ORIGINAL RESEARCH

Evaluation of a rural chronic disease self-management program

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A B S T R A C T

Introduction: Internationally, the prevalence of long-term health conditions is at epidemic proportions. Australia is no exception. The Australian Government's 'Better Health Initiative' has 5 key strategies to build better health care, one of which is the adoption of self-management and self-management support. Self-management allows people to manage their condition and the consequences it brings to their lives in partnership with their health providers. The purpose of this article was to report both the process and patient outcomes following the introduction of the Stanford Chronic Disease Self-Management Program (CDSMP) into an existing service in an Australian rural setting.

Methods: Implementation processes were evaluated using semi-structured interviews conducted with managers, lay and health professional course leaders and participants about positive and negative aspects of providing the CDSMP. Participant outcomes were evaluated using a modified pre-test, post-test design to evaluate changes in activity participation and self-management knowledge and skills.

Results: Both negative and positive aspects of providing the program were represented by two key themes: (1) program content and quality; and (2) logistics of delivery. Throughout the interviews, managers and leaders, and course participants offered recommendations that were thematically grouped into 3 categories: (1) enhancing quality; (2) improving the logistics; and (3) providing resources. Comparison of activity levels with a community sample indicated that participants had significantly decreased participation levels. Scores on the Health Education Impact Questionnaire v2 (heiQ – RETRO) demonstrated statistically

better scores at post-test on the domains of 'self monitoring', 'insight' and 'health service navigation' with a trend towards significance on 3 other domains.

Conclusions: Future implementation of CDSMPs in rural areas will be encouraged by these patient outcomes, and informed by the qualitative findings from managers, leaders and course participants.

Key words: Australia, chronic disease, evaluation, self-management.

Introduction

Internationally, the prevalence of long-term health conditions is at epidemic proportions, placing considerable emphasis and responsibility on health systems and on the broader community for prevention, management and treatment of the effects and impacts of this disease burden[1]. Nationally, more than 80% of premature mortality, morbidity, disability, injury and health care expenditure is due to chronic disease and injury[1], a burden that has already exceeded previous predictions to 2020[2]. Addressing the increasing burden of chronic disease has been prioritised on the Australian national agenda since 2004[3], with specific strategies to encourage collaborative, multidisciplinary and multi-agency approaches to the identification and management of long-term conditions[3,4], including recent, targeted efforts in the primary health sector[5].

International literature[6] suggests significant health and other system changes are required for the care of people with long-term health conditions, including promoting active consumer involvement and self-management. Evidence[7] for the latter is strong in reducing unplanned hospital admissions and/or length of stay in hospital, more efficient use of health professionals' time and improved self-care capacity and skills[8]. Evidence for positive health outcomes is controversial. While many studies, including randomized control trials, demonstrate benefits, some systematic reviews have concluded that positive health outcomes have only been demonstrated for people with diabetes and hypertension, and not for those with arthritis[9,10]. However, these reviews have been selective in their outcomes of interest[11] examining biomedical outcomes only, deliberately excluding outcomes such as quality of life, self-efficacy and activity participation.

In Australia, policy[2] and priority action funding responses[12] have reflected this evidence, although implementing changes poses significant challenges[11]. The purpose of this article is to report both the processes of implementation and patient outcomes following the introduction of the Stanford Chronic Disease Self-Management Program (CDSMP) into an existing service in a rural setting.

Description and implementation of the Chronic Disease Self-Management Program

During the period 2005 to 2007 a series of innovative service approaches to the management of long-term conditions, including a pilot Stanford Chronic Disease Self Management Program[13] was implemented by the South West Area Health Service (WACHS-SW) in the south west of Western Australia (during 2006 the South West Area Health Service became part of the WA Country Health Service [WACHS], to become WACHS-SW. The term WACHS-SW is used in this article).

A total of seven health professionals and three lay (peer) leaders were trained in the CDSMP, and 3 courses were offered between November 2005 and February 2007. The first 2 courses were jointly lead by a health professional and a peer leader. The last was lead by two health professionals because the lay leader was unavailable.

Three main recruitment strategies were used to promote the program in the catchment area:

1. General practitioners: by briefing sessions, 2 direct mail-outs including a referral template, and fortnightly information faxes.
2. Community: by 2 newspaper articles, 8 community presentations and 4 information stands at 3 shopping centres, all of which provided access to a template for self-referral. (Medical confirmation of a chronic condition following self-referral was not required. Condition inclusion criteria were not specified, although type 2 diabetes and congestive heart failure were highlighted as priorities in all recruitment communications).
3. WACHS-SW staff: by 2 staff briefings, numerous meetings with site management, informal conversations and information on the health service intranet.

Exact enrolment rates (ie the number of people who participated in courses compared with the number who expressed interest) cannot be calculated due to the wide range of formal and informal strategies utilised. However, it was estimated that of the 100 potential participants spoken to, 33 enrolled and 21 attended the 3 courses. No referrals came from GPs.

Methods

Evaluation of the Chronic Disease Self-Management Program

Participants: The Centre for Research into Disability and Society at Curtin University was contracted to conduct the evaluation of implementation processes and selected participant outcomes. All aspects of the evaluation were conducted independently of WACHS-SW management. Ethics approval was granted by the Curtin University Human Research Ethics Committee. Thirteen managers and health professionals and 21 CDSMP course participants received letters of invitation to participate in the evaluation from the research group. One manager/health professional declined;

the other 12 were interviewed. Fourteen course participants took part (two by telephone interview but not the self-report outcome measurement), six declined to be interviewed and one was deceased. A profile of the 12 female and 2 male CDSMP course participants is provided (Table 1). Collectively, the 14 participants self-reported a total of 21 conditions with six of 14 participants individually reporting 3 or more conditions.

Research design/ evaluation tools

Implementation processes were evaluated using semi-structured interviews with consistent verbal prompts, conducted with managers, lay and health professional course leaders and participants about positive and negative aspects of providing a CDSMP in WACHS-SW. Interviews were audio-recorded and transcribed.

Participant outcomes were evaluated using a modified pre-test, post-test design to evaluate changes in activity participation and self-management knowledge and skills. Because the evaluation began post-implementation, tools that provide a pseudo pre-test score were required. Activity participation was evaluated using the Activity Card Sort - Australia Recovery Version (ACS-Aus[14]). The ACS-Aus yields scores for previous, current and percentage of retained activity levels. 'Previous activity level' is defined as any activity performed as an adult, 'current activity level' is defined as any activity in which participants still engage. Knowledge and skills were evaluated with the Health Education Impact Questionnaire v2 (heiQ – RETRO)[15]. This version provides both a current and a previous score, thus allowing a comparison of 2 points in time.

Data analyses

Data were thematically analysed to identify emergent themes as well as positive and negative perceptions of the program.

Table 1: Profile of Chronic Disease Self-Management Program course participants

Profile item	Participants
Age (years; n =14)	Mean 66.65 (SD 11.86)
Sex	12 Female; 2 male
Chronic conditions	Diabetes, stroke, heart disease, rheumatoid arthritis, osteoarthritis, osteoporosis, imbalance, vertigo, meniere's disease, back and shoulder problems, high blood pressure, high cholesterol, hip replacement, cancer, glaucoma, chronic constipation, diverticulitis, depression, agoraphobia, crohn's disease, memory difficulties.
Transport	Driving = 13; not driving = 1
Living arrangements	With partner = 6; with family members = 2; alone = 6
Self-reported areas of required assistance	Cleaning, gardening, wheelchair/walking frame, carer/ carer services, meal provision

Descriptive statistics were first calculated for participant outcomes. Scores on the ACS-Aus were calculated using procedures defined in the ACS protocols, and then compared with data available for community dwelling older adults without a chronic condition. The heiQ-RETRO was scored according to standard protocols to obtain the 2 scores needed for comparisons. Due to the small sample size (n = 12) the non-parametric Wilcoxon signed-ranks test was used for all comparisons.

Results
Implementation process and evaluation

Managers and course leaders identified both negative and positive aspects of providing a CDSMP in WACHS-SW. These were represented by 2 key themes: (i) program content and quality; and (ii) logistics of delivery (Table 2).

Chronic Disease Self-Management Program course participants identified positive and negative aspects in 3 main areas (Table 3): (i) health benefits; (ii) program content and quality; and (iii) logistics of delivery.

Throughout the interviews, managers and leaders, and course participants offered recommendations for setting up a CDSMP, and these have been thematically grouped into 3 categories: (i) enhancing quality; (ii) improving the logistics; and (iii) providing resources. These recommendations have been summarised (Table 4).

Participant outcomes

The ACS-Aus scores are reported (Table 5) and also displayed graphically (Fig1), as are data for 2 comparison groups of adult Western Australians without long-term health conditions. Comparison group 1 consisted of 48 community-dwelling adults aged 75 years or under; comparison group 2 consisted of 45 community-dwelling adults aged over 75 years.

In lieu of pre-test and post-test data the 'previous activity' and 'current activity' levels were compared to determine changing activity patterns of program participants (Table 5). The results indicated a significant drop in activity level in this group over time (Wilcoxon signed ranks test Z = - 2.91; p = 0.004). Because previous activity is defined as 'activities performed as an adult' the comparison must be interpreted with caution. Data from comparison groups is provided to further examine participation levels. Comparisons group 1 had a mean age of 67.94 years, making them similar in age to the WACHS-SW group (Table 5). Visual inspection indicates that all 3 groups had similar previous activity scores. However, while the mean age of the WACHS-SW group was similar to comparison group 1, their current and retained activity scores were more similar in pattern to the older subjects in comparison group 2 than to their age-matched peer group.

Table 2: Managers and leaders - positive and negative aspects of the Chronic Disease Self-Management Program courses

Theme	Managers' and leaders' comments	
	Positive	**Negative**
Program content and quality	• The concept of self-management was positive for clients and participants benefitted from participation in courses • The scripted program and thorough training for leaders contributed to repeatability and quality	• Lack of support from local GPs • Perceived negative impact on local GPs • Lack of knowledge of project as a whole • Health professionals were chosen to be leaders based on the mix of disciplines; individuals were not provided with a choice to be involved, nor were pre-existing group facilitation skills considered • Lack of local autonomy for recruitment, identifying leaders, timing of workshops • Preparation and debriefing time required
Logistics of delivery	• Good location, venue, parking • Program charts produced can be re-used • The first self-management group continues to meet • Low cost to administer • Training was fully funded	• Difficult for participants to obtain the course book • Nutritious and funded tea break was not provided • Recruitment of participants was very difficult • Low attendance in some groups negatively affected the group process • A recurrent budget is required to administer the program • Need to pay lay leaders for their time and mileage, as they play a key and equal role in the workshop and need to be valued[†]

†Lay leaders were reimbursed a set amount for each 6-week course they facilitated.

Table 3: Course participants - positive and negative aspects of the Chronic Disease Self-Management Program courses

Theme	Participants' comments	
	Positive	**Negative**
Health benefits	• The relaxation information (breathing, meditation) helped to improve sleep, manage pain and anxiety • Sharing of information; hearing about other people's situations helped to learn new strategies • A proactive approach to health and medicine (eg taking medication regularly, don't sit around and mope but set a goal and do it) • Increased awareness of what to do to look after oneself • Action planning was rated very useful, but was not maintained by the majority of participants • The first group continues to meet socially. An attempt to do a self-management follow-up was not successful • A ongoing spiritual quality to the support within the first group: several participants described reviewing sentences that described them by other group participants when they were feeling down or experiencing ill health • There was a death in one of the groups, and the participants stay in contact and support the spouse of the participant who died	• Lack of formal follow up after the group finished

Table 3: cont'd

Theme	Participants' comments	
	Positive	**Negative**
Program content and quality	• A universal message presented in a positive way • The leaders who ran it were excellent; knowledgeable, very real people • The lay leader who had a disability was knowledgeable and a living example of someone who had applied the CDSMP principles. Many felt it was impressive to have a lay leader be able to present in such a professional manner • Having both the lay leader and the professional be equals	The CDSM Program is American and was not put into the Australian context (eg living wills section) Some groups included participants who did not have a 'recognised' chronic disease Inadequate leadership qualities and group dynamic skills of some leaders The course quality was impacted when participants recognised a leader who was not comfortable, dedicated and/or motivated to lead the course Reimbursing lay leaders for mileage and time was beneficial because they were equal with health professional leaders
Logistics of delivery	• Parking, location and the room were all satisfactory • Some participants were satisfied with the donation and the amount requested for tea break	The most recent edition the course textbook was not available Two groups had too few people Cost of the textbook was high Some participants considered the cost of tea-break coffee ($3.00 per week) too high

CDSMP, Chronic Disease Self-Management Program.

Table 4: Thematic grouping of recommendations from managers, leaders and course participants

Group	Theme		
	Enhancing quality	**Improving logistics**	**Providing resources**
Manager and leaders	• Educate referral sources to establish a mechanism for continuous referral • Increase staff training in the main CDSMP models - Stanford / Lorig and Flinders • Recruit professional leaders according to interest rather than by assignment to ensure they have the required skills and values, and are prepared to deliver the programs as intended		• Dedicate and secure funding in order to establish a known, well established, regular and on-going schedule of self-management programs • Establish a dedicated (part-time resource) to locally administer and recruit to, and process referrals to self-management programs
Course participants	• Improve participant screening and restrict to participants with 'established' chronic diseases • Ensure a heterogeneous group mix of age and gender • Provide courses to younger people and those who are newly diagnosed to increase support • 'Australianise' the course content, including spelling and the section on wills • Increase the time spent on creating goals and developing action plans. Follow up on developing action plans at 1 and 3 months	• Delay and/or vary the start time, to accommodate the routines of care-givers	• Increase the references and resources on relaxation techniques and on anxiety • Include a summary of the notes and reminders (eg on exercising) • Start a local email list so former participants can support each other and find out how people handle different situations

CDSMP, Chronic Disease Self-Management Program.

The Wilcoxon signed ranks test results of the heiQ – RETRO demonstrated statistically better scores at post-test on 2 of the 8 domains (self-monitoring and insight, and health service navigation) with a trend toward significance on 3 other domains (positive and active engagement in life, skill and technique acquisition, and constructive attitudes and approaches) (Table 6, Fig 2).

Discussion

This evaluation sought to describe patient and process outcomes following introduction of the CDSMP into an existing service in a rural setting. Given the small sample size and pilot nature of the project, participant outcomes were measured to provide early information regarding effectiveness and to guide future research. The evaluation process was considered a useful tool for identifying possible barriers and enablers to program implementation throughout rural and urban Australia[16]. Participant outcomes are first discussed, followed by a discussion of the evaluation recommendations in the context of relevant literature on CDSMP implementation and, where available, within Australian rural practice.

Participant outcomes

The participation levels of participants were measured with the ACS-Aus which provides 3 scores. The previous activity level is defined as 'activities performed as an adult'. In this study, participants had significantly lower participation levels compared with their previous activity levels at some time during their adult life. Because the time span does not correspond with participation in the CDSMP program, no conclusions can be drawn regarding the impact of the program on participation. However, on comparison with healthy older adults living in the community, the WACHS-SW group and older adults in comparisons group 2 both demonstrated a reduction in current activity levels from that

of their earlier adult life, and a lower percentage of retained activities than their peers. Hence it can be concluded that the WACHS-SW program targeted a population in need. Future research should use more rigorous pre- and post-test design to increase understanding of the impact on participation.

The heiQ testing allowed a more precise measure of the impact of the CDSMP on participants, rating their abilities just prior to and just after participation. Even with the small sample size significant improvements were found on the domains of self-monitoring, insight and health-service navigation. Trends toward significance were found on 3 additional domains. As the heiQ was specifically developed to measure improvements in self-management skills, this is an indicator that the CDSMP is relevant and effective in rural communities.

Establishing regular cycles of Chronic Disease Self-Management Program courses with recurrent funding

This series of pilot courses demonstrated improved self-management outcomes for participants. However, a need was identified to allocate recurrent funding in order to establish a regular cycle of CDSMP courses, so that they become part of 'usual care'. International attempts to fully fund and sustainably embed CDSMPs into core practice have experienced varied success within disease-specific, state-wide program coordination planning and funding[17], national healthcare[18], and via a health insurance model[19]. While there is little evidence in Australia of factors that will facilitate the uptake and sustainability of CDSPMP courses[20], a lack of full integration into primary care supported by devolved funding models is considered a barrier to full implementation[13].
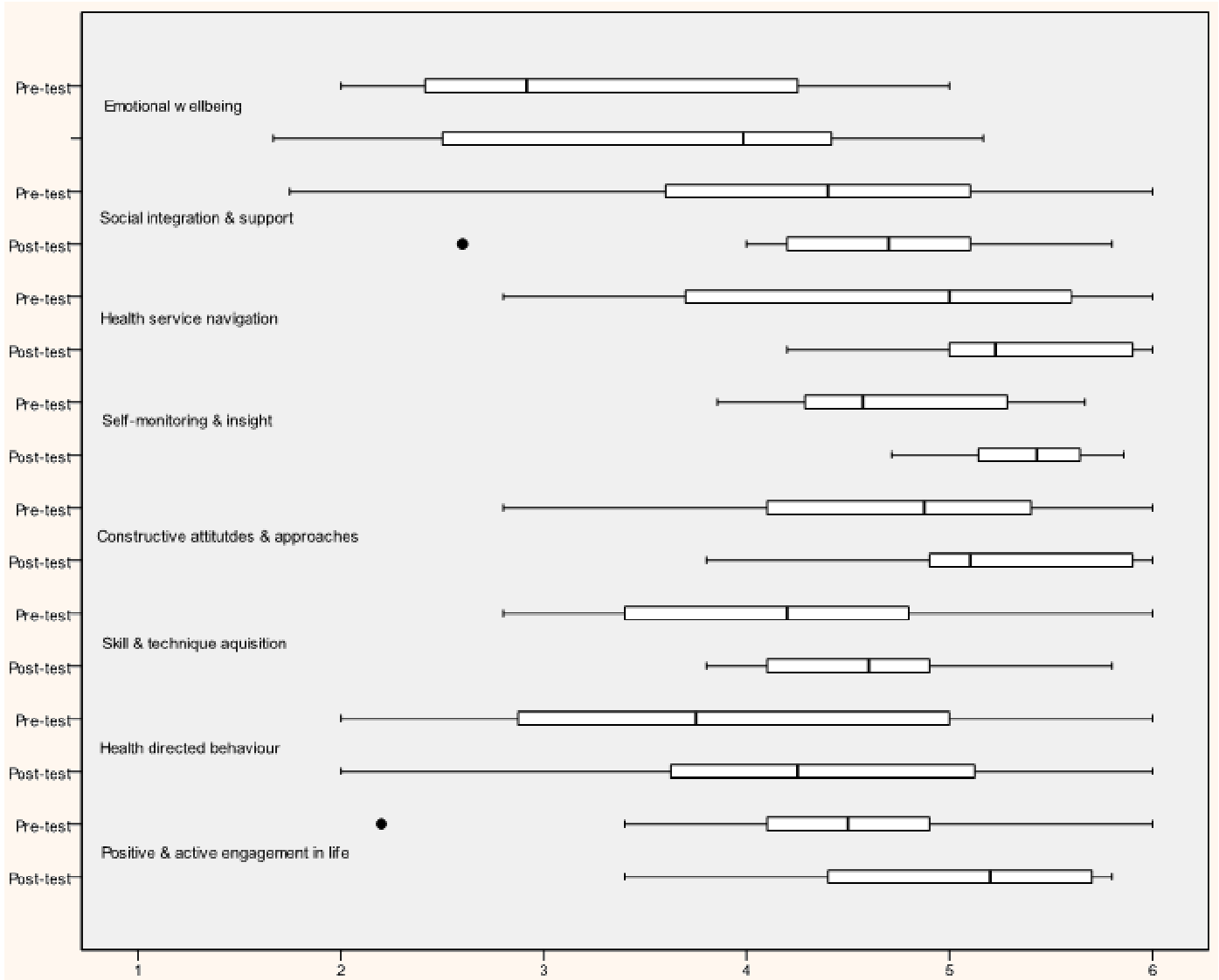
Figure 1: Box plots of the activity card sort for Western Australian Country Health Service – South West participants and 2 comparison groups.

Integrating Chronic Disease Self-Management Program into everyday practice

A whole-of-system approach[18,19] that includes system redesign to focus on continuity of care among service providers[21] and practitioners[20] may assist with integrating the self-management philosophy and principles into everyday practice. This evaluation suggests that, based on demographic and disease-burden profiles within a community, consideration be given to the place of CDSMPs in the local healthcare 'mix' of interventions, that priority costs and processes be identified, and the appropriate resource allocation be provided to maximise program sustainability, an issue of particular importance in rural communities[22,23].

Table 5: Activity card sort scores of the Western Australian Country Health Service – South West participants compared with two other groups of Western Australians

Item scored	Group scores		
	WACHS participants (*n* = 12)	WA Comparison group 1 Age ≤ 75 years (*n* = 48)	WA Comparison group 2 > 75 years (*n* = 45)
Age			
Mean ± SD	68.0 ± 11.3	67.9 ± 4.5	82.2 ± 5.2
Range	49–84	60–75	76–96
ACS Scores			
Previous activity level	56.1 ± 6.2	58.2 ± 7.6	57.5 ± 6.9
Current activity level	49.4 ± 9.6	54.1 ± 8.5	49.2 ± 9.9
% Retained activity	88.8 ± 17.2	93.1 ± 8.2	85.3 ± 12.8

ACS, Activity Card Sort; WA, Western Australians; WACHS, Western Australian Country Health Service – South West.

Table 6: Results of the Health Education Impact Questionnaire

HeiQ Domain	Mean (SD)		Wilcoxon signed ranks test Z score[†]	Significance Level (2-tailed)
	Retro score	Current		
Positive & active engagement in life	4.42 (0.96)	5.03 (0.78)	-1.940	.052[¶]
Health directed behaviour	3.88 (1.25)	4.31 (1.13)	-1.207	.227
Skill and technique acquisition	4.20 (0.95)	4.62 (0.59)	-1.661	.097[¶]
Constructive attitudes & approaches	4.73 (0.93)	5.25 (0.66)	-1.899	.058[¶]
Self-monitoring and insight	4.73 (0.62)	5.36 (0.35)	-2.752	.006*
Health service navigation	4.72 (1.11)	5.35 (0.57)	-1.960	.050*
Social integration & support	4.25 (1.27)	4.60 (0.83)	-1.554	.120
Emotional wellbeing	3.31 (1.07)	3.55 (1.13)	-.653	.514

HeiQ, Health Education Impact Questionnaire.
†Based on negative ranks.
*Significant at *p* = 0.05; ¶trend toward significance (*p* > 0.05 < 0.1).

Establishing and maintaining group leadership skills and responsibilities

Self-management is characterised by a genuine partnership between clients and clinicians[21], a paradigm shift that is not well understood or embraced by all health professionals[13,24,25]. Supporting clients in their attempts to self manage requires healthcare professionals who have a particular interest and belief in the philosophy of self-management and client-centred practice, and whose role to deliver programs is legitimised[25]. Of particular value are general skills in group dynamics and a belief in the behaviour change potential of self-efficacy[26]. Thus, establishing the capacity to deliver courses may be enhanced by identifying a core group of health professional and lay leaders to take full responsibility for program implementation. This would include preparing, scheduling and leading courses; and recruiting, registering and following up participants. Maintaining ongoing capacity, especially in rural areas, requires planned and structured professional development opportunities, including the possibility of at least one person becoming a 'master trainer' to ensure a sustainable resource training base[21].
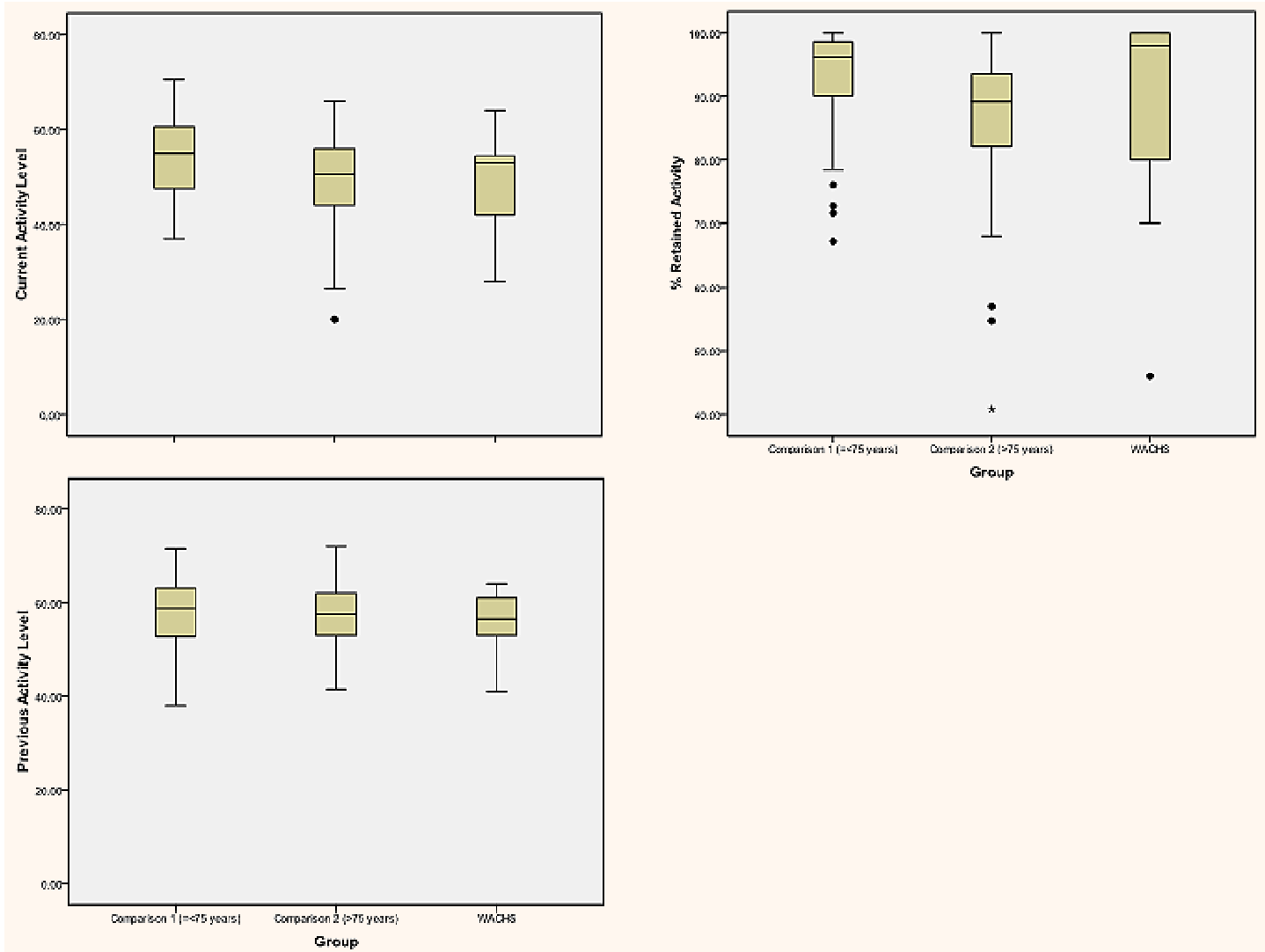
Figure 2: Box plots of the Health Education Impact Questionnaire for Western Australian Country Health Service – South West participants.

In line with overseas findings[19], this evaluation found that lay leaders were well received, and that they need to be included in, and valued within the group of course leaders. To assist with the challenge of retention, they also require specific supports and incentives, with a minimum of a reimbursement for mileage and possibly an ongoing 'retainer' salary, which carries with it additional responsibilities such as assisting with course promotion and wider community education of the goals of self-management programs and the expected benefits to clients. This strategy may help facilitate local ownership of programs[13] and address local needs, especially those of sub-groups[21], all of which contribute to longer-term sustainability.

Group implementation strategies

Recruiting, screening, and reducing cancellations: Recruitment to the 3 locally-run courses appears to have reached those in need of self-management intervention. Levels of retained activity were lower in WACHS-SW participants than in a similar aged peer group without disabilities. This finding supports those from an earlier study in rural Australia, and warrants further investigation, in particular to identify if activity loss is more pronounced in rural than urban communities[22]. However, in the present evaluation, these findings contrasted with interview data indicating that not all participants had what would be generally considered a 'chronic condition'. This could be overcome by using a standardised screening tool designed to identify eligibility[27], including health conditions, and informing care by a multidisciplinary team[28]. Engaging GPs in the recruitment process may also assist in confirming condition status, and in supporting appropriate referral to programs in the longer term[20,22] via standardised referral pathways[21].

General practitioners can also assist program sustainability through personalised and targeted recruitment strategies, such as a signed letter sent to patients by direct mail, recommending a CDSMP to meet a patient's identified needs. Using uncomplicated language may help in reaching those who have lower literacy levels, which can be a limiting factor in rural program delivery[22]. Cancellation rates following course registration can be reduced by simple and cost-effective strategies, such as a reminder phone call following a direct mail out[21]. Together, these strategies may all be complemented by the use of media and community partnerships to improve coordination and access, and to broaden the reach of community-based programs[13].

Contextualise the Chronic Disease Self-Management Program: While exact enrolment rates were not able to be calculated due to the wide range of formal and informal strategies used, approximately one-fifth of all potential participants spoken to attended CDSMP courses, and no referrals came from GPs. Recruiting participants was difficult, with some not recognising the course as a Chronic Disease Self-Management Program. This finding is consistent with the generally low profile, and 'newness' of CDSMPs in Australia[11]. A variety of mechanisms is required to convey messages and to encourage clients to consider alternative ways to manage their health[29]. As such, future implementation could consider conducting research into appropriate and localised marketing strategies, taking into account the local context, population demographic (including long-term condition profile) and self-care needs, specific descriptions of what is being offered and the benefits of attending CDSM courses[30].

Implementation of follow up for participants: Course participants cited lack of post-course follow up as a gap that reduced overall program quality. Access to follow up and review are deemed standard best practice management of long-term conditions and should be included in all program structures[6]. Course participants found scheduled face-to-face meetings with each other and with course leaders to be helpful after courses had finished. Other forms of follow up can be less formal, and may include online meetings and hard-copy and email newsletters via distribution lists.

Limitations

Research design: There are several limitations to the evaluation process and research design reported in this article:

Because the evaluation was undertaken after the CDSMP was completed, true pre-test values were not available, nor was there a control group for comparison.

- Measurement tools were chosen to account for this limitation, and for their capacity to identify any measure of relative change between pre- and post-test, and to describe the participants in the CDSMP relative to a population without chronic conditions.
- Small numbers of participants attended the CDSMP and took part in this evaluation. Even with this small sample size and associated low power,

significantly improved self-management behaviours were demonstrated in 2 of 8 domains with a trend to significance in 3 others. Further research using a larger sample to guard against type II error, and more rigorous testing are warranted to further understand effect on health outcomes and participation in activities following courses.

Conclusions

The evaluation findings reported in this article revealed that participants demonstrated fewer retained activities than their peers without long-term conditions. Despite this apparent loss, trends toward significant improvements were found on 2 heiQ-RETRO domains, along with significant improvements on 3 domains. These are powerful finding given the limitations imposed by the nature of the intervention in practice, the small participant numbers and the compromised research design.

Future implementation of CDSMPs within the WACHS will be encouraged by these patient outcomes, and informed by the qualitative findings from managers, leaders and course participants. Together, these findings may have application for implementation of CDSMPs in other rural and regional areas of Australia.

Acknowledgements

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