

# APPENDIX IX: HISTORY OF SELF-MANAGEMENT PROGRAMS

## 1978+ The Arthritis Self-Management Years

In 1978, Kate Lorig came to Stanford 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.**

Publication: Lorig, Kate, et al. "Outcomes of self-help education for patients with arthritis." *Arthritis & Rheumatism* 28.6 (1985): 680-685.

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

For the next nearly 30 years, the Stanford Arthritis Center, now names 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 of our works today.

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

→ **The Arthritis Self-Management Program reduced costs.**

Publication: Lorig Kate R, Mazonson Peter D, and Holman Halsted R. "Evidence suggesting that health education for self-management in patients with chronic arthritis has sustained health benefits while reducing health care costs." *Arthritis & Rheumatism* 36.4 (1993): 439-446.

→ **Self-Efficacy is one of the factors explaining beneficial outcomes.**

Publications:

Lorig Kate, et al. "The beneficial outcomes of the arthritis self-management workshop are not adequately explained by behavior change." *Arthritis & Rheumatism* 32.1 (1989): 91-95.

O'Leary Ann, et al. "A cognitive-behavioral treatment for rheumatoid arthritis." *Health Psychology* 7.6 (1988): 527.

Lorig Kate, et al. "Development and evaluation of a scale to measure perceived self-efficacy in people with arthritis." *Arthritis & Rheumatism* 32.1 (1989): 37-44.

→ **Reinforcement may not add anything**

Publication: Lorig Kate, and Holman Halsted R. "Long-term outcomes of an arthritis self-management study: Effects of reinforcement efforts." *Social science & medicine* 29.2 (1989): 221-224

→ **Shorter versions of the Arthritis Self-Management Program are not as effective**

Publication: Lorig Kate, et al. "Arthritis self-management program variations: Three studies." *Arthritis & Rheumatism* 11.6 (1998): 448-454.

→ **Lack of strong evidence that professionals are better than peers as program leaders.**

Publications:

Cohen Judith L, et al. "Evaluation of arthritis self-management workshops led by laypersons and by professionals." *Arthritis & Rheumatism* 29.3 (1986): 388-393.

Lorig Kate, et al. "Arthritis self-management program variations: Three studies." *Arthritis & Rheumatism* 11.6 (1998): 448-454.

→ **Spanish Speakers benefit from the Spanish Arthritis Self-Management Program**

Publications:

Lorig Kate, González Virginia M, and Ritter Philip. "Community-based Spanish language arthritis education program: a randomized trial." *Medical care* 37.9 (1999): 957-963.

González, Virginia M, et al. "Translation and validation of arthritis outcome

measures into Spanish." *Arthritis & Rheumatism* 38.10 (1995): 1429-1446.

- **People with arthritis have similar benefits if they participate in disease specific (Arthritis Self-Management Program, or generic (Chronic Disease Self-Management) workshops.**

Publication: Lorig Kate, Ritter Philip L, and Plant Kathryn. "A disease-specific self-help program compared with a generalized chronic disease self-help program for arthritis patients." *Arthritis Care & Research* 53.6 (2005): 950-957.

- **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.**

Publication: Goeppinger Jean, et al. "Mail-delivered arthritis self-management tool kit: A randomized trial and longitudinal followup." *Arthritis Care & Research* 61.7 (2009): 867-875.

- **The Arthritis Self-Management Program leads to sustained (2-year) benefit.**

Publication: Osborne Richard H, et al. "Does self-management lead to sustainable health benefits in people with arthritis? A 2-year transition study of 452 Australians." *The Journal of Rheumatology* 34.5 (2007): 1112-1117.

- **Arthritis Self-Management can be effective for those 80 and older.**

Publication: Lorig Kate, Laurin Janette, and Holman Halsted R. "Arthritis self-management: a study of the effectiveness of patient education for the elderly." *The Gerontologist* 24.5 (1984): 455-457

- **The Arthritis Self-Management Program can be effective when delivered via the Internet.**

Publication: Lorig Kate R, et al. "The internet-based arthritis self-management program: A one-year randomized trial for patients with arthritis or fibromyalgia." *Arthritis Care & Research* 59.7 (2008): 1009-1017.

## 1990+ The Chronic Disease Self-Management Years

In the early 1990s we developed and studied the Chronic Disease Self-Management Program. Early studies were funded by California state tobacco money and the Agency for Health Care Policy and Research. This study 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.

- Publication: Lorig K, Sobel DS, Stewart AL, Brown BW, Bandura A, Ritter P, González VM, Laurent DD, Holman HR. “Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitalization: a randomized trial”. *Medical Care* 1999; 37(1):5-14
- Publication: Lorig K, Ritter P, Stewart A, Sobel D, Brown BW, Bandura A, González VM, Laurent DD, Holman H: “2-year evidence that chronic disease self-management education has sustained health and utilization benefits”. *Medical Care* 2001;39(11):1217-1223.

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.

- Publication: Lorig KR, Sobel D, Ritter PL, Hobbs M, Laurent D. “*Effect of a self-management program on patients with chronic disease. Effective Clinical Practice* 2001;4:256-262.
- Publication: Sobel DS, Lorig KR, Hobbs M. “*Chronic condition self-management program: from development to dissemination*”. *Permanente Journal* 2002;6(2):11-8.

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

- Publication: Ahn S, Basu R, Smith ML, Jiang L, Lorig K, Whitelaw N, Ory MG. “The impact of chronic disease self-management programs: healthcare savings through a community-based intervention”. *BMC Public Health*: 13(1):114,2013 Dec.
- Publication: Ory MG, Ahn S, Jiang L, Smith ML, Ritter PL, Whitelaw N, Lorig KL. “Successes of a national study of the chronic disease self-management

program: Meeting the triple aim of health care reform". *Medical Care*: 51(11):992-8, 2013 Nov

→ Publication: Ory MG, Ahn SN, Jiang L, Lorig K, Ritter P, Laurent DL, Whitelaw N, Smith ML: *National Study of Chronic Disease Self-Management: Six Month Outcome Findings*. *Journal of Aging Health*: 2013,25:1258

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

→ Publication: Kennedy A, Reeves D, Bower P, Lee V, Middleton E, Richardson G, Gardner C, Gately C, Rogers A. "The effectiveness and cost effectiveness of a national lay-led self care support programme for patients with long-term conditions: A pragmatic randomised controlled trial". *Journal of Epidemiology and Community Health* 2007;61(3),254-61

→ Publication: Richardson G, Kennedy A, Reeves D, Bower P, Lee V, Middleton E, Gardner C, Gately C and Rogers A. "Cost Effectiveness of the Expert Patients Programme (EPP) for Patients with Chronic Conditions". *Journal of Epidemiology and Community Health* 2008;62:361-367.

Effectiveness as an on-line program (Better Choices Better Health)

→ Publication: Lorig KR, Ritter PL, Dost A, Plant K, Laurent DD, McNeil I. "The expert patient programme online, a 1-year study of an Internet-based self-management programme for people with long-term conditions". *Chronic Illness* 2008;4(4):247-256.

→ Publication: Lorig K, Ritter PL, Laurent DD, Plant K. "Internet-based chronic disease self-management: A randomized trial". *Medical Care* 2006;44(11):964-971.

→ Publication: Lorig k, Ritter PL, Plant K, Laurent DD, Kelly P, Rowe S. "The South Australia Health chronic disease self-management internet trial". *Health Education and Behavior* 2013 Feb;40(1):67-77.

Effectiveness for people with severe mental health problems

→ Publication: Lorig K, Ritter PL, Pifer C, Werner P. "Effectiveness of the chronic disease self-management program for persons with a serious mental illness: A translation study". *Community Mental Health Journal* 06/2013 (ePub).

## Effectiveness of the CDSMP for people with Diabetes

- Publication: Lorig K, Ritter P, Jacquez A. "Outcomes of border health Spanish/English chronic disease self-management programs". *Diabetes Educator* 2005;31(3):401-409.
- Publication: Lorig, Kate, et al. "Effectiveness of a Generic Chronic Disease Self-Management Program for People With Type 2 Diabetes A Translation Study." *Diabetes Educator* 39.5 (2013): 655-663.

## Effectiveness of the CDSMP as a program delivered through the mail

- Publication: Lorig K, Ritter PL, Moreland C, Laurent DD. "Can a box of mailed materials achieve the triple aims of health care? The Mailed Chronic Disease Self-Management Tool Kit study". *Health Promotion Practice: ePub* 2015 Feb 17.

## Effectiveness of the CDSMP for people with Depression

- Publication: Ritter PL, Ory MG, Laurent DD, Lorig K. "Effects of chronic disease self-management programs for participants with higher depression scores: secondary analyses of an on-line and a small-group program". *Translational Behavioral Medicine*: 4(4):398-406

## 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. 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.

- Publication: Gifford AL, Laurent DD, González VM, Chesney MA, Lorig KR. “Pilot randomized trial of education to improve self-management skills of men with symptomatic HIV/AIDS”. *Journal of Acquired Immune Deficiency Syndrome and Human Retrovirology* 1998: 18(2):136-144
- Publication: Gifford AL, Groessl EJ. “Chronic Disease Self-Management and Adherence to HIV Medications”. *Journal of Acquired Immune Deficiency Syndromes* 2002: 31:S163–S166.
- Publication: Webel AR. “Testing a peer-based symptom management intervention for women living with HIV/AIDS”. *AIDS Care* 2010 Sep;(9):1029-40.

## 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. It is hoped that a Spanish translation of this workshop will be available in 2016.

- Publication: LeFort S, Gray-Donald K, Rowat KM, Jeans ME. “Randomized controlled trial of a community-based psychoeducation program for the self-management of chronic pain”. *Pain* 1998;74,297-306
- Publication: Mehlsen M, Heegaard L, Frostholm L. “A prospective evaluation of the Chronic Pain Self-Management Programme in a Danish population of chronic pain patients”. *Patient Education and Counseling* 2015:(5)677-680.

## 2004+ The Diabetes Self-Management Years

Of the most common chronic conditions, diabetes, is the most behaviorally complex. 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 American Diabetes Association and the American Association of Diabetes Educators. There are 3 diabetes programs, Spanish (the first program developed), English, an adapted translation of the Spanish program, and Better Choices Better Health, the online diabetes program. All of these programs have been shown to lower A1C, and improve health behaviors and health status.

- Publication: Lorig K, Ritter PL, Villa F, Piette JD. “Spanish diabetes self-management with and without automated telephone reinforcement”. *Diabetes Care* 2008;31(3):408-14
- Publication: Lorig K, Ritter PL, Villa FJ, Armas J. “Community-based peer-led diabetes self-management: A randomized trial”. *The Diabetes Educator* 2009 July-August;35(4):641-51.
- Publication: Lorig K, Ritter PL, Laurent DD, Plant K, Green M, Jernigan VBB, Case S. “Online diabetes self-management program: A randomized study”. *Diabetes Care* 2010;33(6):1275-1281

## 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.

In 2013 we received a grant from the Archstone Foundation to adapt the online BBC to small face-to-face group format. This trial will come to an end in 2016, after which we hope to release the small group program for general community use.

- Publication: Lorig K, Thompson-Gallagher D, Traylor L, Ritter PL, Laurent DL,



Plant K, Thompson LW, Hahn TJ. "Building Better Caregivers: A pilot online support workshop for family caregivers of cognitively impaired adults". *Journal of Applied Gerontology* June 2012;31(3):423-437

## **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 Stanford was asked by the University of Hawaii to develop an online program for cancer survivors and to assist with its evaluation. This collaboration resulted in Cancer Thriving and Surviving.

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 version of online Cancer Thriving and Surviving. This was released for public use in 2015.

Publication: Bantum EO, Albright CL, White KK, Berenberg JL, Layi G, Ritter PL, Laurent D, Plant K, Lorig K. "Surviving and thriving with cancer using a web-based health behavior change intervention: Randomized controlled trial". *Journal of Medical Internet Research* 2014 Feb;16(2):e54

Publication: Risendal BC, Dwyer A, Seidel RW, Lorig K, Coombs L, Ory MG. "Meeting the challenge of cancer survivorship in public health: results from the evaluation of the chronic disease self-management program for cancer survivors". *Psycho-Oncology*. 2015 Apr 10 (ePub). doi: 10.1002/pon.3783.