

History of SMRC Self-Management Programs

References to all studies can be found in the bibliography

1978+ The Arthritis Self-Management Years

In 1978, Kate Lorig came to Stanford University to create an arthritis education program. This program was mandated by a grant from The U.S. National Institutes of Health to the newly funded Stanford Multipurpose Arthritis Center, part of Stanford University School of Medicine.

By early 1979, the Arthritis Self-Management Program had been written and the first 14 Leaders trained. Over the next year, nearly 300 people attended programs, and by 1980 Kate had completed her doctoral dissertation for University of California Berkeley, *Arthritis Self-Management: A Joint Venture*.

→ This study showed that a small-group, peer-led arthritis program could change health status and health behaviors.

Based on this evidence, the U.S. National Arthritis Foundation disseminated the program nationally and continued to do so into the 21st century.

For the next 30 years, the Stanford Arthritis Center, later named the Stanford Patient Education Research Center, conducted a number of studies of community-based arthritis education programs and established some of the evidence that underlies all the SMRC programs.

The following are some of the key findings from this period and their references.

- → The Arthritis Self-Management Program reduced costs.
- → Self-Efficacy is one of the factors explaining beneficial outcomes.
- → Reinforcement may not add anything.
- → Programs of less than six weeks were not effective. (We tried 2,3,4 and 6 weeks.)

- → Lack of strong evidence that professionals are better than peers as program Leaders.
- → Spanish-speakers benefit from the Spanish Arthritis Self-Management Program.
- → People with arthritis have similar benefits if they participate in disease specific (Arthritis Self-Management Program), or generic (Chronic Disease Self-Management) workshops.
- → A mailed version of the Arthritis Self-management program was successful in English, Spanish and for African Americans who had called and asked for the mail delivered tool kit.
- → The Arthritis Self-Management Program leads to sustained (2-year) benefit.
- → Arthritis Self-Management can be effective for those 80 and older.
- → The Arthritis Self-Management Program can be effective when delivered via the Internet.

1990+ The Chronic Disease Self-Management Years

In the early 1990s we developed and studied the Chronic Disease Self-Management Program. This study was funded by California state tobacco money and the Agency for Health Care Policy and Research and was conducted in conjunction with Kaiser Permanente. We found that treatment participants when compared to randomized controls increased healthful behaviors, improved health status, and had less health care utilization.

The original CDSMP study was followed up by a longitudinal study that included several Kaiser Permanente regions. This study had findings similar to the original study.

This was followed by a study of the program offered in Spanish.

As part of the U.S. Recovery Act following the recession of 2009, a second large translation study included 22 sites in the United States. Again, the findings were similar to the original study.

In 2018 the University of Georgia completed a study of a Workplace Chronic Disease Self-Management program. This program is offered twice a week for six weeks, each session lasting 1 hour. Content is very similar to that of the original CDSMP with additional content on work/homelife balance and stress management.

In response to the COVID-19 in 2020, Virtual and Mailed Tool Kit plus small group telephone calls delivery systems were developed as well as virtual Leader and Master training.

There were several other key studies showing the effectiveness of the CDSMP outcomes and cost savings in England.

A number of studies were also conducted to assess the effectiveness of CDSMP:

- → As an on-line program (Better Choices Better Health)
- → For people with severe mental health problems
- → For people with Diabetes
- → As a program delivered through the mail
- → For people with Depression
- → For the wCDSMP (workplace)

The CDSMP is considered an evidence-based program by the Administration for Community Living and the Centers for Disease Control Arthritis Branch.

1994+ The HIV Self-Management Years

In response to the HIV/AIDs crisis, the CDSMP was adapted for use in people who were HIV positive and was named the Positive Self-Management Program (PSMP). This was done in conjunction with Allen Gifford MD, who at the time was a Robert Wood Johnson Clinical Scholar at Stanford. There have been several trials of both the original program as well as a program revised in the mid-2000s. Since that time, mainly because of new drugs, the face of HIV has changed to look more like other chronic conditions. Thus, the workshop was revised again and released in early 2016. It is currently available in face-to-face and virtual formats.

The PSMP is considered an evidence-based program by the Administration for Community Living.

1995+ The Chronic Pain Self-Management Years

In the mid-1990s, Dr. Sandra LeFort in St. John's Newfoundland adapted the ASMP for use by people with chronic pain. The workshop has been used for many years in Canada and more recently in Denmark. In 2015, the workshop was completely revised, and a book was written to accompany the workshop. It was released for public use in mid-2015. In 2020 we introduced a Chronic Pain Self-Management Tool Kit and telephone conference call scripts. A revised edition of both the workshop and book will be released in 2021. The face-to-face and virtual formats are available in Spanish.

The CPSMP is considered an evidence-based program by the Administration for Community Living and a promising program by The Centers for Disease Control Arthritis Branch.

2004+ The Diabetes Self-Management Years

Diabetes is the most complex behaviorally of the common chronic conditions. For this reason, we decided to explore the possibilities of using a community-based self-management program to assist with the growing problem of type II diabetes. Funding for these studies came from the National Institute of Nursing Research, the Archstone Foundation and the National Institute for Diabetes and Kidney Disease. We were assisted by many members of both the Association of Diabetes Care and Education Specialists, and the American Diabetes Association. There are 4 ways to present SMRC diabetes programs. Face-to face first developed in Spanish and then adapted to English, virtually using zoom or similar platform, and with mailed tool kits with or without six scripted telephone calls. All programs are in both English and Spanish. Face-to-face programs have been shown to lower A1C and improve health behaviors and health status. The other two modes are currently being evaluated.

The DSMP has been accepted as part of the diabetes education programs eligible for Medicare reimbursement and as an evidence-based program by the Administration for Community Living. It has also been recognized by the American Diabetes Association as meeting the Diabetes Support Initiative criteria for support program.

2010+ The Building Better Caregivers Years

In approximately 2010, the U.S. Veterans Administration approached us about developing and evaluating an online program for the caregivers of veterans who suffered from traumatic brain injury, post-traumatic stress disorder, or other cognitive problems. The result was the

online Building Better Caregivers, which underwent a small study and is currently used by the V.A. caregiving program, as well as other organizations in the United States. This program is available from Canary Health.

In 2013 we received a grant from the Archstone Foundation to adapt the online BBC to the small face-to-face group format. The program is now available in face-to-face and virtual formats in English and Spanish.

BBC is recognized as a best practice program by the Benjamin Rose Institute on Aging and the Family Caregiver Alliance. It is eligible for title III E Older Americans Act Funding.

2012+ The Cancer Thriving and Surviving Years

In the early 1990's the Macmillan Trust (a cancer charity in the United Kingdom), adapted the CDSMP for use with cancer survivors. In addition, Dr. Lorig is a cancer survivor and her personal experience led to an interest in this topic. These two factors came together when the University of Hawaii asked Stanford to develop an online program for cancer survivors and to assist with its evaluation.

In 2012, a second collaboration was formed between Cancer Centers in Colorado, Virginia, and Texas, as well as the Stanford Patient Education Research Center. This collaboration developed and studied a small group, face-to-face Cancer Thriving and Surviving program. This was released for public use in 2015 and is available in English and Spanish in both face-to-face and virtual formats. Unfortunately, the online program is no longer available.

Cancer Thriving and Surviving is recognized as an evidence-based program by the Administration for Community Living.

2020 COVID-19 and Pivoting to Remote Delivery

With the pandemic just a few weeks old (April 2020), SMRC started advising the organizations offering workshops on how they might do this using digital platforms. They also worked quickly with their publisher to develop mailed tool kits of materials for Diabetes Self-Management and Chronic Pain Self-Management. It soon became obvious that two problems highlighted by the pandemic were social isolation, and the inability to use or the unwillingness to use internet-based technology. To mitigate these problems, SMRC developed phone scripts for each of the tool kits so that Leaders could offer programs to small groups of 3-5 people in weekly 45-minute phone calls. By October 2020, SMRC had developed virtual Leader manuals, a system for training new Leaders online, and an additional certification webinar to prepare existing Master Trainers to offer Leader and other

trainings online. By the end of 2020, 4000-5000 people had participated in virtual SMRC programs, approximately 50 new Leaders had been trained and 200 Master Trainers had been prepared to offer virtual trainings. Working with the Evidence Based Leadership Collaborative, these new program modes will be evaluated for effectiveness in 2021. In 2021 SMRC began offering virtual Master Training.