

# Effectiveness of the Chronic Disease Self-Management Program for Persons with a Serious Mental Illness: A Translation Study

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**Abstract** Evaluation of evidence-based interventions in new settings and new populations is the hallmark of successful translation. We evaluated the Chronic Disease Self-Management Program in persons with serious mental illness who were receiving care through Michigan Community Mental Health Services (N = 139). At 6-months, participants demonstrated improvements in health indicators (fatigue, quality of life, sleep, depression, health distress, and days health bad) and health behaviors (medical adherence and communication with doctor). The program was successfully administered in a “real world” setting and continues to be used. In addition, the program appears to be an effective resource for people with serious mental illness.

**Keywords** Self-management · Translation study · Comorbid conditions · Chronic illness

Persons with serious mental illness (SMI) are at high risk for comorbid physical conditions (Goldman 2000; Jones et al. 2004; Kilbourne et al. 2007; Meyer and Nasrallah 2009; Sokal et al. 2004). They also experience significant barriers

to managing those illnesses (Brown et al. 1999; Daumit et al. 2005; Kreyenbuhl et al. 2008) and to receiving primary medical care (Miller et al. 2003). In 2006, the National Association of State Mental Health Program Directors released a report demonstrating that persons with a serious mental illness are dying 25 years earlier than the general population (Parks et al. 2006). Poor medical care for persons with SMI is exacerbated by the organizational separation of mental and physical health care (Horvitz-Lennon et al. 2006). At the same time people with SMI are underserved by self-management programs which could provide the supports and skills for individuals to address their medical conditions outside the immediate limitations of the health care system. As a result persons with SMI are in double jeopardy for poor health outcomes. This suggests that there may be an opportunity to integrate mental and physical self-management support for those with SMI. This study represents an attempt in this direction.

In recent years several self-management programs have been developed to assist individuals with a serious mental illness. The Wellness Recovery Action Planning (WRAP) is the best known evidence-based practice developed specifically for individuals with SMI. A recent randomized trial demonstrated the effectiveness of this program in improving symptoms, quality of life and hopefulness (Cook et al. 2012). WRAP is used extensively in the United States and abroad. A randomized pilot study of a bipolar disorder medical care model (BCM) found that BCM appeared to slow decline in physical health-related quality of life compared to usual care (Kilbourne et al. 2008). Sterling and colleagues (2010) have offered a summary of several other self-management programs addressing the needs of those with SMI.

Another recent program, Health and Recovery Peer Program (HARP), is a derivative of the Chronic Disease

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Self-Management Program (CDSMP) (Lorig et al. 1999), which addresses specific mental and physical health needs as well as providing one-on-one peer support. It was tested in a randomized pilot study. Participants compared to controls were found to have improvements in Patient Activation, and reductions in the number of primary care visits. There were also trends toward improved physical health, quality of life and medication adherence (Druss et al. 2010).

In October of 2009, the Michigan Department of Community Health (MDCH) received the Transformation Transfer Initiative, a federally funded grant from National Association of State Mental Health Program Directors and Substance Abuse Mental Health Services Administration. The purpose of the grant was to implement a peer-to-peer wellness initiative for people with SMI. The Stanford Chronic Disease Self-Management Program (CDSMP) was chosen after consultation with the MDCH's Division on Chronic Disease. The WRAP and Wellness Recovery Action Planning are also used by the MDCH, and the CDSMP was intended to be complementary. Program delivery was by Michigan Certified Peer Support Specialists (CPSS).

The Chronic Disease Self-Management Program is one of the most widely used programs for people with comorbid physical conditions (Lorig et al. 1999). Since 2010 it has reached more than 100,000 people in the United States. There is also a large literature demonstrating its effectiveness in improving health behaviors, health status, self-efficacy and in some cases in reducing health care utilization, including several randomized studies that compared the CDMSP to usual-care control groups (Lorig et al. 1999; Kennedy et al. 2007). For patients with arthritis who were randomized to either the CDSMP or an disease-specific arthritis self-management program, those in the CDSMP had similar improvements to those in the arthritis-specific program (Lorig et al. 2005a). Canadian patients with type 2 diabetes participating in a diabetes education program were randomly assigned to also participant in the CDSMP. Those also in the CDSMP had greater improvements than those in the diabetes education program alone (McGowan 2011). With the exception of a trial in Australia (Lawn et al. 2007), the CDSMP has not been evaluated specifically with an SMI populations.

This paper reports on the first such study to evaluate the CDSMP specifically with an SMI population within the United States. It consists of a 6-month longitudinal study with three aims: (1) to determine the effectiveness of the CDSMP for people with SMI delivered by Certified Peer Support Specialists (CPSS); (2) To test this effectiveness in a naturalistic setting far removed from the investigators; and (3) to evaluate the acceptability of the program within

the Community Mental Health Service Programs (CMHSP).

### The CDSMP Workshops

The Chronic Disease Self-Management Program (CDSMP) consists of community-based, peer-led patient self-management education workshops (Lorig et al. 1999). Three principal assumptions underlie the CDSMP: (1) people with different chronic diseases have similar self-management problems and disease-related tasks, (2) people can learn to take responsibility for the day-to-day management of their disease(s), and (3) confident, knowledgeable people practicing self-management will experience improved health status. Workshops utilize face-to-face, peer-led small group sessions over 6-week periods. Topics covered include exercise; use of cognitive symptom management techniques; nutrition, fatigue, pain and sleep management; use of community resources, use of medications; dealing with fear, anger and depression; communication with others including health professionals; problem-solving; and decision-making. Each workshop has 8–16 participants and is taught by a pair of trained volunteer peer leaders. The content of the workshop has been published as a book, *Living a Healthy Life with Chronic Conditions* (Lorig et al. 2006), which is also used as a reference book for workshop participants.

The program is based on self-efficacy theory and incorporates skills mastery, reinterpretation of symptoms, modeling and social persuasion to enhance a sense of personal efficacy (Bandura 1997). These included guided mastery of skills through weekly “action planning” and feedback of progress, modeling of self-management behaviors and problem solving strategies, and social persuasion through group support and guidance for individual self-management efforts.

In a randomized trial targeting participants with arthritis, stroke, heart disease or lung disease, the CDSMP was found to be associated with moderate and statistically significant improvements in health behaviors, health status and decreases in hospitalization compared to control subjects at 6 months (Lorig et al. 1999). These results were maintained up to 2 years (Lorig et al. 2001a, b). The CDSMP has been widely disseminated and has been adapted for use in twenty-five countries (Fu et al. 2003; Giffiths et al. 2005; Kennedy et al. 2007; Lorig et al. 2005b; Siu et al. 2007; Swerissen et al. 2006). Previous translation studies have demonstrated its likely applicability to participants with a wide variety of chronic diseases, including arthritis, heart-disease and diabetes. The current study addresses the question, do patients with serious mental conditions also benefit from these programs?

## Methodology

### Workshops

The CDSMP workshops were offered throughout the Michigan by local Certified Peer Support Specialists (CPSS). There were no modifications in the format and content from CDSMP workshops offered elsewhere for people with other chronic conditions. The difference between the CDSMP offered elsewhere and that offered to the SMI population in Michigan is that all leaders were also CPSS.

### Workshop Leaders

To obtain certification as a Certified Peer Support Specialist (CPSS), individuals must have a mental health diagnosis or co-occurring diagnosis of mental health and substance use disorder, be in recovery for at least 1 year, and have a high school diploma, GED or meet similar requirements. CPSS complete a 60-h program, and receive three credit hours from Lansing Community College. In addition to the above requirement, CDSMP leaders also completed 18 h of additional training in how to facilitate the CDSMP.

The use of CPSS as leaders in teaching the CDSMP has the added advantage that when included with the individual's treatment and support plan, the CDSMP becomes eligible for Medicaid reimbursement (Michigan Department of Community Health 2012).

### Study Population and Recruitment

There are 46 Community Mental Health Service Programs (CMHSP) in Michigan that have been offering the CDSMP since 2009. During this same time 168 CPSS have been trained as CDSMP leaders.

The Michigan Department of Community Health, Behavioral Health and Substance Abuse Services Administration, Bureau of Community Mental Health Services approached the community health centers offering the CDSMP concerning their willingness to participate in the present study. Ten centers responded and arranged to have someone at their center trained in data collection. Following IRB approval and HIPAA training, informed consents and questionnaires were sent to each of the participating health centers. These were completed by participants either at the first session of the workshop or an information session, which took place 1 week before the start of the workshop. Potential participants were recruited by CPSS and other mental health staff.

Once questionnaires were completed, the data collector immediately mailed them to Stanford. At Stanford each

questionnaire was coded and participants were called for missing or ambiguous data. Six months after the start of each workshop, follow-up questionnaires were mailed to the individual participants. Non respondents were called and sent a second questionnaire.

It should be noted that this is a true translation study. There was no special selection of sites. All sites had been offering the program before the start of the study. The Stanford investigators had no direct input into the sites chosen, the recruitment of subjects, or the training of leaders. Their only roles were data collection and analysis. The sites chosen for study continued to offer workshops after the study.

### Data Collections and Measures

Data were collected by self-administered (mailed) questionnaires at baseline and 6 months. Baseline questionnaires included demographic information (age, gender, years of education, marital status and ethnicity) and information about types of mental illnesses and other chronic diseases. Workshops leaders also logged which of the six workshops sessions each participant attended.

Baseline and follow-up questionnaires included ten health indicators. The single-item Self-Rated Global Health came from the US National Health Survey and has been found to be predictive of future health status (Idler and Angel 1990). Stress, Sleep Problems, Fatigue/Tiredness and Quality of Life were measured by visual numeric scales (VNS) (Ritter et al. 2006). The VNS were adaptations of visual analogue scales (VAS) (Dixon and Bird 1981; Downie et al. 1978a, b). VNS differed from VAS in that they used size of lines, shading, numbers and words, rather than just a double anchored line (Ritter et al. 2006). Depression was measured by the PHQ-8 (Kroenke et al. 2009). The Health Distress Scale, adapted from the Medical Outcomes Study, focused on the distress specifically associated with health problems (Stewart et al. 1992). Participants reported the number of days that physical health was not good in the last month, the number of days that mental health was not good and the number of days that poor physical or mental health illness prevented participation in normal activities over the past month. This later question was adapted from the Behavioral Risk Factor Surveillance System Survey (BRFSS) (Centers for Disease Control and Prevention 2011). For nine of the health indicator variables, a lower score was more desirable (e.g. less stress). For the Quality of Life VNS scale, a higher score (better quality of life) is more desirable.

Two health-related behaviors were measured. These included use of techniques to improve communication with health care providers (a three-item, six-point scale). This instrument was developed and validated by the Stanford

Patient Education Research Center during use in previous studies (Lorig et al. 1996). Participants also were asked how often they adhered to their medication regime over the last 6 months (Morisky et al. 1986). For the health-related behaviors, higher scores were desirable (e.g. more use of communication).

Two utilization measures were used: self-reported visits to medical doctors and emergency department visits. In a previous study, we found that self-report of medical visits correlated  $r = 0.70$  with chart audit data, and discrepancies were consistent over time and across treatment groups (Ritter et al. 2001).

### Data Analyses

Outcomes at 6 months were compared to baseline using paired  $t$  tests. All participants who returned questionnaires were included in the analyses regardless of how many sessions they had attended. Intent-to-treat analyses were also conducted, and all participants were included. Data for those missing a questionnaire were substituted by using the last-known responses (Streiner and Geddes 2001). This is a conservative analysis that assumes that the participants neither benefited nor were harmed by the intervention.

In addition, those who completed 6-month questionnaires were compared to those who did not on baseline characteristics and baseline outcome variables.

General linear models (either ANCOVAs or regression, as appropriate) were used to test whether there were differences in 6-month outcomes by demographic conditions, type of SMI or class (site).

## Results

### The Workshops

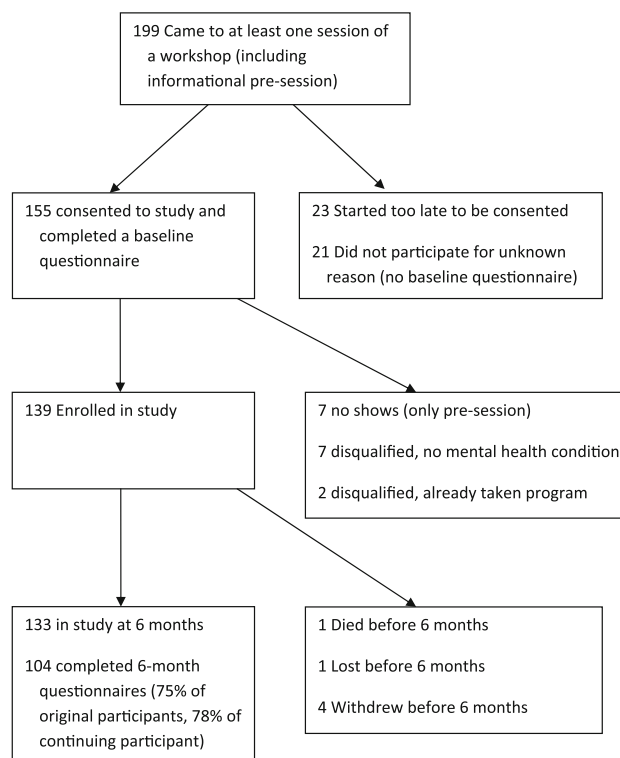
Twenty workshops were scheduled, although five were cancelled because of a lack of participants or poor turnout. The fifteen study workshops were held between May and October 2011. Three workshops were held at faith-based organizations, five at community mental health drop-in centers, and seven at social services or mental health agency facilities.

Each workshop was led by two CPSS trained leaders. There were 23 leaders, seven of whom led two different workshops. Twenty females (77 % of the leaders) led 27 workshops, while 3 males led three. Eighteen of the leaders were non-Hispanic White, 4 were Black and 1 described herself as “other.” Most of the leaders (87 %) were staff members of the Community Mental Health Service Programs (CMHSP) while three were volunteers. Leaders had led a mean of 2.7 previous CDSMP workshops.

### Participants

One-hundred and seventy-six participants came to either an information pre-session or the first session of a workshop, and of these 155 consented to participate in the study and completed a baseline questionnaire (Fig. 1). Seven of those who had consented at a pre-session did not attend any of the actual workshops, and were not included in the study. An additional nine were disqualified, either because they had no mental health condition or had already participated in the program. This resulted in 139 participants enrolled in the study. The most frequent mental condition was depression (55 %, see Table 1), followed by bipolar disorder (45 %), schizophrenia (17 %), schizoaffective disorder (15 %). A large proportion reported anxiety or other mental health conditions (64 %). Many of the participants also had substance abuse problems (26 %). The mean number of mental conditions reported was 2.2 with 67 % reporting more than one mental condition. The average age of the participants was 48.2 (SD = 11.0), 24 % were African-American, and 73 % were female.

Of the 139 participants, 133 remained in the study at 6-month (i.e. had not died or been otherwise lost to possible followup, see Fig. 1). Of these, 104 (78 %) completed 6-month questionnaires. The mean number of workshop sessions attended was 4.2 out of six (SD = 1.6). The sixth



**Fig. 1** Participants in the Michigan CDSMP Mental Health Study

**Table 1** Baseline characteristics, entire sample (N = 139)

Variable	Mean or percent	SD
Age	48.2	11.0
Years of education	13.0	2.83
Percentage male	26.6 %	
Percentage married	18.0 %	
Percentage African American	24.1 %	
Percentage Hispanic	2.1 %	
Percentage other (including non-Hispanic White)	73.8 %	
Percentage with depression	54.6 %	
Percentage with bipolar	45.3 %	
Percentage with schizophrenia	16.5 %	
Percentage with schizoaffective disorder	15.1 %	
Percentage, mental health condition with substance abuse	25.9 %	
Percentage with anxiety or other mental health condition	64.0 %	
Number of conditions (physical and mental)	5.88	2.79
Insurance: medicare	54.6 %	
Insurance: medicaid	63.1 %	
Insurance: SSI	24.1 %	
Insurance: veterans benefits	3.5 %	
Insurance: private insurance	0.0 %	
No insurance	7.1 %	

and final workshop session was attended by 62 % of the participants, but only 23 % attended all six sessions.

### Six-Month Outcomes

When we compared the baseline demographic conditions and outcome scores of those who failed to complete 6-month questionnaires (N = 35, including the six who dropped, were lost, or who died before 6 months) with those who had (N = 104), there were few differences. The non-completers were lower on their medical adherence score (1.2 vs. 1.8,  $p = .04$ ), attended fewer sessions (3.2 vs. 4.5,  $p < .001$ ), and had slightly lower overall health (3.9 vs. 3.3,  $p = .006$ ). None of the other 29 baseline variables that were tested were significantly different at  $p < .10$ .

Table 2 presents the 6-month change scores for the outcome variables. Eight of ten health indicators (fatigue, quality of life, sleep, PHQ depression, health distress, days physical health bad, days mental health bad, and days health kept from usual activities) and both of the health behaviors (communication with physician and medical adherence) had improvements that were statistically significant (using  $t$  tests). Effect sizes of improved outcomes

ranged from 0.22 to 0.42. None of the four medical utilization measures changed significantly. The  $p$  values were virtually identical whether we assumed no-change for variables missing at 6-months (intent-to-treat), or only included the cases that had completed 6-month questionnaires.

When types of mental conditions were included as independent variables in general linear models estimating 6-month changes in outcomes, there was no indication that individuals with specific mental conditions benefited more or less from the program. Similarly, when demographic conditions were included as independent variables, there were little suggestion of any groups benefiting more than others. The single exception was that non-Hispanic Whites had greater mean reduction in the number of days that health interfered with usual activities ( $p = .006$ ). Finally, when we looked at whether any sites had greater or lesser improvements, there were no consistent differences between any one of the 15 sites when compared to the other 14 sites.

### Discussion

This translation study was successful in answering the three key questions. It appears that the CDSMP, when utilized by persons with SMI, is associated with improved health behaviors, health status and adherence. The context of the study was an ongoing program offered by a state mental health department with only minimal technical assistance from the investigators. Thus, the effectiveness of the program outside of a controlled context is noteworthy and argues strongly for the ability of the program to be translated into real world setting.

We also examined how well the program fit into the settings where it was offered. As noted the program was on-going from before the start of the study. In the 9 months since the end of the study, these same centers have offered an additional 11 workshops. Thus it would appear that the program is a good fit for the community mental health setting and continues to be chosen as a health and wellness self-management support by persons with SMI.

Individuals who failed to complete 6-month questionnaires had slightly worse baseline overall physical health but otherwise had no differences in demographic or baseline health indicators. In addition, intent-to-treat analyses did not change the pattern of improved health conditions. This would suggest that the improvements are unlikely to be purely the result of those with the worse outcomes having failed to complete 6-month questionnaires. Those who did not complete 6-month questionnaires did have lower baseline medical adherence and attended fewer sessions of the workshop suggesting that their failure to

**Table 2** Six-month change scores (N = 104)

Variable	Baseline	6-month change	Effect size of change	<i>p</i> intent to treat (N = 139)	<i>p</i> (actual cases only, N = 104)
General health (1–5) ↓	3.47 (1.03)	0.038 (0.955)	(0.037)	(0.681)	(0.682)
Fatigue (0–10) ↓	6.26 (2.79)	−0.615 (2.86)	0.220	0.031	0.030
Quality of life (0–10) ↑	5.25 (2.34)	0.683 (2.67)	0.292	0.011	0.011
Sleep (0–10) ↓	6.17 (3.34)	−0.942 (3.79)	0.282	0.013	0.013
Stress (0–10) ↓	6.76 (2.74)	−0.471 (3.35)	0.172	0.155	0.155
PHQ depression (0–24) ↓	12.1 (6.08)	−2.27 (6.03)	0.373	<0.001	<0.001
Health distress (0–4) ↓	2.17 (1.15)	−0.486 (1.10)	0.423	<0.001	<0.001
Days physical health bad, past month ↓	14.9 (11.3)	−2.85 (10.9)	0.252	0.009	0.009
Days mental health bad, past month ↓	16.7 (10.4)	−4.00 (11.3)	0.385	<0.001	<0.001
Days health kept from usual activities ↓	15.0 (11.3)	−4.23 (10.9)	0.374	<0.001	<0.001
Communication with Doctor (0–5) ↑	2.51 (1.35)	0.336 (1.23)	0.249	0.007	0.006
Medical adherence (0–4) ↓	1.65 (1.37)	−0.413 (1.18)	0.301	<0.001	<0.001
Physician visits for physical health, last 6 months	4.18 (5.46)	−0.204 (5.76)	0.037	0.720	0.720
Emergency dept. visits for physical health, last 6 months	0.935 (2.73)	−0.147 (1.89)	0.168	0.433	0.434
Physician visits for mental health, last 6 months	2.72 (5.46)	−0.010 (2.54)	0.002	0.969	0.969
Emergency dept. visits for mental health, last 6 months	0.101 (2.73)	−0.010 (0.589)	0.004	0.867	0.867

Possible ranges are given in parentheses after each variable. ↓ indicates a lower score is better

↑ indicates a higher score is better. *p* values in parentheses indicate the outcome variable worsened

complete the questionnaires may have been part of larger pattern of less participation. It is possible that those who do not fully participate in the workshops may have been less supported by the program. Some of the non-available supports may have included lack of transportation or discharge from the program.

The relatively high proportion of participants with bipolar disorder (45 %) suggests those with bi-polar may have been proportionally more likely to participate in the CDSMP, although it should be noted that most participants reported multiple mental conditions and only 13 % of the participants reported only bi-polar disorder. There was no targeting of any specific SMI in the recruitment of participants. A major weakness of the study is the lack of randomized design. However the goal of presenting the program in a natural setting within the mental health provider community precluded such a randomized approach. Previous randomized studies of the CDSMP (Lorig et al. 1999; Kennedy et al. 2007) suggest that any attention effect (e.g., improvement resulting from being asked to complete and then completing questionnaires) is not a major factor in improvements. However the lack of a randomized control group for this population of participants with SMI prevents us from being absolutely sure there was no attention effect.

Future work and future studies will offer more insight into the use of the CDSMP for people with SMI. In Michigan, the goal of the community mental health programs is to integrate self-management support across chronic conditions. Thus community members without

SMI can attend workshops offered by mental health facilities and people with SMI can attend workshops in non mental health community settings. This practice and philosophy of self-management views that individuals with a SMI experience comorbid physical conditions and have self-management needs similar to those with non-mental health chronic conditions. It should be noted that others believe that SMI self-management support is best offered in specialized programs only for those with SMI. The current study does not address the question of whether those with SMI would have been better served by one of the programs specifically designed to address mental-health conditions, only whether those with SMI appear to benefit from the CDSMP offered in addition to usual care. It is our hope that future studies will explore the comparative effectiveness of self-management programs specially designed for the SMI population and those like the CDSMP, which are designed for a wide range of people with mental and/or physical illness.

The results of this study and Michigan's successful statewide implementation of the CDSMP by CPSS support the conclusion that CDSMP should be considered as a widely available self-management resource for those with SMI and/or other chronic conditions.

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