## It's Time for a Return to Person-Centered Care

### Efficiency Is No Substitute for Care "Kinder than Kindness Itself"

early 70 years ago, a religious woman of great courage and vision decided to act on her belief that elders entrusted to her care should live in a homelike environment that reflected the means of Americans of the time. She believed that each person should be treated as a unique, individual human being. The woman was Mother Mary Angeline Teresa, O Carm, the foundress of my congregation. She and six companions decided that they would teach others by their example-an example that many others would followand the congregation of the Carmelite Sisters for the Aged and Infirm was born, in Bronx, NY, on September 3, 1929.

Mother Mary Angeline Teresa exhorted her sisters and those who worked with them to be "kinder than kindness itself." She believed that those who minister to the elders of our society should bring Christ to each person. In one of her letters to her sisters she said, "Bringing Christ means giving them His compassion, His interest, His loving care, His warmth morning, noon, and night. In another letter she said, "Old age is a lonely period. At no time in a person's life is kindness so much needed and appreciated. Efficiency is wonderful, but it should never replace kindness. All professional skill should stem from the kindness and compassion of Christ."

Mother Mary Angeline Teresa answered the call to serve the aged and infirm in an era before President Franklin D. Roosevelt signed the Social Security Act on August 14, 1935. Most people in the 1930s worked until they were physically unable to continue working (or died). Those who exhausted personal and familial resources lived out the remainder of their days in charity-run old-age homes. Although some states and municipalities had relief programs for the indigent, most people resisted the "dole" as humiliating. To compound the problem, by 1930, 8 percent of the nation's population was over the age of 65. (Thanks to better nutrition and medical advances, the number of elderly had doubled since 1920.)<sup>1</sup>

Mother Mary Angeline Teresa's challenges in 1929 were just as daunting as some of the challenges—budget cuts, reimbursement problems, and so forth—that long-term care faces today. But our biggest challenge today is not financial. Our biggest challenge is finding a way to continue providing unique, individual care—what we call "person-centered care"—in a culture that has for many years concentrated on developing efficient medical models. How do we change the culture? How do we provide individual, unique care to each person in an environment of increasingly progressive illnesses, shorter stays, and the various forms of dementia?

### WHAT IS PERSON-CENTERED CARE?

Person-centered care values the person one is caring for according to his or her needs, wants, and choices. Person-centered care develops personal relationships with residents, staff, and families. A caregiver who is serious about person-centered care evaluates his or her facility's culture and asks such questions as: Do the residents we serve have choices? Do they enjoy a homelike environment? How do we ensure quality of life?

Everyone who needs health care expects the health care staff to be competent in its specialty area and to provide high-quality care. In long-term care, a resident expects to receive good skin care,



### BY SR. M. PETER LILLIAN DIMARIA, O.CARM

Sr. Peter Lillian is director, Avila Institute of Gerontology, Carmelite Sisters for the Aged and Infirm, Germantown, NY. proper nutrition, and other forms of care. Personcentered care provides all that—plus an improved quality of life. Quality of life improves when the caregiver (no matter what his or her discipline) knows the resident's likes and dislikes and is willing to "change the culture" to help make the "likes" happen and the "dislikes" not happen.

In person-centered care, the resident's personal preferences are met even in such activities of daily living as dressing, bathing, and eating. Quality of life is improved by implementing menus that allow mealtime choices to fit the resident's preferences. Relationships improve when caregivers understand that a resident's usual routine is to take a bath in the morning, not a shower at night (or perhaps vice versa), and that the source of the resident's agitation at night has to do with feeling that his or her lifestyle has been disrupted and personal preference is not respected. Improved quality of life occurs when a caregiver is willing to make reasonable accommodations so that, for example, an 87-year-old resident with dementia is not forced to change his or her life's routine by taking a shower in the evening.

Why do we create fixed daily schedules? Is it for the convenience of staff or for the convenience of the resident who has come for compassionate care? The traditional medical model is based on a medical diagnosis; it is designed to make the staff efficient at treating the illness, not the person. It is not uncommon for caregivers to determine how quickly medications can be dispensed and how many room visits can be finished within a certain amount of time due to imposed time constraints. It is easy to lose sight of a frail elder's need for time to talk, partly resulting from the vague feeling of loss often experienced by those who have dementia.

As a result of the quest for efficiency, quality of life is lost as residents suffer feelings of loneliness and isolation. Person-centered care is based on recognizing the resident's individual needs and strengths within the context of his or her medical diagnosis. It recognizes that one resident's Alzheimer's disease or cancer is not the same as that of the resident's neighbor. In person-centered care, schedules are framed around the needs of the resident, and staff assignments are made to ensure that relationships between the caregiver and the resident are maintained.

### How DID PERSON-CENTERED CARE GET LOST?

Over the last 30 years, I have seen a chipping away at Catholic health care's mission by outside forces that ask us to change our culture to fit the culture of bureaucracy and secularism. We who serve the ministry must be careful not to turn it into an industry. We must continue to be defined by our example of Christ's compassion—his love—not solely by regulation and economics. It is time that we begin to manage our facilities' culture, before outside forces manage us.

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Currently, care providers perform multiple assessments, each designed to assist them to know the resident better and, at the same time, facilitate appropriate government reimbursement. If we simply fill in boxes by placing human beings into fixed categories, we ignore their uniqueness. How often has one read the obituary of a person one cared for and said, "I didn't know she (or he) accomplished that!" Person-centered care, on the other hand, develops and manages relationships. In delivering such care, we do conduct an assessment, but we also ask questions that aid us in understanding the resident as an individual, as a unique human being.

Here's an example of what I mean: Let's say that I, Sr. Peter Lillian, at age 86, am a resident with moderate dementia being admitted to a facility in which person-centered care is provided. Let's also say that you are conducting my assessment. As we talk, you will find that I enjoy, along with prayer and spiritual exercises, watching sports—any sports. You will find that I especially enjoy watching and listening to baseball games. In fact, further conversation reveals that I am a diehard Boston Red Sox fan (2004—the year we won the World Series—was a great year!).

Now, having learned this about me—and striving to provide person-centered care—would you escort me to a bingo game or to a televised baseball game? Even if I had dementia, when I heard the announcer's voice and the roar of the crowd, I would connect with the days I spent watching baseball with my dad. By taking me to a TV set so I can watch a baseball game, you are providing a memory that is so dear and precious to me, and one you know I may understand and enjoy. You are giving me an opportunity to meet my entertainment needs; and also giving yourself, the caregiver, an opportunity to be rewarded by my enjoyment.

Many behaviors that we see in our elders, and especially in residents who have some form of dementia, are actually a result of getting either too much stimulation or not enough of it. According to Jiska Cohen Mansfield, PhD, and Allan Bester, RN, residents with dementia who participate in activities that are relevant to their self-identities showed a significant increase in interest, pleasure, and involvement in those activities.<sup>2</sup> Such residents also experienced increased orientation and fewer agitated behaviors. These results suggest person-centered care is not only more humane than other methods; it may also be more economic.

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### **PROBLEMS WITH CURRENT METHODS**

A very knowledgeable colleague of mine, Alfred Norwood of Behavior Science, a Rochester, NY, consulting firm that specializes in the care of people with dementia, has shared with me many studies conducted over the past few years in dementia care. These studies affirm that personcentered care is the ultimate compassionate care. Losing focus on the resident is easy; it results from increases in regulations; the seriousness of resident illness; staff turnover; and concurrent decreases in reimbursement, funding, and the available number of nurses. With decreased resident stays and increasing dependency, caregivers are forced into sequential crisis management.

Problems associated with the contemporary care model include the following.

**"Whack-a-Mole" Care Has Become the Standard** In this chronic crisis environment, the conventional reaction is to tighten up facility management, which means centralizing decision making, increasing the number of reports, employing stronger nurse managers, increasing discipline,

and, in general, assuming the management structure of a military entity under siege.

According to Norwood, a geriatrician once told him that long-term care has taken on the attributes of "Whack-a-Mole," the county-fair game in which a player is given a big sponge-rubber hammer and challenged to hit one of many moles that randomly pop up out of holes on a board. In long-term care facilities that operate on "Whack-a-Mole" lines, everyone involved focuses on solving the current crisis (rather than focusing on the resident), right up until the next crisis arrives. The results of "Whack-a-Mole" management show up in national nursing home statistics covering the period 1999 to 2005.

**Long-Term Care Is Replacing Registered Nurses (RNs) with Certified Nurse Aides (CNAs)** The average number of hours that a RN spends with residents during a working day has decreased 25 percent, whereas the number of hours a CNA does so have increased 15 percent.<sup>3</sup>

**Long-Term Care Increasingly Meets Behavioral Issues with Drugs** The number of residents with dementia increased 10 percent, and the number with psychiatric diagnoses increased 43 percent, and the use of psychoactive drugs increased by 13 percent.

Although Long-Term Care Has Fewer Bed-Bound Residents than Formerly, Skin Problems Have Increased The number of residents with pressure sores has increased 4 percent despite the fact that the number of bedfast residents has dropped by 37 percent. The number of chair-bound residents has increased by 14 percent.

Decisions Have Been Made with Fewer Clinical Resources, Resulting in Increased Deficiencies in the Following "F-Tags" ("Federal Tags" Indicating Deficiencies) More than doubling over the six-year period were F280 (failure to meet care plans) and F281 (poor professional standards), closely followed by F279 (failure to provide comprehensive care plans), F282 (failure to provide qualified personnel), F386 (inadequate physician visits), and F387 (inadequate frequency of physician visits).

Although Deficiencies for CNA Training Decreased, CNA Proficiency Has Decreased Also Long-term care saw a paradoxical 70 percent decline in deficiencies in F494 (required training) and a 66 percent increase in F498 (proficiency of nurses aides) deficiencies.

### **RETURNING TO PERSON-CENTERED CARE**

Experience shows that "Whack-a-Mole" care management makes a facility more reactive and

job-centered, which is the opposite of personcentered care. Fortunately, only four steps are required to ensure person-centered care. **Shift Responsibility for Care to CNAs** As noted, RN shortages and reduced physician visits result in increased deficiencies. RNs spend only an average 12 minutes per eight-hour shift; CNAs spend 46 minutes per eight-hour shift.<sup>4</sup>

As a result, consciously or not, CNAs have increasingly been hired to compensate for the lack of RNs and physicians. This is not without some logic. Experienced CNAs have been found to be an accurate and underused asset. One study found that "the CNAs' ability to assess functional health correlated highly with their nurse practitioner's assessments and should be used in health care planning."5 Research also shows that CNAs seek job satisfaction, being part of a team and engaging in socially useful work.6 Even so, in most facilities, CNAs are utilized only minimally. In those facilities, "nursing assistants (NA) fulfill a primarily custodial function, and the manner in which they interact with patients can reinforce dependent behavior."7

### PROVIDING CNAs with Increased Knowledge and Responsibility

Given the growing ratio of CNAs to clinical staff (nurses and physicians), health care will have to increase CNAs' contributions by making use of their latent talents. And to tap into CNAs' talents, we will have to do a better job of meeting CNAs' needs. For example, one study found that providing CNAs with interventions designed to reduce dementia resident agitation and self-stimulation during unstructured time proved to be effective.<sup>8</sup> Another study found that "working with nurse assistants to appropriately increase decision latitude related to their work has the potential to enhance the work environment by reducing job strain and improving staff health and morale."<sup>9</sup>

The key to gaining CNAs' participation is educating them about aging and dementia. The key to learning is to make training interactive. The organization I direct, the Avila Institute of Gerontology, Germantown, NY, conducts exercises in which we ask our students to simulate dementia. These exercises are geared to change even the most experienced CNA's perception of dementia and make her or him want to learn more about it. We offer a 12-hour training curriculum on all aspects of dementia. With Norwood's help, the institute also provides team The key to gaining CNAs' participation is educating them about aging and dementia. The key to learning is to make training interactive.

training in which care teams learn how to cope with various behaviors by making, carrying out, and measuring their own decisions. Such training can be invaluable in the care of people with dementia. As has been noted, "educating staff in long-term care facilities about AD [Alzheimer's disease] minimized the unnecessary use of antipsychotic drugs."<sup>10</sup>

### SUPPLYING CNAs with Progressive Tools and Measured Successes

Because CNAs spend so much time with residents, they know them better than other staff members do. If a facility were to equip its CNAs with simple behavior-assessment tools—tools, moreover, that were cross-correlated to easily deployed interventions—the CNAs could immediately see fruit of their labor.

Such tools can also help nurses train CNA care teams. At the Avila Institute, we have found that it is important to apply the "crawl/walk/run" philosophy to any new program. Nurses who act as team consultants (not leaders) help their teams learn by, first, assigning them low-risk/highprobability team tasks and, then, using success in those tasks to build the team's confidence before giving it more complicated tasks. As a result of this training, we can create for each resident an individualized program that fits his or her current medical and psychosocial needs. We cannot control the progression of a disease such as Alzheimer's, but we can help the resident, the resident's family, and the caregiver to learn how to manage and cope with the disease symptoms.

### **PROVIDING A PHYSICALLY PROPHYLACTIC ENVIRONMENT**

As caregivers' knowledge of care requirements becomes general, they can make adjustments to the care environment to improve the quality of life. Simple interventions, such as playing music throughout the night, can often reduce nighttime wandering by residents. "Hiding" doorways by painting them the same color as the walls can help keep residents from roaming away from their floors. However, the key to creating a prophylactic environment must begin by meeting individual resident needs. Making one floor of a facility a copy of all the other floors only makes sense if you have only one type of resident need.

### AN EXAMPLE OF PERSON-CENTERED CARE REGAINED

How do we transform an existing building into "neighborhoods" and "communities" that reflect a homelike environment? Sr. Pauline Brecanier, O.Carm, administrator of the 300-bed Teresian House facility in Albany, NY, took on this challenge in 1997. Sr. Pauline and her staff believed in the concept of person-centered care. They believed the task-based medical model needed transformation into a more intimate team-based form of care that focused on each individual. In order to effect this transformation, Teresian House created "neighborhoods" for its residents. This resulted in the decentralization of individual departments, such as the Activities Department.

Today, each member of that department shares "global duties," which means that he or she is expected to work outside of his or her normal roles, cleaning kitchens, washing dishes, and washing personal laundry, as well as conducting activities. The coordinator of each "neighborhood" is responsible for hiring and managing the staff who work in it. Nurse's stations were decentralized as well. Residents are cared for according to their specific needs and wants, within an atmosphere that involves relationships with each staff member. A resident is permitted to sleep late, have a leisurely breakfast, and participate in activities of his or her choice.

### **IS PERSON-CENTERED CARE NEW?**

Of course, person-centered care is *not* new. We all share the healing mission of Jesus, knowing that if we remain focused on his compassion, love, and kindness, we will bring high-quality life to all the elders confided to our care.

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JOURNAL OF THE CATHOLIC HEALTH ASSOCIATION OF THE UNITED STATES

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