Health Promotion for the Mind, Body, and Spirit: A college course for older adults with dementia

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Abstract

This article describes a pilot study of an experimental college course for individuals with newly diagnosed dementia, with a focus on teaching methods for promoting and maintaining optimal health. Community involvement included recruitment by the local Alzheimer's Association chapter and an off-campus site at a local assisted living center with easy access for the students. Course topics covered over the 10-week period, included modules on: physical and cognitive fitness, nutrition, recreation, communication, understanding the disease process, depression, coping, relationships, and driving issues. Stress, depression, self-efficacy, and self-esteem were evaluated both prior to and after the 10-week course. Providing education early in the course of the disease, empowers the older adult student and provides an element of personal control and dignity. The course also attempts to prevent future problems by teaching new habits and lifestyles early in the disease process. Attempts to change habits and behavior later in the course of the disease often fail due to the difficulty of learning new behaviors.

Key words: community-based care, dementia, education, early stage, empowerment

How do you feel when you are given a diagnosis by your physician for a disease that has no treatment to stop its progression? What do you do? Many people search for information on the Internet, ask friends, healthcare providers or others with the same diagnosis for advice, read articles, and attend workshops and conferences. When the diagnosis is Alzheimer's disease (AD) or another type of dementia, what does that person do? Where do they get information—especially since most services and education are aimed at the caregiver?

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Introduction

When it comes to quality of care, Alzheimer's disease (AD) is a major challenge for society. The goal of preserving the individual's personal control, dignity, and quality of life is an enormous task. Very few services are available for older adults in early stages of dementia. People who are diagnosed early in the course of the disease rarely have opportunities to get their questions and concerns addressed. Physicians do not always have time to explain the condition, the problems to expect, and methods of preventing these problems. Individuals in early stages of dementia often become isolated and stigmatized, even though they may still have good communication skills, are otherwise healthy, and will function quite well for a number of years. While they may no longer be able to engage in work or certain other lifelong roles, many still drive, are typically able to live at home, do most of their own personal care, and continue to engage in their past leisure time activities.

Until now, education and services have been directed primarily at family or professional caregivers—not the patient with the disease. Most individuals in early stages of a cognitive impairment are given some sort of cholinesterase inhibitor for cognitive symptoms and left waiting for the disease to progress, or a problem to arise, to obtain any services for themselves. Such problems include injuries and falls, difficulties with mobility, nutritional problems, depression, delirium, adverse reactions to medication, difficulties in communicating, or problems performing activities of daily living.

This article reports on the results of a pilot study of an

experimental college course for older adults with early stage dementia. The course was designed to teach health behaviors to prevent commonly occurring problems and to give the individual dignity and a sense of pride. This pilot study attempted to answer three questions:

1. Is it possible to develop an educational method that enables individuals with early stage dementia to learn new information?

2. Can participation in an educational course change health behaviors in individuals with early stage dementia?

3. Can participation in an educational course impact depression, self-esteem, self-efficacy, and stress?

Literature review

Researchers agree that early diagnosis and intervention are key to managing dementia.[1] First, these types of diseases require an early diagnosis so healthcare professionals have the chance to intervene to relieve symptoms and possibly delay progression. Figure 1 displays how learning healthy behaviors might impact later dependency as well as compress disabilities. Second, earlier intervention with therapy (both medication and psychosocial interventions) is now seen as essential.[2] Finally, referrals by specialists, when done early in the disease, can also improve the quality of clinical management and help patients avoid more expensive institutional care.[3]

The service models currently available may not have homed in on the specific needs of clients in the early stages of dementia who reside in the community. In most areas of the US, counseling, referral services, family support groups, respite services, community education, and awareness programs for the caregiver are available. Research shows that common initiatives for dementia caregivers, such as support groups, respite care, or day-care programs, are used by only a small percentage of caregivers.[4-7] Much of the literature on early stage dementia focuses on the caregiver's perspective, while little is known about the perspective of persons with dementia, such as how they learn to live with the chronic condition.[8] This focus on the caregiver can create a learned helplessness in individuals facing this new diagnosis, who may assume that they are incapable of having any control over their life or the course of the disease.[9] Early-stage support groups for older adults in the early stages of dementia are becoming a service option in many areas. They provide an emotional outlet and an opportunity to socialize with peers in a safe, comfortable setting. However, recreation centers are scarce, and, when they do exist, they are available during limited times, and are often used like an adult day-care program for individuals in moderate stages.

Until now, few, if any, formal educational programs for individuals with dementia have been attempted. The characteristics of dementia, especially memory problems, are thought to be a barrier to learning. For a person to learn new habits or behaviors, what is learned must be moved from their short-term memory into long-term memory. Long-term memory stores information that the brain retains because it is important to the individual. There are two types of long-term memory: explicit and implicit memories. Explicit memory is characterized by consciously recalling specific items of information, such as what one had for breakfast that day. Implicit memory is when prior learning impacts a current task but does not involve making a conscious effort to recall the earlier experience. For example, an individual driving a car is unconsciously remembering the rules of the road as well as the skills necessary to drive. Early evidence from neurology and cognitive psychology indicates that individuals with dementia have impaired explicit memory and preserved implicit memory.[10]

According to recent research, explicit memory tasks are still possible, especially in individuals in the early stages of the disease.[11,12] A memory training program of 12 sessions led to significant improvements in attention and performance, related to activities of daily living, using specific memory strategies.[13] A study of cognitive rehabilitation for motor-type procedural memories found retention of the procedure lasted for three months in participants with severe cognitive impairments and up to 20 months in those with mild impairments.[14] In another study, the preliminary evidence showed that training produced a significant result in face-name association, with gains maintained for six months in the absence of practice.[15] Specific learning techniques for improving autonomy in activities of daily living, use of a cell phone, was hypothesized to be a consequence of relatively preserved procedural memory.[16] Problem-solving therapy was attempted for individuals with both cognitive impairments and depression. The 12-week study supported remission of depression and fewer disabilities. This was explained by the participant's improvement of skills in generating alternatives and in decision-making.[17]

These studies provide encouraging evidence that supports formal education for individuals with cognitive impairments. This inspires attempts at changing lifestyles and habits while the individual is still in the early stages of the disease. Repeated explicit memory learning and motor-type procedural learning, performed early on, may generate implicit memories that will be unconsciously remembered later in the course of the disease. These promising findings

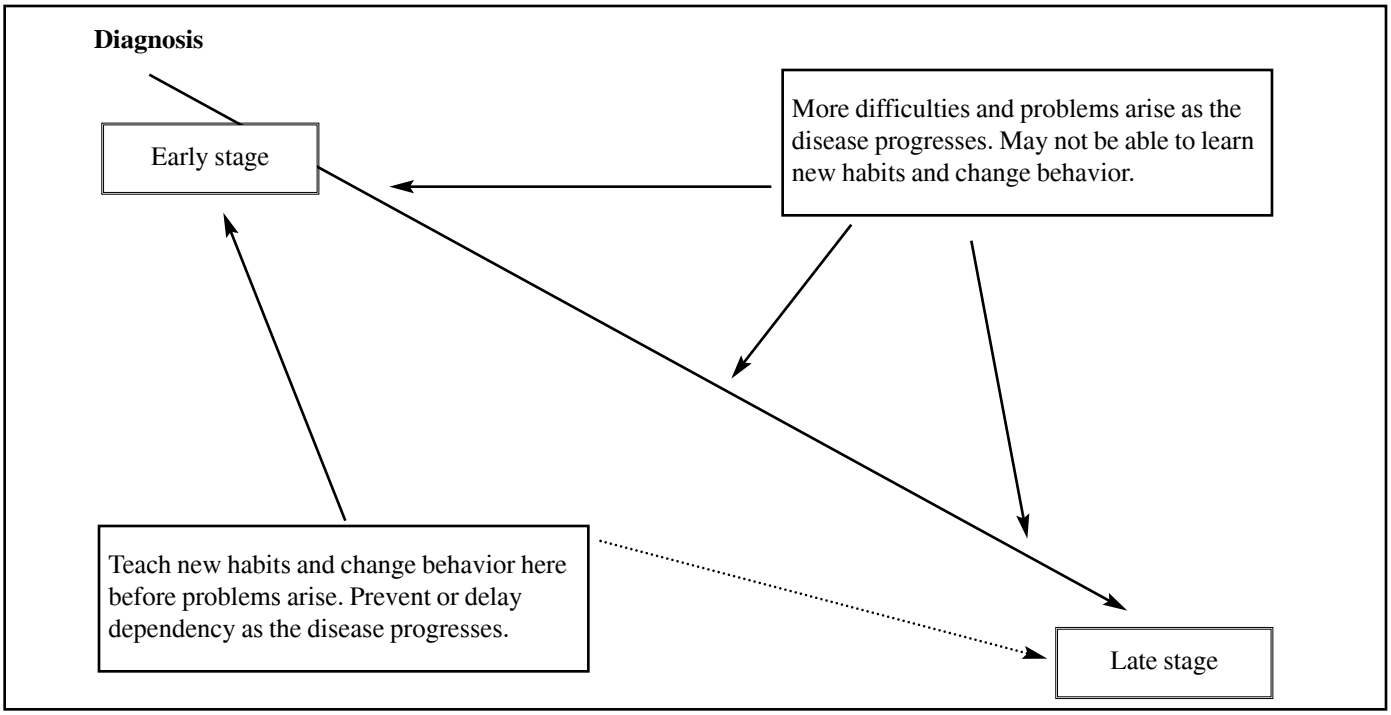

Figure 1. Impact of education for individuals with early stage dementia.

led the authors to create a college course, *Health Promotion for the Mind, Body, and Spirit,* for individuals with a newly diagnosed dementia.

The conceptual framework for this pilot project is based on the Corbin and Strauss Trajectory Model,[18] which posits that a chronic illness course can be shaped and managed over time, even if the course of the disease cannot be modified. This model defines chronic illness as the irreversible presence, accumulation, or latency of disease states or impairments that involve the total human environment for supportive care and self-care, maintenance of function, and prevention of further disability. "Trajectory" implies a multidimensional course or unfolding of chronic illness that profoundly affects individuals and those around them in all aspects of life. The illness and its symptoms influence a person's life, and aspects of life influence a person's ability to manage their illness. This model details the stages that occur for a patient with a chronic illness. Part of this model is the understanding that an illness is not just experienced as part of life, but must be managed and requires work by the patient, family, and caregivers. Until now, for individuals with dementia, the healthcare providers, family, or friends have accomplished this work. According to Corbin and Strauss, the goal of healthcare providers within this model is to help those afflicted shape their course while maintaining quality of life. Our Health Promotion course is an attempt to help the older adult with dementia deal with self-care or management of the chronic condition.

Recruitment/participants

Participants for this course were recruited through the Gulf Coast Chapter of the Alzheimer's Association (GCCAA) and a local press release. Participants had to be 65 years of age or older, had to be medically diagnosed with dementia, and had to be able to read. The course was limited to 10 participants, all of whom were required to register as students through Florida Gulf Coast University (FGCU). As all of the participants were over the age of 65, this was offered at no cost. The $20 registration fee required of all students was funded by the GCCAA. All books and supplies were donated by FGCU's Interdisciplinary Center for Positive Aging. The course took place at a local assisted living center for easier accessibility. The room provided was spacious, quiet, and equipped with chairs and long tables. Class was held on Wednesdays from 10:00 a.m. to noon, for 10 weeks. Spouses and caregivers were not allowed to stay in the classroom during these times.

Ten participants signed up for the course, with seven completing all sessions. Of the three "dropouts," two suffered hip fractures the week before the start of the program, and one relocated after the fourth week. Demographic data were collected at the beginning of the first class. Five of the participants were female and two were male. The Mini-Mental State Examination mean was 21.7 and the mean age was 77.9, with a range of 70.7 to 85.5. One participant lived in an assisted living center;

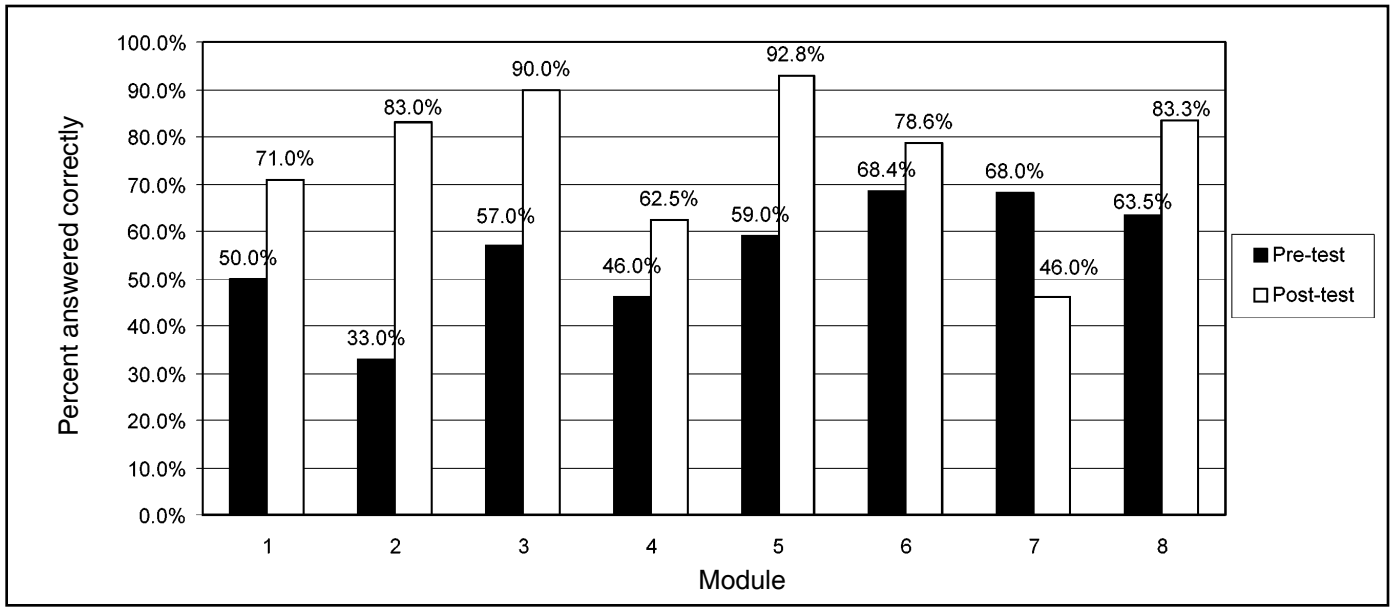

Figure 2. Module pretest and post-test scores.

the remaining six lived in their own homes and, of those six, two lived alone. Four of the participants drove themselves to class, two were driven by their spouses, and one took public transportation. All were self-ambulatory, with one using a walker.

Procedure

Participants were evaluated during the first class session for depression, self-esteem, self-efficacy, and stress. Since all instruments were self-administered, they were chosen for their simplicity and length and included the short-form Geriatric Depression Scale,[19] the Rosenberg Self-Esteem Scale,[20] the Matthias and Schwarzer General Self-Efficacy Scale,[21] and four questions from the Perceived Stress Scale by Cohen, Kamarck, and Mermelstein.[22] The participants expressed no difficulty in reading and responding to these evaluations. All evaluations were performed again at the end of the last class.

The participants also evaluated the course on the last day. Prior to the start of each class, the participants were pretested on the material to be presented during that class, and post-tested with the same questions at the end of each class. This procedure was used to evaluate the effectiveness of the teaching methods. These tests consisted of seven to 11 open-ended questions.

Educational methods

The course was designed to provide information on the disease process and on healthy behaviors to prevent problems that are common later in the course of the disease. It was designed in 10 weekly modules, with different experts and students providing information each week. Content was designed to meet the needs of the participants as assessed by the authors prior to the class. Syllabus information, broken down by weekly module, is presented in Table 1.

To provide consistency and familiarity, the instructor of the course, a geriatric nurse practitioner, administered all tests, taught some of the modules, and was present during all classes. Each class followed a structured format: the module pretest was administered, handouts were provided, a lecture was given, and post-testing took place. Guest lecturers from the community taught specific modules based on their expertise.

During the first class session, participants were provided with name tags and a FGCU binder with their name on the cover. This binder was the basis of the education method for the participants, the premise being that the notebook would become a resource for both the participants and their families to use in the future. The binder contained 10 dividers, one for each module to be covered during the course. To prevent stress, participants were informed at the start of each class that they were not required to remember anything. They were repeatedly informed, many times in each class, to look in their notebook for answers or help. During post-testing of materials for each module, the participants were allowed to use their notebooks to find the answers, thus reinforcing the use of the notebook to answer the questions. Each week, handouts were provided to be added to the notebook based on the material being covered. All handouts had a consistent format, with short statements or bulleted items and space to write notes. The handouts closely followed the lectures for each module, and important material was

Table 1. Course syllabus			
Week	**Module**	**Speaker**	**Content**
1	Healthy lifestyles	Gerontologist	What healthy behaviors are and why this is important. Taking control over one's health.
	Dementia	Gerontologist	Types of dementia, how diagnosed, disease course, what to expect.
	Depression	Geriatric nurse practitioner	Signs and symptoms, methods of prevention, nonpharmacological treatments, when to see a physician.
	Delirium	Geriatric nurse practitioner	Signs and symptoms, methods of prevention, nonpharmacological treatments, when to see a physician.
2	Cognitive activities	Psychologist	Keeping the mind active, tips for remembering information.
3	Communication	Geriatric nurse practitioner	Types of communication, methods for optimal communication. Development of a communication notebook: A 5" x 7" three-ring binder with six dividers. For most, the dividers were: Family & Friends, Store & Restaurants, Doctors, Household Items, Events, and Words. Participants were helped to develop each section with their personal information. Photographs and store logos were included, as were birth dates. Participants were instructed to add to the binder any time they had difficulty coming up with a word, or look in the binder to find the word they need.
4	Relationships and coping	Gerontologist/ social worker	Changing relationships, dealing with emotions and loved ones.
5	Physical fitness	Gerontologist/ physical therapist	Falls prevention, exercise.
6	Nutrition & hydration	Dietitian	Healthy eating, importance of hydration, use of supplements.
	Medications	Geriatric nurse practitioner	Medication management and adherence. Avoiding adverse drug reactions.
7	Recreation & leisure	Certified Therapeutic Recreation Specialist	Importance of remaining active, socialization, leisure education.
8	Home and traveling safety	Occupational therapist	When to stop driving, alternate transportation, keeping safe in the home, traveling safety, prevention or getting lost while walking or in car.
9	Lifelong learning	University OT, PT, RT students	Importance of education. Group project: Float for the local Alzheimer's Association Memory Walk. This module was designed to give the healthcare students an opportunity to understand and learn from the older adult participants. Younger students practices discipline-specific assessments on older participants. Older participants explained to healthcare students what it is like living with dementia.
10	Future planning and graduation	Alzheimer's Association	Local resources available, future financial and legal needs. Graduation with certificates, and family and friends attending a party.

emphasized and repeated. Materials in handouts were written in a manner that could be applied to the participants' lives, when possible. The handouts included local phone numbers for various resources.

Teaching methods included lectures, PowerPoint presentations, Q&A periods, and interactive hands-on learning. Participants were encouraged to ask questions and make comments at any time.

Results

Due to the small sample size, the data could not be analyzed for significance or correlations. The Geriatric Depression scores improved from a pretest means of 3.5 to a post-test of 2.67, suggesting that the program may have an effect on reducing depression. The Self-Esteem Scale has a maximum of 30 points; the higher the score, the greater the self-esteem. This score improved from a pretest means of 18.4 to a post-test of 22.0. This suggests a trend toward improved self-esteem of the participants. The Self-Efficacy Scale, with 40 points possible, remained relatively stable from a pretest of 33.17 to a post-test of 33.0. Scores for the Perceived Stress Scale dropped from a pretest of 7.83 to a post-test of 7.0, showing a slight reduction in stress. Figure 2 shows the scores for pretest and post-test of information within the 10 modules, expressed by the percentage of questions answered correctly. For the course evaluation, the participants rated a series of questions on a Likert-type scale of 1 to 10, with 10 indicating the greatest importance. The questions and results are shown in Table 2.

Findings

The quantitative and qualitative data provide encouraging pilot information on an educational program for older adults with dementia. The findings below relate to the original three questions this study attempted to answer.

1. *Is it possible to develop an educational method that enables individuals with early stage dementia to learn new information?* Based on the pretest and post-test data on module content (Figure 2), we feel it is possible to teach the material in a way that improves knowledge and understanding in the students. Much was learned from the students themselves, and, based on their feedback, the syllabus and content will be modified in the future. For one module (module 7), participants scored lower on the post-test because the lecturer did not follow the handout and the abstract content of the material. Students commented they preferred having the PowerPoint presentation along with the lecture. Seeing the information on the screen as it was being discussed seemed to help.

2. *Can participation in an educational course change health behaviors in individuals with early stage dementia?* As a result of information learned in the course, several subjects reported short-term changes in lifestyle. Two of them started regular exercise programs (one swimming, one walking). One participant decided to stop driving when he learned that having near misses means you are no longer a safe driver. One participant recognized in herself the signs of depression and started to socialize with others on a daily basis. Another participant began taking a cell phone with him on his daily walk and leaving a note stating what time he left and where he was going. Several, with the help of the instructors, developed a method for remembering to take their medications. Three kept their communication notebook with them wherever they went, referring to it when needed and adding information when appropriate. Several starting playing board games with their spouse or grandchildren, both as a leisure activity and to keep their minds engaged. One took up watercolor painting, a former passion she assumed she could no longer do. Several decided never to take over-the-counter medications or supplements without talking to the pharmacist first. One had handrails added to her bathroom. How long these changes lasted is not known since longitudinal data were not collected, but during a follow-up session six months later, the participants were still dedicated to the behavior changes they had made.

3. *Can participation in an educational course impact depression, self-esteem, self-efficacy, and stress?* Although this was a small sample, the mean scores for all tests did improve. A larger sample and a control group would be needed to show that significant change was due to the course. These results were promising and deserve further study.

Discussion

Test score data alone cannot describe the impact this program had on the participants as well as from family members, guest lecturers, and the core instructors. It was originally assumed that the participants could learn but might either forget to come or forget their notebooks or name tags. This assumption was found to be incorrect; the students never forgot to attend and always had their notebooks and name tags with them. There was a concern that

Table 2. Course evaluations	
Questions	**Ranked importance (scale of 1 – 10)**
In regard to the course you just took:	
How important was it to you to meet classmates with your same problem?	8.0
How important was it to you to learn how to be healthy?	9.4
How important was it to you to learn how to take control of your life?	9.8
How important was it to you having instructors to answer your questions?	9.6
How important was it to you to have a comfortable emotional outlet?	9.6
How important was it to you to have a notebook to use as reference?	9.6
How important was it to you to be a college student?	9.0
How important was it to you to have something of your own to attend?	9.4
How would you evaluate the course's main instructor?	9.9
What is your overall evaluation of your experience with this course?	9.6
Questions	**Number of responses**
Was the length of each class:	
Too short?	0
Too long?	0
Just right?	7
Was the number of classes:	
Too few?	4
Too many?	0
Just right?	3
Was the location of the classes:	
Convenient?	7
Inconvenient?	0

two hours might be too long for class time; originally a break was scheduled halfway through. Not one of the students ever wanted to take time for a break. It was assumed that the testing might be stressful and difficult for the participants. Again, this proved incorrect. After the first class, the students seemed to know the routine and never complained. They took notes, paid close attention, asked good questions, and used their notebooks to find the answers. They were, by far, the best college students any of the instructors ever taught!

During the first two or three classes, the participants were polite and reserved. The first module covered a difficult topic for them—the detailed information about dementia and what to expect. One participant later said, "I went home and cried for hours after the first class. Then I decided, 'Okay, now you know what to expect. It's time to get on with my life.' I felt like a new beginning had occurred for me and I could handle it."

From the second class came the "plaques and tangles" joke. One participant, having difficulty finding a word, said "Well, it's hard to remember when you have all those plaques and tangles!" From then on, this was their standard reply when having difficulty finding a word. At the start of the third class, one participant asked if we could rearrange the seating; she wanted the tables to face one another so they could see each other. By that time, the class members were bonding. They helped each other and consoled, complimented, and hugged their classmates. They brought items from home to share each other: a recipe, photographs, books, articles, even a 1956

Table 3. Advice lists developed by class participants after completing the course	
Group addressed	**Advice from course participants**
To my family, friends, and caregivers:	• Include me in social events and activities. • Take me out. • Know that I'd rather drive myself, but I can't. • Remind us of events of the past; it keeps us alive. • You would be surprised at what I can still do, if you would just let me. • Sometimes, we feel lonely and scared; don't be afraid to call. • Acknowledge me; I am not an empty shell. • I am not contagious, so don't keep away. • Don't announce my diagnosis to the world.
To the staff at assisted living centers:	• Don't grab me and hold me like a criminal. • Your voices are too loud in the halls at night; when you yell to each other, it keeps us awake. • The only exercise I get around here is walking to meals; take me on walks! • I want to stay active, but I can't remember when and where things take place. Remember to ask me if I want to attend.
To people recently diagnosed with Alzheimer's disease and other dementias:	• Be upfront and honest. • Don't be ashamed. • Make jokes out of your problems. • Focus on what you can do, not of what you can't do. • Right at the beginning, tell people your problem and get it over with. • Keep track of old friends.

Studebaker. They spent a Saturday participating as a team in a local Memory Walk and had a picnic afterward.

Various family members also gave us some feedback:

- "This is the most important thing in her life right now."
- "Everywhere she goes, she brings her class notebook and shares it with others."
- "Every Wednesday we talk on the phone and she tells me what she learned that day. She even faxes me the handouts so I can learn too!"
- "She tells everyone she is a college student!"
- "Talk about a turnaround, now he comes home from class and is teaching me about health issues!"

The last class was an emotional time, as students expressed sadness over the course ending. They had found a comfortable space where they could express themselves without ridicule or fear. They had someone to answer their questions and to advise them. They received their college course completion certificates with both tears and pride. They asked if they could continue to meet monthly, and they now take turns hosting monthly get-togethers at each others' homes. They also developed lists of advice for others involved in their care and treatment. This information is summarized in Table 3.

Conclusion

This pilot study of a college course for individuals with newly diagnosed dementia was a hugely successful program. The students who took the course were extremely satisfied with the opportunity to learn and with the content of the 10-week program. They were able to improve their knowledge and skills and made some short-term changes in their health behaviors. Most importantly, they learned the information firsthand and were able to have some control over their lives. This improved their mood, self-esteem, and self-efficacy.

This is a very different way of providing services to older adults with dementia, one that needs to be an option in every community in the nation. It is dignified and respectful of the lives and abilities of older adults

facing one of the toughest times in their lives. Based on input from the participants and guest lecturers and on test scores, the course has been modified into one 12 weeks long. For information on obtaining the course materials for replication, please contact the authors.

A week after the course ended, the instructors received the following letter from one of the participants:

> "Just a note to say thanks to you and the University for holding this course. I found every Wednesday class extremely helpful, very knowledgeable and well presented. Each week's subject was of personal interest to me and concern to me, since I was just recently diagnosed with AD. Starving for all the information related to this problem and how one copes with the reality of the disease, how I will get by each day, continue to communicate, keep relationships, what steps need to be taken to stay healthy, improve mobility, protect myself from falls and make my home safe. Another important highlight for me was the interaction with the other students. It showed me I was not alone with my struggle, but there were others, some with more or less memory impairment. I felt an immediate camaraderie with them all. The information I received was very valuable and I believe I could apply it in my everyday living as long as possible and then, my family will have a guideline also. I am truly grateful and feel this course could be the most helpful tool the medical and health community could offer to folks with this condition."
>
> AW, retired nurse

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