Can Person-Centered Care Be Saved?

Person-Centered Care, considered part of the culture change movement in long term care, has been called an "attitude," a "transformation," and a "gold standard of care" and its popularity is sweeping through the long term care industry. Already, it is the biggest thing in assisted living marketing since the term "homelike."

Unfortunately, like many popular trends, the concept of person-centered care is already being watered down and over-used. The concept is even being extended to other industries besides health care. For example, there is now a builder in Florida who advertises "Women-Centered Homes." What do such obvious attempts to exploit the concept signal to consumers? How far does it go? Will there next be "Child-Centered Daycare," or "Pet-Centered Veterinary Clinics?" Consumers wonder, if assisted living facilities have not been **person**-centered all along, then what **have** they been "centering" on?

To address the dilution of culture change and PCC, Bill Keane, COO of Harbor Senior Concepts of Illinois, wrote in Nursing Homes magazine in November, 2005:

> To many who saw the early principles of the Eden Alternative as just another "fur and feathers" fad, culture change has become the ongoing fad of fun things to do as work plans, resident census, risk management, and survey processes permit.

How can the industry preserve the real impact of Person-Centered care without diluting the core ideals? To answer this question, we need to look back to the beginnings of the concept itself.

The culture change movement in long term care originated for nursing homes. Nursing home care was based on a hospital model. Although the patients were ill and needed care, they were not ill enough to warrant daily physician monitoring, and hospital beds were needed for more intensive cases. The mind set of hospital expectations filtered into nursing homes: when one is in the hospital, one expects the medical illness to be treated. Unlike hospitals, though, people actually lived in nursing homes and in that sense, expectations were different. Because of the disconnect between the inception of the nursing home in a medical model and the actual use of the nursing home as a quasi-residence, people rightly perceived the nursing home as an institution that was cold, disease–focused and that simply saw people as room numbers. In such a setting, diseases might be "managed," but all hope of any quality of life for the individual was lost. In such a context, culture change was indeed a welcome transformation. Culture change had as its basic precept the care of the **person** rather than management of a disease. With the institution of culture change, the days of bathing only those people on the right or left side of the hallway on certain days a week, people's lining up for a set mealtime with no menu choices, medications given only at certain times of day, and nurses stations built like bunkers were quickly disappearing. Culture change makes sense in nursing homes as does its major tenet--Person-Centered Care.

Actually, though, the concept was not original to nursing home care. The wheel had already been invented by Carl Rogers, an influential psychologist and psychotherapist who was the founder of "client-centered psychotherapy" which he later renamed as the Person-centered approach (PCA) to reflect that his theories were meant to apply to all interactions between people, not just to those between therapist and client. Carl Rogers developed client-centered counseling as a way to increase the psychotherapy patient's active participation in the process and to provide a non-judgmental format for psychotherapy. The word "client" in the business world is akin to "customer." A client is one who seeks something they need – a service or a product - makes choices and decisions, and can negotiate in obtaining what is needed. Thus, Carl Rogers replaced the word "patient" with "client" in order to de-medicalize the relationship and empower the patient/client.

Similarly, the concept of Person-Centered Care when applied in the long term care setting seeks to de-medicalize the relationship between resident and caregiver, to increase the long term care resident's active participation in the process of care, to engage the staff and the resident in a relationship, and to provide a non-judgmental format for care. The term "resident" implies that the person is at home. Much like changing "patient" to "client", changing "patient" to "resident" eliminates a stigma of sorts. "Resident" becomes an empowering term that says, "I am at home and I am in charge."

Perhaps the best way to view the ideal of Person-Centered Care is to imagine how your care of a resident would be different if that resident were your own family member. You would take into account personality factors, personal history, knowledge of likes and dislikes, and so on. This information would be based on your longstanding relationship with the person, and it would be based on your knowledge of their patterns of behavior. So, of course, you would actually use that knowledge when you approach the person, when you speak to them, when you touch them, when you engage in activities with them, and when you talk about them with others. But wait a minute—wasn't the whole point assisted living centered on a different attitude from nursing homes? Wasn't assisted living supposed to be a place where one could maintain autonomy while getting some help with a few activities of daily living? The answer is yes, but with after a decade of "aging in place," the assisted living facility now looks similar to the nursing homes. What began as a place for ambulatory, active seniors who needed a little help has turned into a place where wheelchairs, walkers, medication carts, and private nurses abound. Rather quickly, the assisted living model has become the "Mini-Me" of nursing homes. Even more significant is the fact that with 50 to 70% of assisted living residents having some form of dementia, PCC has become PCDC – Person-Centered Dementia Care.

How is Person-Centered Dementia Care currently conceptualized in long term care? Some say that caregiving is "heart, not knowledge." Some have said that the **person** should be treated, not the disease. Although both of these sentiments sound good and feel quite warm and fuzzy, neither is true for dementia. In caring for residents with dementia (50-70% in assisted living), it is not sufficient to have compassion and sympathy. A competent caregiver must be able to synthesize the personal information about the resident with knowledge about the disease. The caregiver must know someone's personal history, understand how dementia affects the brain, understand

how the diseased brain can change behavior, and then use that knowledge to provide care that meets the needs of the resident in a compassionate and dignified way. Knowing all of this, doesn't a bumper sticker sentiment such as "heart, not knowledge" seem inadequate?

The Eden Alternative, conceived as a humane model for nursing home care, has suffered from misapplication to the care of persons with dementia. The Eden Way was never designed for dementia care. In applying the Eden principles to residents with dementia, well-meaning reformers actually robbed the movement of much of its power and helped it to become just another fad. For instance, a bird atrium is used to allow residents more natural stimulation, or a calming place to go and perhaps start conversations with other residents, or a place where families can entertain each other with the antics of the birds. However, if an extravagantly expensive bird atrium is added to a facility populated by residents with dementia without proper understanding of the purpose of the atrium, what really happens is that wheelchairs of sleeping residents are placed in front of it as a babysitting technique. Were the Eden Alternative principles applied in dementia care, then the staff and families could use the bird atrium to redirect an anxious, confused, or even agitated resident. But the missing piece is the knowledge about dementia. If you know about dementia, then you know how to use the bird atrium as a tool and not merely as a decoration.

So the missing link in our current concept of Person-Centered Dementia Care is the knowledge about dementia. If we are to prevent PCDC from becoming a marketing fad, it will only be with a commitment to real training, real education, and real expectations of what dementia care should be. Unfortunately, training is currently considered a cost rather than an investment.

Family caregivers of a loved one with dementia are constantly trying to figure out how to manage the behavior problems and still have a meaningful relationship. However, the stress of care and the perceived burden become so great, that they can no longer provide care in an objective way. So they bring their loved one to you. They believe that you, as the professed expert in dementia care, know that if the person has dementia, then their behavior will be altered. They believe that you know enough about dementia that you can detect changes in patterns of behavior and understand the reason for those changes. More importantly, they believe that you will use that knowledge when you approach their loved one, when you speak to them, when you touch them, when you engage in activities with them, and when you talk about them with others. This is the real meaning of person-centered care. If you have real knowledge about dementia and if you apply that knowledge in caring for residents in a dignified and compassionate way, then you will have enacted person centered care and it will be a meaningful and integral part of your care rather than just another fad.