Abstract

A strong emphasis on self-management for health maintenance in a variety of chronic diseases has been shown to benefit patients’ outcomes and quality of life. However, little has been published on such programs in patients with chronic kidney disease.

We studied the feasibility and effectiveness of the Chronic Disease Self-Management Program (CDSMP) in 14 patients with ESRD undergoing conventional hemodialysis. This program is designed to enhance skills in the areas of medical, emotional, and role management. Outcome measures in health status, self-management behaviors, self-efficacy, and health care utilization were evaluated through use of questionnaires at baseline and after six months.

Introduction

The case for ESRD self-management

Patient education efforts are common in dialysis centers; however, disease self-management education—the teaching of problem-solving skills in an attempt to allow chronic disease patients the best quality of life—is lacking in the current care delivery for end-stage renal disease (ESRD) patients. The primary emphasis of education addresses the dialysis treatment and related comorbid conditions—mainly anemia, bone mineral disease, nutrition, and the restriction of fluid and salt intake. Limited attention is focused on addressing problems outside dialysis, accounting for a considerable part of the disease burden. The responsibility of managing one’s health ultimately falls on the patient requiring the use of tools for problem solving, decision making, and action planning.¹

Enhancing skills in self-management is particularly important for patients living with severe and/or chronic health conditions. ESRD is no exception. Education on self-management may provide an opportunity to favorably impact outcomes, including hospitalization and mortality. Considering the high relevance of self-management skills for ESRD patients, learning the key features of self-management may help patients and clinicians maximize positive outcomes for people living with this challenging disease.²
Self-management can lower costs, improve care

ESRD is moving towards a more coordinated care model that emphasizes treating comorbidities, addresses patient quality of life, and explores ways to excel at the new health care imperative defined by the Institute for Healthcare Improvement’s triple aim: improved population management with better patient experience at lower costs. Self-management education presents as an important aspect for not only helping patients live a better life, but also for decreasing costs through enhanced patients skills in dealing with a tough disease. Therefore, one would assume that ESRD self-management would be a top priority in today’s U.S. health care system.

Unfortunately, this is not the case. Various barriers for a broader dissemination of self-management education exist within the ESRD population, ranging from a lack of data to the difficulty of administering such a program. In addition, the recognition by health plans and CMS to focus on this small but costly group with such interventions is only just starting. This may partially stem from prioritizing other major chronic conditions (i.e. diabetes, coronary artery disease, congestive heart disease, asthma, and chronic obstructive pulmonary disease) that trump efforts from payers to make ESRD the focal point for disease self-management.

Self-management can be broken down into two major domains: self-management of health care (self-care activity, partnership in care, communication, self-care self-efficacy, and adherence) and self-management of everyday life (achieving/maintaining “normality” in everyday roles and functioning). If utilized correctly, these focus areas may improve patient outcomes for patients diagnosed with ESRD.
Why the Chronic Disease Self-Management Program for ESRD patients?

The Chronic Disease Self-Management Program (CDSMP) was created by Dr. Kate Lorig, professor of medicine and director of Stanford’s Patient Education Research Center, and is designed to empower patients living with a chronic condition by improving their skills in medical management, role management, and emotional management. This includes a strong focus on teaching participants about process skills, such as action planning, disease-related problem solving, and decision making. It is one of the most well-studied, evidence-based self-management programs available with over 20 years of federally-funded research. It is also one of the most highly-adopted self-management programs worldwide, offered by numerous organizations in at least 19 countries.

In May 2011, the Center for Disease Control and Prevention (CDC) published the executive summary of the Arthritis Self-Management Program (ASMP)/Chronic Disease Self-Management Program Meta-Analyses, the first comprehensive investigation of 23 CDSMP research studies, to evaluate the effectiveness of CDSMP interventions on health status, health behaviors, and health care utilization. The findings suggest that “CDSMP contributes to improvements in psychological health status, self-efficacy, and select health behaviors and that many of those improvements are maintained over 12 months.” Furthermore, the summary concluded that CDSMP interventions provided patients with chronic diseases the opportunities to develop the knowledge, skills, and confidence to appropriately address, or self-manage, disease-related problems.

Many of the chronic conditions covered by the CDSMP such as diabetes, hypertension, heart disease, COPD, depression, and stroke are common in the ESRD population. The program does not provide specific skills uniquely attributed to ESRD or dialysis therapy. However, considering the wide range of health issues patients with ESRD face, and the intent of the CDSMP to address many different types of chronic conditions, it is conceivable that an all-encompassing self-management program such as the CDSMP could benefit the ESRD population. Some researchers have even suggested that by using the CDSMP model as a guide, many of the tools used within the program could be adapted specifically to ESRD, and may help to determine whether or not an ESRD specific self-management program could have an impact on patient outcomes. For the purpose of this small scale pilot-study, the standard CDSMP curriculum was taught with one modification of adherence to the renal diet.

Pilot Study Objectives

The objectives of this study were to:

- examine changes in health status, self-management behaviors, self-efficacy, and health care
Utilization/medical literacy for ESRD patients undergoing hemodialysis from baseline to six months was evaluated to assess the feasibility of enrolling 10-16 ESRD patients undergoing hemodialysis into the CDSMP track attendance rates of enrolled participants, and assess the safety of the CDSMP for ESRD patients undergoing hemodialysis.

Methods

Basic program structure

The CDSMP consists of six, two-and-a-half hour workshops conducted once a week for six weeks. Participants received supplemental materials, including a copy of the book, “Living a Healthy Life with Chronic Conditions,” which serves as a reference for the material presented during the program.

Each class is comprised of a highly structured curriculum developed by Stanford’s Patient Education Research Center. Sessions are led by two certified Master Trainers, one or both of whom are required to have at least one chronic disease. These leaders are employed by The Health Trust of Silicon Valley, a non-profit organization that has extensive experience teaching the CDSMP. Table 1 provides an overview of the CDSMP and a list of the topics discussed per session.

Logistics

Institutional Review Board approval was obtained for the study and patients signed consent forms. Recruitment took place at three Satellite Healthcare dialysis centers in the San Francisco Bay area. The sessions were held in a conference room at one of the corporate offices on non-dialysis days to facilitate attendance.

Six sessions were held once a week on Thursdays from 9:30 am to 12:00 pm beginning in early October 2013 and ending by mid-November 2013. All costs associated with the CDSMP were covered through Satellite Healthcare’s Research Program. Patients received a small weekly stipend to secure transportation for the six-week program. In addition, a shared lunch was provided at the end of each session.

Participants

Participants were recruited during their dialysis treatments or by phone call. From 54 eligible patients in the three pilot dialysis centers, 21 were approached to participate and 14 signed the consent. Two of the 14 enrolled participants dropped out of the program after the first workshop. One patient left due to severe fatigue, and the second due to feeling uncomfortable sharing personal information with the group. The remaining 12 participants attended at least half of the six sessions; nine participants attended at least five sessions. The mean attendance rate of all participants was 74%, and the mean attendance rate of the participants excluding dropouts was 83%. Table 2 summarizes the demographic characteristics of the participants.

Modifications specific for dialysis patients

The original CDSMP curriculum was modified for diet education to fit the recommendations appropriate for a renal diet. After seeking approval from Stanford and coordinating with the leaders of The Health Trust, we replaced the standard “healthy eating” section of the fourth session with a modified version developed to reconfirm the importance of the renal diet. The modified section includes: 1) reasons for limiting salt; 2) concerns about fluid intake; 3) how to break the cycle of excess fluid gain; 4) potassium intake; 5) protein...
Section was taught by a registered dietitian and included an interactive teaching style similar to the CDSMP in which participants had the opportunity to reflect and share past experiences based on the topics discussed.

**Measures Overview**

Patients were asked to complete questionnaires to assess the effectiveness of this pilot study at baseline (1-2 weeks prior to attending the first workshop in October 2013) and six months after the last workshop in November 2013. Outcome measures were based on the following four major fields: health status, self-management behaviors, self-efficacy, and health care utilization/medical literacy. Changes in outcome measures were evaluated using paired t-tests between baseline and six months.

<table>
<thead>
<tr>
<th>Table 2: Baseline demographics of participating patients (n = 14)</th>
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<tbody>
<tr>
<td>Age, years</td>
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<td>Male</td>
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<tr>
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<td>Hypertension</td>
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<td>Lupus</td>
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<td>Depression/anxiety</td>
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**Results**

**Health status**

The first field covers a variety of questions related to the participants’ perceived health. We observed improvements in the overall health status of our participants during the six-month period. Significant changes were noted after six months in several major areas of health status, based on the personal health questionnaire (PHQ-8) These included:

- an increase in quality of life (1.2± 1.5; \( P = 0.01 \))
- a decrease in the number of unhealthy mental days within the prior month (-3.4± 4.6; \( P = 0.02 \))
- a decrease in depression (-1.9± 3.0; \( P = 0.04 \))
- Additional improvement trends were identified in the following areas:
  - a decrease in fatigue (-0.6± 3.6; \( P = 0.5 \))
  - a decrease in pain (-0.6± 2.1; \( P = 0.3 \))
  - a decrease in sleeping problems (-1.0± 3.3; \( P = 0.3 \))
  - a decrease in stress (-0.8 ± 3.4; \( P = 0.4 \))
  - a decrease in social/role limitations (-0.4 ± 0.9; \( P = 0.1 \))
- a decrease in number of unhealthy physical days within the prior month (-1.5 ± 6.0; \( P = 0.4 \))
- a decrease in the number of days during prior month that poor health kept them from doing usual activities (-1.2 ± 8.5; \( P = 0.6 \)), and finally
- an increase in perceived general health (0.4 ± 0.7; \( P = 0.1 \)).

**Self-management behaviors**

Self-management behaviors cover the following two sub-categories: physical activity and communication with physicians. Physical activity questions include a combination of stretching/strengthening exercises and questions related to aerobic exercises, including walking, swimming, bicycling, and other (i.e. Stairmaster, rowing, skiing machine, etc.). There was a significant increase in the number of minutes spent on aerobic exercises during the prior week (51.9± 81.3; \( P = 0.04 \)), and a trend toward an increase in the number of minutes per week spent on stretching/strength training (21.4± 53.8; \( P = 0.2 \)) six months after participation in the self-management program.

**Asking physicians questions**

Communication with physicians is based on a 6-point frequency scale (0 = never and 5 = always) that addresses how often the participants prepare questions for their physicians, ask important questions concerning their health, and discuss problems related to their illnesses. Participants indicated improvement in this area (0.1± 0.9; \( P = 0.6 \)).

**Self-Efficacy**

Self-efficacy covers several important areas of self-management that are common to many chronic diseases, and focuses on the confidence level of participants for each of these areas based on a 6-item scale. These areas include symptom control, role function, emotional functioning, and communication with physicians. The score of each of the six questions is based on a 10-point rating scale (1 = not at all confident and 10 = totally confident). During the 6-month period, significant increases in self-efficacy were noted (1.6± 1.3; \( P = 0.0008 \)) suggesting that confidence levels in self-management increased among participants.

**Health care utilization/Medical literacy**

The last field combines health care utilization and medical literacy. Health care utilization covers the number of visits to health care providers within the previous six months of completing each of the two questionnaires. There was a significant decrease in:

- physician visits, not including visits to the hospital or emergency room (-4.1± 6.2; \( P = 0.04 \))
- emergency visits (-1.0 ± 2.4; \( P = 0.1 \))
- hospitalizations (-0.3 ± 0.9; \( P = 0.3 \)), and
- nights spent in the hospital (-1.8 ± 5.3; \( P = 0.2 \))

Medical literacy was evaluated based on the confidence level of each participant in filling out medical forms. Based on a 5 point rating scale (0 = not at all confident and 4 = extremely confident), improvements in medical literacy were identified (0.5 ± 0.8; \( P = 0.03 \)) as participants reported higher confidence levels at six months.

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**Selecting patients for this study**
Patient selection for this CDSMP pilot was confined to a well-defined patient population who was more likely to comply with program attendance and its demands compared to the general ESRD population. This was done on purpose, as the pilot program was intended to be a “proof of concept” program to explore further scalability of this approach with ESRD patients.

Inclusion criteria for entry into the study:

- ESRD ≥ 90 days undergoing thrice weekly HD
- 18-65 years old
- English speaking only
- Adequate cognitive function for participation
- Willing to participate in the weekly workshops and complete all evaluation tools
- HD sessions on Monday/Wednesday/Friday (in order to participate on a non-dialysis day, i.e. Thursday)

Discussion

Patient engagement has been shown to result in improved outcomes and quality of life in several chronic disease conditions, including diabetes, COPD, and heart failure. However, the suitability of chronic disease self-management has not been investigated in patients suffering from ESRD. With a strict schedule for thrice weekly dialysis appointments, attending additional classes to learn self-management skills may be a difficult proposition.

We set out to explore the feasibility of an established program with a proven structure in a pilot study. The goal of enrolling 10-16 patients was achieved – with 67% of patients approached enrolled in the program. Although two of the 14 patients dropped out after the first day of class, the mean attendance rate of 83% for the remaining participants reflects an adequate commitment level on the part of the participants, especially considering six (43%) participants had perfect attendance and nine (64%) only missed one class. The program was safe for our participants in all aspects of the curriculum with the exception of the recommendations for healthy eating, which required modifications appropriate for ESRD. All other recommendations including exercise and relaxation techniques were safe and seemingly effective.

We found that the CDSMP provided significantly improved outcomes in all major fields of measure: self-management behaviors, self-efficacy, health status, and health care utilization/medical literacy. Trends toward small improvements in these areas were also observed.

Study limitations

It is important to acknowledge the limitation of this pilot study, given the small scale in a selected geographic location of English speaking patients. The patients participating in this study did so voluntarily and therefore likely introduced a bias. How applicable the results would be in the general ESRD population will need to be seen. The statistical analyses need to be considered with caution given the small sample size. However the experience and outcome of this pilot study are encouraging to consider the CDSMP as a viable option for ESRD patients for improving self-management skills in medical management, role management, and emotional management.
Key features of the CDSMP

The action plans created by our participants were of particular interest to this pilot study because they represent desirable goals attainable through activities that have significant potential. Action plans are developed by each participant at the end of each session and must be achievable, action-specific, desirable, and measurable.\(^1\) Many patients developed action plans that were dialysis specific. Examples include increasing protein intake, decreasing high phosphorus foods, decreasing fluid intake, and reducing salt intake. Participants also chose action plans specific for increasing their physical activity, including attending Zumba classes, yoga, hiking, walking/light jogging, weight lifting, and stretching. Other notable action plans included getting more sleep at night, attending cooking classes, painting, and volunteering at charitable organizations. Each participant was required to report on whether or not the action plan was achieved at the following session that promoted a sense of accountability. Many of our participants committed to their goals, and a high percentage of action plans were achieved during the program.

The CDSMP contains features similar to other support group where patients share experiences and interact with their fellow participants for support and encouragement. ESRD patients face unique hardships and restrictions that they must be able to cope with while trying to maintain the demands of hemodialysis. Failure to cope with the everyday issues that arise could be detrimental. Research has even suggested a connection between a decreased perception of social support and mortality in ESRD patients.\(^11\) The CDSMP provides a platform to offer and receive such support, which could help patients to cope with the challenges of ESRD in every-day life.

Conclusion

The CDSMP is intended to be a workshop that promotes interaction among participants. The driving force for this is the peer-taught aspect of the program. Two people, one of them with a chronic health condition, taught this pilot study. However neither of the trainers had ESRD. The effectiveness of the program increases when participants can identify and relate to their peers based on similar experiences and knowledge. One might argue that recruiting dialysis patients to be certified as master trainers for future CDSMP workshops may increase the effectiveness of the program. Our first promising experience deserves to be further evaluated as a potential tool for improvement in ESRD care delivery and outcomes.

References


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The authors are from Satellite Healthcare Inc., based in San Jose, Calif. Mr. Slesnick and Pienkos were research associates at the time of the study. Dr. Sun is director of Applied Research and Data Analysis. Ms. Doss-McQuitty is director of Clinical Programs and Research, and Dr. Schiller is the chief medical officer at Satellite.