

# Chronic Disease Self Management Programs: Relevance for Persons with Dementia\*

Nina M. Silverstein, PhD  
Gerontology Institute  
Univ. of Massachusetts Boston

Michael Splaine  
Splaine Consulting  
Columbia, MD

---

**National Council on Aging Webinar**  
**March 17, 2015**

---

\*Adapted from Silverstein, N.M. & Gottlieb, A. S., 2011

[http://scholarworks.umb.edu/gerontologyinstitute\\_pubs/1/](http://scholarworks.umb.edu/gerontologyinstitute_pubs/1/)

# Acknowledgment

The 2011 study was conducted at the request of, and funding was provided by, the Alzheimer's Association under Cooperative Agreement 1U58DP002945-02 from the Centers for Disease Control and Prevention (CDC) Healthy Aging Program.

The authors are grateful for the cooperation of Dr. Kate Lorig, the researcher who developed CDSMP. Dr. Lorig is the Director of the Stanford Patient Education Research Center and Professor of Medicine in the Stanford School of Medicine.

# QUESTION #1 TO THE AUDIENCE

Is CDSMP a model that should be considered for persons with dementia and their care partners?

- YES
- NO

# Overview of Research Questions

- ▶ Is CDSMP a model that should be considered for persons with dementia and their care partners?
- ▶ Do persons with dementia and their care partners currently attend CDSMP workshops?
  - ▶ Do they attend separately or in pairs?
  - ▶ What benefits do trainers perceive for the individual and for the care partner?
- ▶ What aspects of the curriculum or training approaches are helpful or not helpful to persons with dementia?
  - ▶ Do trainers adapt content and approaches?
- ▶ What recommendations do the trainers have for the Alzheimer's Association?

# Methods

- ▶ Electronic Survey developed in Fall 2010 with input from the Alzheimer's Association and Dr. Kate Lorig
- ▶ 6 open-ended questions; 14 close-ended
- ▶ Institutional Review Board Approval through UMass Boston (Nov. 2010)
- ▶ Survey Monkey link disseminated by Dr. Lorig to her listserv of trainers in the US (1827), Canada (433) and International (313).
- ▶ Data collection period (Dec. 1, 2010-Jan. 14, 2011)
- ▶ Response (n=253)
- ▶ Qualitative Analysis using NVIVO 8

# Sample Description: Trainers (n=253)

- ▶ 93% Female
- ▶ 57% Health care professionals
- ▶ 83% have chronic conditions
- ▶ 90.7% USA;  
8.8% Canada;  
1.3% other international
- ▶ Age
  - ▶ 4% < age 30
  - ▶ 17%, 30-39 years
  - ▶ 16%, 40-49 years
  - ▶ 36%, 50-59 years
  - ▶ 27%, >60 years

# Trainers as Health Care Professionals with Chronic Conditions (n=224)

**Do you have a chronic health condition?**

<b>Are you a health care professional?</b>	<b>Yes 186 (83%)</b>	<b>No 38 (17%)</b>
<b>Yes 126 (56%)</b>	101 54%	25 66%
<b>No 98 (44%)</b>	85 46%	13 34%

# Training Experience

- ▶ Median # workshops led in past 2 yrs.= 4  
(range, 0 to >10)
- ▶ Median # participants per workshop= 7 to 15  
(range <6 to >20)
- ▶ *79.8% report that more than 30% of their participants are age 65+*



## QUESTION #2 TO THE AUDIENCE

Do people with memory loss attend CDSMP workshops?

YES

NO

**Our sample said, YES**

**People with Dementia/Memory Loss do attend  
CDSMP Workshops**

# Percentage of Participants that “may have” Dementia/Memory Loss (n=252)

	Percent	Frequency
None	17%	42
1 to 5%	46%	117
6 to 10%	17%	43
11 to 15%	8%	21
16 to 20%	4%	11
21 to 25%	3%	7
26 to 30%	2%	4
Greater than 30%	3%	7

## Percentage of Trainers who Think CDSMP Workshop Could be Helpful to People with Dementia (n=253)

	Percent	Frequency
Yes	62%	157
No	13%	32
Don't Know	25%	64

# CDSMP Components & Approaches Helpful/Not Helpful

# CDSMP Components commented on by trainers in relation to people with dementia/memory loss

- ▶ Action Plans (goal setting)
- ▶ Effective Communication
- ▶ Communicating with Health professionals; health system
- ▶ Dealing with Difficult Emotions
- ▶ Advanced Directives; Planning for Future
- ▶ Medication Management
- ▶ Physical Activity and Exercise
- ▶ Healthy Eating (Nutrition)
- ▶ Symptom Management
- ▶ Relaxation
- ▶ Guided Imagery
- ▶ Distraction Techniques
- ▶ Positive Thinking

*“One gentleman decided on walking as an action plan, which he repeated each week so he wouldn’t forget. His wife reminded him and walked with him. He received much enjoyment and the benefits of walking from this, and he felt empowered because he accomplished a weekly goal.”*

*“Some of the tools could be helpful - possibly better breathing, muscle relaxation, and dealing with difficult emotions. I am specifically thinking of one participant who had memory loss issues, and she felt those tools were helpful to her. She said that she would become stressed when she forgot and then got more upset, ... that it became a vicious circle. She said that breathing and relaxation were helpful.”*



# CDSMP Approaches commented on by trainers in relation to people with dementia/memory loss

- ▶ Group Process, Peer Support
- ▶ Paired Activities, Buddy System
- ▶ Problem Solving Process
- ▶ Group Brainstorming
- ▶ Written Materials
- ▶ Writing Activities Encouraged
- ▶ Overall Structure
  - ▶ Scripted
  - ▶ Built-in Repetition
  - ▶ Consistent weekly routine
- ▶ Lecturettes (too long, detailed)
- ▶ Other – cueing, modeling, role play

*“The buddy system is a great way for people with memory issues to attend the workshop, form friendships and a support network.*

*...amazing how these groups work together to help each other out, from rides to the workshop, to offering to workout/walk with people who have no one to go with them, to long time friendships.*

*...phone calls to 'check' on the participants action plan progress. There are so many avenues available to folks that they have no idea about till someone in the workshop mentions it.”*

## QUESTION #3 TO THE AUDIENCE

Have you done anything to adapt your program to persons with dementia?

- YES
- NO
- Not Applicable

# Experience with Adaptations

Have you done anything to adapt program to PWD?	Yes	No	N/A, Not encountered
	111 (47%)	79 (33%)	47 (20%)

*Among trainers who had encountered people with dementia (190), the majority (58%) indicated they had made program adaptations.*

# Perceived Helpfulness by Experience with Adaptations (n=236)

Have you done anything to adapt program to PWD?	Percentage PWD in workshops?				
	None	1-5%	6-10%	11-15%	16% +
	35 (15%)	112 (48%)	43 (18%)	20 (8%)	26 (11%)
<b>Yes</b> <b>111 (47%)</b>	0 0%	52 (46%)	30 (70%)	14 (58%)	15 (58%)
<b>No/NA</b> <b>125 (53%)</b>	35 (100%)	60 (54%)	13 (30%)	10 (42%)	11 (42%)

*Likelihood of adapting program not associated with percentage PWD in workshops.*

# Adaptations to CDSMP for People w. Dementia

There were no major adaptations; trainers made small adjustments (to retain program integrity/fidelity).

- ▶ Buddy, pairing activities
- ▶ Reduce distractions (sit in front or near leader)
- ▶ Extra attention from leader (during breaks, before/after, calls)
- ▶ Find out what PWD needs (from person, MD, care partner)
- ▶ Redirection, cueing
- ▶ Reinforcement (praise, encouragement, modest expectations)
- ▶ Repetition
- ▶ Slower pace
- ▶ Simple action plans
- ▶ Encourage writing

## Adaptations – sample comments

- ▶ *“I encourage them to write things down. I repeat things when necessary. That is adapting as a facilitator. We do not adapt the program. Stanford requires that nothing be taken out, added to, or adjusted. It is part of our license agreement.”*
- ▶ *“I have seen other participants go the extra mile supporting these folks and it helps.” “More often than not, the other participants are the ones to step in and help a fellow participant.”*
- ▶ *“We did a lot more repeating (not a bad thing for the rest of the group, too) of what the purpose of the workshop is, steps for brainstorming, steps for problem solving, steps for action planning - EVERY time we did any of these activities.”*

## QUESTION #4 TO THE AUDIENCE

Have care partners attended your programs with persons with dementia?

- YES
- NO
- Not Applicable



# Percentage of PWD Attending Workshops with Friend, Family Member, or other Care Partner (n=202)

	Percent	Frequency
None	28%	57
1 to 5%	33%	66
6 to 30%	13%	27
Greater than 30%	26%	52

# Benefits to Individual by Attending with Care Partner

## Care Partner assists individual

- ▶ Assists with action plan process and follow through
- ▶ Recall assistance
- ▶ Clarifies, explains, interprets, reinforces instructions & information
- ▶ Takes notes
- ▶ Liaison between individual and group leader

# Benefits to Individual by Attending with Care Partner

## Individual feels safe, grounded, less confused

- ▶ More focused, pays more attention
- ▶ Provides “a frame of reference,” familiar face
- ▶ Sense of security
- ▶ Care partner provides reassurance, guidance

# Problems for Individual by Attending with Care Partner

- ▶ Caregiver speaking for Individual
- ▶ Individual leans on caregiver to answer for them
- ▶ Care partner gets uncomfortable when individual can't stay on task

*“The leaders just need to use judgment and intervene if the caregiver is speaking for person with memory loss--make sure their voice is being heard. We can't assume who is benefitting and who is not (I've been wrong too many times).”*

# Benefits to Care Partner by Attending with PWD

## Greater knowledge and understanding of PWD

- ▶ See PWD as more capable than care partner had assumed
- ▶ Understand PWD's concerns and fears (through sharing activities)
- ▶ Understand better PWD's cognitive limitations and needs
- ▶ Validation that individual really has dementia/memory loss
- ▶ Normalizes the condition (in context of other diseases with similar challenges)
- ▶ Understand better how to work with and support PWD

# Benefits to Care Partner by Attending with PWD

## Learn CDSMP tools & information to help with caregiving

- ▶ Tools for caregiver stress (muscle relaxation, better breathing, guided imagery)
- ▶ Importance of self-care to maintain strength
- ▶ Understanding and skills to manage difficult emotions
- ▶ Develop action plans to cope with caregiver stress
- ▶ Group brainstorming, problem solving around caregiving challenges
- ▶ How to navigate health care system and access resources

# Benefits to Care Partner by Attending with PWD

## Peer support

- ▶ Social outlet, interaction, peer support
- ▶ Realization that they are not alone; connecting with other care partners
- ▶ Gain reassurance & confidence being with others in similar situations
- ▶ *“I think the main thing I have seen is the tremendous support the care partner gets from the group itself. One husband who came to help his wife felt very isolated. He had a buddy call from a group member each week, and this bond continued even after the program ended.”*

# Benefits to Care Partner by Attending with PWD

## CDSMP in general (by accompanying PWD)

- ▶ Same benefits as anyone – life skills, empowerment, improved daily life
- ▶ Opportunity to learn all the CDSMP information and skills
- ▶ Opportunity to plan for their future (which otherwise looks bleak)
- ▶ Opportunity to voice their concerns & frustrations
- ▶ *“The one caregiver that came was helped from the entire workshop including communication skills, medication management, physical activity, and problem-solving. The caretaker told us that the workshop gave her, her life back.”*



# Benefits to PWD/caregiver partnership

- ▶ Develop greater mutual understanding.
  - ▶ *“I feel like they are working in partnership and get a greater understanding on both sides of what the person is experiencing.”*
- ▶ Reinforces sense of teamwork.
- ▶ They share a common language (from CDSMP program).
- ▶ Improved communication.
  - ▶ Opportunity to share challenges and difficulties with each other.
- ▶ Improves PWD/caregiver relationship.

# Additional Insights

# Benefits of group participation

- ▶ *“The one thing that stands out to me more than anything else was the brainstorming suggestions from students to the early stage dementia students. MANY of the suggestions they had for things like locating misplaced keys, or other “lost” items were so very helpful to maintain independence for these persons. Things I would not have thought of or heard of in my work were offered to them and appreciated by post reports of successes in their issues. It is amazing really.”*

# Benefits of participating in early stage

- ▶ *“Many individuals have been able to state to me what their diagnosis is and they are aware of the consequences of the diagnosis. While they still are able to make some decisions for themselves, they can add to their own quality of life by managing their own symptomatology with the help of the program and friends/family.*
- ▶ *The program also makes participants aware of their own strengths and areas that they still have capacity. Using the tools within the program is very helpful and puts everyone in the family/community on the same page. Although there may be a diagnosis of dementia, the individual may experience health in other areas.”*

# Positive Endorsement for PWD Participation

- ▶ *“The people I have encountered who had received a diagnosis of dementia/memory loss were all thankful for the CDSMP program. CDSMP restores self esteem as participants develop tools that enable them to self manage. The feeling of loss of control diminishes. They no longer feel helpless.*
- ▶ *Participants learn that no matter what their level of health (or disease), they can still make positive changes in their lives. They do not have to be victims who just roll over and give up. CDSMP empowers, educates, and offers hope. I think it would be wonderful for people with dementia/memory loss particularly in early and intermediate stages.”*

# Negative comments regarding PWD participating

## Discomfort of other participants

- ▶ *“One must be cautious as some individuals with a dementia can make others in the group uncomfortable...I found that people in workshops are more tolerant of physical disabilities but are uncomfortable with individuals with observable cognitive impairment. I believe we need to be aware of this.”*

## Lack of evidence-based effectiveness with PWD

- ▶ *“There is no evidence that I am aware of that CDSMP, in its current form of 1 day a week for 2 1/2 hours for 6 weeks, helps people with dementia/memory loss remain independent in the community. Other community resources are vital for this purpose and the state-designated Memory Centers would be better able to answer this.”*

# Benefits Depend on PWD or group composition

## Balance of people with and without memory loss

- ▶ *I think it is important that most of the group does not have memory loss problems so that they can support the ones who do and help them to problem solve. When I had one group that all had memory problems the problem solving did not occur.*

## Depends on group dynamics

- ▶ *I think it would very much depend on the class composition. In the one workshop I had with the one lady with memory loss, everyone else also had brain damage for all different reasons. They were all very compassionate.*

# (Self) Screening & Attrition

## Screening/assessment needed

- ▶ *“A very good assessment will need to be done first in the participants’ recruiting process.”*

## Self selection

- ▶ *“It is probably best to let all who wish to try the program to do so. In my experience people with dementia who don't benefit self select out.”*
- ▶ *“It is my opinion that if a person believes that they are capable of taking the workshop, they usually do OK. If a person has doubts, they usually don't sign up and we don't push them. We trust them to trust the process.”*



## (Self) Screening & Attrition

- ▶ *“We've found that CDSMP participants who call to register for a workshop and show up at the first session decide fairly quickly if it's something they want to continue. The act of following through with the registration process itself can be a good litmus test and we've had more "no shows" and drop outs when others call on behalf of another person to register.”*

# Final Thoughts from Trainers

- ▶ CDSMP should be open to people with dementia or memory loss
- ▶ *“In the early stages of dementia, I absolutely believe that the participants would be still able to gain significant benefit from these courses and I would never turn a patient away that was able to attend.”*
- ▶ *“I can't think of any reason to discourage a person with Alzheimer's or dementia/memory loss from attending the workshop.”*
- ▶ *“I believe the groups work well with memory loss folks.”*
- ▶ *“Please consider CDSMP for your population and their caregivers.”*

# Update: Response to Study Recommendations

- ▶ New insights about cognitive impairment detection (BRFSS)
  - ▶ [http://alz.org/documents\\_custom/public-health/2013%20BRFSS%20Cognitive%20Data.pdf](http://alz.org/documents_custom/public-health/2013%20BRFSS%20Cognitive%20Data.pdf)
  - ▶ [http://alz.org/documents\\_custom/public-health/2009-2010-Combined-Caregiving.pdf](http://alz.org/documents_custom/public-health/2009-2010-Combined-Caregiving.pdf)
- ▶ Insights about cognitive impairment and other chronic diseases
  - ▶ <http://www.aarp.org/home-family/caregiving/info-10-2012/home-alone-family-caregivers-providing-complex-chronic-care.html>
- ▶ Medicare Annual Wellness Visit
  - ▶ <http://www.alz.org/national/documents/2012annualwellnessvisit.pdf>

# Update Continued

- ▶ <http://www.ncoa.org/improve-health/center-for-healthy-aging/content-library/ARRA-GRANTEE-Capping-Report-Final-6-25-1.pdf>
  - ▶ Partnerships with untraditional partners
  - ▶ Adherence to fidelity
  - ▶ A pathway to adopt in other Evidence Based Programs

# QUESTION #5 TO THE AUDIENCE

Is CDSMP a model that should be considered for persons with dementia and their care partners?

- YES
- NO



Mike Splaine

[mikesplaine@verizon.net](mailto:mikesplaine@verizon.net)

Nina Silverstein

[nina.silverstein@umb.edu](mailto:nina.silverstein@umb.edu)