12 Chronic Disease Self-Management Education: Program Success and Future Directions

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Self-management is increasingly recognized as an essential element for improving chronic illness care in America [1]. The accumulating knowledge base provides the field with a greater understanding about the different aspects of self-management [2], an inventory of evidence-based programs for enhancing self-management behaviors [3], and guidelines of how such models can be better integrated within geriatric care programs [4].

The Stanford Chronic Disease Self-Management Program (CDSMP), the flagship CDSME program, is one of the most widely tested and disseminated self-management models. It is becoming a model for geriatric practice and increasingly being delivered to older patients with a wide array of chronic conditions [5]. This chapter addresses several questions about the application of CDSME programs designed to help older adults and their caregivers deal with chronic conditions. While the primary focus will be on the broadly disseminated small group Stanford CDSMP, it is important to note that the entire suite of Stanford self-management programs share a common philosophy and approach to self-management. Hence, basic information will be reported about the suite of programs.

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Setting

While CDSMP was first developed and delivered in California [6, 7], it has now been delivered across the USA and in over 30 countries worldwide [8]. In the USA, as part of the funding for the American Recovery and Reinvestment Act of 2009 (ARRA), CDSMP has been widely disseminated through a diverse delivery infrastructure involving community and clinical sectors. In approximately 2 years, as indicated in a national review of CDSME programs [9], 100,000 participants were enrolled in 8,702 workshops in 5,586 unique implementation sites across 1,786 counties. The majority of participants enrolled in Chronic Disease Self-Management Program (CDSMP) workshops (78.4 %). Diabetes Self-Management Program (DSMP) workshops and Tomando Control de su Salud (Spanish CDSMP) workshops were also popular, accounting for 20 % of the participants. The five most common delivery sites were senior centers or Area Agencies on Aging (29.2 %), health care organizations (21.1 %), residential facilities (17.6 %), community/multipurpose facilities (9.9 %), and faith-based organizations (8.4 %). Other settings included correctional facilities, malls, RV parks, fire departments, county administration buildings, private residences, casinos, and career centers. The majority of participants attended workshops delivered in English (89.6 %) and in metro settings (79.6 %).

Consistent with the ARRA initiative goals [10], the dissemination of CDSMP placed importance on establishing better coordination between community and clinical settings and emphasized increasing referrals from primary care settings. While CDSMP is often offered in residential care facilities such as senior housing and assisted living, it is not seen as an appropriate intervention for skilled nursing facilities, given that most care recipients are cognitively impaired.

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Additionally, since CDSMP involves multiple interactions over time (typically six workshop sessions hosted over a 6-week period), it is also not appropriate for in-patient hospital settings.

Problem to be Addressed

Self-care or self-management is now seen as an adjunct to health care, with patient empowerment included as a major component of the National Prevention Strategy [1]. CDSMP is based on the premise that the majority of health care is what individuals do for themselves outside of traditional clinical settings. CDSMP addresses the fundamental problem of helping the growing number of individuals with chronic disease(s) gain skills and confidence to live healthier lives [11]. This is especially important given the shortage of geriatricians and other health care professionals available to treat the rapidly growing population of aging Americans [12]. While national dissemination efforts have extended to adults residing in health professional shortage areas, individuals living in more remote areas where the entire county was designated as a health professional shortage area were less likely to complete workshops (i.e., indicating less intervention dose was received) [13]. Thus, more work is needed to identify strategies to improve delivery, recruitment, and successful completion of programs to monitor national dissemination efforts.

Patients Who Benefit

Designed to accommodate a wide range of patients with a variety of chronic conditions, the generic and disease-specific versions of CDSMP have benefitted persons with multiple chronic conditions as well as those with specific conditions common in old age such as heart disease, diabetes, or arthritis [5]. Additionally, recent studies demonstrate benefits to those who are depressed or experience mental health problems [14]. Recent national studies also indicate health and health care benefits among participants from diverse socioeconomic backgrounds [15]. For example, the program attracts and benefits participants from disadvantaged educational and income backgrounds as well as those from underserved geographical areas (e.g., rural settings) or racial/ethnic groups [16]. For groups with low literacy, lay leaders can adapt classes to minimize reading. While the average age of participants in the national study was 65, younger participants also enroll and report positive outcomes [17]. The program has had more difficulties recruiting men and those from rural areas, but those who do enroll experience health improvements [15]. Given the emphasis on group interaction that includes problem solving, decision making, and action planning, adults with marked cognitive impairment are assumed to do less well in CDSMP workshops. Hence, program developers discourage participation from those with dementia and recruitment from nursing homes and skilled nursing facilities.

Model Overview

The CDSMP is part of a larger suite of chronic disease self-management education (CDSME) programs offered by Stanford University Patient Education and Research Center [5]. Some of the programs are disease specific (e.g., diabetes, arthritis, HIV, cancer, chronic pain), while others are more general in nature (e.g., CDSMP). Programs are offered in English and Spanish (e.g., Tomando Control de su Salud, Tomando Control de su Diabetes). The format of these programs varies, with small group programs representing the vast majority. Programs are also offered via the Internet and mail.

All CDSME programs are based on Social Learning Theory [18] and emphasize skill-driven processes of problem solving, decision making, goal setting, and action planning. Small group workshops with about 10–15 participants consist of six sessions held once a week for 2.5 h each over 6 consecutive weeks. The workshops cover a range of topics intended to empower participants by helping them develop self-management skills to take care of their chronic conditions outside of traditional health care settings. Figure 12.1 illustrates the topics covered over the 6-week intervention.

The workshops are hosted by two trained facilitators, many of whom have a chronic condition themselves. Peer lay leaders use a uniform manual when hosting a workshop to ensure program consistency. Each participant also receives a book containing general information related to the session content and serves as a resource throughout the workshop [11]. Table 12.1 displays the basic elements of CDSME programs.

CDSMP utilizes a train-the-trainer model where certified Master Trainers (MTs) conduct trainings to certify lay leader workshop facilitators. The small group format provides participants with high levels of both instrumental and emotional support and holds participants accountable for completing behavioral assignments. Further, lay leaders delivering CDSMP have access to various resources and tools that can be individualized to help participants overcome barriers and remain committed to the program. MTs are typically sent to Stanford to receive Master Training, or such trainings can be held by T-Trainers at local sites (depending on the availability of T-Trainers in a given state). Once Master Trained, MTs can be cross-trained and certified to host other programs in the CDSME program suite. To grow the CDSMP delivery infrastructure, MTs can host lay leader trainings to expand

	Week 1	Week 2	Week 3	Week 4	Week 5	Week 6
Overview of self-management and chronic health conditions	★					
Making an action plan	★	★	★	★	★	★
Relaxation/cognitive symptom management	★		★	★	★	★
Feedback/problem-solving		★	★	★	★	★
Difficult emotions		★	★			
Fitness/exercise		★	★			
Better breathing			★			
Fatigue			★			
Eating well				★		
Advance directives				★		
Communication				★		
Medications					★	
Making treatment decisions					★	
Depression					★	
Informing the health care team						★
Working with your health care professional						★
Future plans						★

Fig. 12.1 Topical overview by weekly session

Table 12.1 Basic elements of the CDSME program model

Uses structured protocol that outlines content and methods
Train-the-trainer model
Emphasis on group participation, problem solving, decision making, goal setting, and action planning
2½-h group sessions that meet once per week for 6 consecutive weeks (incorporates a CD and participant book)
Uses two trained lay leaders in each workshop
Targets people with any chronic condition
Works to increase self-efficacy through skill mastery, modeling, reinterpreting symptoms, and persuasion
Fidelity monitoring protocol

the number of lay leaders in a particular community. Lay leaders can facilitate CDSMP workshops, but they cannot train others.

Program Fidelity

Maintaining fidelity during program implementation is an integral part of delivering the program successfully [19]. Translational studies especially emphasize the importance of maintaining fidelity, which can be defined as the adherence of actual treatment delivery to the protocol originally developed [20]. Failure to secure fidelity raises many questions about the validity of the intervention outcomes [21].

In recognition of its dissemination across time and space by different parties, CDSMP program developers have created multiple systems to maintain fidelity of program delivery. First, a centralized training and certification system (http://patienteducation.stanford.edu/programs/cdsmp.html) can support programmatic adherence to implementation aspects of CDSMP. As an example, certified lay leaders from organizations with licensure to operate CDSMP learn its content and structure using the standardized resource materials including CDSMP leader manual and a textbook [11]. At the same time, more detailed fidelity guidance is provided in the CDSMP Fidelity Manual (http://patienteducation.stanford.edu/licensing/FidelityManual2012.pdf). This manual provides a fidelity checklist of what should be done before, during, and after the sessions by different key players in the implementation and dissemination of CDSMP.

Barriers to Implementation

Given the diverse composition of the middle-aged and older adult population, there are many competing demands when selecting and subsequently implementing community-based health and wellness programs. With the array of Tier I evidence-based programs endorsed by the National Council on Aging [22], communities have the freedom to select

programs that best match their community's needs. As such, CDSMP may not always be the obvious program choice in all communities. Often there are difficulties reaching especially vulnerable populations with chronic conditions. Individuals who are homebound or reside in remote areas may not have access to CDSMP, even when it is offered in their community. Additionally, there are licensing and delivery costs associated with CDSMP listed at http://patienteducation.stanford.edu/licensing/. The range of costs to deliver the intervention are based on whether or not the program has been delivered in the community previously (i.e., has a history and already accounted for the one-time start-up costs), the number of participants served, and the number of participants enrolled in each workshop. For some communities, the costs associated with CDSMP delivery may be perceived as too great. These communities may select other interventions without licensure requirements and lower delivery costs.

Outcomes to Be Monitored

The Stanford Patient Education Research Center [23] provides a list of standardized evaluation tools for assessing program impact. These include measures of self-management behaviors, self-efficacy, health status, and health care utilization. For use in community and clinical settings, we recommend pragmatic measurements [24] that are not burdensome to collect but that can help program administrators understand who is being reached, the extent to which participants attend the different workshop sessions, and outcomes of interest to different stakeholders. From a practice and policy point of view, it may be useful to assess the extent to which CDSMP helps achieve the triple aims of health care reform [25]. Of particular relevance to geriatric care is the extent to which there is improved coordination between different care sectors, and specifically improved doctor-patient communications.

Evidence of Benefits

CDSMP earned its evidence-based title after successfully conducting a randomized controlled trial in the late 1990s. Dr. Kate Lorig, the program developer of CDSMP, conducted a 6-month randomized controlled trial and found that CDSMP participants demonstrated improvements in exercise, cognitive symptom management, communication with physicians, self-reported health, health distress, fatigue, disability, and social/role activity limitations [6]. In her 2-year follow-up study, CDSMP participants maintained their increase in self-efficacy and decreased their health distress and emergency room (ER)/outpatient visits [7]. Nevertheless, the 10-year-old findings necessitated reexamination of the effectiveness of CDSMP, especially in light of the widespread dissemination of CDSMP under the ARRA initiatives.

The *National Study of CDSMP* ($n = 1{,}170$), conducted from 2010 to 2012 among 22 licensed sites in 17 states, tested the effectiveness of the CDSMP by evaluating if CDSMPs could accomplish the *Triple Aim* goals emphasized by the Affordable Care Act [15]. Berwick and his colleagues [25] argued that improving the US health care system requires simultaneous pursuit of three goals (i.e., *Triple Aims*) including improving the experience of care (i.e., better care), improving the health of populations (i.e., better health), and reducing per capita costs of health care (i.e., better value). With regard to better care, CDSMP study participants in the *National Study* displayed improvements in communication with physicians, medication compliance, and health literacy between baseline and 12-month follow-up. In terms of better health, CDSMP study participants demonstrated improvements in self-assessed health, fatigue, pain, depression, and unhealthy physical and mental health days between baseline and 6- and 12-month follow-ups. Regarding better value, CDSMP study participants reported a 5 % reduction in ER visits between baseline and 6-month follow-up as well as another 5 % reduction between baseline and 12-month follow-up. Study participants also reported a 3 % reduction in hospitalization between baseline and 6-month follow-up. The better value component was further assessed to estimate health care cost savings. Reductions in ER visits and hospitalization among CDSMP participants could equate to potential net savings of $364 per participant and a national savings of $3.3 billion if CDSMP could reach 5 % of American adults with at least one chronic condition [26].

Buy-In from Health System Leaders and Patients

In parallel with the ARRA initiatives [5], the aging services network has provided technical assistance to help community program managers learn how to make the business case for CDSMP and more effectively reach out to health care providers [27, 28]. However, more health care leaders need to be aware of benefits of patient referral and assured that there will be a consistent delivery system for continuous referral [15]. To help communities make the business case for CDSMP, a new health care cost savings estimator was developed to facilitate understanding about the cost-effectiveness of this intervention. The cost estimator tool can be tailored by users to ensure that the details of program delivery match their specific community and/or clinical setting [26]. As a patient empowerment model of care, CDSMP reflects a patient-centered approach in which patients helped design the CDSMP model of care, are often co-facilitators, and have an active voice in when and where workshops are being held.

Program Scalability

The CDSMP presents an excellent example of a research study being transformed into a scalable best practice. From its initial origins as a tightly controlled research study in California, it flourished with support from the Administration on Aging (AoA), which propelled dissemination through the aging services network with early evidence-based disease prevention initiatives to 14 communities, beginning in 2003. With additional AoA support from 2006 to 2009, CDSMP delivery grew to reach 28,855 participants in 27 states. Based on this success, additional federal support was received to disseminate CDSMP in 45 states and two territories, reaching over 160,000 participants from 2010 to 2013. While the delivery of CDSMP expanded substantially over the past decade, additional funding is needed to support ongoing efforts to reach the millions of adults with chronic conditions.

A variety of funding mechanisms exist to further support the growth of CDSMP to new markets. A new ruling for Area Agencies on Aging to direct their Title III-D health promotion dollars toward evidence-based programs that have been shown effective is likely to help sustain and grow CDSMP programming to even larger numbers of seniors. Having Medicare reimbursement (e.g., the Diabetes Self-Management Program is now eligible for Medicare funding) will help institutionalize self-management programs in clinical settings. As another example, the NIH and CDC are supporting efforts to learn more about CDSMP delivery among working-aged individuals in workplace settings (i.e., individuals less commonly reached by CDSMP because it is delivered through the aging services network).

To facilitate the embedment of CDSMP in communities across the USA, a variety of tools and resources have been created to educate decision makers and program administrators about the benefits of each evidence-based program and for whom it is most effective [22]. Further, these resources assist communities to learn “best practices” associated with gaining partner support, embedding CDSMP in multiple community sectors, recruiting and retaining participants, and seeking/securing funding to support implementation.

Integration with the Electronic Health Record

Electronic health records (EHRs) allow for integration of patient or resident medical/health information into an easily retrievable/accessible digital format [29]. For those with multiple chronic conditions, the use of EHRs is necessary to improve care transitions [30] and facilitate the provision of high-quality and efficient care [31–33]. Coordinating health care for those with chronic conditions is an essential concept conveyed to participants during CDSMP workshops. EHRs have the potential to serve as a way for physicians and patients to monitor self-management success. For example, the use of EHRs in diabetes coordinated care has been linked with improved health outcomes, better communication between providers, and better access to data [34]. Successful integration of EHRs and chronic disease management may be effective for electronic decision support [35]. Further investigations into this potential integration will be needed to determine potential benefits. Policies that support reimbursement for CDSME programs are critical to support future integrations with EHRs. For example, CDSMP has been supported via Medicaid waivers or Medicaid state plans [36]. Policy makers will need to continue to support CDSME programs if we are to extend the benefits of CDSME programs to greater numbers of participants throughout the nation.

Future Plans

The role of CDSMP is dynamic and evolving. CDSME programs have been met with great success in improving the lives of participants, enhancing health care, and curbing medical costs. There is a continual updating and expansion of CDSME programs through Stanford’s Patient Education Research Center, as evidenced by the cancer-specific program being launched in 2015. The success of CDSME programs alone may be improved with the delivery of multiple complementary evidence-based programs, such as fall prevention or hands-on physical activity programs. Adults may suffer from multiple types of chronic conditions (e.g., diabetes, heart disease), many of which may be comorbid. Thus, many adults may benefit from programs that target multiple chronic conditions in a variety of ways [37]. The delivery of multiple evidence-based programs to vulnerable populations is currently under way throughout the USA, but is still limited [38]. Additional efforts are under way to translate CDSMP for implementation in workplace settings to expand the target market [39]. Continued monitoring over time will be needed to identify long-term success in the delivery of multiple types of evidence-based programs to meet the diverse needs of our aging population.

Application to the Patient Protection and Affordable Care Act

The Patient Protection and Affordable Care Act (2010), also known as the ACA, has several provisions that target the amelioration of chronic conditions. Title IV of the ACA, Prevention of Chronic Disease and Improving Public Health,

includes provisions specific to evidence-based programs and older adults. For example, Section 4202 subsection (b) ACA directs the Secretary of the Department of Health and Human Services to develop a plan for promoting healthy lifestyles and chronic disease self-management for Medicare beneficiaries.

In addition to identifying evaluations of the effectiveness of evidence-based programs for improving health outcomes, one of the underlying goals of the ACA is to identify ways to lower health care costs and provide better value. This is evident with several provisions targeting prevention and wellness programs, accountable care organizations, value-based purchasing, and provider incentives for preventing potentially avoidable hospital readmissions [40]. All of these provisions affect older adults, specifically Medicare beneficiaries, either directly (e.g., waived co-payments for annual wellness visits) or indirectly (e.g., Medicare payment policies for hospital readmissions) [40]. CDSME programs are strategically positioned to target these goals of better health outcomes, lower cost, and better value. In particular, the CDSMP has been shown to improve health outcomes and lower hospitalizations, thereby potentially reducing health care costs [15]. Thus, CDSMP is a prime example of an evidence-based program integrating several goals of the ACA and the triple aims of health care reform.

Further supporting the growth and sustainability of CDSME is the articulation of a value proposition for self-management interventions. As stated by the Self-Management Alliance [41], “Self-management interventions create and sustain behavior change that improves chronic disease health outcomes and lowers health care costs.” As such, the future supports the development of an infrastructure for supporting further growth and sustainability of CDSME programs.

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