Health Service Research

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

Catherine Hudon*a,b,*, Maud-Christine Chouinardc,d, Fatoumata Diadiouc, Danielle Boulianee, Mireille Lambertc and Émilie Hudond

Département de Médecine de Famille et de Médecine d’urgence, Université de Sherbrooke, Sherbrooke, Québec, Centre de Recherche du Centre Hospitalier Universitaire de Sherbrooke, Sherbrooke, Québec, Centre Intégré Universitaire de Santé et de Services Sociaux du Saguenay-Lac-Saint-Jean, Saguenay, Québec and Département des Sciences de la Santé, Université du Québec à Chicoutimi, Saguenay, Québec, Canada.

*Correspondence to Catherine Hudon, Département de Médecine de Famille et de Médecine d’urgence, Université de Sherbrooke, 3001, 12e Avenue Nord, Sherbrooke, Québec J1H 5N4, Canada; E-mail: catherine.hudon@usherbrooke.ca

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); and case management nurse. Groups included patients with different chronic diseases.

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

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

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 audiorecorded.

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 dependent variables: yes or no) were examined using univariate logistic regression. Only higher HADS score was significantly associated with higher acceptance rate (Table 5).

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).
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 everyone 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 clientele. 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
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 clienteles.

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 clienteles’ 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 clienteles. 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

References