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Version: Version of Record

Link(s) to article on publisher’s website:
http://dx.doi.org/doi:10.1016/j.pec.2014.08.022

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Self Management

An evaluation of a self-management program for patients with long-term conditions

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ARTICLE INFO

Article history:
Received 18 March 2013
Received in revised form 3 June 2014
Accepted 30 August 2014

Keywords:
Long-term conditions
Self-management program
Patient activation
Co-delivery

ABSTRACT

Objective: To evaluate a group-based self-management program (SMP) delivered as part of a quality improvement program, Co-Creating Health, for patients living with one of four long-term conditions (LTCs): chronic obstructive pulmonary disease, depression, diabetes, and musculoskeletal pain.

Methods: The 7 week SMP was co-delivered by lay and health professional tutors. Patients completed self-reported outcome measures at pre-course and 6 months follow-up.

Results: 486 patients completed (attended ≥5 sessions) the SMP and returned pre-course and 6 months follow up data. Patients reported significant improvements in patient activation (ES 0.65, p < 0.001), with 53.9% of all patients reporting a meaningful >4 point improvement. Health-related quality of life (ES 0.06, p = 0.04), and health status (ES 0.33, p < 0.001) were also significantly improved. Patients’ anxiety (ES 0.37, p < 0.001) and depression (ES 0.31, p < 0.001) significantly improved. Patients also reported significant improvements in their self-management skills (p values from p < 0.001 to p = 0.028).

Conclusion: Attending the SMP led to improvements in a range of outcomes. Improvement in patient activation is important, as activated patients are more likely to perform self-care activities.

Practice implications: Co-delivered SMPs provide meaningful improvements in activation for >50% of those who complete and are a useful addition to self-management support provision.

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1. Introduction

The burden of noncommunicable diseases (NCDs), which are also known as long-term conditions (LTCs), is rapidly increasing worldwide [1] and it is predicted that by 2020 LTCs will account for almost three-quarters of all deaths worldwide [2]. By 2025 the number of people in England with at least one LTC will rise by 3 million to 18 million [3]. Government policy places emphasis on self-management as a means of improving the management of LTCs, and supporting patient participation in healthcare is seen as a key mechanism to improve self-management [4,5]. National Health Service quality improvement programs position patient centeredness and patient involvement, as well as self-management support for LTCs, at the heart of government initiatives [6]. Many patients with a LTC want to participate more in their health care and would feel more confident with the support and encouragement from their health care provider. However, the majority of patients feel this support and encouragement is currently lacking [7]. Nearly two-thirds of patients also believe that their confidence to self-care would increase with the provision of support from others who had similar health concerns [7]. The push towards greater involvement of people in their own care reflects the pressure on the NHS from the rising number of people with LTCs.

In the UK, self-management programs (SMPs) delivered by patients (lay-led), such as the Expert Patient Program (EPP), have emerged. A systematic review and meta-analysis involving nearly 7500 LTC patients who attended lay-led and lay and health professional co-delivered SMPs reported small improvements in self-efficacy, depression, pain, disability, fatigue, self-rated health, aerobic exercise and cognitive symptom management [8]. The largest UK randomized controlled trial of the EPP showed improvements in energy, self-efficacy and other psychosocial outcomes and that it was cost-effective [9]. Despite these benefits, primary and secondary care services were reluctant to engage with
the EPP [10]. Evidence suggests patients in the EPP feel that the inclusion of health care practitioners to provide condition specific information would be a useful addition to the valuable social modelling provided by lay tutors [11].

The Health Foundation, which is an independent charity working to continuously improve the quality of healthcare in the UK, sought to develop a national quality improvement demonstration program. The approach, called Co-Creating Health (CCH), was influenced by the policy context around self-management in the UK and on reviews of research and practice, and emerging quality improvement programs, especially those using some or all of Wagner’s chronic care model (CCM) [12]. According to the CCM, one of the main objectives for health services is to support self-management, which needs to be embedded in a system that includes knowledgeable and confident patients, prepared clinicians and a responsive and flexible administrative structure [13]. Hence, CCH provides support at the patient, clinician and service level.

In this paper we describe the development and evaluation of an SMP for patients with a LTC. CCH Clinician self-management support practices are reported elsewhere[14,15]. The primary aim of this evaluation was to see whether the SMP improved patient activation, which refers to the extent that patients have the knowledge, skills, and confidence to use self-management support skills in their lives [16]. The evaluation also looked at whether the SMP improved health related quality of life, health status, mental health and self-management skills.

2. Methods

2.1. Patients and procedure

Each of the CCH demonstration sites spanned primary and secondary care. CCH focused on four LTCs: chronic obstructive pulmonary disease (COPD), depression, diabetes, and musculo-skeletal pain across eight NHS sites, with two sites each focusing on the same condition. LTC patients seen in primary or secondary care settings were informed by their healthcare provider about the SMP. LTC patients' inclusion criteria were to be over 18 years of age, have one of the four LTCs of interest (COPD, depression, diabetes and pain) and be physically able to attend a seven session group-based SMP. The SMP was delivered for groups of patients with the same LTC, so that patients recruited from COPD sites attended a COPD specific SMP, and the same applied for the other three conditions. Patients' comorbid status was not a factor for recruitment to the SMP. Data were collected from patients who attended SMPs between 2007 and 2011. The study protocol was approved by the Brighton and Hove City Teaching PCT Multi Center Research Ethics Committee 07/H1107/143.

2.1.1. Procedure

Patients who wished to attend the SMP registered their interest via a dedicated recruitment telephone helpline. The contact details of patients who consented to take part in the evaluation were passed to the evaluation team. Pre-course questionnaires (Time 1) were mailed out to patients by the evaluation team. Reminder and follow-up calls prior to attendance were made to improve response rates. In keeping with the real world setting of the evaluation, LTC patients who chose not to participate in the evaluation were not excluded from the SMP. All patients were mailed out 6 month follow-up questionnaires (Time 2). Two reminder follow-up contacts were made. During the second attempt patients were offered the option to verbally complete the primary outcome measure, the Patient Activation Measure.

2.2. Intervention

The Health Foundation commissioned the Expert Patient Program Community Interest Company to develop the SMP. The Co-Creating Health SMPs are four condition specific programs, which are supplemented by generic core modules and activities (e.g. goal setting, problem solving, and relaxation). Table 1 provides a description of the course content.

The condition specific content was developed by the demonstration sites, with input from clinicians and patients who were

<table>
<thead>
<tr>
<th>Session number</th>
<th>Session activities</th>
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<tbody>
<tr>
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<td>What is self-management? How is it different from before?</td>
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<td>Balancing life with a long term condition</td>
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<td>What is . . . (diabetes, COPD, depression, pain). . . ?</td>
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<td>Boom and bust-over-activity/under-activity</td>
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<td>Condition specific activity</td>
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<td>Counting blessings/saying thanks</td>
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<td>Condition specific activity</td>
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<td>Managing setbacks</td>
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<td>Setting the agenda</td>
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<td>Making the most of our consultations with health professionals</td>
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<td></td>
<td>Physical activity/relaxation</td>
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<td>What have we covered? Should we revisit anything?</td>
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<td>Goal setting and planning for action</td>
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* Condition specific activities were different for all of the four long-term conditions.
members of the demonstration site project steering group. The SMP was a 7 week, 3 h group-based SMP co-delivered by a health professional tutor (e.g. psychologist, clinical nurse specialist, physiotherapist) who worked locally in the relevant pathway of care, and a patient (lay) tutor who had experience of these services.

The SMP is grounded in social learning theory [17] and includes four efficacy enhancing strategies: skills mastery, social modelling, social persuasion and reinterpretation of symptoms. Tutors attend 4 days of classroom based training, which involves brief motivational interviewing and behavior change skills, group facilitation skills and delivery practice of the SMP activities. Delivery is guided by a tutor’s manual to ensure consistency of delivery and content. Tutors are trained and accredited to a rigorous set of quality standards with training and course delivery focusing on adherence to the timing, sequence and coverage of activities as set out in the manual to ensure fidelity. All activities can be either delivered by the health professional or lay tutor. Tutors decide in advance which activities they would like to lead on. Our observations of the SMP (reported elsewhere) using process evaluation using a Self Determination Theory [18] showed co-delivery was a successful model and that lay and health professional tutors had similar motivational styles to promote participant engagement and learning [19].

2.3. Outcome measures

Demographic information such as age, gender, employment status and co-morbidity, was collected at baseline only. A range of outcome measures was selected to best capture the important outcomes of the SMP.

2.3.1. Patient Activation Measure (PAM)

The PAM assesses patient activation [16], which is conceptually similar to self-efficacy [17]. It comprises 13 items that assess patient knowledge, skill and confidence for self-management. The PAM has a theoretical range from 0 to 100. Higher scores indicate greater activation. An improvement in 4 points on the PAM scale is considered meaningful as this is the level of increase which is associated with performing a range of self-management behaviors [20–22].

2.3.2. EuroQol

The EuroQol index (EQ 5D index) and the EuroQol Visual Analog Scale (EQ VAS) are widely used measures of health status and health-related quality of life respectively [23]. The EQ-5D index assesses patients’ health state across five dimensions (self-care, mobility, anxiety/depression, usual activities and pain/discomfort) that are weighted to provide a utility value based on a population tariff, scores range from 0 (death) to 1 (perfect health). The EQ VAS is a vertical rating scale health scored between 0 (worst imaginable health) and 100 (best imaginable health).

2.3.3. Hospital Anxiety and Depression Scale (HADS)

The Hospital Anxiety and Depression Scale (HADS) [24] provides separate scores for anxiety and depression ranging from 0 to 21, with higher scores indicating greater anxiety and greater depression. Scores ≥11 are considered to indicate probable clinical anxiety and depression (“cases”).

2.3.4. Health Education Impact Questionnaire (heiQ)

Self-management ability was measured using the heiQ [25]. Patients are asked to rate items on a 4 point likert scale ranging from “strongly disagree” (1) to “strongly agree” (4). Higher scores represent higher levels of self-management abilities. The eight scales are: positive and active engagement in life; health directed behavior; skill and acquisition technique; constructive attitudes and approaches; self-monitoring and insight; health services navigation; social integration and support; emotional well-being.

Condition specific measures for COPD, depression, diabetes and pain were also collected at baseline and 6 months follow-up. Interviews were also conducted with patients and tutors across all 4 conditions. These data are reported separately in other publications [26].

2.4. Analysis

All data analyses were conducted using IBM SPSS Statistics 20. The main analysis involved only those patients who attended ≥5 SMP sessions (defined as course completers) and returned 6 month follow-up questionnaires. The level of statistical significance was set at p = 0.05. An intention to treat (ITT) analysis was also performed on all patients, irrespective of the number of sessions attended to ensure that the effectiveness of the program has not been overestimated. Missing 6 month follow-up data (T2) were replaced with baseline data, last observation carried forward.

Changes in the mean values of the patient outcomes were compared over time using paired t tests and General Linear Model for repeated measures. The outcome variables were normally distributed. For the main analysis only important prognostic factors such as age, gender, long-term condition, co-morbidity, number of sessions attended and socioeconomic factors (education, employment status) were adjusted for using analysis of covariance. Effect sizes (Cohen’s d) [27] were calculated using the following calculation: the mean score at 6 months minus the mean score at baseline divided by the standard deviation at baseline. Recommended boundaries [27] were used to determine small (0.2), moderate (0.5) and large effect sizes (0.8). The heiQ scale developers recommend a distribution-based cut-off of ES = 0.5 as a standardised cut-off [28]. Based on this cut-off, three categories of change were defined: ‘substantial improvement’ (ES >0.5), ‘minimal/no change’ (−0.50 < ES < 0.50), ‘substantial decline’ (ES < −0.5). We also looked the proportion of patients whose PAM scores improved by 4 points. Changes in “caseness” for anxiety and depression between baseline and 6 months follow-up were tested using McNemar’s test.

3. Results

3.1. Demographic variables

In total, 1850 patients contacted the EPPCiC recruitment helpline, and of these, 563 (30%) patients did not register to attend the SMP. 1170 patients completed baseline questionnaires, and 568 patients (49%) completed 6 months follow-up questionnaires. Patient characteristics are summarised in Table 1. Patients were on average 56.3 years of age, predominantly white ethnicity and female. A quarter were in full or part time employment. Nearly two-thirds had a co-morbid condition. Musculoskeletal pain patients were the largest patient group (31%).

SMP completion rates (≥5 SMP sessions) averaged 69% (805/1170) across all 4 LTcs. Where we could establish direct pairing of data from patients who completed baseline and 6 month surveys and who attended ≥5 SMP sessions for the main analysis, there were 486 matched PAM scores. Response rates were lower for other outcome measures as we only collected PAM data at

1 Missing data for 47 patients and these were deemed to have attended ≤4 sessions 12 patient activation over time. ITT analysis produced similar results. 53.9% of patients showed a meaningful improvement (i.e. ≥4 points) in patient activation scores.
6 months follow-up among those patients who were subject to repeat follow-up attempts.

Patients who completed the SMP tended to be significantly older (mean age 59 years compared to 55 years), significantly less anxious (mean 10.0 compared to 10.9) and significantly less depressed (mean 8.0 compared to 8.6) than those who dropped out of the SMP (attended 0–4 sessions). These findings are confounded with the lower completion rates among patients with depression (63% compared to CCH average of 69%), who also tended to be younger and more anxious than patients with other LTC diagnoses. There were no other demographic differences, between patients who completed the SMP and those patients who did not complete the SMP on variables of gender, ethnicity, house ownership, living arrangements, education, employment, co-morbidity, patient activation, health status or quality of life (Table 2).

3.2. Outcomes

3.2.1. Patient activation

Patient activation significantly improved 6 months after completing the SMP (p < 0.001, effect size = 0.65) (Table 3). None of the prognostic and demographic factors predicted patient activation over time. ITT analysis produced similar results. 53.9% of patients showed a meaningful improvement (i.e. ≥4 points) in patient activation scores.

3.2.2. Health status and health-related quality of life

Patients’ health status as measured by EQ-VAS significantly improved 6 months after completing the SMP (p < 0.001, ES = 0.33) (Table 2). None of the prognostic and demographic factors predicted health status over time. Intention to Treat (ITT) analysis produced similar results.

Patients’ health-related quality of life significantly improved 6 months after completing the SMP (p = 0.042, ES = 0.06) (Table 2). Condition was a predictor of change in quality of life over time (p < 0.045). Health-related quality of life was lower at baseline for depression and patients with musculoskeletal pain in comparison to that of patients with COPD and patients with diabetes.

Furthermore, improvements at 6 months follow-up were greater in these patients. ITT analysis produced similar results.

3.2.3. Psychological distress

Patients’ anxiety and depression decreased significantly 6 months after completing the SMP (both p < 0.001, ES = 0.37 and 0.31 respectively) (Table 2). Condition was a predictor of change in anxiety over time (p < 0.001). Patients with depression and musculoskeletal pain had higher levels of anxiety at baseline compared to patients with COPD and patients with diabetes. Furthermore, their improvement was greater at 6 months follow-up. Condition was also a predictor of changes in depression over time (p < 0.001). Patients with depression and patients with pain had higher levels of anxiety at baseline compared to patients with COPD and patients with diabetes and their improvement was greater at 6 months follow-up. ITT analysis produced similar results. At baseline 39.8% of patients were clinically anxious (caseness (≥11)) and at 6 months follow-up this had significantly reduced to 29.7% (p < 0.001). Compared with baseline, 17% moved from clinical to non-clinical anxiety, 7% moved from non-clinical to clinical and 76% stayed the same. At baseline 25.6% of patients were clinically depressed (caseness (≥11)) and at 6 months follow-up this had significantly reduced to 16.0% (p < 0.001). Compared with baseline, 15% moved from clinical to non-clinical depression, 6% moved from non-clinical to clinical and 79% stayed the same.

3.2.4. Self-management skills

Patients’ self-management skills in all eight heiQ domains significantly improved 6 months after attending the SMP: Health Directed Behavior: (p = 0.028); Positive and Active Engagement; Emotional Well-Being; Self-Monitoring and Insight; Constructive Attitude Shift; Skills and Technique Acquisition (all p < 0.001); Social Integration and support; p = 0.002, and Health Service Navigation (p = 0.012). Effect sizes ranged from 0.67 for Skills and Technique Acquisition to 0.17 for Health Service Navigation (Table 2). Condition was a predictor of change in three of the domains: patients with depression reported a statistically significant improvement over time on Positive and Active Engagement, Constructive Attitude Shift (both p < 0.001) and Social Integration and Support (p < 0.002). Patients with diabetes also reported an improvement in this domain (p = 0.03). ITT analysis produced similar results. About a quarter of patients showed substantial improvements in self-management skills, the exceptions being skill and technique acquisition (35.4%) improvement and health service navigation (18.3%) (Table 4).

4. Discussion and conclusion

4.1. Discussion

The WHO has called upon all countries to provide interventions, including self-care interventions, to address the worldwide LTC epidemic [29]. This study, which describes an evaluation of a group-based SMP carried out in a real world health care setting showed that, it has the potential to improve patient activation, quality of life, psychological distress and self-management skills.

We do not know the total number of LTC patients who were approached by health care staff at each site to register with the SMP recruitment helpline. We do know that 30% of patients who contacted the recruitment helpline did not subsequently attend the SMP.

The SMP completion rate, (≥5 sessions) among those who completed the pre course questionnaire, of 69% compares favourably against those of two other UK self-management studies, which reported completion rates of 60% [9] and 51% [30]. Factors affecting uptake, such as being referred by a known
clinician, who also co-delivered the SMP may have contributed to the high completion rates achieved. We have reported elsewhere that the co-delivery model was well received by patients [19].

Generally, more men, ethnic minorities, people who lived alone, who had no educational qualifications and did not own their own homes, attended the SMP when compared to other UK self-management programs [9]. This suggests that the SMP was relatively successful at recruiting patients who traditionally do not attend self-management programs.

Irrespective of condition, patients who completed the SMP were more activated. The 8.0 point mean improvement in the PAM score compares to a 4.7 mean improvement reported by patients attending a similar self-management program in the United States [31]. Over half (53.9%) of patients reported a meaningful (≥4 point) improvement in activation. Improved activation on the PAM is important because other research has shown that activated patients are more likely to participate in collaborative decision-making with their clinicians, report improved health-related behaviors and clinical outcomes and adhere to physical therapy [32,33].

Patients with depression and patients with musculoskeletal pain enjoyed better health status after attending the SMP. Only patients with depression enjoyed a significantly improved health related quality of life as measured by the generic EQ VAS. Two other self-management studies [34,35] similarly found no improvement using the EQ VAS among patients with arthritis and patients with COPD respectively. A recent meta-analysis of Stanford University’s arthritis self-management programs (ASMP) and generic chronic disease self-management course (CDSMC) suggested that improvements in quality of life might take longer (i.e. >12 months) to emerge compared to other outcomes such as self-efficacy [36]. Further, it has been suggested that some generic measures may not be sensitive enough to adequately capture quality of life improvements after attending self-management programs [37].

Patients with depression and patients with musculoskeletal pain, who were more anxious and depressed at baseline compared to patients with COPD and patients with diabetes, reported significant reductions in these outcomes at follow-up. More patients, approximately 10%, were no longer clinically anxious or depressed. NICE recommends a collaborative care approach for LTC patients with co-morbid mental health problems in primary care which includes patient education and self-management support [38].

The finding that patients across all 4 conditions were significantly more often using self-management skills and techniques, as measured by the heiQ subscale skills and technique acquisition, is important given that the primary aim of the SMP is to enhance patients’ ability and capacity to self-manage their condition. Patients with depression showed improvements in 7 out of 8 domains, and patients with diabetes showed improvements in 6 out of 8 domains. These patients were using more self-management techniques compared to patients with COPD and patients with musculoskeletal pain who showed improvements in 2 out of 8 domains. Where improvement occurred most of the effect sizes were small. It has been argued that modest effects have public health significance when experienced on a population level [34]. Patients with depression had lower self-management scores at baseline compared to patients with the other three conditions and so had more opportunity to improve. Recent evaluations of the Stanford University, lay-led, Chronic Disease Self-Management Programme has shown improvements in depression and other health outcomes for people living with serious mental health conditions [39,40]. The finding that self-management programs can benefit patients with depression and other serious mental health conditions is noteworthy. Mental ill health accounts for 13%
of all lost years of healthy life globally, rising to 23% in high-income countries [41,42].

For most of the heIQ domains approximately a quarter of patients made substantial improvements, the exception being in skill and technique acquisition where more than a third reported substantial improvement. This is lower than reported by LTC patients in Australia, which showed that one third of patients showed substantial improvement in the majority of the heIQ domains [28]. The difference could be explained by the fact that Australian data were collected at post-course whereas our data were collected at 6 months follow-up and there may be some attenuation of effects.

4.1.1. Limitations

The questionnaire return rate at 6 months is lower than we have achieved in other self-management evaluations (e.g. 83% [34] and 80% [43]). We are unsure as to the exact reasons why this lower return occurred and can only speculate that the pragmatic, real world design of the study, where greater emphasis and importance were afforded to implementation and delivery of the interventions rather than to the recruitment and retention of patients in the evaluation, could have impacted on this. The main analyses on SMP completers (attended ≥ 5 sessions) present the most favourable estimation of outcomes as it focuses only on those patients who received a high dose of the SMP and completed baseline and 6 month follow-up questionnaires.ITT analyses showed similar improvements at 6 month follow-up, but were of a smaller magnitude.

The biggest limitation is the lack of a control group, which means that there are alternative explanations for the improvements reported by patients completing the SMP. However, the size of improvements is generally consistent with randomized controlled trials of S MPs which are similar in process and content [9,28,34,43,44]. Future research designs should involve a randomized controlled trial of the SMP using alternative self-management interventions as a comparison group. Clinical outcome (e.g. HBA1c for diabetes and FEV1 for COPD) and health care utilisation data should also be collected in any future studies.

4.2. Conclusions

Over half of all patients made meaningful improvements in patient activation after completing the SMP and about 10% were no longer classified as “cases” for anxiety and depression. A quarter of patients reported substantial improvements in self-management skills. Targeting and recruiting patients, especially patients with depression, with greater needs will deliver the greatest benefits.

4.3. Practice implications

Over twenty countries provide a version of the Stanford University SMP, which is delivered by lay tutors [45] and continues to be positively evaluated [46]. This evaluation showed that a co-delivered (lay and professional tutor) SMPs can produce meaningful improvements in important outcomes such as activation, self-management skills and psychological distress for LTC patients. The SMP can be embedded in existing pathways of care at relatively low cost and has a potential to generate significant health care savings if improvements in activation are translated into lower use of services.

Consent

I confirm all patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the story.

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