Focus

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The premier educational resource for home and community-based care

Spring 2010:
The Aging Population in Home Care

inside:

Behavioral Health Challenges in Home Health Care

by Michael B. Friedman, LMSW

Michael B. Friedman, LMSW, is the Director of the Center for Policy, Advocacy, and Education of the Mental Health Association of New York City and Chair of the Geriatric Mental Health Alliance of New York. He can be reached at center@mhaonyc.org. For further information about geriatric mental health, visit www.mhaofnyc.org/gmhany.

Mrs. S appeared to have saved every newspaper and magazine that she had ever had. They were piled everywhere. Her apartment was beyond cluttered. There was a narrow passageway from her front door through her living room, just enough for a small, thin person walking sideways. Her kitchen appeared not to have been cleaned in months. Dirty dishes were piled in the sink and on the counter tops. Food was rotting. The smell had gotten so bad that her neighbors complained. A worker was sent to help her, but she adamantly refused to allow anything to be removed. She seemed, in fact, to be terrified of the idea. Reasoning with her had no impact. Eventually, the health department ordered the apartment cleaned. Mrs. S. screamed at them and then began to cry.

Mental and behavioral problems are among the greatest challenges faced by caregivers who go into the home to help people with disabilities—especially older people—live in the community, where almost everyone prefers to live. This became clear during focus groups we did a few years ago in which we asked, "What makes it most difficult for you to continue to provide care for people in their homes?" "Behavioral problems," they said. When we asked what they meant, they told us about people who refuse to follow their treatment plan, or who are abusive to their caregivers, or who wander out of the home, or who have held onto all the stuff they have ever felt was important to them, or who forget or don't care enough to eat food that is left for them, or who complain endlessly about the same thing, or who are paranoid, or who become acutely psychotic, or who sink into lethargic depressions, or who are painfully agitated, or—well, the stories went on and on.

Continued on Page 2

Behavioral Health Challenges...

Continued from Page 1

We also learned from our conversations with home care workers that, while some of them have a gift for helping people with mental illnesses and behavioral problems, most seem to be at a loss. I certainly found this to be true in my own experience. For many years I was responsible for an aunt who had developed a severe mental illness as well as an array of physical ailments in older age. I hired home health workers to stay with her, and they were absolutely wonderful. Their compassion and commitment were obvious. They had great skill at tending to my aunt's many physical complaints. But when my aunt became psychotic from time to time, much as they tried, they just didn't know what to do.

Mrs. C lived alone in the apartment in which she and her husband had raised their children. She had always been a bit distrustful. The butcher put his thumb on the scale. A teacher had it in for a daughter who wasn't doing well in school. But after her husband died, she became increasingly suspicious of everyone. She double checked the pills she got from the pharmacist. She refused to hire a new cleaning woman when the one she had had for years retired. Her daughter visited. "You bitch," she screamed, "You stole my diamond ring." The daughter was tolerant to a point but eventually insisted that her mother have help in the home, in part so she didn't have to face her mother's abuse every day. "You say my daughter sent you," the mother yelled through the door when the worker arrived. "Does she want you to kill me?" She did not open the door. Eventually she opened the door, but she continued to yell accusations at the woman who was trying to help her. She fired her and the next worker and the next.

The lack of adequate behavioral health intervention in the home contributed to hospitalizations that I am sure could have been avoided, and ultimately to my decision to allow her to be placed in a nursing home. I have talked about my personal experience frequently in speeches to large audiences. I always get nods of agreement. I am very obviously not alone.

This suggests, of course, that home care workers should learn a great deal more than is included in their basic training about mental and behavioral problems and how to manage them. I have come to believe that this is one of two measures that should be taken. The other is to develop cadres of home care workers with special skills related to mental and behavioral problems. I simply don't think we should expect that every home care worker can develop these skills—in part because some people just do not have the disposition that is needed to be patient, tolerant, and personally forgiving with people who can be extremely trying.

What would this special training include?

Screening

It is very important for home care workers to learn to identify signs of mental disorders that should be assessed by a professional. This can be done with very basic mental health education, and there are also several very simple screening tools that are easy to learn and highly accurate in flagging concern about a patient's mental disorders.

Medication Management

Physicians often prescribe medication to treat a mental illness. Psychotropic medications can be very helpful to some older people with mental and behavioral problems, but they can also be dangerous. Dosages for older adults who are frail are quite different from dosages for those who are younger and/or healthier. Home care workers should know enough to be cautious and precise in administering, or helping their clients to self-administer. these medications.

Continued on Page 3

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Community Health Care Services
Foundation, Inc.
99 Troy Road, Suite 200
East Greenbush, NY 12061

Tel: 518/463-1167 Fax: 518/463-1606
www.chcfoundation.org

Behavioral Health Challenges...

Continued from Page 2

Understanding the Relational Character of Behavior Problems

As crucial as they are, knowing that someone may have a treatable mental health condition; involving mental, and physical, health professionals; and knowing the rudiments about medication are not enough. Home care workers also need to have some skill in engaging and helping clients whom they find difficult to serve. Fundamental to developing these skills is understanding that behavior problems are not "in" the person. Behavior problems are in the relationship between the troubled person and the caregiver. Behavior that is a problem for a caregiver who may, by nature, be impatient or is highly reactive to stressful situations may very well not be a problem for a person who has greater equanimity, patience, and tolerance for a bit of disorder. Helping home care workers understand that their reactions may be part of the problem and helping them learn how to control their own reactions is very important.

> *Mr. F. believed that he had been prescribed too many pills and that they couldn't be good for him. He also thought that they cost too much money, not just to him but to Medicare. It offended him that the price was so high. As a result, he took his pills selectively, often cutting them in half to make them go further. He thought that this had nothing to do with his being out of breath much of the time and not having enough energy to take a walk. His worker tried to insist that he take the pills. He became even more stubborn over time.*

Understanding Inner Experience

One of the ways that those who work with people with mental and behavioral problems can develop more helpful reactions related to trying behavior is learning to understand the inner experience of people whose behavior is difficult to tolerate or manage. For example, a person who accuses a home care worker of wanting to rob them is clearly living in a state of fear and distrust. They are also probably feeling powerless and alone. They may be miserable that they need care, that they've lost their independence, or that it is humiliating to wear diapers and be wiped clean after an episode of incontinence. Angry outbursts may be more an expression of inner despair than of the disdain, disrespect, and dislike that they seem to reflect.

Engaging One's Client as a Person

There is a tendency to blame trying behavior on a disease. He or she is difficult, we often think, because s/he has dementia or is depressed or has an anxiety disorder or is psychotic. That can be an important insight, but when it comes to engaging a client in ways that help to quell their trying behavior, it is not very helpful to blame it on a disease. The inner experience of each person is different. Knowing that a person is depressed does not help too much with understanding that individual's unique experience. And thinking that the

Continued on Page 5

CHC's Spring Education Spectacular

Forum #48:
Aging & Women's Health
March 18, 2010
Audio Conference

Stages of Dementia: Challenges for Day-to-Day Care
March 24, 2010
Webinar (Contact hours available!)

Up Your Revenue with New Marketing & Sales Strategies
April 8, 2010 (8 am - 4:30 pm)
St. John's University
101 Murray Street
New York, NY
Easily accessible by NYC subway and NJ Path trains

Using Social Networking to Build Client Relationships and Grow Your Business
April 14, 2010
Webinar

Coordinator Training
April 28, 2010 (8:30 am - 4:30 pm)
Crowne Plaza LaGuardia
East Elmhurst, NY

To register for any CHC program, visit www.chcfoundation and click on "educational seminars," or call 518.463.1167.

Effects of Tai Chi/Qigong Among Senior Apartment Residents

by Ruth Camann, RN, BSN, People Inc. Quality Assurance Coordinator

Ruth Camann is a registered nurse who holds a Bachelor of Science degree from Niagara University. She has over 15 years of experience with the Developmentally Disabled population and over 20 years of experience with the senior population in Western New York. She has been a member of the People Inc. Quality Assurance team for three years and is currently working with People Inc's Special Needs CHHA for the Developmentally Disabled. Ruth's evolving role includes new policy development, clinician training, and identification of areas to concentrate continuous quality improvement efforts.

Physicians, nurses and other home care professionals know that older adults who increase their level of physical activity maintain greater mobility, experience fewer falls, and lower blood pressure, among other benefits. Apart from physician-ordered physical therapy or group exercise classes, self-directed activities that are done in the home, including yoga, Tai Chi and Qigong, can be safe and effective for older adults, and should be encouraged, when appropriate, in home care plans of care.

CHC is pleased to share highlights of a grant-funded project to assist older adults that have challenges in mobility that may limit their participation in community-based programs.

Residents of senior apartment housing often have mobility challenges affecting their ability to meet recommended guidelines for physical activity and subsequently their quality of life. In response to this challenge, People Inc. of Buffalo, NY secured a grant from the Community Health Foundation of Western and Central New York and in collaboration with Dr. Penny Klein, PT, EdD, a professor of Physical Therapy at D'Youville College, developed a modified Tai Chi/Qigong program for residents of senior apartment housing. The research protocol was registered with Clinicaltrials.gov.

The purposes of the pilot were to determine (a) if residents of Senior Apartments could safely engage in independent practice of a modified program of Tai Chi/Qigong with minimal instruction from a Tai Chi instructor, (b) if they would enjoy the activity and perceive benefit, and (c) at what rates would they continue to practice this health promoting physical activity as part of their daily life routine.

The programming was constructed using Aizen's Theory of Planned Behavior which proposes that human action is guided by three considerations: 1) expectations of outcome; 2) motivation to comply with the expectations of significant others; and 3) beliefs about whether one can actually engage in the new behavior. The behavior in question was 'adopting and persisting in home practice of Tai Chi/Qigong'.

Three 'Fall Prevention' fairs were utilized as an opportunity to recruit participants for the project. The fairs were well attended by residents from eight senior housing apartment buildings, and the following information was disseminated: facts about falls prevention, ways to decrease fall risk factors, overview of Tai Chi/Qigong, and details about how to participate in the pilot program. Interested residents volunteered to participate in the Chi Time program. Nineteen participants from two sites were randomly assigned to receive a series of instructor-led group classes in Tai Chi/Qigong once weekly for four weeks. Fifty-two participants from six other sites received one class of Tai Chi/Qigong instruction. At the initial class, both groups were provided with an instructional DVD demonstrating Chi Time exercises in both a standing and sitting format for home practice. All participants were instructed to complete Daily Exercise Logs including length of each exercise session for the five week duration of the study. A post-study survey of program experiences and home exercise was also administered.

Many lessons were learned through analysis of results which can apply to future programming. First, at the conclusion of their first instructor-led class, all participants felt confident that with assistance of the DVD, they could do the exercise on their own. There was one caveat – several participants needed instruction in how to use a DVD player. Overall, 64% reported exercising with others by meeting in each others'

Continued on Page 5

Effects of Tai Chi/Qigong...

Continued from Page 4

apartments and/or attending a participant-led group in the common room of the apartment buildings. As might be expected, many participants had mobility challenges, with 30% reporting that they exercised primarily in a sitting position rather than standing. The average exercise length was 25 min/day. Although overall, 80% of participants reported regular exercise over the first week of the study, it gradually declined over time in both groups. After five weeks, 68.4% of the participants who received weekly instruction continued exercising regularly as compared to 55.8% of the group which received one instructor-led class. Currently the participants are continuing the program independently in their apartments.

The major perceived benefits from the program were improved sense of well being, energy, vitality and quality of sleep, reduced pain, and improved mobility and balance. The research results indicate that residents of senior housing can achieve the skills and confidence in performing a Tai Chi/Qigong program safely in their homes when given one instructor-led class and an instructional DVD for home exercise use. However, the real impact of the program may be experienced on the individual level. This impact may be typified in the comments of one participant.

"I never thought I would do something as exotic as Tai Chi. I enjoy it. I sleep better. I feel better and my family is very impressed."

The challenge, now, is to find ways to make this and similar programs widely available to others with limited mobility whose lives might be similarly changed by exposure to this ancient health-promoting physical activity. ◆◆◆

Behavioral Health Challenges...

Continued from Page 3

disease causes the behavior often leads to failing to think about other factors. What is it that the behavior reflects about an individual's desires? Are there ways to help them achieve what they want? What are their personal interests? Maybe asking questions will provide information about interests and desires, and maybe there are ways of engaging with otherwise trying people based on what you know about them as a person, rather than just as a sick and disabled person.

Techniques of Interaction

I have emphasized the importance of learning to understand the unique, inner experience of each individual client, but there are also techniques of interaction that have been developed that work with some people. For example, there are ways to help people with significant memory loss ranging from the simple, obvious, and sometimes neglected tactic of writing it down and putting it in a place where the person will see the reminder to ways of adapting brain fitness exercises to individual interests.

Mental and behavioral problems are among the greatest challenges confronted by home care workers. Meeting these challenges calls for the development of cadres of home care workers who specialize in serving this population, and it calls for training regarding identification of mental health conditions, linking to professional services, and improved engagement of behaviorally trying clients. "Long-term care reform", which is one of the major elements of overall health care reform in the United States, cannot move ahead effectively without a major policy initiative built on recognition of the centrality of behavioral health in long-term care. And we urge both state and Federal governments to provide the resources needed so that long-term care providers to serve people with mental or behavioral problems effectively in their homes. ◆◆◆