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

EXECUTIVE SUMMARY

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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.