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Chronic Disease Self-Management Programs: Relevance for Persons with Dementia

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June 1, 2011

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EXECUTIVE SUMMARY

The context for this study is the work of the Healthy Brain Initiative. The CDC has established a cooperative agreement with the Alzheimer's Association to develop and implement a multifaceted approach to look at cognitive health as a public health issue. Late in 2010, the Association commissioned a review of the major chronic disease prevention programs from a systems approach to begin to understand the source of findings that Medicare beneficiaries with Alzheimer's and related disorders are much higher cost than those simply with a single chronic disease and no AD. This led to the conclusion that Chronic Disease Self-Management Program (CDSMP) is the current "gold standard" initiative in this arena. Thus, the Association in cooperation with Dr. Kate Lorig, the researcher who developed CDSMP, began systematic research to explore the extent to which persons with AD are served in CDSMP workshops. Dr. Lorig is the Director of the Stanford Patient Education Research Center and Professor of Medicine in the Stanford School of Medicine.

The Chronic Disease Self-Management Program (CDSMP) provides training in group settings to people with differing chronic diseases on daily skills needed to manage their health and maintain active and fulfilling lives. The purpose of this study was to explore whether CDSMP is a community resource that should be considered for persons with dementia and their care partners.

An electronic survey was developed with input from the Alzheimer's Association; Mari Brick, National Association of Chronic Disease Directors; and Dr. Kate Lorig, Director of the Stanford Patient Education Research, who developed CDSMP. The survey, which consisted of both structured and open-ended questions, was disseminated by Dr. Lorig to her listserv of over 2000 master trainers. Respondents (253) represented trainers from 39 states and the District of Columbia and five other countries. They provided close to 200 narrative responses to the open-ended questions, providing a rich data set, more than adequate to answer the qualitative research questions. Responses were organized into themes, and many quotes convey trainers' perceptions about their experiences with people with dementia in CDSMP workshops.

Over 80% of master trainer respondents (the majority were health care professionals) reported having one or more individuals with suspected dementia/memory loss in their workshops. Moreover, greater than 70% of these trainers reported that some individuals attended with care partners. The majority of trainers, 80%, reported that more than 30% of their participants are age 65+.

Overwhelmingly, respondents thought that CDSMP could be helpful to individuals with dementia. When asked to comment on specific elements of CDSMP they believed could be helpful or not helpful to individuals with dementia, respondents spoke to the range of topics covered by CDSMP. Comments on the helpfulness of health-related topics outweighed comments on not helpful topics five

to one. All topics covered in the CDSMP curriculum were viewed as potentially helpful to individuals with dementia; however, the manner in which topics are presented can be overly challenging for some individuals with dementia.

Respondents also mentioned the approaches used in the CDSMP workshops. Comments on the helpfulness of CDSMP approaches outweighed comments on approaches viewed as not helpful two to one. Action planning, a key management tool within CDSMP, was viewed as helpful because of the concrete, short-term, achievable goals with weekly repetition that provided opportunities for experiencing success.

“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.”

On the other hand, action planning was viewed sometimes as not helpful because people with memory loss might find the process too challenging or frustrating; for example, generating goals, setting up goals within the prescribed structure, and following through with Action Plans during the week.

Many aspects of the overall program structure were viewed as particularly helpful to people with dementia (PWD), especially the scripted format, built-in repetition, and consistent weekly routine and practice. However, some respondents reported the fast pace, homework assignments, and large group process overly challenging to PWD. Respondents reported that group brainstorming and problem-solving often led to group-generated ideas on how individuals with dementia might manage daily routines despite their memory loss.

“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.”

In contrast, other respondents reported problem-solving activities as too abstract and complicated for PWD. Respondents reported that the group process, integral to CDSMP, often provided peer support, opportunities for positive feedback, and validation. Optional use of a buddy system was viewed as helpful to PWD, primarily for between-session reminder calls, but also potential friendships. Written activities served as memory tools for PWD.

Many respondents qualified these comments. They reported that CDSMP was more helpful to people in early-stage memory loss. As well, PWD often benefitted more from CDSMP when they were accompanied by a care partner.

Most master trainer respondents who reported having PWD in their workshops also reported making minor adaptations or accommodations for these individuals. Adjustments included making greater use of approaches integral (repetition) or optional (buddy system) to the program. Workshop facilitators also provided extra time and attention to PWD during breaks and after class, provided praise and encouragement, or made minor adjustments such as reducing distractions, slowing the pace of activities, or redirecting the individuals' comments to keep them on track.

Respondents were asked about care partners attending with PWD. They reported on the benefits to PWD associated with having care partners accompany them as well as benefits to the care partners when they attended with PWD. Many respondents reported that individuals with dementia benefitted by having their care partners assist them with workshop activities. Care partners served as liaisons between the PWD and group leader, assisted the PWD with Action Plans, reinforced instructions and information, and served to interpret or clarify the PWD's comments during group discussions. As well, the PWD often felt safer, grounded, and less confused when accompanied by care partners. A few respondents commented on instances when having care partners attend with the PWDs was problematic: for example, when the care partners spoke for the PWD or when the care partners became uncomfortable when the PWD could not stay on task.

Respondents also spoke of many benefits to care partners who attended with the family member with dementia. Care partners sometimes gained greater understanding of the PWD (their capabilities, limitations, and fears), learned tools to support their caregiving (importance of self-care, managing caregiver stress and difficult emotions, navigating the health care system), and experienced peer support, as well as learning tools to manage their own chronic conditions. Moreover, they reported that when care partners and PWD attend CDSMP workshops together, a sense of teamwork is reinforced that can result in improved communication and relationships.

When asked to provide additional insights about PWD attending CDSMP workshops, a number of respondents provided recommendations for accommodating PWD. A small number of respondents suggested customizing programs specifically for PWD. This would require training leaders on characteristics of Alzheimer's disease/dementia as well as appropriate strategies. The same core program could be used but should include a focus on memory loss content and memory management strategies. Specific suggestions included using additional materials (visual aids, charts), slowing the pace, simplifying information, and reducing homework. A PWD program should include opportunities for greater personal attention and

reinforcement (via smaller classes, caregivers/volunteer aides), and spreading out the workshop into shorter sessions over more weeks.

Most comments, however, supported integrating individuals with dementia/memory loss into mainstream classes, while better preparing leaders for including PWD by adding instructional material in the leaders' manual and including a section on memory loss management into the curriculum. Many thought that participants with and without dementia benefitted from each other.

In summary, this study suggests that most trainers welcome PWD in CDSMP workshops and report positive benefits for individuals in early-stage dementia.

"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."

Trainers welcome care partners attending with PWD and recommend this as a helpful strategy for multiple reasons. Trainers are open to making minor accommodations to better include PWD in CDSMP workshops. They would like leader training materials to include information on Alzheimer's disease/dementia as well as useful strategies for working with PWD. There was little support for specialized workshops for PWD; respondents believed there are mutual benefits to integrated classes and that group activities may not be (as) effective with only participants with dementia/memory loss.

Currently, CDSMP can be described as *dementia-friendly* because PWD are not turned away from participating. The program would benefit by becoming *dementia-capable*. A step in that direction would include providing trainers with information and skills related to managing Alzheimer's disease and related disorders. Creating a *dementia-specific* program is not recommended.

INTRODUCTION

The context for this study is the work of the Healthy Brain Initiative.¹ The CDC has established a cooperative agreement with the Alzheimer's Association to develop and implement a multifaceted approach to look at cognitive health as a public health issue. Late in 2010, the Association commissioned a review of the major chronic disease prevention programs from a systems approach to begin to understand the source of findings that Medicare beneficiaries with Alzheimer's and related disorders are much higher cost than those simply with a single chronic disease and no AD. This led to the conclusion that Chronic Disease Self-Management Program (CDSMP) is the current "gold standard" initiative in this arena. Thus, the Association in cooperation with Dr. Kate Lorig, the researcher who developed CDSMP, began systematic research to explore the extent to which persons with AD are served in CDSMP workshops. Dr. Lorig is the Director of the Stanford Patient Education Research Center and Professor of Medicine in the Stanford School of Medicine.

Chronic Disease Self-Management Program workshops (CDSMP) bring people with differing chronic diseases together to provide training in daily skills needed to manage their health and maintain active and fulfilling lives. CDSMP workshops focus on symptoms and how to manage them (not on the disease). The purpose of this study was to learn more about CDSMP workshops and the extent to which these community resources might benefit persons with dementia and their care partners. Specifically, the research questions we explored were:

- 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?

¹ <http://www.cdc.gov/aging/healthybrain/index.htm> Retrieved May 13, 2011

METHODS

An electronic survey was developed through Survey Monkey in fall 2010 with input from the Alzheimer's Association; Mari Brick, National Association of Chronic Disease Directors; and from Dr. Kate Lorig. The survey contained six open-ended questions and 14 close-ended, structured questions. The project protocol received approval from the Institutional Review Board (IRB) through the University of Massachusetts Boston in Nov. 2010.

The Survey Monkey link was disseminated by Dr. Lorig to her listserv of trainers in the US (1827), Canada (433) and International (313). The data collection period was Dec. 1, 2010-Jan. 14, 2011 and yielded responses from 253 trainers in 39 states and the District of Columbia and five other countries. As this was primarily a qualitative study, the response was more than enough to allow a full analysis of major themes generated through the narrative responses. While there is no set number of respondents required in qualitative research -- the rule of thumb is until no more new information is elicited--truly qualitative studies are typically small (30 people). This study used semi-structured questions with no opportunity for follow up by interviewer. Still, there were 123 to 200 narrative responses per open-ended question. This rich narrative response ensured that almost all important trainer perceptions were represented.

The participant responses were downloaded from Survey Monkey into an Excel file. Responses to open-ended questions were then uploaded into NVIVO 8, a software program designed to assist with qualitative data analysis. Themes were identified for each survey question, and responses were coded accordingly. Themes were further subdivided. These themes were organized for the report. Quotes that illustrate themes were extracted.

Sample Description

The majority of the trainers was female (93%), from the United States (91%), with the greatest number of trainers conducting workshops in New York (18), California (15), Michigan (13), Florida (12), and Oregon (10), and having chronic conditions themselves (83%). There were 20 respondents from Canada, and one each from Australia, Italy, New Zealand, and Sweden. Almost two-thirds of the trainers, 63%, were 50 years of age or older, with 27% age 60 and older. Over half (57%) were health care professionals, age 50 or older (63%), with just over a quarter, 27%, age 60 or older. Over 80% of facilitator participants had chronic health conditions. Of those without chronic conditions, two-thirds were health professionals. (Proportionally fewer health professionals had chronic health conditions than did non health professionals.) The major specializations noted

were: nursing, social work, health care education, and dietary science. The trainers reported having led a median number of 4 workshops within the past two years, ranging from 0 to more than 10 workshops. The median number of participants per workshop was about 10 and ranged from less than 6 participants to more than 20. The majority of trainers, 80%, reported that ***more than 30% of their participants were age 65+.***

RESULTS

Do Persons with Dementia and Their Care Partners Currently Attend CDSMP Workshops?

Eighty three percent of respondents reported having at least one person whom they suspected of having dementia/memory loss in their workshops over the past two years. Most commonly, master trainer respondents (46%) reported from 1% to 5% of their participants with dementia/memory loss (PWD), but a third of the respondents reported over 5% of their participants with dementia/memory loss and 20% reported over 10%.

Of respondents reporting participants with dementia/memory loss in their programs, 72% reported that care partners attended with the PWD. (We do not know the frequency of PWD attending with care partners as compared to those persons with dementia who attended alone.) Thus, in answer to our research question, it is clear that persons with dementia/memory loss currently attend CDSMP workshops and often attend with care partners.

What Aspects of the Curriculum Are Helpful or Not Helpful to Persons with Dementia/Memory Loss?

We asked respondents: *Do you think the CDSMP workshops might be helpful to people with dementia/memory loss?* The large majority of respondents reported positively about having (or the potential of having) PWD in their workshops. We intentionally asked this question regardless of whether respondents reported having had experiences of PWD in their workshops so we would learn of trainers' opinions and receptivity to serving PWD. Nearly two thirds of respondents (62%) thought the workshops might be helpful to PWD while only 13% thought they would not be helpful; 25% responded that they did not know whether or not the workshops would be helpful.

“Being able to talk about memory loss seems to help. Achieving the action plans every week and reporting that they achieved them seems to boost self-confidence. A participant who reported memory loss performed a solo in church after years of loss of confidence to stand in

front of an audience. My firm belief is that the reason was the participation in the workshop. “

We next asked respondents to comment on specific elements of CDSMP (content or approaches) they believed could be helpful to PWD as well as CDSMP content and approaches that might not be helpful to PWD.

CDSMP Workshop Content

Respondents commented on the full range of topics covered by CDSMP, with comments on the helpfulness of topics outweighing comments on not helpful topics five to one. (See Appendix.) Based on trainers' responses, all topics were potentially helpful to PWD. However, a consistent theme throughout the trainers' responses was that the presentation of topics could be overly challenging for some PWD.

Specifically, many participants thought that techniques for using one's mind to manage symptoms (especially relaxation techniques) and physical exercise were helpful. They also reported on the helpfulness of techniques for medication management and for effective communication with family members and medical professionals. In addition, managing difficult emotions was mentioned as important, as well as planning for the future (e.g., preparing advanced directives).

“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.”

Less often, some of the same topics were reported as potentially not helpful to people with memory loss/dementia. However, comments on topics that were less helpful typically referred to the way material was presented rather than the topics themselves, for example, too much detail, the lecturettes too long, or the activities/exercises too difficult, frustrating, or confusing.

CDSMP Workshop Approaches and Activities

There were even more comments associated with the many strategies or approaches built into the CDSMP curriculum. Again, there were more comments on the helpfulness of the CDSMP approach than lack of helpfulness (by 2:1). Most often mentioned was action planning, a core activity within the CDSMP that is repeated weekly. Participants who reported this as helpful to PWD mentioned the short-term

(one week) goals and simple, concrete, achievable Action Plans. Participants reported that choosing goals (rather than having goals chosen for them) and achieving even simple goals can boost self confidence.

“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.”

“People with dementia/memory loss are still ‘self managers,’ especially those who are not receiving full care (i.e., nursing home). They are still making choices everyday and are faced with stress, difficult emotions, etc. One workshop stands out in my mind in particular. We were having a workshop in an assisted living facility and we had one elderly woman who clearly had difficulty with memory, etc. She made an Action Plan (AP) just like everyone else at the end of session #1. Session #2, when we were reporting on our APs, it was her turn and she said ‘I have no idea of what my Action Plan was.’ (By the way, we’ve had many, many participants forget their APs so not just those with dementia, etc.). So, we did problem solving and she concluded that this time she’d write it down. She made an AP at the end of session #2 and wrote it down. Session #3, when it was her turn to report how her AP went, she said she forgot. We problem solved and she was able to figure out on her own that she needed to write her AP down AND post it on her refrigerator along with her other important notes (i.e., doctor appointments, bills, etc.). The next session, she returned with the biggest smile on her face; she not only remembered her AP but she was also successful in completing it!! The biggest difference between CDSMP and other traditional patient education is that we first asked her what ideas she had to solve the problem and avoided giving her advice unless she wanted it. She created her own path using her lived experience. The group embraced her and were patient with her. “

Respondents who reported action planning as not helpful reported that people with memory loss found the process too challenging or frustrating (coming up with and setting up the goal within the prescribed structure or remembering and following through with the Action Plan during the week).

Respondents often spoke of the overall structure of CDSMP. Commented on as particularly helpful to people with memory loss/dementia were the scripted format of the sessions and activities, built-in repetition, consistent weekly routine (which PWD may find comforting), and weekly practice (reinforcement) of skills. Other aspects of the CDSMP structure were reported as less helpful: too much

information, fast pace of the sessions with frequent switching between activities, homework assignments, and large group activities (which some believed were overwhelming and frustrating to PWD).

In addition, respondents reported problem-solving and group brainstorming activities as potentially helpful or problematic for PWD. The problem-solving activities were helpful because of the formulaic technique and weekly repetition that provided structure and reinforcement. Both problem solving and group brainstorming often led to strategies and ideas generated from the group to help with daily living (such as memory cues).

"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."

One respondent reported the beneficial effect of being able to contribute ideas helpful to others.

"I truly believe this program is beneficial to those who have dementia/memory loss. Sharing ideas to help others increases self-esteem."

Others reported that problem-solving activities were too abstract and complicated, requiring critical thinking skills. The group brainstorming activities were often overwhelming to PWD because of the fast pace with many ideas to process. For both activities, PWD sometimes had difficulty expressing their ideas or felt discomfort with group sharing.

Other aspects of the CDSMP were reported largely as helpful. The group process often resulted in peer support. It provided opportunities for socialization, positive feedback, and recognition that other people also face challenging problems. While an optional strategy within CDSMP, a number of respondents spoke of the value of the buddy system for PWD, largely because of buddy reminder calls, but also because of the potential for friendships. (Note: The buddy system is an optional strategy in CDSMP. Buddies are chosen by participants, not assigned by trainers.)

"The buddy system is a great way for people with memory issues to attend the workshop, form friendships and a support network. It is 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. As well as the phone calls to 'check' on the participant's Action Plan progress. There

are so many avenues available to folks that they have no idea about till someone in the workshop mentions it."

Many participants also mentioned the importance of writing activities within CDSMP – both as a way to remember material from the workshop, and as memory tools to help with daily life (post-it reminders, lists for medical appointments).

In response to aspects of CDSMP that were helpful or not helpful to PWD, many respondents commented on the helpfulness of care partners attending with the PWD or qualified their endorsement of CDSMP for most PWD to cases where a care partner was present.

Many respondents qualified their remarks by stating that the program was (or potentially was) helpful to participants only in early-stage Alzheimer's/mild memory loss. A number thought the program helpful only to people with early stage/mild dementia if they attended with care partners, while still others stressed the importance of care partners only for people with somewhat more advanced memory loss. However, many also recognized that the helpfulness of the program is individualistic. Several spoke of the ability to self-manage at least some aspects of their lives for PWD to gain self-management tool(s) from the program.

"People with dementia or memory loss can certainly benefit from the CDSMP. The degree of disease will play a huge role in the appropriateness of the various lessons in the course. Probably the main issue is the ability of the participant to self-manage other aspects of their lives. If they are capable of managing several aspects of their lives, then they will probably do OK with CDSMP. If not, then a care giver's participation would be paramount."

"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 for which 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."

Do Trainers Adapt Content and Approaches?

We next asked respondents if they had done anything to adapt the CDSMP workshops for people with memory loss/dementia. Among trainers who reported encountering people with dementia in their workshops (190), over half (58%) indicated they had made program adaptations. We were reminded by a number of respondents that leaders are not permitted to modify the CDSMP under the license agreement. Nevertheless, the trainers reported a variety of small adjustments and accommodations they made to accommodate people with dementia/memory loss, while retaining the program's integrity. Many trainers were simply doing more of what is already integral to the program (repetition) or a recommended option (buddy system), while other accommodations involved giving extra time and attention to PWD. Many were adjustments they said they would do with anyone having difficulty with a workshop activity. Comments on adaptations were categorized as follows:

- Buddy, pairing activities, and maximizing participant support
- Extra attention from trainer (during breaks, before/after, calls)
- Find out what PWD needs (from person, MD, care partner)
- Reduce distractions (sit in front or near leader)
- Redirection, cueing
- Reinforcement (praise, encouragement, modest expectations)
- Extra repetition
- Slower pace
- Simplified Action Plans
- Encourage writing

Although the buddy system is an optional activity, many respondents spoke of using this effectively with PWD: advising a buddy on how to speak with a PWD for greater clarity, having the PWD sit with a buddy who took on the task of assisting, or having the buddy call more frequently between sessions or after completing the course. Respondents mentioned other efforts to elicit support from other participants: pairing the PWD with a willing, understanding participant as a helper to support and encourage them, and special efforts to gain support of other participants to accept and include PWD. Moreover, many respondents commented on how supportive other participants are (spontaneously) to PWD: *"They pick up on 'Helping someone else helps you,'"* part of the program's tool box.

"I have seen other participants go the extra mile supporting these folks and it helps."

"More often than not, though, the other participants are the ones to step in and help a fellow participant."

Many respondents spoke of providing extra attention to PWD. This included providing more personal attention and assistance with Action Plans, providing extra detailed explanations of instructions, spending extra time with them during breaks or before or after sessions to clarify questions, making follow-up calls between sessions, and pairing with them for the paired activities. They also used coaching and prompting, asked the PWD for confirmation that they understood the content/instructions. A few trainers commented that they made efforts to find out what the PWD need to support their participation: by asking the person directly, following their lead, and listening.

“... and most of all listening to what they are asking for or are having any difficulty with. Really isn't it what we do with all our participants -- watch, listen, clarify”

Some respondents conferred with the PWD's spouses/companions, while one contacted a referring physician.

Other modest adaptations included: reducing distractions for the PWD by moving him/her near the front or close to the leader; redirecting PWD's comments to keep them on track, cueing or prompting to assist the PWD remember his/her Action Plans, and modeling how to do a participatory activity. Many used extra repetition, restating content material, repeating and rephrasing directions, and repeating exercises.

“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.”

Respondents also reported speaking more slowly and clearly and pacing activities more slowly to accommodate note-taking and facilitate comprehension. They also allowed more time for PWD to respond to questions or report back in group activities when they were having trouble getting their ideas across. For the action plans, respondents reported allowing PWD to set very basic, reasonable, one-step action plans and focusing on achieving simple tasks they were struggling with, even if repeated from one week to the next.

Respondents made greater use of written materials and writing activities than were prescribed by the program. They wrote things on a flip chart or chalk board, especially step-by-step directions. Some allowed the PWD to follow along by reading the script in the leader's manual; they encouraged use of the resource book, and pointed out useful pages. Respondents encouraged PWD to take notes (offering notebooks and writing equipment). They distributed action plan forms, encouraging PWD to write out their Action Plans and referring to them during the week (as well as modeling this).

"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."

Finally, respondents spoke of providing extra encouragement and positive reinforcement, even for small accomplishments. They also spoke of using patience and treating PWD with respect and kindness.

When Care Partners Accompany People with Dementia/Memory Loss to CDSMP, What Benefits Do Trainers Perceive for the Individual and for the Care Partner?

Benefits to the Individuals with Dementia/Memory Loss

Respondents reported many benefits to individuals with dementia/memory loss associated with having a care partner (usually a spouse) attend with them. A common theme was that PWD benefited by having their care partners assist them with workshop activities. This hands-on assistance helped individuals get more out of the workshop; this assistance was also helpful to the leader and other participants and made workshops run more smoothly. Specific assistance provided by care partners included:

- Liaison between the individual and group leader
- Assisting with the Action Plan process (developing the plan and following through during the week)
- Helping the PWD by explaining and reinforcing instructions and information
- Helping the group understand PWD's contributions in group activities by clarifying, interpreting, etc.
- Taking notes to facilitate follow-through and carry over between sessions
- Assisting PWD with recalling instructions and information presented in the workshops

Many respondents also reported that the individuals with memory loss/dementia felt safe, grounded, and less confused when care partners accompanied them. Themes mentioned by respondents included the following:

- The PWD are more focused and pay more attention.
- Care partners provide “a frame of reference” and familiar face.
- Care partners provide reassurance, guidance.
- Care partners provide a sense of security.

The following quotes illustrate this:

“An individual who came with her partner told me that she felt safer when he was with her. She wasn’t afraid to try and answer or make a statement.”

“The individual was more comfortable since he could check in with a trusted person when he got confused.”

“They look to this person as a source of comfort when they are unsure about what is going on. I think it is most beneficial for this group to attend with someone who cares about them.”

In some instances, respondents were thinking of a PWD who accompanied a spouse who was attending the workshop; that is, the care partner spouse was the CDSMP participant. In these cases, they reported on the PWD benefitting from the opportunity for socialization or receiving emotional support from the group and leader (feeling listened to and valued). Several commented that PWD should be encouraged to take the workshop on their own because they could benefit, as did the care partners.

A few respondents commented on instances where having care partners attend with the PWD was problematic. Trainers felt that PWD were disadvantaged in benefitting from the program when the caregivers spoke for individuals rather than supporting them to speak for themselves; when individuals “lean on” the caregivers to answer for them, or when care partners display discomfort when the individuals are unable to stay on task. A trainer respondent offered advice about how to handle such situations to give PWD a chance to participate as individuals:

“The leader just need to use judgment and intervene if the caregiver is speaking for [the] 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 Partners

Respondents reported many benefits to care partners who attended with individuals with dementia/memory loss. Comments clustered into the following general topics: greater understanding of the PWD, learning tools from CDSMP to assist them with caregiving, peer support, and learning CDSMP tools for their own well-being. By attending with individuals with dementia/memory loss, care partners (who, in most of the trainers' comments, were spouses) gained greater knowledge and understanding of the PWD living with this condition. The following specific themes emerged; by attending with PWD, care partners can:

- See the PWD as more capable than they had assumed
- Understand the PWD's concerns and fears (through sharing activities)
- Understand better the PWD's cognitive limitations and needs
- Receive validation that the PWD really has dementia/memory loss
- Experience the condition as more normal (within the context of other diseases with similar challenges)
- Understand better how to work with and support the PWD

Care partners learn CDSMP tools and information to help them with caregiving. Examples of CDSMP components respondents mentioned as particularly helpful to care partners to support their capacity for long-term caregiving include:

- The importance of self-care to maintain strength
- Tools for caregiver stress (muscle relaxation, better breathing, guided imagery)
- Skills to manage difficult emotions
- Developing Action Plans to cope with caregiver stress
- Group brainstorming and problem-solving around caregiving challenges
- How to navigate the health care system and access resources

Since much of CDSMP involves group process and participants are encouraged to support and help each other, attending workshops with individuals with dementia/memory loss, often provides care partners the benefits of peer support (even though CDSMP is not a support group). For care partners who may experience isolation associated with the responsibilities of caregiving, the workshops provide a social outlet, interactions with others, and peer support. They may connect with other care partners and realize they are not alone. By participating with others in similar situations, they can gain reassurance and confidence. As one respondent stated:

"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."

Other respondents spoke of care partners benefiting in general terms from attending CDSMP, even if the care partners had thought they were attending primarily to support the PWD. They get an opportunity to learn the CDSMP information and skills and thus get the same benefits as everyone: life skills, sense of empowerment, and improved daily life. As one respondent reported:

"They have the opportunity to perhaps make a plan for the future when currently the future looks bleak. "

Another respondent stated:

"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."

A number of respondents noted the *mutual benefits* experienced by care partners and PWD, apart from the individual benefits. These benefits supported the strengthening of a PWD/caregiver partnership that benefitted both parties. The trainers spoke of the partnership as participating in CDSMP as a unit. For example, joint attendance at workshops can promote greater mutual understanding. [Dr. Lorig referred to this as "pair and share," where the person with dementia and the care partner as a unit are paired with another participant.]

"I feel like they are working in partnership and get a greater understanding on both sides of what the person is experiencing."

Joint attendance can reinforce a sense of teamwork. Doing the workshop together, care partners and PWD share a common language (from CDSMP tools). Many respondents spoke of improved communication between care partners and PWD and within families. (Tools for effective communication are key components of CDSMP, and by attending together, both family members learn the tools and have opportunities to practice them.) This provides opportunities to share challenges and difficulties with each other and can improve the PWD/caregiver relationship.

"Feel like they are working in partnership and get a greater understanding on both sides of what the person is experiencing."

"The memory loss participant benefits by the fact that through the six weeks the person who has come with them sees the memory loss partner in more capable terms through Action Plan accomplishments. Everyone is able to do something and this gets seen. "

Additional Insights

Finally, we asked respondents for additional insights they wanted to share with the Alzheimer's Association. Many of these were specific recommendations (reported in detail below) and provide insights that were distinct and noteworthy.

Occasionally, respondents reported that attending the workshop led to a medical evaluation for memory loss for some participants. (Since many people have undiagnosed early stage Alzheimer's disease or other dementias, participating in CDSMP may be a mechanism for individuals or family members to realize there is cognitive impairment and learn the pathway to further diagnosis.)

"One individual who was concerned about memory loss (living in a senior housing facility) took steps to be evaluated as a result of the workshop and support of the other participants."

There is potential for sustained behavioral improvement and control over their lives.

"One of our Master Trainer's husband has early-onset Alzheimer's. He graduated CDSMP and appears to have been able to regain some of his acuity and mental sharpness. He now frequently attends meetings, carries on conversations, and participates in NCOA focus groups without people realizing his condition. This was not behavior that he exhibited before CDSMP. His episodes of hostility and behavior swings appear to have diminished."

"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."

Respondents also provided caveats about including people with dementia/memory loss in CDSMP. One cautioned that,

"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."

Another cautioned that there is no evidence that CDSMP helps people with dementia/memory loss remain independent in the community. Other comments concerned the decision to include PWD in workshops and rate of attrition of such persons completing the full duration of the workshop. Some thought that people should be screened (via a comprehensive assessment or medical opinion) before being admitted to the workshops. Others thought the decision should happen naturally through 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 people believe that they are capable of taking the workshop, they usually do OK. If they have doubts, they usually don't sign up, and we don't push them. We trust them to trust the process."

There may be less attrition when participants sign up themselves rather than have others register them.

"There's [sic] probably some folks with dementia/memory loss who aren't coherent enough to understand or track the activities presented--the dilemma is 'who decides who might benefit.' Far too often, others make inaccurate assumptions about a person's abilities. 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 other people to register."

TRAINERS' RECOMMENDATIONS TO THE ALZHEIMER'S ASSOCIATION

Trainers provided input on a number of recommendations for ways to provide the benefits of CDSMP to people with dementia/memory loss. Many of these recommendations were suggested by only one trainer, though some ideas were repeated by several trainers.

Customizing CDSMP Specifically for People with Dementia

A number of trainers proposed designing a CDSMP program specifically for people with early-stage dementia, which could be run under the auspices of Alzheimer's disease groups. For this to be successful, trainers believed that facilitators needed training on characteristics of Alzheimer's disease as well as specific strategies known to be helpful with people with dementia. They thought that the same core program could be used, but it should include specific focus on memory loss content and memory management strategies.

Trainers suggested a number of specific approaches they thought would be helpful with people with dementia. These included use of visual aids (e.g., real food

for the nutrition component; bigger, more colorful charts; flash cards); running the program at a slower pace; and simplifying the program by limiting the amount of information provided and reducing homework. They also thought a program specific to PWD should include more opportunities for personal attention and reinforcement. Some trainers suggested that the program should require PWD to attend with care partners or, if care partners are not available, to enlist peer volunteers. Further suggestions included pairing PWDs with their caregivers (rather than a peer participant) for paired activities and arranging daily action plan reminder calls.

Trainers also made suggestions for modifying the workshop format to better serve PWD. Suggestions included limiting the size of the group and breaking up the workshops into shorter segments. This could be done by shortening the sessions while extending the workshop (running it for 8 weeks with 1 ½ hour sessions) or including additional rest breaks. A follow-up memory loss/memory management workshop with support group could be offered for continued support. One trainer thought a pilot study was needed to determine if such modifications were effective.

Rather than a specialized program for PWD, the current CDSMP could be supplemented to better accommodate PWD. A section on memory loss and memory loss management could be added, and the leaders' manual could include instructional material on dementia/Alzheimer's disease.

Separate Class or Integration?

While some trainers suggested it would be better for PWD to have separate CDSMP workshops, many more thought it better that PWD were integrated with people without dementia.

A proponent of separate classes said:

"Providing a class specifically for clients with dementia/memory loss would be perfect as the class may be held at a slower pace."

Another participant thought workshops should include a balance of people with/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."

There was openness among many participants to include PWD (whether or not the leaders had prior experience with PWD):

"Is there any harm in trying? I am a supporter of integration of abilities of all ranges and certainly feel that if dementia is included as a chronic condition the people living with it should attend integrated classes. If

condition-specific classes are planned, participants will be the best judges of effectiveness."

The following quote provides support for having PWD included in mainstream CDSMP classes, with the potential of benefitting all participants:

"When my husband and others with Alzheimer's from his Memory Minders Alzheimer's Association support group spoke on a panel at a recent Neurology meeting at the local hospital they were asked, 'What do you say to someone with dementia?' They all said some variation of, 'Look us in the eye and say, Hi! Don't forget we are people first not just a disease. We are still here, we're still just people.' Maybe that is what we need to do to keep people functioning as well as possible as long as possible -- just see them as individual people first. And meet their needs in class as we would anyone else. I think, depending on the stage of their disease, they certainly benefit from being in just a regular CDSMP group. And, the class benefits too. "

Design Program Specifically for Caregivers

A number of trainers suggested designing CDSMP programs specifically for caregivers of PWD. It should be noted that many respondents, when commenting on benefits to caregivers who accompanied PWD, commented on CDSMP classes addressing caregiver issues and thought caregivers (not PWD) would benefit from CDSMP and should be able to attend on their own. One recommended providing Adult Day Care vouchers so caregivers could attend without the PWD.

"I do think if there was enough care partners, friends or loved ones who wanted to take CDSMP together in a class, those participants might benefit from meeting together. If, as I have heard and read frequently, a person with dementia fares only as well as their caregiver does, then an additional thing we could do to foster prolonged independence for dementia patients is to hold a class for dementia care partners. If they are similar to any of the caregivers in my Alzheimer's Association caregivers support group, they have trouble taking any time to take care of them. Frequently, when someone accompanies a participant to class, s/he says they are "just a caregiver, they have no health problems." But almost always the caregiver after listening to the first class signs up also and participates in the series. So far I've not had one of the caregivers fail to say that they benefited greatly from the course. Many have said they are so focused on the person they are caring for they have real trouble stopping to take care of them."

Final Thoughts from Trainers

For the most part, trainers believed CDSMP should be open to people with dementia or memory loss. In their own words:

"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."

And finally, a trainer with considerable experience with PWD in CDSMP workshops supported including people with acknowledged Alzheimer's or dementia in the workshops because there are undoubtedly many more who have as yet unrecognized/acknowledged dementia and because the success of participation depends more on the individual than the diagnosis.

"I know I have had more than 12 participants who were self-identified with Alzheimer's or a related dementia in class and, from what I can tell, many more who were having memory issues (not related to medication or dehydration). Depending on the individual, full participation in class is more than possible. Just as participation depends on any individual participant's conditions (hearing or sight loss, depression, high pain levels, impaired mobility, speech difficulties from a stroke, etc.) participants with dementia can access all elements of the class to the best of their ability. I don't think we should presuppose a participant's ability to actively and fully participate in class if they already have a dementia diagnosis. Perhaps they were fortunate and got a correct early diagnosis and are trying to take charge of their health care while they still can. I suspect, however, that, considering the age of the participants we serve (many of whom are over 70 or 80), there are many participants with undiagnosed Alzheimer's or a related dementia. Considering how late a dementia diagnosis frequently is (missed many times by many doctors before confirmation) and that there is nothing other than a clinical diagnosis for it (nothing definitive other than autopsy), we probably serve MANY participants who are in the MCI, early, mild or even moderate stages and they have not yet been diagnosed."

DISCUSSION/CONCLUSIONS

Is CDSMP a Model that Should Be Considered for Persons with Dementia and Their Care Partners?

Based on this survey, it appears most trainers welcome PWD in CDSMP workshops. Most trainers reported positive benefits for persons with dementia attending CDSMP, especially if they are in early-stage dementia. Trainers also support having care partners attend with PWD, and most recommend this as a helpful strategy for multiple reasons: to maximize program benefits for the person with dementia/memory loss; to support the caregiver in dealing with stress and fatigue associated with caregiving; and as an opportunity for both persons in the PWD/dyad to improve understanding of the others' experiences. Care partners both over- and under-estimate the person with dementia's capabilities.

Many trainers also reported making modest modifications to the CDSMP to better accommodate PWD, although a number suggested these were only "common sense" and that good leaders respond to any person presenting with special challenges. Others suggested more structural changes specifically for the PWD, such as shortening the sessions or simplifying the material. However, when considering separate classes for PWD, most leaders thought workshops where persons with dementia participated in combination with individuals without cognitive issues would be most beneficial for the PWD and that other participants could learn from the PWD as well.

At this time, CDSMP is *dementia-friendly*. That is, persons with cognitive impairments are not turned away from participating in the workshops. To become *dementia-capable* suggests that the trainers would need to build their knowledge and skills related to managing Alzheimer's disease and related disorders. A starting point for that might be learning the *Ten Warning Signs* or becoming familiar with the content of *Facts and Figures*.² *Dementia-specific* implies that the special workshops are designed specifically for the PWD or care partners, although the trainers cautioned against that approach and favored chronic disease-integrated composition for the workshops.

² http://www.alz.org/alzheimers_disease_know_the_10_signs.asp
http://www.alz.org/alzheimers_disease_facts_and_figures.asp Retrieved May 13, 2011

Appendix

Helpful and Not Helpful CPSMP Content and Approaches

HELPFUL	NOT HELPFUL
CDSMP Topics/Components	
Action Plans (goal setting) Short term, simple, achievable Chosen by person Can boost self confidence	Action Plans (goal setting) Too challenging & frustrating (required structure & process)
Effective Communication With family members about memory loss, fears Using “I” messages	Effective Communication Skills and exercises (too hard)
Health Professionals (communicating with) Write list/journal of questions, etc. Take notes during visits, Bring someone to advocate Learning how to negotiate health care system	Health Professionals (communicating with) Too difficult to take notes, write questions Too difficult to understand how to negotiate health care system
Dealing with Difficult Emotions (associated with living with chronic disease) Learning how to deal with anger, fear, frustration Sharing personal feelings, stories	Dealing with Difficult Emotions (associated with living with chronic disease)
Advanced Directives; Planning for Future Sensitive topics especially important for people in early stages to discuss with family members	Advanced Directives; Planning for Future
Medication Management Brainstorming ways to remember to take meds. Medicine logs	
Physical Activity and Exercise	Physical Activity and Exercise Too much detail
Healthy Eating (Nutrition)	Healthy Eating (Nutrition) Too much detail Not appropriate for people in congregate settings who do not have much choice
Using Your Mind to Manage Symptoms Relaxation techniques (including deep muscle) Deep breathing techniques Guided imagery, visualization Distraction techniques Symptom Wheel and how to manage Positive thinking, self-talk	Using Your Mind to Manage Symptoms Relaxation activities (if unsupervised) Guided imagery, visualization (transported to another time/place could cause confusion, fear) Distraction techniques (too confusing, counter-productive) Positive thinking, self talk (frustrating attending to one’s internal dialogue)

HELPFUL	NOT HELPFUL
Understanding Chronic Disease, Symptom Cycle	
CDSMP Strategies/Approaches	
Group Process, Peer Support Socialization, camaraderie Validation, respect, acceptance, encouragement Positive feedback/ reinforcement, Realize others also face challenging problems Reinforces effective behaviors	Group Process, (lack of) Peer Support Participating in group activities If discouragement is expressed by leader or other participants
Paired Activities, Buddy System Reminder calls Working in pairs (help writing action plan) Form friendships (counters isolation)	Paired Activities, Buddy System Remembering to call buddy Listening activity (reporting back partner's problems is very difficult to recall and articulate) If partner is unfamiliar with someone with dementia
Problem Solving Formulaic technique repeated every session Application: memory clues & strategies for daily activities Interactive	Problem Solving Too abstract, critical thinking skill Difficulty remembering structured steps Discomfort with group sharing
Group Brainstorming Ideas from group on how to remember things	Group Brainstorming Fast pace, too many stimuli, overwhelming Difficulty processing multiple ideas Difficulty expressing thoughts Stressful, frustrating
Overall Structure Scripted Built-in Repetition Consistent weekly routine - comforting Weekly practice (reinforcement) Reminders (calls, etc.)	Overall Structure Too much information Too fast paced, switching between activities Separation from care partners (for pairing activities) Large group activities Homework assignments Time elapse between sessions (1 week – too long)
Written Materials Visual charts and posters Textbook and CD (for home reinforcement)	Written Materials
Writing Activities Encouraged Writing action plans and displaying at home Journaling medical/emotional issues Learning to write reminder lists, medical questions, use post-it reminder notes	

HELPFUL	NOT HELPFUL
	Lecturettes Too long Too much detail Problems with retention and integration
Other approaches (Cueing, Modeling, Role Play)	
GENERAL	
All Content and Approaches Helpful Depending on level of dementia Especially if attend with caregiver	CDSMP Not Appropriate for People w. Dementia
	Frustration (stress, anxiety provoking) Remembering and doing homework Expectation of group participation Pace and switching activities
Facilitator Approach - leader should be: Understanding & model that to other participants Skilled at group management	Facilitator Approach – should be: In a hurry Have high expectations Alternate leaders within a session
Content Helpful even if Not Retained between Sessions	Difficulty with Retention, Applying Lessons to Daily Life
Care Partner Involvement Helpful	Care Partner Involvement Helpful
Depends on Level of Dementia, Memory Loss	Depends on Level of Dementia, Memory Loss