
Health Service Research

The Chronic Disease Self-Management Program: the experience of frequent users of health care services and peer leaders

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Abstract

Background. Large amount of evidence supports the contribution of the Stanford Chronic Disease Self-Management Program (CDSMP) to a global chronic disease management strategy. However, many studies have suggested further exploring of the factors influencing acceptance and completion of participants in this program.

Objective. This study aimed to describe and examine factors associated with acceptance and completion rates of the CDSMP among frequent users of health care services, and to highlight the experience of patients and peer leaders who facilitated the program.

Methods. A descriptive design with mixed sequential data was used. Acceptance and completion rates were calculated and their relationship with patient characteristics was examined in regression analysis ($n = 167$). Interviews were conducted among patients who accepted ($n = 11$) and refused ($n = 13$) to participate and with the program coordinator. Focus groups were held with the seven peer leaders who facilitated the program. Data were analysed using thematic analysis.

Results. Of the 167 patients invited, 60 (36%) accepted to participate in the program. Group format was the most frequent reason to decline the invitation to participate. Twenty-eight participants (47%) completed the program. Participants who dropped out during the program raised different reasons such as poor health and too much heterogeneity among participants. Factors such as location, schedule, content, group composition and facilitation were considered as important elements contributing to the success of the program.

Conclusion. The CDSMP could therefore be considered as a self-management support option for this vulnerable clientele, while taking measures to avoid too much heterogeneity among participants to improve completion rates.

Key words. Chronic disease, frequent users, mixed-method, primary health care, program evaluation, self-management, support group, Stanford.

Introduction

Self-management support implies different ways health care professionals or peers support patients in the self-management of tasks related to their conditions. The Stanford Chronic Disease Self-Management Program (CDSMP) has already proven its value for different conditions (1). This program is based on the premise that all people with chronic diseases share similar preoccupations and have the capacity to take responsibility in managing several aspects of their health. This standardized program proposes weekly 2.5-hour meetings of 10–12 people for 6 weeks, facilitated by 2 peer leaders with chronic diseases. During group meetings, several issues are discussed: techniques to deal with problems such as frustration, fatigue, pain and isolation; appropriate exercise for maintaining and improving strength, flexibility and endurance; appropriate use of medication; communicating effectively with family, friends and health professionals; nutrition; decision-making and how to evaluate new treatments (2). Peer leaders follow standardized training to become accredited as facilitators in the program.

A few studies on CDSMP using quantitative (3–7) and mixed (8) methods examining factors associated with completion (attendance greater than or equal to four out of six sessions), documented that participants reporting depression were less likely to complete the program (3), while completion rates for participants aged 75 years or more were higher than for younger participants (8). Participants who perceived better health were more inclined to complete the CDSMP (4). Completion was not influenced by race/ethnicity or socio-economics (4). Studies seldom report on implementation success or failure. In a study examining patient perceptions of the impact of the CDSMP (5), participants reported various positive effects of the program: from having a profound impact on one area to affecting all aspects of their lives. A systematic review by Foster *et al.* (1) concluded that further research was required to explore qualitatively how participants experience the CDSMP, and such issues as why people drop out.

The aim of this study was to describe acceptance and completion rates of the CDSMP in primary care among frequent users of health care services with chronic diseases, to examine factors associated with acceptance and completion and to highlight the experience of this clientele and peer leaders.

Methods

Design

A descriptive design with mixed sequential data, quantitative and qualitative was used. The quantitative part was a cross-sectional predictive correlational design examining associations between patient characteristics (independent variables) and acceptance or completion of the CDSMP (dependent variable). The qualitative data were collected through a descriptive qualitative approach as defined by Sandelowski, incorporating individual and focus group interviews (9).

Context

This study took place in the context of an implementation analysis of the VISAGES project, described elsewhere (10), aimed at implementing and evaluating a 6-month case management intervention by a nurse and the CDSMP in 4 (4) family medicine groups (FMG), including 38 practices, in the Saguenay-Lac-Saint-Jean region of the Province of Quebec (Canada). A FMG is an administrative arrangement for existing practices in which primary care physicians are

grouped together to collaborate with nurses to offer primary care services to a group of registered patients.

Study participants

Patients had to be aged between 18 and 80 years, with at least one chronic disease (diabetes, cardiovascular, respiratory or musculoskeletal disease or chronic pain) and targeted by their family physician as a frequent user of health care services who would benefit from participating in a case management intervention by a primary care nurse (10). The family physicians received a list of their frequent users (who consulted the Emergency Department and/or were hospitalized three or more times in the previous year). The CDSMP was explained and offered to each patient by his or her case management nurse. Groups included patients with different chronic diseases.

In total, 167 frequent users of services who were recruited for case management were also invited to participate in the CDSMP, of whom 60 accepted. Of these 167 frequent users, a sample of 24 patients (Tables 1 and 2) was selected for an interview between November 2013 and October 2014, using a maximal variability sampling approach regarding their age, sex, clinic, chronic disease and acceptance ($n = 11$) or decline ($n = 13$) to participate in the CDSMP (11). Patients with severe cognitive impairment, uncontrolled psychiatric illness or a serious hearing deficit were excluded from the study. All peer leaders with chronic diseases or having a family member with chronic diseases ($n = 7$, Table 3), who facilitated the sessions, took part in a focus group (A or B). An interview was conducted with the coordinator ($n = 1$) who implemented the program.

Data collection

Quantitative data

Of the 167 patients invited to participate in the CDSMP, acceptance and completion rates (attendance to four or more sessions) were calculated. Characteristics of participants were measured with self-administered questionnaires in the presence of a research assistant. Socio-demographic data (age, sex, marital status and family income) were obtained. The other variables were measured using validated French-language versions of these instruments: patient activation measured with the Patient Activation Measure (12); multimorbidity measured with the Disease Burden Morbidity Assessment (13);

Table 1. Characteristics of the participants in the CDSMP and in the qualitative interviews ($n = 11$)

Patient	Age	Sex	Marital status	Annual family income (CAD) (2013–14)	Number of meetings attended
01	65	Male	Divorced	15 000–19 000	5
02	70	Female	Married	30 000–34 000	5
03	34	Female	Married	45 000–49 000	1
04	72	Female	Widowed	15 000–19 000	1
05	48	Male	Married	30 000–34 000	6
06	55	Male	Married	≥50 000	6
07	74	Male	Married	40 000–44 000	1
08	76	Male	Married	≥50 000	6
09	54	Male	Divorced	40 000–44 000	5
10	77	Female	Married	25 000–29 000	6
11	72	Female	Married	≥50 000	4

CAD, Canadian dollars.

health literacy measured with the Newest Vital Sign (14); mental health measured with the Hospital Anxiety and Depression Scale (HADS) (15).

Qualitative data

In-depth interviews with 24 patients and the coordinator of the program, and 2 focus groups with 7 peer leaders, were used to capture the richness and nuances of their experience. After providing written informed consent, patients, peer leaders and the coordinator completed a short demographic questionnaire and participated in a 1-hour interview, or focus group, conducted by a social worker (DB). The interview guide included open-ended questions asking them to describe their needs and previous experience with health care services (patients only); the reasons why patients chose to participate or not in the CDSMP (all) and the reasons why they dropped out and their experience with the program (all). All interviews were audiotaped.

Analysis

Quantitative data

Characteristics of all 167 frequent users were measured using means and standard deviations (continuous variables) or percentages (categorical variables). The associations between patient characteristics (independent variables) and acceptance or completion of the program (dichotomous dependant variables: yes or no) were examined in bivariate analysis. The variables with a significant association with acceptance or completion and covariables (age and sex) were used as potential predictors in the multivariate logistic regression models. Correlations between predictor variables were examined to

determine the presence of collinearity. All analyses were performed with PASW Statistics 20 (SPSS Inc.). The α significance level was set at 0.05.

Qualitative data

Two of the authors, from different professional backgrounds (FD, a social worker, and ML, an anthropologist) read the transcripts and analysed them independently using mixed coding as described by Miles and Huberman (16). Discrepancies and disagreements were discussed with other co-researchers with different backgrounds (medicine, nursing and social work). Pair debriefing, triangulation among patients, peer leaders and the coordinator, and team validation minimized the influence of researcher subjectivity, thus improving the credibility of the work (11). The NVivo 10 software (QSR International Pty Ltd) was used to manage the qualitative data.

Quantitative and qualitative data were integrated at the end of the study. The qualitative data were used to complete and interpret the quantitative data (11).

Results

Acceptance to participate in the CDSMP

Of 167 patients invited, 60 (36%) accepted to participate in the program (Table 4). Among patient characteristics, only higher HADS score was significantly associated with higher acceptance rate (Table 5).

Qualitative data informed that many participants did not have any specific expectations. Others hoped they would acquire new skills to better manage their health: 'Being able to have tools to cope

Table 2. Characteristics of participants in the qualitative interviews who refused to participate in the CDSMP ($n = 13$)

Patient	Age	Sex	Marital status	Annual family income (CAD) (2013–14)
12	76	Female	Widowed	20 000–24 000
13	47	Female	Married	≥50 000
14	77	Female	Married	40 000–44 000
15	50	Female	Single	35 000–39 000
16	59	Male	Married	15 000–19 000
17	36	Female	Married	45 000–49 000
18	72	Male	Married	30 000–34 000
19	34	Female	Married	40 000–44 000
20	81	Female	Married	15 000–19 000
21	74	Female	Married	40 000–44 000
22	54	Male	Divorced	40 000–44 000
23	59	Female	Married	–
24	44	Female	Married	10 000–14 000

CAD, Canadian dollars.

Table 3. Characteristics of the peer leaders ($n = 7$) who participated in the focus groups

		Sex	Age	Occupation
FGA	01	Female	62	Retired
	02	Female	60	Retired
	03	Male	59	Retired
	04	Female	63	Retired
FGB	05	Male	63	Retired
	06	Female	50	Entrepreneur
	07	Male	74	Retired

Table 4. Characteristics of the frequent users ($n = 167$) who were invited to participate in the CDSMP

Characteristic	Participation in CDSMP		P value
	Refused ($n = 107$)	Accepted ($n = 60$)	
Age, years—mean (SD)	59.6 (13.3)	61.8 (12.3)	0.299
Male, %	43.9	40.0	0.744
Marital status, %			0.665
Married	61.3	66.7	
Single	14.2	8.3	
Divorced	14.2	16.7	
Widowed	10.4	12.5	
Annual family income (CAD) (2013–14), %			0.753
<\$20 000	25.7	24.6	
\$20 000–\$49 999	48.6	42.1	
≥\$50 000	25.7	28.1	
PAM—mean (SD)	62.7 (16.2)	60.2 (14.3)	0.315
Level 1, %	12.1	18.3	
Level 2, %	22.4	18.3	
Level 3, %	35.5	33.3	
Level 4, %	29.9	30.0	
DBMA—mean (SD)	12.1 (8.1)	14.03 (7.8)	0.138
NVS < 4, %	67.0	68.3	0.860
≥4, %	33.0	31.7	
HADS—mean (SD)	10.8	13.5	0.035*

CAD, Canadian dollars; DBMA, Disease Burden Morbidity Assessment; NVS, Newest Vital Sign; PAM, Patient Activation Measure; SD, standard deviation.

* $P < 0.05$.

without seeing the doctor' (P09) or feel less lonely by connecting with other people: '(...) I was interested because I wanted to meet and talk with people who can understand me' (P01).

Refusal to participate in the CDSMP or withdrawal

One hundred and seven patients declined the invitation to participate in the program (Table 4). The most frequent reason to refuse to participate was that the group format was not appropriate for them because of their personality or they did not want to talk about themselves with others: 'Telling my personal affairs to everybody does not appeal to me' (P16). The second most frequent reason was associated with logistic concerns such as lack of time or transportation issues: 'I have no car, I have to take taxis, then it's expensive' (P19).

Of those who accepted to participate (60), 17 (28%) did not start the CDSMP. Some patients, who initially accepted, later decided not to participate because their diseases were better controlled, while others changed their mind: 'There are people who had said yes to the nurse who did not start the program. When I called, they told me they were no longer interested' (coordinator). Weather conditions were unfavourable to the participation of some patients: 'In the winter, it's not interesting. With the snowstorms, people don't want to go out' [focus group A (FGA)].

CDSMP dropout and attendance

Table 6 presents the number of patients who attended at least one session, three sessions or more and four sessions or more in the CDSMP.

Of the 43 subjects who started the program, 28 (65%) successfully completed it and 15 (25%) frequent users attended all sessions of the CDSMP.

Participants who dropped out during the program raised different reasons such as the fact that they considered the content to be too abstract: 'We were ten people and many decided to stop the program. Bad start because it was too abstract' (P01). Lack of experience of peer leaders could explain this situation. One of them talked about difficulties she had at the beginning: 'At the first meeting I was a little nervous, it seemed, I had less control to give information' (FGA).

Some patients dropped out because they did not appreciate others talking about their disease during meetings: '(...) to hear another one complain, I do not like that' (P18). However, while some abandoned

the workshops because of this problem, others would have preferred that the peer leaders give them more time to explain how they live with their illness.

The poor health of some participants was a barrier to their attendance at workshops. Indeed, some reported fatigue, lack of energy or having to go for surgery during those times; other reasons such as unavailability due to scheduling conflicts were raised to justify their absence.

Finally, too much heterogeneity among participants was raised as an important reason for dropout, as explained by the coordinator and peer leaders: 'It was difficult to get homogeneous groups. (...) there were different levels of vulnerability that made the connection between participants difficult' (coordinator). 'You have some people who have significant cognitive difficulties, you have others that are fully present and they are both at the same table and it is not obvious' (FGB).

At least four patients also raised the issue of heterogeneity. Some people had the impression that their situation was less serious than other participants: 'It is true that I have chronic pain syndrome ... but I felt like my situation was less serious than other people' (P03). Age differences were also pointed out, as noted by a 36-year-old participant who felt she was too young to be in a group where the mean age was 62.

The fact that the groups included patients with different chronic diseases was also reported: 'It's because I think ... the people with whom I was, did not suit me (...). And the questions they posed had no connection with my illness' (P18).

Some participants reported problems with sharing courses with some patients who have mental health problems: 'There is a woman who stopped participating. She was always on the move (...). In my opinion it was a mental health patient (...). Then she finished eating her lunch and she said: I'm going, I find you don't fit with me. We were so relieved' (P23).

CDSMP completion and impact

Most participants who attended at least half the sessions considered the program had positive impacts such as improved knowledge, motivation and self-confidence. Some reported being more motivated to take charge of their health conditions: 'It [the program] motivated me to start exercising again' (P02). While others believed they developed more confidence: 'I learned to support myself better ... I have more self-confidence' (P08). In general, patients admitted having acquired more knowledge about certain diseases. Some patients reported that the group enabled them to realize that despite their illnesses: '(...) we can realize that we can still do things, have projects' (P02).

Ease of access was an important issue. Consideration of people with reduced mobility or visual impairment was appreciated, as well as a location not too far from participants' residence. Offering availability in the evening was facilitating for participants who worked.

Regarding group composition, the participants' view was shared by the peer leaders who thought that it was better to avoid large disparities. During the meetings, promoting interaction among participants was important, keeping in mind that some people are more comfortable than others with talking about themselves.

Discussion

Despite the fact that we recruited a clientele of frequent users of health care services, who could be considered more complex or vulnerable, the acceptance rate (36%) was similar to that found in studies with other clienteles. A systematic review of self-management programs for chronic conditions by Foster *et al.* (1) including 17 trials that involved 7442 participants reported acceptance rates ranging from 11% to 65%. Four of these trials had an acceptance rate

Table 5. Multivariate logistic regression for acceptance to participate in the CDSMP

Variable	β^a	P value	Exp (β)	95% CI for exp (β)	
				Lower	Upper
Age	0.019	0.147	1.020	0.993	1.047
Sex	-0.109	0.747	0.897	0.463	1.736
HADS	0.049	0.023*	1.050	1.007	1.095
Constant	-2.187	0.034	0.112	-	-

CI = confidence interval.

^a β is a regression coefficient.

*P < 0.05.

Table 6. Attendance in the CDSMP

Number of sessions	Number of participants (out of 60)	%
At least one session	43	72
Three or more out of six	32	53
Four and more	28	47

ranging from 37% to 44%. Several authors discussed the difficulties experienced in recruiting adequate numbers (1). Often, patients who declined the invitation to participate were not interested in group sessions or were not available due to scheduling conflicts (6).

We observed that, of those who accepted to participate, 28% (17/60) did not start the CDSMP. Of the patients who started the program, 65% completed it. In a recent study among adults with type 2 diabetes (4), these percentages were 27% and 75%, respectively. In our study, 53% of participants attended at least half the sessions. In five studies in Foster's review (1,7,17–19), between 51% and 87% of participants attended at least half the sessions. In our study, 25% of frequent users attended all the sessions of the CDSMP. In three studies in Foster's review (7,18,19), participants who completed the program ranged from 16% to 33%. When comparing our results to the literature, completion of the program among frequent users of health care services seems comparable to other clientele.

As in a previous study by Helduser *et al.* (4), completion was not influenced by socio-economic factors. Another study by Erdem and Korda (3) documented that participants reporting depression were less likely to complete the program. We found that participants who scored higher on the HADS were more likely to accept to participate in the program. This association deserves to be further examined in future studies.

The experience of frequent users of health care services with the CDSMP is similar to other clientele's experience on several points. Other studies (2,3) observed that CDSMP with homogeneous groups had higher completion rates. As described by Johnston *et al.* (5), many noticed positive impacts on knowledge, motivation and self-efficacy. Poor health was a reason for dropout (20) as well as bad weather conditions and transportation issues (2). Access in terms of location and schedule was emphasized as an important aspect that had a positive impact on completion (2).

Limits

Measuring the quantitative impact of the CDSMP on the clientele of frequent users of health care services would have been interesting. However, since participants in the CDSMP were also recruited in a case management intervention that could have biased the efficacy evaluation of the CDSMP, we decided to focus on experience with the CDSMP. The efficacy of this program is already well documented. Qualitative data were obtained to complement the quantitative data. Sample size (24 patients, 1 coordinator and 2 focus groups with 7 peer leaders) was adequate for this purpose. The association between higher score on the HADS and higher acceptance in the CDSMP deserves more attention in future studies.

Conclusion

Acceptance and completion rates as well as global experience among frequent users of health care services were similar to those documented in other clientele. Participants who completed the program reported an overall positive impact on their self-management capabilities. The CDSMP could therefore be considered as a self-management support option for this vulnerable clientele, while taking measures to avoid too much heterogeneity among participants regarding age, severity of chronic diseases, cognitive functioning and mental health and to ensure accessibility of the meetings in terms of location and schedule, to improve completion rates.

Acknowledgements

We would like to acknowledge the patients and peer leaders who participated in this study and Ms Susie Bernier for her editorial assistance.

Declaration

Funding: Fonds de Recherche Santé Québec.

Ethical approval: Centre Intégré Universitaire de Santé et de Services Sociaux du Saguenay-Lac-Saint-Jean, Saguenay.

Conflict of interest: none.

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