CHRONIC DISEASE PREVENTION HEALTH PROMOTION





Volume 4, Issue 1 April 2012

Living Well Alaska: An Evaluation of a Distance Delivery Project

Contributed by Barbara Stillwater PhD, RN

Abstract

Living Well Alaska is based on Stanford University's Chronic Disease Self-Management Program (CDSMP). It is a six-week workshop designed to help Alaskans manage their chronic conditions. The program's current infrastructure is based in Anchorage. The disadvantage of this situation is that workshops are less likely to be available to rural Alaskans. This *Chronicle* describes our efforts to bring this program to two remote regions of Alaska using distance-delivery technology.

Suggested citation for this article: Alaska Section of Chronic Disease Prevention and Health Promotion. Living Well Alaska: A Distance Delivery Pilot Project. Chronicle Volume 3, Issue 2, October, 2011. Contributed by: Barbara Stillwater PhD, RN Alaska Diabetes Prevention and Control Program. Available from: www.hss.state.ak.us/dph/chronic/

Background

The Chronic Disease Self-Management Program (CDSMP) was developed by the Stanford University Stanford Patient Education Research Center, where self-management programs for people with chronic health conditions have been tested and evaluated for the past 20 years. Initially developed to address arthritis, the program was subsequently expanded to be applicable to a wide range of chronic conditions. Each variant of CDSMP has been designed to help people gain self-confidence in their ability to manage

their symptoms and to understand how their health problems affect their lives. Programs are released by Stanford University for dissemination only after they have been shown to be safe and effective through randomized controlled trials. ¹

CDSMP operates on several assumptions:

- People with chronic conditions have similar concerns and problems;
- People with chronic conditions must deal not only with their disease(s), but also with its impact on their lives;
- The process or the way CDSMP is taught is as important as the subject matter; and
- Lay people who complete CDSMP leader training can effectively facilitate CDSMP workshops.

All of these assumptions have been evaluated in published studies.²⁻⁴ CDSMP was first evaluated in a five-year randomized study involving more than 1,000 subjects. This study found that people who participated in the program, when compared to people who did not,



State of Alaska, Sean Parnell, Governor

Department of Health and Social Services William J. Streur, Commissioner

Division of Public Health Ward Hurlburt, MPH, MD, Chief Medical Officer and Director

> Andrea Fenaughty, PhD Chronicles Coordinator

improved their healthful behaviors (exercise, cognitive symptom management, coping and communications with physicians), improved their health status (self-reported health, fatigue, disability, social/role activities, and health distress), and decreased their days in the hospital. The decrease in hospital days was associated with a cost savings of 1:4.²

In one randomized trial, it was found that although subsequent health service utilization did not differ between the control and treatment groups, the treatment group did report considerably greater health-related quality of life, which is translatable as a cost savings since quality of life can be quantified.⁵

CDSMP is designed to be led by trained lay persons, although health professionals can also co-lead the workshops. These leaders meet with groups of 8-12 persons with chronic conditions. The sessions are 2 1/2 hours long, once each week for six consecutive weeks. The workshop is intended for persons experiencing any type of chronic health condition; their significant others and caretakers are encouraged to attend.

CDSMP workshops address the following:

- starting an exercise program;
- cognitive symptom management;
- healthy eating;
- breathing exercises;
- relaxation;
- creating and modifying an action plan;
- problem solving;
- communicating with family, friends, and health care providers; and
- dealing with the emotions of chronic illness, particularly anger and depression.

In the traditional model of patient education, an educator communicates disease specific information with the hope that compliance will improve clinical outcomes. In contrast, CDSMP targets improving self-efficacy, that is, confidence in one's capacity to make life changes. CDSMP

does not replace traditional patient education but rather complements and reinforces it. CDSMP workshop participants obtain new information, learn new skills and abilities, and develop new ways to manage and cope with their chronic conditions. Participants give and receive support from others who have comparable challenges from living with a chronic health condition.

Sessions are highly interactive and emphasize strategies to help individuals more effectively manage their chronic conditions. The theoretical basis of the CDSMP include skills mastery, which is accomplished through weekly action plans or self-contracts to do specific activities, as well as through feedback and modeling. During the workshops, leaders frequently use group problemsolving strategies as well as brainstorming.

Recently the National Council on Aging licensed an online version of the CDSMP workshop. Better Choices, Better Health workshops are held entirely online and enable persons to participate from any computer with an Internet connection. Workshop participants join with up to 25 other persons in an interactive workshop in easy-to-follow online sessions, which are posted each week for six weeks. Participants log on at their convenience two to three times per week for a total of about two hours per week. Although participants do not need to sign on at the same time, the sessions are highly participatory through internal messaging and online discussion boards. This facilitates mutual support which helps build participants' confidence in their ability to manage their health. The content of the online workshops is comparable to the face-to-face workshop version of CDSMP.

Context

Since 2006, there have been 137 Living Well Alaska workshops, with 837 participants from 20 communities. Sixty-one percent (61%) of the workshops were located in the Anchorage Bowl; 8% were located in communities with populations of up to 2,200 persons and 10% were

located in communities not connected to the Alaska road system.

From the onset, we very much wanted to be able to offer workshops to rural Alaskans. To accomplish this, we recruited 30 persons from small rural communities and trained them as workshop course leaders. Although we ask course leaders to commit to teaching at least two workshops, less than 50% ever fulfilled that expectation and among rural course leaders, the percentage was less than 30%. In a post leader training survey of rural leaders, although many intended to lead a workshop, they experienced barriers that prohibited them from following through. These barriers included job scope changes, lack of administrative support, and challenges with recruiting participants.

In December 2010, we collaborated with the Alaska Native Medical Center Diabetes Program and planned a distance delivery pilot project by which we could lead CDSMP workshops from Anchorage for participants in rural communities. To accomplish this, we planned using a poly-com system of communication with video conferencing. Poly-com systems create virtual meeting experiences by allowing real-time and two-way interaction between multiple sites simultaneously. Poly-com systems are widely used in Alaska for telemedicine to bring quality primary healthcare and specialty services to remote areas of the state. As our plans materialized, we partnered with Chugachmiut and Eastern Aleutian Tribes as our pilot project host sites.

Chugachmiut serves the Alaska Natives living in seven Chugach communities: Anchorage, Chenega Bay, Cordova, Nanwalek, Port Graham, Seward, Tatitlek, and Valdez. Two Chugachmiut CDSMP and DSMP (diabetes self-management program) leaders co-facilitated the 6-week DSMP workshop from Seward while connecting to participants in six different communities, spanning a distance of 720 miles.

Eastern Aleutian Tribes (EATS) serves the Alaska

Natives living in the eight EATS communities: Adak, Akutan, Cold Bay, False Pass, King Cove, Nelson Lagoon, Sandpoint, and Whittier. The pilot project participants were located in a small community in the Aleutian Chain, 580 air miles from Anchorage. The two co-facilitators were located at the EATS office in Anchorage.

Methods

Pilot sites self-selected to participate in the distance pilot project. Both were familiar with CDSMP and both had CDSMP and DSMP course leaders on staff. Both agencies routinely utilize poly-com systems for video communications with their remote villages. The systems are used for meetings, lectures, classes, patient visits, education, medical procedures, and clinical consultations. Both agencies recruited local coordinators in each community as their initial step. The local coordinators were all employed by the local health clinics which gave access to participants and a location for the workshops. Both agencies used flyers, phone calls, and word of mouth to advertise the workshops. Once participants were recruited, workshop dates were set and locations were secured. All the participants came to the clinics for the workshops except a few who were confined to their homes and participated via phone. Between 4 and 8 hours were spent preparing the local coordinators. Technical assistance included reviewing the workshop manual, the charts, and the ground rules. The workshops were evaluated using standard Living Well Alaska pre- and postworkshop survey forms and post-workshop communication with the leaders.

Results

Twenty persons with diabetes from six different remote communities participated in the DSMP workshop and six persons with various chronic conditions from one remote community attended the CDSMP workshop. The persons who attended the DSMP workshop were considerably younger

than the CDSMP participants although this difference did not seem to affect attendance or the workshop completion rate. See Table 1.

Table 1. Workshop Participant Data

	Chugachmiut Multi-Site	EATS Single Site
Type of Workshop	DSMP	CDSMP
# participants	20	6
Gender F/M	15/5	6/0
Age range	21-67	50-78
Mean age	41	66
Completed 4/6 classes	16 (80%)	5 (83%)
Completed 6/6 classes	8 (40%)	3 (50%)
Chronic conditions reported by # of participants	Diabetes 20	Arthritis - 4, Diabetes - 2, Lung disease - 1, Hypertension 1

Workshops were conducted according to the guidelines established by Stanford University. Both agencies used brainstorming, modeling, skill practice, and small group discussions to promote self-efficacy among the participants. Both used the required workshop charts specific to each session but only one had a set of charts at the remote site. The agency that did not have the full-size charts at the site, created charts on PowerPoint which allowed participants to read them though for some they were difficult to see. Other similarities to the standard CDSMP delivery model included their use of incentives to encourage workshop completion and the use of the buddy system to reinforce action plan completion by participants. Costs for the distance delivery workshops were comparable to the traditional model of delivery.

The primary differences between the traditional in-person workshops and these two distance workshops were related to the delivery technology and the role of the local coordinator. Technical difficulties were anticipated; both agencies prepared for them by having IT available during workshop sessions and by checking the equipment at the origin and remote sites prior to each session. As it turned out, the technical difficulties were quite minor and were quickly resolved. The difficulty that both agencies initially underestimated was the role of the local coordinator during a workshop. Since all the local coordinators had some familiarity with CDSMP, there was a tendency for them to vacillate between being a participant and a third leader. The problem this created was they knew more than the other participants and there was a tendency for them to re-direct the group dynamics. The difficulties this presented were not immediately recognized but both sites resolved in the future to either have the co-leader on site or have the local coordinator function in the role of a participant. See Table 2.

Feedback was collected from course leaders and a subset of participants. The leaders reported that the participants were engaged in the workshop and their action plans. All of the participants who completed the post workshop survey rated the workshop as 10 out of 10 in terms of how much they liked it. When asked if they learned new tools to manage their chronic conditions, they responded affirmatively with an aggregated score of 4.6 out of 5. All of the participants reported engaging in new activities, such as walking, visiting with friends, and limiting snacks, as a direct result of the workshop. In terms of confidence level, that is the confidence to live a healthy life with a chronic condition, the aggregated level before the workshop was 7.8 and the after the workshop was 8.6. (For detailed evaluation results of the Living Well Alaska program go to:

www.hss.state.ak.us/dph/chronic/pubs/assets/ChroniclesV1-1.pdf.

Table 2. Pilot Program Descriptions, by Component and Site

	Chugachmiut Multi-Site	EATS Single Site
Technology		
Equipment	Polycom, Connect Pro, Phone	Polycom
Supplies workshop leaders used	Charts, PowerPoint charts	Posters, charts, dry erase board, post-it pads, leader's manual, <i>Living a Healthy Life</i> book
Supplies at local sites	Charts	Posters, charts, dry erase board
Technology problems	Charts were created on PowerPoint and emailed ahead to each site and to those folks participating via phone. Still it was challenging for everyone to see the charts close enough.	There were minor transmission disruptions but they were able to re-establish connection quickly. There were a few problems with speaking voice volume & hearing participant comments.
Pre-workshop planning to reduce technology problems	They beta tested a class. Group gave feedback which was incorporated into the pilot workshop.	They set up room 30 minutes early, turning on equipment to make sure no problems existed. They practiced ahead of time to make sure charts were visible and that each end could hear. Technical support was scheduled and available during most sessions.
Roll-Out		
Recruitment of participants	Newsletters, word of mouth, individual invitations, announcements at community events, board meetings	Posters placed throughout community, advertised at community events, personal calls. Participants recruited through primary care clinic by staff member.
Local Support		
Selection process for local coordinator	Health aides who had taken the workshop previously.	The local coordinator worked in the clinic which enabled her to recruit participants.
Role of local coordinator	Recruit participants and set up the Poly-com and/or Connect Pro.	Recruit participants, advertise, organize incentives, put up appropriate charts, get workshop supplies, get feedback forms completed & returned; set up room; arrange for meals to be brought to site; post the necessary charts for each session.
How much time did lo- cal coordinators spend	27hrs at each site	34 hours
Costs		
Staff time:		
Leaders	\$1440	\$1974
Local coordinators Admin Asst	\$2700	\$1088
7.0		\$246
Incentives	\$250	\$450
IT	\$600	0
Supplies	\$1050	\$326
Total Costs	\$6040	\$4084

Conclusion

The need for a local leader or a clearly structured role for the local coordinator was apparent to both sites. One agency is planning a course leader training so that there is at least one leader in each community who can co-facilitate with the primary leader at the main administrative site. Knowing that trained leaders in all their multiple remote communities is not an option, the other agency felt that the local person should help with logistics and then participate in the workshop as a participant.

Recruitment was challenging in all of the communities. In post workshop discussions with the leaders this was felt to be related to two factors: concern regarding confidentiality and lack of familiarity with CDSMP. Maintaining one's privacy and residing in a small community is difficult. People are frequently reluctant to discuss their challenges openly. Although CDSMP

workshops do not require self-disclosure, there is often the perception that personal issues will be revealed in small groups and thus open for discussion. One agency plans to develop a regional PSA to be televised in each of their communities. It is hoped that advertising will increase the number of participants and address some of the misconceptions about the workshops. Since both agencies identified low participation rates due to low recruitment and drop-out as an issue, they both acknowledged the need to solicit commitment from a larger number of participants before starting a workshop.

Although there were many challenges, the pilot project was an enthusiastic first attempt by both tribal health departments at delivering CDSMP to their remote communities. Because participant feedback was positive, both sites have committed to delivering future CDSMP and DSMP workshops using distance technology.

For more information about Living Well Alaska please visit: www.hss.state.ak.us/dph/chronic/smp/default.htm

References

- 1. http://patienteducation.stanford.edu/programs/ Accessed September 2011.
- 2. Lorig KR, Sobel DS, Ritter PL, Laurent D, Hobbs M. Effect of a Self-Management Program on Patients with Chronic Disease. *Effective ClinicalPractice*, 4(6), 256-262, 2001.
- 3. Lorig KR, Ritter PL, Stewart AL, Sobel DS, Brown BW, Bandura A, González VM, Laurent DD, Holman HR. Chronic Disease Self-Management Program: 2-Year Health Status and Health Care Utilization Outcomes. *Medical Care*, 39(11),1217-1223, 2001.
- 4. Nolte S, Elsworth GR, Sinclair AJ, Osborne RH. The extent and breadth of benefits from participating in chronic disease self-management courses: A national patient-reported outcomes survey. *Patient Education and Counseling*, 65 (3):351-60, 2007.
- 5. 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*, 61(3), 254-61, 2007.