of enquiry and the start of the course. The delay measured in days ranged from 1 to 500 days, and was on average 51.49 days (SD=80.09 days). The median delay was 24 days. The average delay was shorter for completers than all other groups, and no difference emerged in terms of gender or age. Although this finding indicates the need to respond quickly to enquiries, it is important to note that the variation in delay time was considerable, suggesting that completion was not only dependent on speedy response times. Indeed, there appeared to be a large group of participants for whom enrollment was not pursued at the time of enquiry, but became appropriate over the next year or more. This finding could indicate a right-censoring effect on the conclusions in that many more enquirers may become completers if the study was extended.

There was a modest negative correlation between the size of the course and attendance at later sessions (p<.002, with a Pearson correlation of -.18), indicating that larger course sizes were associated with lower attendance. However, leader characteristics also appeared to have a significant impact on attendance. The experience of the leader team (as rated by Master Trainers) was coded as 22 for two inexperienced leaders, 23 for one experienced and one inexperienced, and 33 for two experienced leaders. Leaders were also coded as being either a Health Professional or a Lay Leader and team status was coded as HH for two health professionals and HL for one health professional and one lay leader. The combination LL did not exist.

At week 2, both Team Experience and the interaction between Team Experience and Team Status were associated with attendance. Week 2 attendance was remarkably low for HH pairs with low experience levels. However, these courses were all held in rural areas, indicating the possibility of an alternative explanation for poor attendance. At week 3, attendance rebounded to high levels, creating a main effect (p<.039) for HH teams, but no interaction. No effects were found from weeks 4 through 6.
## Qualitative Themes on Attendance

| Build on Enthusiasm Quickly | Building on enthusiasm in a timely manner was seen to be extremely important. For instance, participants commented about the value of the short waiting period between finding out about the program and being able to start a course. Immediate access to a course was seen as crucial to their ongoing enthusiasm. Attendance data confirmed that those who started a course immediately were more likely to complete than those who did not. In support of this conclusion, a common reason for non-completion was that people had lost interest. |
| Importance of the First Session | The importance of the first session of the CDSM was highlighted as it generated enthusiasm and positive expectations for participants. “I was quite excited because I flicked through the book [in the first session] and it was really interesting” (U3, p. 15). However, participants mentioned many occasions when individuals in their CDSM group did not return after the first session, as found in the attendance data. |
| False Enquiries and Enrolments | Although a strong source of referral, referrals by health professionals sometimes left participants feeling pressured to attend in fear that if they declined, it would impact on their healthcare. It is likely that this group represents a large proportion of those people who withdraw from the program without completing, thus wasting resources. “I got a letter from the physiotherapy department [referring to the CDSM] and my reaction was that maybe they just wouldn’t take me if I didn’t go to the class…. maybe they just won’t take me in” (U1, p. 3). |
| Practical Issues | Several small factors created significant barriers to participants, including cost, travel and venue. The cost of the CDSM was $45, which covered the cost of the manual. As one participant noted, “when all is said and done it’s very cheap really” (CLL2, p. 9). However, “from the perspective of a person who is struggling with their .. pension..and it’s not for us to criticise how they spend their money, but for many people struggling financially they do find that a lot to pay out. (CLL2, p. 9). Other participants thought cost was a positive feature of the CDSM, in that people were more likely to value something for which they had to pay. “If you paid forty-five dollars for the course, you have to get your money’s worth” (R1, p. 10) … whereas a freebee … you don’t have to go” (CLL, p. 9). A “location that is accessible” (CLL2, p.2) was crucial. The venue itself was important, not only in terms of its location, but also its physical and psychosocial features, as illustrated by one woman’s story. “Ours [CDSM] was held at Centrelink …. sometimes you just had to sit outside among the Centrelink people … I am never happy sitting in there at all”. (U3, p. 16) Although many participants needed to access public transport, this option was time-consuming and costly. |
| Role of Support Networks | Participation and attendance were affected profoundly by support networks. Most participants benefited as a result of strong support and encouragement and believed that this support either allowed them to participate or motivated them to keep coming to the group. “My family reckons that it is the best thing they ever saw me do ….since I have come here I have got a different attitude on life and they were quite supportive of that” (R3, p. 19). In contrast to this facilitative impact, several participants spoke about the strong family opposition they had to overcome to attend the CDSM. “They [family] didn’t like the idea of me coming (R3, p. 18). Not only did the social environment have the potential to impede participation, but also to act as a barrier to successful ongoing self-management. Participants who completed the course openly spoke of the important role of social contact in attracting them to the CDSM in the first instance. They also noted that their learning often came from others in the group rather than the course material itself. |
| Time | Time was a significant challenge to attendance. Even those who were committed to the six week CDSM found that a variety of obligations and commitments that prevented them from attending some sessions. Medical appointments and family obligations were regularly identified as barriers to attending the CDSM. When lay leaders offered their views about the factors that might prevent people from participating in the CDSM, they also raised the time commitment. Although they agreed that “they could not shorten it [CDSM]” (CLL, p. 10), there was an issue surrounding the extent of commitment required by participants that needed to be addressed. It was noted, however, that no timing or duration would suit everyone. |
Satisfaction

The participants were overwhelmingly positive in their evaluation of the course. Eighty-five to ninety-five percent of participants found the course to be appropriate in venue and facilities, content and impact on knowledge and lifestyle. Ninety-four percent of participants agreed that the course was a good investment of their time.

Satisfaction with Course

Participants were asked to contribute further comments and suggestions as to how the course could be improved. Only 32% of participants and companions provided written feedback. Some participants recommended a more flexible approach to the group, allowing for more time for discussion. Others suggested the course was too short and that a refresher course would be beneficial. Some respondents requested more appropriate equipment for the display of visual material. Two responses recommended the need for a review of their action plans that had been set during the course.

Satisfaction with Leaders

Over 95% of participants agreed that the course leaders were well organized, approachable, knowledgeable and helpful. Slightly less (87.5%) indicated that the course leader was contactable. However, some participants responded to this question as ‘not-applicable’, based on the assumption that no formal ongoing contact had been organized.

Participants and companions also had the opportunity to provide written feedback about the course leaders. About 40% of the respondents provided brief comments. Most responses provided a general affirmation of the course leaders ability to facilitate the course as well as an acknowledgement of their help and concern. Many respondents indicated their appreciation toward the course leader and their enjoyment of the course. Some responses gave more direct feedback. Approximately ten participants requested that the course be extended to include more time for discussion and follow up. Several participants recommended the need for leaders to speak louder, indicating that some people had hearing difficulties. Some respondents recommended less reading from notes and better use of the material (book). Two people requested larger chart sizes and better visual displays, indicating visual difficulties that had not been taken into consideration.

Given the possible impact of leader experience, leader status and course size on satisfaction with leaders, a model was tested for main effects and interactions using these variables. The results showed a significant main effect for Experience ($F_{2,340}=3.019, p<.05$) and an interaction between Leader Team Experience and Course Size ($F_{2,340}=3.191, p<.042$). For teams of inexperienced leaders, satisfaction increased with increasing course size, irrespective of the leader constitution (i.e, Health Professionals only or Lay Leader). For teams with one experienced leader, this effect disappeared, and satisfaction decreased with increasing course size.
Qualitative Themes on Satisfaction

<p>| Simplicity and Relevance | The content of the CDSM was applauded for its simplicity, relevance and practicality, enabling group members to readily grasp the concepts. “They really put it down to our level didn’t they? There was nothing that you could not understand” (R1, p.8); “It really brought to my knowledge things that I would never have thought about” (R2, p. 1). “I found it very helpful and the things were simple and easy to follow” (U1, p.1). In the event that there was some confusion regarding the CDSM content, the leaders ensured that the information was accessible to participants --“If you don’t understand they [leaders] explain it all” (U1, p.5). Participants were particularly satisfied with the topics on problem-solving and goal setting. They also valued the opportunity to practice techniques such as relaxation and exercises. |
| The First Session | The first session was one of the aspects of the CDSM that generated mixed feelings from participants. Participants commented on the fact that they were expected to share personal information about themselves and their condition at the initial session, when group members were unacquainted with each other. “Our introductions on the first [day of the CDSM]… I thought that was the hardest part about it. You know saying ‘Why are you here’, ‘Who sent you here’, ‘What are your ailments’, ‘What medication’ - we did not know one another [then]. Now we do” (R1, p.1). A consequence of commencing with such a ‘confronting’ approach was that particularly vulnerable or sensitive individuals failed to return. “We lost one of the girls that day… she did not come back, she was obviously very depressed. She burst into tears; it was too much for her” (R1,  p. 1). However, the importance of the first session in establishing open communication and sharing was highlighted. |
| The Leader Personality | The majority of participants spoke of their leaders in positive terms. “The two women who ran it were helpful and they explained things very well” (R1, p.1). “I couldn’t fault the work they did and how hard they tried they were very, very good” (U3, p. 5). Participants particularly valued leaders who “injected a bit of fun”, “were not too straight laced” and were “casual and relaxing” (R1, p.7). Participants commented about the approachability of leaders, their ability to answer questions and their caring nature. When participants asked questions leaders were unable to answer, they appreciated it when the leaders followed up. |
| It Doesn’t Have to be a Professional | Most participants noted the benefit derived from the combination of a lay leader and a leader with a health professional background. Clearly, participants valued both lay leaders and professional leaders. Interestingly, participants in the first urban focus group debated the role of a professional leader. “Why does it have to be a professional I was just thinking that someone who was pretty experienced and have had problems in life and got over them with a very positive approach I thought would be just as good as a professional”, “…but you don’t have to be professional perhaps to do that”. (U1, p.12). Lay leaders felt that their personal experience with chronic illness was an asset when it came to connecting with the CDSM participants. “You do relate to their situation because you have been there and that’s what they feel. They appreciate that you understand and that comes through” (LL2, p. 19). |
| Leaders who Don’t Deliver | Some participants noted the delivery of information was an area that required significant improvement. Leaders’ experience and skill in managing group dynamics was identified as an important responsibility that was not always managed well. In cases where leaders were able to manage the group effectively, participants spoke of positive experiences. “[Leader] was very good at sort of chasing somebody, a couple of times people would get a little carried away and she was ready to move along” (U1, p. 12). The majority of feedback in this area, however, focused on presentation skills. The perception participants held of leaders is extremely important to the evaluation of the CDSM, as they attributed their likelihood of mastering a particular self-management technique (i.e., relaxation or breathing techniques) to the skill of their leaders. |
| Materials | In some instances, participants felt strongly that the quality and standard of materials must be improved. “…we had ours [material] written on scrappy bits of paper and they would hold up the bit of paper and say ‘we are sorry it is a bit torn here…can you read this?’” (U3, p. 14), “they had them [materials] in the wrong order the bits of paper so they had to go through them all” (U3, p. 15). Other focus group participants indicated that they would not have tolerated substandard quality. Participants spoke highly of the book, describing it as “helpful”, remarking that it had “a lot of information in it” (U1, p.1), and “I found lots of wisdom in the book for a whole lot of areas” (U1, p.11). Participants expressed strong dissatisfaction with the American flavour of the book and course content. “The thing I didn’t like was that it was so American” (U2, p. 2). This topic prompted discussion on the need for a more relevant version to enhance its usefulness, appeal and sustainability in Australia. |</p>
<table>
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<tr>
<th>Modelling</th>
<th>The importance of leaders’ ability to model self-management skills appropriately was a matter of concern for some participants. One participant believed that if leaders failed to achieve their action plans on a regular basis, this was a poor example for self-management. Conversely, another participants explained that when their leaders were honest about encountering obstacles to achieving their weekly action plans, that this helped to normalise participants’ own experiences.</th>
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<tr>
<td>Social Processes</td>
<td>One of the most important topics raised by participants was their level of satisfaction with the social processes that emerged from the group. There were a large number of people for whom the group format was not appropriate. However, the majority of participants who completed the course believed that social processes were crucial to its success. The group provided a supportive context where people understood each other’s needs. This shared experience enhanced the likelihood that friendships were made, even if only temporary. Having time and opportunity to socialise before and after the CDSM session was a valuable experience for many participants. One participant pointed out that any group could bring these benefits. “Any group therapy helps you though… it is just a case of getting together and finding other people….You are not on your own” (R3, p. 3). The support of the group instilled motivation. “Over the period of time, I think the group helped one another.” (R1, p.?). When participants were dissatisfied with their group, it was due to lack of rapport, leading to unmet expectations for socialization in the group -“I think I was hoping for it to be a little more social for people like a little more friendly” (U3, p. 16).</td>
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<td>Group Dynamics</td>
<td>A number of participants commented on how important the composition and dynamics of the group were to the success of the CDSM and to the benefits they derived from the course. “I think a lot of it has to do with the people who are in the class” (R1, p.16). This thought was echoed in the stories of shared by other participants who felt that the make-up and dynamics of the group had a negative impact on their satisfaction with the CDSM and their achievements. Participants shared how the poor motivation levels of some fellow CDSM group members impacted on their own psychological well-being and experience. “A lot of people did their weekly plan [only with] prompting….they never did it”; “they would make excuses” (U3, p. 10). This lack of motivation in other CDSM members had negative consequences for several participants. “[it] made you feel depressed”; “oh yes, I did too, I got depressed too” (U3, p. 10). Similarly, several participants discussed feeling isolated in the group due to different backgrounds or socio-economic status. Conflict in the group was a significant source of discontent in those cases where it occurred. For participants who had been exposed to conflict, the group had been a negative experience.</td>
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<td>The Buddy System</td>
<td>The buddy system was another aspect of the CDSM process that generated discussion. Most participants found the buddy system useful. “I thought that [buddy system] was very, very good early in the piece to get everybody to come back the next week” (R1, p. 10); “We had a buddy system and that was good because we all rang each other” (U1, p. 6). The buddy system was identified as “such a good idea”, particularly for those who lived alone. However, there were examples where the buddy system did not work well, possibly because buddies had not been selected well. “Nobody did it [called their buddies] and I felt really silly because I got the attitude when I did ring that I was a sticky nose that I was interfering. I got that impression from them.” (U3, p. 11)</td>
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<td>Shared Learning</td>
<td>The social context also facilitated learning, sometimes in a more significant manner than the skills training components. Participants particularly appreciated the exchange of ideas that could occur amongst group members that enabled new learning to take place. “You might have a certain problem but if you start talking to one another, ‘Oh yes I had that and this is how I got around it’. In other words, it is a swapping of thoughts” (R1, p. ?). The sharing of information and resources that emerged through the group context served to strengthen the group -- “and I think that is a great bonding within the group” (R1, p. ?). The data revealed that the group process facilitated new learning and the sharing of resources within a milieu of social support.</td>
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Outcomes

The purpose of the CDSM is to enable people with chronic disease(s) to better manage their condition(s) and develop the confidence to apply self-management skills on a day-to-day basis. As a result, participants not only cope better with their disability and adhere to treatment regimes, but also learn to modify their behaviors to minimize undesirable outcomes, adjust their social/ work lives to accommodate their symptoms and functional limitations, and deal with the emotional issues. Thus, it would be expected that the CDSM would result in improved health status and health behaviours, greater self-efficacy and less health care utilization. Although all these variables were measured in the current study, the interpretation of changes over time must be qualified. Several factors influenced the validity of these findings:

Size of comparative groups (e.g. the bias towards females, urban participants, and older participants may account for significance or non-significance of findings). In some cases, the small size of a group meant that comparisons were not possible (e.g., indigenous participants).

Attrition and missing data were systematic and substantial, meaning that any interpretation of change over time was potentially meaningless, particularly those based on univariate analyses.

A complex multi-variate analysis that corrected for missing data was able to address this issue to some extent, but produced complex findings that require considerable interpretation.

Giving consideration to the above qualifications, the sections below present a summary of the trends and significant changes in the data. Full statistical modeling of the data can be found in the complete report for this project and will be published in the future.

Outcome over Time

Few outcome variables changed significantly over time following the CDSM. Aerobic activity increased from baseline to six months, and remained constant thereafter. Concern for symptoms decreased from baseline to six months and remained constant and coping increased over the same period. An unexpected finding was the fact that intrusiveness of illness increased from baseline to six months and remained constant thereafter. This finding was consistent with the qualitative data that indicated a trend for participants to become more aware of their illness when they enrolled in a course and/or completed the questionnaire.

From baseline to six weeks, CDSM participants reported that their lives became significantly less stressful, and more meaningful and organized. They felt more supported and reported making progress. From 6 weeks to 1-year follow up, however, these indicators significantly declined, back to baseline levels or lower. Importantly, these variables interacted with several other outcome variables, indicating that the course may have an indirect or mediated impact on health outcomes by altering perceptions. For instance, reports of fatigue increased as participants’ perceptions of progress and organization decreased and as stress increased. Similarly, reports of pain and shortness of breath increased with perceptions of less progress and more stress. As would be expected, intrusiveness of illness declined with increasing
perceptions of organization and progress, and decreasing perceptions of stress. Similarly, greater life satisfaction was reported with increasing perceptions of progress, greater support and decreasing perceptions of stress.

Rural participants were more physically active at all points in time and reported greater levels of coping and confidence than urban participants. Rural participants also reported significantly less intrusiveness of illness and stress and greater meaningfulness, organization, support and progress than the urban participants. None of these differences could be attributed to the CDSM, but perhaps suggest that the course could capitalize on these differences for rural participants. This issue needs further investigation.

In terms of health service utilization, visits to specialists declined significantly from baseline to 6-month follow up whereas visits to nurses increased. This finding may simply reflect the fact that leaders were recruited primarily from the community health nursing population in the early stages of the project, thus providing a link between participants and community nursing staff. Significant interactions were present in the data, however, in that visits to all health care providers increased across time if concern about symptoms, shortness of breath, fatigue and pain increased. This finding indicates that usage of health services was legitimately associated with the perception that symptoms were increasing. In contrast, visits to all healthcare providers decreased across time if life was perceived to be more meaningful, organized, supported, and if participants judged themselves as having made progress. If they perceived their life to be less stressful, visits also declined across time for all health providers. Visits generally increased if there was a corresponding decline in aerobic activity and physical abilities. However, interestingly, visits to health providers also increased if there was a corresponding decrease in confidence, coping, positive feelings and life satisfaction.

The rate of GP visits were most strongly associated with levels of general health, coping and feelings, whereas specialist visits were most strongly associated with reports of pain and coping. Nurse visits were associated with levels of aerobic activity and physical activity and emergency department visits were associated with general health, shortness of breath, physical ability and negative feelings. Cumulatively, these findings suggest that a reduction in health service usage may be associated with the course, but only indirectly through the impact of the course on confidence and coping. In contrast, the course may be associated with increasing usage of nurses as a result of the exposure to community health leaders.

**The Impact of Follow-up**

The participants who joined a follow-up support group after the CDSM were compared to those who did not join a follow-up group.

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<tr>
<th>CDSM Goal</th>
<th>Quantitative Findings</th>
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<td><strong>Health Behaviours</strong></td>
<td>Significantly higher levels of physical ability and aerobic activity were reported over time for the follow-up group, but this difference was also present at baseline indicating that those who elected to join a support group were already more likely to be physically healthy.</td>
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<td><strong>General Health</strong></td>
<td>The non-follow-up group reported significantly poorer health and greater concern regarding symptoms than the follow-up group.</td>
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<td><strong>Coping, self-efficacy and confidence</strong></td>
<td>The follow-up group reported better ability to cope and greater confidence over time than the non-follow-up group.</td>
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<tr>
<td><strong>Perceived Progress</strong></td>
<td>The perception of progress increased for the follow-up group and was sustained at one year following the course.</td>
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### Qualitative Outcomes

<table>
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<th>CDSM Goal</th>
<th>Qualitative Themes</th>
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<td>Improved Health Behaviours</td>
<td>For some participants, the CDSM was the first time they had identified as having a chronic disease(s) and was therefore a catalyst for recognizing the need to change behaviour. “With a chronic condition .. you have got to accept and once you accept it you can cope. You have to accept your limitations. There are things that you just can’t do and that is okay” (R3, p. 21) Following the course, the majority of participants reported employing strategies to improve their health behaviour, particularly prioritizing, listening to their bodies, engaging in exercise and relaxation. “You do not go like a bull at a gate….You have got to pace yourself and if you get tired, if the anxiety gets to you, you forget about that job and you go back and do something else. In other words just do not keep push, push, push” (R1, p. ?). “It slowed me down a lot - I realized that I am not superwoman any more” (R3, p. 24). “I hadn’t done exercises for years and now I, well I don’t do them regularly, but I try to, like walking and simple exercises like stretching your fingers and that type of thing. I find that is very good” (U1, p.3). “The practices, sitting down and watching your breath as you breathe in and out. That can sort of undo tension at the time” (R3, p. 26).</td>
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<td>Improved Health Status</td>
<td>Goal setting techniques and other strategies that were acquired during the CDSM allowed participants to maintain better health status. “By following the goals that were written to start with [we improve our health]. We are probably still all following them to an extent, though our lifestyles have changed” (R3. P. 24). However, the perception of one’s health status often changed as a result of several social processes. For instance, social comparison reminded people of their own well-being. “And the fact that there’s always somebody worse off than yourself” (U2, p. 3). The social support provided during the group enabled people to feel less lonely and depressed about their health. “The fact that they’re not isolated in their condition and that other people share similar things” (CLL, p. 5). Further, this support encouraged people to keep going when they might otherwise have given up. “Encouragement’s another thing. Encouragement from this course” (CLL2, p.5) Finally, mixing with others enabled participants to learn new ways of coping that minimized the impact of illness on their lives. “The other thing is the fact that once again, you are seeing people with similar problems or people with chronic problems and you are seeing what they are doing and you think well you know I could still do that. So that means I could still go out into the community and be a part of the community, I don't have to sit at home” (CS1, p. 10).</td>
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<td>Self-Efficacy and Confidence</td>
<td>When participants were asked about the benefits of the course, many reported increased confidence and improved communication with others “it gave me a lot more confidence being able to speak to people” (U2, p. 3). Having control over one’s life and engaging effectively in activities was mentioned by several participants as an important outcome of the CDSM. “I think empowerment - if you want a one word answer, it's empowerment mainly - people still, having full control or having control of their lives. I think at a community level … people are living independently they are participating in the community in so many different ways” (CS1, p. 10) Several participants discussed how the course had been a catalyst for altered thinking about life, that ultimately lead to greater belief in their own ability to do things. “My thought on the course was that I was not the only one in the community going through pain or disability. Now I thought that the course has broadened my outlook on life…. I was getting to a stage where I was throwing the towel in the waste paper basket” (R1, p. 6)</td>
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<td>Improved Health Service Utilization</td>
<td>Participants generally reported that one of the major benefits of the CDSM was to facilitate better communication with their health care providers. “You know that is why I stick to these sort of things, anything that I think will help me self-manage. It takes some of the load off her [GP] instead of whingeing to her [GP]” (U3, p. 25). Several participants provided insight into why the CDSM was beneficial in terms of healthcare usage. “Because it is really about improving the communication between the GP and the patient, it's about the patient really having</td>
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that understanding - ‘do I really need to see the GP about this or is it something that I can manage on my own?’” (CS1, p. 11). The important interaction between confidence, skills and healthcare usage was highlighted in several conversations. “I feel that I have got just a bit more [after completing the CDSM] than going along to see my local medical practitioner now, I have more resources” (U1, p.3)

More importantly, the qualitative data highlighted the fact that amount of health service usage is not the only issue to be considered. The CDSM appeared to be useful for participants in helping them to use their healthcare providers more effectively when they did visit, possibly minimizing the need for so many visits. “They [CDSM] told us how to ask more questions to the doctor which I thought was a wise idea…. Because you are inclined to say ‘Yes’ and ‘No’, and ‘All right’, instead of ‘Why?’” (R1, p.1). A healthcare provider also noted the fact that CDSM participants were better users of healthcare, not only because they were willing to ask questions, but because they were more informed. “I guess the big thing you see in general practice is that patients are becoming more informed about their condition so they are in a better position to go to their GP and ask a lot of questions. … they are better equipped to go to their GP with the right questions” (CS1, p. 11).

Better use of healthcare was reflected in more efficient use that may, in fact, be more frequent. “It [CDSM] teaches you how to talk to the doctor, … like today I would go and get a second opinion, when I would have kept to the one doctor…. [the CDSM] would say if you are not happy go and get a second opinion and I would not have known that before” (U1, p.3)

**Outcomes x Gender**

An analysis of gender differences in outcomes was unreliable due to participation biases leading to small samples for men. While males tended to report greater concern about their symptoms, at all times, than females, they also reported better general health and engaged significantly more often overall in aerobic activities. Generally males were more confident than females and felt more positive towards their health. At all times male reports of meaningfulness, organization, progress and support were significantly higher than those of females. Reports of stress were significantly lower than females. While females tended to report a greater life satisfaction, physical ability and ability to cope than males, illness appeared to intrude on their lives more. Although these trends could not be attributed to the CDSM, they indicate that there may be a need for the course to capitalize on the higher levels of activity among men. Further, there may be a need to address the fact that men perceive themselves to be more supported and healthy than women.

**Outcome Trends x Age**

There was little significant difference across age for any of the outcome variables. However small trends could be observed in that older age groups tended to report slightly higher levels of health, greater life satisfaction, less concern about their symptoms and less fatigue or pain than younger groups at baseline. At 6-month follow-up, older groups reported more positive feelings about their life and perceived their lives to have greater meaningfulness. They tended to report greater organization and less stress in their lives as well as more progress. By one year after the course, older groups reported a slight increase in perceived levels of support.
Sustainability Issues

The majority of participants who took part in the focus group discussions indicated that they would like to see the CDSM continued in future.

“I met some very nice people…I learnt different things….that is why I am here today - I hope the government keep it going for a lot more people” (R1, p. 6).

They saw the value of the CDSM as an adjunct to the current range of supports available to people with chronic conditions was also highlighted in participant comments.

“Doctors just say go home and look after yourself…whereas if you know there’s a group you can go to [CDSM] and their ideas are so important because one of the persons in that group might have had an illness before and know how to handle situations” (CLL2, p. 1)

Further, most participants representing organisations or health professionals agreed that the CDMS should become part of mainstream health care.

“Look I think if we are serious about developing, improving the health care cycle where people with conditions are partners in the management of those conditions, these courses have to become not add-ons, they actually have to be mainstreamed into the management of the condition, and I think the earlier the better…” (CS1, p. 12).

Although satisfaction with the CDSM is evident, the sustainability of this model within the current health care system will ultimately depend on:

- maximising the opportunities available in the current system to strengthen and resource the notion of self-management;
- creating a broader cultural shift that supports and sustains the concept of self-management in the wider community.

To achieve these objectives, it will be necessary to adopt a systems perspective of integrating and sustaining the CDSM within the current health care system. More specifically, the current evaluation has suggested that sustainability will warrant scrutiny of:

1. the barriers to integration;
2. the possibilities for supporting a sustainable system; and
3. strategies for creating a sustainable system.

This section of the report discusses each of these issues in more detail.
## Barriers to Systemic Sustainability

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<td><strong>A Fundamental Shift</strong></td>
<td>Some potential problems were associated with changing ingrained routines to facilitate a more preventive approach to the management of chronic conditions. “We have had some issues at [name of hospital] trying to get them to give people information about the groups … it just doesn’t happen routinely.” (CS1, p.14) A preventive approach to health care in the context of an ageing population and increasing numbers of people with chronic conditions required a fundamental shift that would not be easily facilitated. “If we are talking about a systemic change, we need to be looking at going right back to the fundamentals where children are taught, in primary school, about healthcare… it is that fundamental a shift that we should be looking at rather than just tacking it on …it just becomes ingrained through the system” (CS1, p. 13) The nature of the traditional relationship between the health provider and patient inhibited the integration of the CDSM due to the emphasis on the medical model. (CS1, p. 18) “[it is] heavily promoted by providers who work within the medical model .. they [clients] say ‘Oh I get that from my GP - why do I need this [CDSM]?’”</td>
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<td><strong>The General Practitioner as Gatekeeper</strong></td>
<td>Many participants suggested that GPs played a vitally important role in the long-term sustainability of the CDSM within the Australian health care system. GPs occupy a vital role in the referral of people with chronic conditions to CDSMP. To this extent, they occupied a key ‘gate-keeper’ role. “Now I believe that the doctors … who know their patients can sort of work out if this course [CDSM] is going to be of any benefit to them” (U3, p. 28). There was significant risk associated with GPs selecting patients they thought would benefit from the CDSM. “Perhaps a couple of the ones who did my course might not get to the course if the GP knows that they are not ready or suitable” (U3, p. 29). Nevertheless, most participants agreed that the GP was an important source of endorsement and legitimacy who could most effectively encourage and motivate people to engage with self-management. “GPs are vital at this part really because you know people are going to go to the doctor and unless it is coming from the doctor, they are not going to do anything about it” (CS1, p. 13)</td>
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<td><strong>Lack of GP Awareness</strong></td>
<td>Given their vital role, many participants stressed the importance of GPs acquiring a thorough understanding of the CDSM. They remarked on the lack of awareness. “Well my GP did not know very much before I did it [CDSM]” (U3, p. 30). The level of understanding has implications for the ‘gate-keeping’ role. Participants believed that GPs should take into consideration “What was it [CDSM] like [for clients]?’ and, ‘Do I send other people or don’t I?’” (U3, p. 29). “… my GP doesn’t really know what the course was all about and that is why he wanted me to do it”.</td>
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<td><strong>Turf Wars</strong></td>
<td>Participants representing the organizational and health care professionals debated the merits of different organizations actively participating in the CDSM. In particular, they commented on the conflict between some professionals and lay leaders. “[It was] their [professionals] first exposure [to lay leaders] …we can’t possibly have lay people talking to [clients]’ health professionals don’t want lay people who train as leaders, they are throwing up all sorts of reasons like privacy. There is some ownership as part of health professions.” “I think the turf wars is an issue .. some people are scared about the changing status quo, because the status quo has served served us very well in the community for a long time. … accept that there will always be pockets of resistance”. One participant indicated that the conflict was embedded within a traditional health care provider-consumer dynamic that in some ways was under threat from the notion of self-management. “jealousy, turf wars amongst health professionals, there is a certain fear and apprehension of health professionals - we are changing the dynamic of the relationship. (CS1, p. 18-19)</td>
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<td><strong>Consumer Discomfort</strong></td>
<td>Several participants noted that there was some discomfort in response to the concept of self-management among consumers, that could range from reluctance to attend through to derision. “There is also an element within the consumer group who are uncomfortable with the change in the dynamic [relationship between clients and professionals] – ‘what is this business about self-management, my GP tells me what to do?’ They don’t want to be active in the relationship, they are quite happy as a passive recipient” (CS1, p. 18-19)</td>
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<td><strong>Cynicism about the Motive for CDSM</strong></td>
<td>Although not prevalent, there was cynicism among some participants, particularly the urban groups. There was a negative perception that the CDSM course was a cost-saving exercise and that participants with chronic conditions were going to be left to their own devices in future. The impact of this perception on participation is unknown, but is likely to have significant influence among those from lower socio-economic status groups. “That must surely be the government’s aim promoting this sort of course, because it stops you going to the physio or the doctor when you have self-management, you can do it yourself” (U1, p.4).</td>
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### Possibilities for Supporting a Sustainable System

| Building on Current Enthusiasm | There was some recognition of the emerging interest in self-management within the current system. Some aspects of the system were conducive to the concept of self-management and the integration of the CDSM. “At a Commonwealth and State level there is some due recognition [of need for CDSM]. We are going to live longer and we all make this blind assumption that we are also going to live morbidity-free until the night we die. The reality is that people are living longer with chronic diseases, and it is actually a question whether some people will want to live like this….a whole lot of moral questions …but if we don't have a community where people can self-manage, we are not going to be able to afford this. The system will be just unsustainable…. The curative model just doesn't work with chronic disease, it is a management model, so yes it [CDSM] should be built into the system, and where it best fits I think is actually where people interact with the community settings, which community health, which is the GP's section settings, and self-help groups resulting from community” (CS1, p. 13) |

### Strategies to Enhance Systemic Sustainability

| Building a Broader Referral Base | Discussion drew attention to the vital role all health providers occupied in referring people with chronic conditions to the CDSM. “I feel that our medical men or women should be approaching these people, they know the people who have got all these problems and they should be the ones pushing the wheelbarrow, saying ‘listen matey, I’ve got a nice course for you, why don’t you go and check it out?’” (R3, p. 8) “If the GPs aren’t going to say ‘Mary, I think it’s about time you’d go to this course, or Johnny I think you could go to this course you might get something out of it’. they [GPs and Health Professionals] are the people that are looking after your health, know what you are going through” (R3, p. 17). Although the risks of filtering referral through GPs and Health Professionals was recognized, it was also seen as crucial to the generation of a sustainable CDSM model in future. |
| Educating Health Professionals | The benefits of educating health professionals to adopt the philosophy of self-management and to work within a self-management model were evident in participant comments. One indigenous health worker shared his important insights and learning that he had derived from the CDSM. “It gives you a better insight into what is wrong and you can understand other people a lot better when they have something wrong with them and you know it stops a lot of the stereotyping…” (R3, p. 3) |
| Incentives and Targets | It was frequently noted that “professionals whatever sector, whatever level, they want to do the right thing but either time or circumstance beats them, and I think what you really need to do is to make the argument with this has to be this is the best practice”. There was clearly a need for appropriate incentives and benchmarks. “…So, we have to look at the classic management tools of systems, - audit… benchmarks…. best practice. I would place some weight and you would tie some dollars to it, it is amazing how incorporated it gets when you tie some dollars to it.” (CS1, p. 14) |
| Facilitating Follow-Up | There was a significant demand for ongoing follow-up, which to some extent provided sustained outcomes, a sense of encouragement and positive reinforcement of healthy behaviours. Individuals who had participated in the CDSM often approached the leaders seeking opportunities for further support. “ I have had a number [of people] that asked for more specific [information and training], after they’ve done the course”. (CLL2, p. 11). Leaders were unable to provide ongoing support in a voluntary capacity, but felt that there was an obligation to do so to ensure the benefits of CDSM were not lost. Indeed, it was evident that the absence of ongoing follow-up may potentially threaten the sustainability of CDSM. “They [participants] end [CDSM] on a very positive note, and [think] right now I know what to do and I can do it, and they’re so positive in themselves that they can do it - they’re very much determined to do it until they start doing it on their own and the slide sets in and a couple of weeks later [things go downhill]” (CLL2, p. 12) “I would like to see, I like to think that once it becomes entrenched in the system, that the follow-up is systemic. So that if my GP says to me go and do the course, the next time I go back to my three monthly check up or whatever the case might be there's a flag …it actually becomes part of the fabric of the whole health system - build it into the fabric of the whole system” (CS1, p. 21). |
| A Network of Leaders | A critical component of ensuring the sustainability of the CDSM within the Australian healthcare system is the development of a network of leaders. Understanding how to recruit, train and retain leaders is an important consideration given that they have a significant impact on participation in the CDSM and the outcomes achieved. As noted in the satisfaction section, many people who participated in the CDSM were influenced by the quality of leaders and comments by participants in the client focus groups stressed the need for leaders to inspire them. “If you’ve got good leaders they give you a little bit of inspiration you yourself pick it up and add to it. I think that’s where you get your benefit” (R2, p. 12). It is therefore necessary to capitalize on the enthusiasm and motivation of people to become leaders and ensure that they are given appropriate training. Although participants strongly supported the combination of a lay leader and a professional leader, the potential for lay leaders to feel overwhelmed was raised. Although her initial unsuccessful attempt, one lay leader explained that she was planning to give it another try. “I always wanted to do it but when I led a course, half a course I felt it wasn’t me, so no, I backed out. I’m going to be doing a course with [name of another leader] next weekend so I’ve decided to put a better foot forward this time. (CLL2, p. 12). |
| Quality Assurance | Four issues were apparent from the current study in relation to the quality of the leader network.  
- First, there were issues about how to identify a high quality leader, particularly given that qualifications were not always a good indicator and the importance of personality. Important resources would be wasted if the leadership role was marketing in an untargeted fashion, attracting inappropriate people.  
- Second, clear identification of the skills necessary to be a high quality leader was necessary – skills mentioned regularly included 1) Intrinsic Qualities such as honesty and empathy; 2) Organisational Skills – being well prepared and having clarity of purpose; 3) Building Rapport – the importance of comfort and safety in groups; 4) Managing Dynamics – ability to recognize and prevent negative cycles from ‘pulling the group down”; 5) Empowerment – giving participants ownership and value.  
- Third, maintaining adequate motivation for leaders, both lay and health professional was problematic in that incentives operated against engagement as a leader. Incentives and disincentives were different for lay and health professional leaders. For lay leaders, incentives focused on altruism and giving back to the community, whereas for Health Professionals, incentives involved increasing qualifications and understanding. Disincentives for lay leaders included the impact on their own health and financial situation. In contrast, lack of organizational support, job/time demands were major disincentives for Health Professionals.  
- Fourth, the maintenance of quality and monitoring of performance over time emerged as an ethical and moral issue, in light of the powerful impact of leaders on positive and negative outcomes. Clearly, there is a need for a systematic method of accrediting and monitoring leaders that will not exclude lay leaders. Although a tertiary education context would favour Health Professionals, particularly if such training was integrated into their career paths, this context would inhibit lay leaders. |
| Special Circumstances | Indigenous communities and rural communities emerged from the research as special circumstances that require much more investigation before the CDSM would be sustainable. In particular, for Indigenous communities, both the content and delivery methods were problematic. In rural communities, the development of trained leaders was difficult, given the high level of community commitment already provided by these people. These issues require considerable thought rather than simply adopting an urban, middle-class, majority culture approach as has been the case in the past. |
Discussion and Conclusions

The most significant issue that has arisen from the current study is the systematic bias in participation and retention that plagued the analysis. Participation in health promotion activities has been reported to be a particularly problematic and complex issue for researchers and policy makers around the world (Boyce, 2001; Buchner, 1989; Michaels Miller & Iris, 2002). It has been recognised that a common challenge for public health care advocates is engaging the target population, stimulating their interest to participate in health promotion campaigns and maintaining attendance rates over time. Further, a great deal of research investigating participation in health promotion programs has confirmed the difficulties associated with recruitment (Boyce, 2001; Kocken & Voorham, 1998) and has highlighted the presence of systematic rather than random participation in health programs (Bybee, Bellamy & Mowbray, 2000). A growing body of evidence has suggested that participation in programs such as the CDSM may also be biased.

There is currently a void of information regarding the factors that influence participation in health programs. However, the current study has shed some light on the importance of such an investigation. The current study has shown that participation in CDSM is problematic in that only a select sub-sample of the population with chronic illness is likely to participate. Despite a wide marketing campaign, the course primarily attracted inquiries from females, which confirms previous research (Scott & Jacks, 2000). Males were extremely unlikely to make any enquiries and were even less likely to enrol in a course. However, the completion rate for men was the same as for women. Although only a small sample of men enrolled in a course, most went on to complete that course, indicating that if men could be encouraged to participate in self-management programs, they may be likely to do so successfully. Indeed, participation for men has been recognised as a problematic issue for some time and across many health interventions (see Scott & Jacks, 2000 for review). However, it is clear from the current study that the traditional forms of marketing fail to attract men in the first instance.

The course also failed to attract indigenous people and people of non-English speaking background. For this population, confusion about eligibility rules, course information and enrolment procedures is likely to prevent participation (Neumann et al., 1995). In the current study, no attempt was made to disseminate information about the course in other languages. Similarly, no attempts were made to directly attract indigenous people. Nevertheless, this participation rate is particularly problematic given that over 80 percent of Australian Aboriginal people have reported up to four chronic, disabling conditions, especially asthma, diabetes and kidney disease (Kamien, 1993).

In absolute numbers, people who nominated arthritis as their primary condition were most likely to inquire, enroll, attend and complete the course. However, it is likely that this finding was an artefact of the course having been delivered and co-ordinated through Arthritis Queensland. Although the course was marketed widely to other illness populations without any obvious links to arthritis, it seems that people with other conditions were still less inclined to make contact. Nevertheless, the course did attract a number of participants with other target conditions, particularly diabetes, which was the most common co-morbid condition.

The current study has indicated, however, that even if self-management is seen as acceptable, barriers associated with inconvenience (e.g., time, location, other responsibilities, transport) were commonly reported. Indeed, inconvenience has been found to be a common barrier to
participation across a range of health promotion programs (Remler & Glied, 2003). It is, therefore, highly likely that this issue also impacted greatly on those who failed to even enquire about the course despite the marketing campaign. The current study has suggested that attempts must be made to increase the ease with which people can acquire self-management skills, particularly those who are already managing significant burden associated with time pressure, caring responsibilities, other socio-economic constraints and mobility issues.

There was also a health bias in the findings. Despite experiencing chronic conditions of sufficient severity to be referred or make an enquiry, a number of people stated that they were either too well for the course or that the course did not seem right for them. Similarly, those who failed to complete a course often reported being either very well or too unwell to attend. The finding that people made their own judgments about whether or not they were sufficiently unwell to attend a CDSM course indicates that there may be some stigma associated with the program. The impact of this variable was significant in that those who remained in the course and the research were likely to be those who had average health, thus obscuring any changes over time. Similarly, those who enrolled in the first place were likely to be those with fewer health concerns, but not those whose condition had not yet deteriorated. From a health promotion perspective, this trend is alarming.

Irrespective of these participation and recruitment biases, a growing body of literature supports the positive impact that self-management programs have on clinical outcomes, health behaviour and self-efficacy of people with chronic conditions such as asthma (Berg, Dunbar-Jacob & Sereika, 1997; Lorig & Holman, 1989; Gibson, Coughlan & Abramson, 1999), heart disease (Clark, Janz, Dodge, Schork, Wheeler, Liang, Keteyian & Santinga, 1997), arthritis (Barlow, Turner & Wright, 2000; Kruger, Helmick, Callahan, & Haddix, 1998), diabetes (Lorig & González, 2000) and chronic pain (LeFort, Gray-Donald, Rowat & Jeans, 1998). Previous research has also indicated that self-management programmes are associated with reductions in health care costs and health service utilisation (Bodenheimer et al. 2002; Lorig et al., 2001; Kruger, Helmick, Callahan, & Haddix, 1998).

The current study has shown that the impact of the course on actual health status may be minimal. Nevertheless, as would be expected, the course did appear to influence perceptions of well-being, confidence, stress, feeling of being supported and concern over symptoms. These effects were particularly evident during the six week course and to some extent at 6 months post-course. However, by the 12 month follow-up period, any positive impact of the course had disappeared. For participants who engaged in a follow-up support group, outcomes were sustained to some extent, indicating the importance of ongoing support and refresher courses. Given that those who engaged in follow-up support groups tended to have higher levels of health and physical activity prior to the course, this finding must also be interpreted cautiously.

As one of the primary aims of the CDSM is the development of self-efficacy, it was particularly important to note that participants reported a strong sense of confidence and the perception of greater control over their lives as a result of participating in the course. The benefits of perceived control have been highlighted by Chipperfield, Perry and Menec (1999) who found it contributed to motivation, positive health and well-being for individuals with a stroke or other disablising condition. Other researchers (Johnston, Morrison, MacWalter & Partridge, 1999; Lorig, Sobel et al., 1999; Peng, Adams & Gentile, 1998) have also confirmed the importance of perceived control as individuals face the challenges of adjusting to and
managing the impact of ongoing conditions such as stroke. In contrast, perceived loss of control has been associated with poor coping, ill-health, depression and anxiety (Chipperfield et al., 1999).

Chronic disease self-management implies that patients and their medical practitioners will learn to work together to maximise patient contribution and involvement in their own healthcare (Jayasuriya, Roach, Bailey & Shaw, 2001). However, the current study found that GPs are actually a primary gatekeepers for access to this program. They are also a primary source of legitimization of CDSM if they have knowledge about the course. One principle of CDSM is that participants will become partners in their healthcare, but will also rely less on their healthcare providers. In terms of health service usage, there was evidence in the current study that the CDSM enabled people to work collaboratively with their GP and gave them the confidence to ask questions. There was also some evidence that health service usage rates declined in the short-term if participants experienced a reduction in stress and concern about their symptoms. Changes in service usage appeared to be related to changes in the participant’s perception of their illness and their environment rather than as a result of behavioural change. However, changes in perceptions were associated with the course, suggesting a complex relationship between cognitive, behavioural and health factors.

A crucial finding of the current study, however, was the absence of long-term benefits. The majority of positive outcomes from the course returned to baseline levels by 12 months with the exception of those who engaged in a support group. There was a trend for outcomes to be maintained for this group. This evidence indicates that the course must be delivered within an infrastructure that is capable of providing ongoing support and follow-up, particularly in the first year of completing a course. However, other evidence suggested that this need for ongoing support raised concerns for the leaders, many of whom were volunteers and felt threatened by the demand on their time. While they wanted to provide follow-up support, they were usually people who were already fully committed in terms of time. There was clearly a need to sustain the leader network.

In relation to leaders, previous research has indicated that the involvement of ‘lay’ or ‘peer’ leaders contributes to the positive outcomes of the CDSM (Lorig et al., 1998). There was evidence in the current study that participants related well to lay leaders because they have personal experience of the issues faced by consumers. The use of lay leaders can aid in the effectiveness of the CDSM, and can reduce the difficulties associated with involving health professionals in the implementation of a program (Weeks et al., 2003). In turn, self-management programs become more cost effective when managed by lay leaders, which may increase the sustainability of the program (Weeks et al., 2003). The current study has clearly confirmed the importance of lay leaders, but has also highlighted the need for experienced teams of leaders and leaders who are able to manage the complex dynamics of a group.

The group itself was a crucial factor in the success of the CDSM. This finding corresponds with evidence that social support is a critical factor in the adjustment process, potentially mitigating the impact of a disabling condition, ameliorating anxiety and enhancing quality of life (Heszen-Niejodek, Gottschalk, & Januszek, 1999). Although it is possible that a social gathering alone could have facilitated similar outcomes for this population, the evidence suggested that the course simultaneously provided skills that enabled participants to manage their lives more effectively, resulting in a sense of greater organization, less stress and more support. Thus, it is the combination of skills acquisition in a social setting that may be important to the success of the CDSM.
The conceptualisation of self-management that dominates current practice continues to be one in which:

- The individual is perceived as dealing with the consequences of disease illness,
- The individual is perceived as being concerned with problem solving, decision-making and self-confidence, and
- The individual is placed in partnerships with a health professional

In this model, health professionals are primarily responsible for the medical management of the disease with which the individual is faced and for the day-to-day management of the illness. This approach views self-management as an individual concept, framed within a medical model. In contrast to this conceptualization, the current study has indicated that a social model may be a better way to understand and develop self-management as a sustainable intervention. In the current study, responses and ways of self-managing were clearly situated not only in the private lives of individuals but in collective processes where individuals were encouraged and motivated not only by their social supports, but also through the social exchanges and opportunities that arose during the course of participating in the self-management program.

It is readily acknowledged in the disability literature that social isolation and sense of social inclusion are associated with a greater sense of confidence, which attracts more social contact (Kendall et al., 2000). Like other community-based health promotion approaches, building confidence and a sense of control among people with chronic conditions relies on a combination of education, community outreach, maintaining natural community supports and resources and protecting supportive relationships and infrastructures (Kendall et al., 2000). Given the findings of the current study concerning the role of social support, policy makers and professionals must become concerned with activities and interventions that developing both a sense of mastery and control at the individual level and a supportive environment, if we are to change the historical dependence on service providers and continue to support genuine control and choice.
References


