

Person-Centered Dementia Care: An Escalating Societal Challenge

The United States is facing unprecedented growth in the number of people living with dementia, with an estimated 5.3 million Americans—one in nine individuals age sixty-five and older—currently living with the disease. Classified as a neurocognitive disorder, dementia includes conditions such as Vascular dementia, Dementia with Lewy Bodies (DLB), and Frontotemporal lobar degeneration (FTLD), each of which present with their own specific symptoms and brain abnormalities. Alzheimer’s disease, the most common cause of dementia, accounts for 60-80 percent of cases. Dementia is characterized by a decline in memory, language, problem solving, and other cognitive skills that affect a person’s ability to perform everyday activities (Alzheimer’s Assoc. 2015).

Dementia is one of society’s costliest chronic diseases. According to the Alzheimer’s Association (2014), total per-person payments from all sources for health care and long-term care for Medicare beneficiaries with Alzheimer’s and other dementias, were three times as great as payments for other Medicare beneficiaries in the same age group.

“According to the Alzheimer’s Association, total payments in 2015 (in 2015 dollars) for all individuals with Alzheimer’s disease and other dementias are estimated at \$226 billion. Medicare and Medicaid are expected to cover \$153 billion, or 68 percent of the total health care and long-term care payments for people with Alzheimer’s disease and other dementias.”

Most importantly, dementia affects not just the persons living with it, but their families, friends, and social/communal networks as well. The need to recognize this expansive impact has been highlighted worldwide

(Wortmann, 2013, Batsch and Mittelman 2012, Prince, Guerchet, and Prina 2013). People living with dementia, those who love them, and those who assist them face many challenges. In addition to managing cognitive and physical changes to their health, they deal with social isolation and stigmatization because negative perceptions often fuel misunderstanding, distrust, and add to the burden of living with the condition.

The Origin and Adoption of Patient-Centered and Person-Centered Care

In 2001, the Institute of Medicine’s report, “Crossing the Quality Chasm: A New Health System for the 21st Century,” described our nation’s health care as fragmented and impersonal, and called for a redesign of the system, including a shift to patient-centered care practices. The report defined patient-centered care as being “respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions.” (IOM 2001.)

Patient-centered practices are rooted in the humanistic work of Carl Rogers, Ph.D., a founder of the client-centered approach to psychology, and Abraham Maslow, Ph.D., best known for his theory of self-actualization, among others. Humanism affirms that people are unique and multidimensional. Their psychosocial and spiritual dimensions are as important as their physical health for their well-being (Rogers 1961).

By 2011, the terms *patient-centered care* and *person-centered care* were both being used in our country to describe these humanistic practices. Patient-centered care was most often used to describe practices carried out in healthcare settings (hospitals, physicians’

offices), while person-centered care was generally preferred and used in residential and home and community-based settings (Maslow 2013).

However, dementia experts across the country were very concerned about the lack of adoption and use of such practices in the care and support of people living with dementia. They recognized the need to create and publish a consensus white paper to advance professional understanding and use of person-centered dementia practices in all settings.

Creating the Framework for Person-Centered Dementia Care

From January 2012 through January 2013, a grassroots dementia initiative of more than sixty experts representing practice, policy, research, people living with dementia, and care partners, collaborated on a consensus framework for person-centered dementia care:

- Researchers at UCLA's School of Public Health conducted an extensive review in peer-reviewed journals and gray literature (Levy-Storms 2013).
- Dementia experts delineated core values and person-centered practices.
- A smaller team wrote the final white paper, "Dementia Care: The Quality Chasm," which continues to be widely disseminated throughout the world.

Most significantly, the paper extolled both quality of care and quality of life for people living with dementia by:

- Supporting their sense of self and personhood through relationship-based care and services
- Providing individualized activities and meaningful engagement
- Offering guidance to those who care for them.

As guest editor of *Generations* (2013), Katie Maslow noted that our nation faced (and continues to face) opportunities and challenges in advancing person-centered dementia practices. "Greater availability of person-centered care for all people could result in better care, better quality of life, and better functioning for people with dementia in a wide array of care settings. At present, however, the general lack of understanding about what person-centered means for people with dementia and how it can be

implemented in day-to-day practice, coupled with stereotypical images of what people with dementia are like and negative assumptions about whether person-centered care is appropriate and feasible for these people, blocks the achievement of these positive outcomes." (Maslow 2013.)

Sam Fazio, director of Special Projects, Constituent Services, for the Alzheimer's Association in Chicago (2013), wrote, "The concept of person-centered care is not complicated. I think we have much more work helping care professionals embrace the underlying philosophy, and allowing it to influence care practices and organizational policy."

Guiding Your Clients through Person-Centered Dementia Care

Your clients may represent some or all of the following life situations:

- a person living with dementia,
- has a loved one with dementia at early/mid/late stage of the disease,
- does not have dementia nor a loved one with it at this moment in time.

Whatever their life situations, you are well-positioned to guide your clients on this highly-personal, often misunderstood journey through dementia.

According to the Alzheimer's Association (2015), "The pace at which symptoms advance from mild to moderate to severe varies from person to person. As the disease progresses, cognitive and functional abilities decline. People need help with basic activities of daily living, such as bathing, dressing, eating, and using the bathroom. They can lose their ability to communicate, fail to recognize loved ones, and become bed-bound and reliant on around-the-clock care."

Professionals who work with older adults can serve as knowledgeable, caring guides to clients facing this life-changing experience, whether they are the ones living with the condition, the family caregivers; non-caregiving family members, friends, or others within the communal network.

Encourage them to be reasonable, realistic, and open-hearted towards their loved one and themselves as they consider appropriate care, services, legal, and financial planning at different stages of dementia. Help them recognize that some issues and decisions will need to be reconsidered as the disease progresses. Ask them:

- At this point in time, what services or supports would make daily life better for your loved one? For you?
- At this point in time, what kinds of interactions and involvement would make your loved one's life more meaningful? Yours more meaningful?
- At this point in time, what care and living environment will best serve your loved one's wants and needs? Your wants and needs?
- Do you and your loved one have signed documents reflecting your personal health care, long-term care and end-of-life care wishes?
- Do you and your loved one have your legal and financial documents in order, including power of attorney and wills?

When evaluating in-home services or community-based settings (i.e., hospital, assisted living, nursing home), make your clients aware that certain interrelated elements are foundational in fostering positive care experiences:

- **Direct caregivers** are trained in knowing the person as an individual, creating authentic relationships with individual, being flexible and adaptable in routines based on understanding of individual's preferences as well as needs, being sociable and spontaneous to engage the person in meaningful activities (Love 2013).
- **Person-centered services** require that provision of care and support is based upon individual preferences, values, lifestyle choices, and needs to support one's unique rhythms of daily life (Love 2013).
- **Physical and social environments** "can have a significant impact on the overall well-being and quality of life for people who have dementia (in all settings). The goal of positive environments is to enable them to achieve maximum functioning, comfort, safety, and well-being." (Love 2013.)
- **Each person's experience of care and support.** Jason A. Wolf, Ph.D. (2012) cogently noted that, "The healthcare experience... is based on every interaction a person and/or their family have on the care journey, and is ultimately measured by the very perceptions those individuals have of their experience."

Sharing the Essence of Person-Centeredness

Essence is defined as:

- The intrinsic nature or indispensable quality of something, especially something abstract, that determines its character.
- A property or group of properties of something without which it would not exist or be what it is.

You cannot guide your clients through person-centered dementia care without recognizing and sharing the following three intrinsic and indispensable qualities that determine person-centeredness:

Personhood: See Me, Not My Dementia

In life, "perception is reality," so help your clients to "see" themselves or their loved ones as the whole persons they are, rather than the condition they have. Such *seeing* requires knowing their preferences, values, and experiences. It requires treating them as we all wish to be treated—with dignity, respect, and individuality (Edvardsson et al. 2010). It means including them and ensuring their choices are reflected in care and life-planning processes. Fazio (2013) notes, "The loss of memory is not equivalent to the loss of self. If someone thinks of a person with dementia as someone without a self, they think of him or her as not being a person... As care partners, we need to be the support that maintains the self and we need to structure the environment and interactions within it to effectively do so."

You can heighten your clients' awareness and sensitivity by sharing the perspectives of those living with dementia who have written about their journey:

"How you relate to us has a big impact on the course of the disease. You can restore our personhood and give us a sense of being needed and valued... Give us reassurances, hugs, support, a meaning in life. Value us for what we can still do and be, and make sure we retain our social networks." (Bryden 2005.)

Relationships, Connections, and Community

Having meaningful relationships and social connections are important aspects of one's sense of belonging to a community. For individuals living with dementia, that sense of belonging and being included in a social community are especially important.

Although Carter Williams, founder of the Pioneer Network for person-centered culture change in Rochester, New York, did not have dementia, she beautifully

captured the profound impact relationships had on her sense of being alive:

“When I am with someone with whom I have a relationship, I know that I am living. Surrounded by people who are strangers, funneled into daily routines that are unfamiliar and uncomfortable, my life is unknown to others. I’m not sure I am alive. It’s as though I have fallen out of life...

Relationships are not only the heart of long-term care, they are the heart of life.” (Williams 2003.)

Purpose and Meaningful Engagement

Richard Leider (2012), founder of Inventure—The Purpose Company, noted counselor, and guest lecturer at Harvard Business School, spent more than thirty years interviewing thousands of people over sixty-five, asking each of them what mattered most to them in

TERMS TO KNOW

Behavioral expression — Term preferred by the *Dementia Initiative* experts rather than “behavioral problem.” Included are behaviors such as agitation, anxiety, aggression, and screaming. It is important to understand the root cause of behaviors as they are often expressions of unmet needs, such as pain, hunger, thirst, boredom, loneliness, or an underlying medical condition that the person with dementia is challenged to communicate to a care partner or to address him or herself.

Care partners — People actively engaged in providing care and/or support such as family members and others known through a personal relationship and formal caregivers.

Dementia — Refers to symptoms typically characterized by a loss of cognitive ability, impairment in memory, and brain changes in areas such as language, reasoning, and judgment severe enough to interfere with everyday functioning.

Dementia care stakeholders — People living with dementia, family members, care partners, service providers, healthcare practitioners, policy-makers, researchers, consumer advocates, funders, academicians, and regulators among others.

Holistic — Refers to a bio-psycho-social-spiritual orientation to healthcare and well-being.

Personalized approach — Term preferred by the *Dementia Initiative* experts rather than “non-pharmacologic” as the latter has a medical model of care connotation instead of a holistic one.

Personalized practices — This term defines

specific person-centered practices. These practices are individualized and are intended to support the personhood and authenticity of each person who is living with dementia.

Person-centered core values and philosophy — The Dementia Initiative participants believe there is a moral and ethical responsibility to support persons living with dementia as holistic, existential beings. Every person has his/her own meaning of life and authenticity (personality, spirit, and character) that supersedes any physical condition. This forms the foundation for person-centered dementia care.

Person-centered operational practices — This term refers to the broad processes that anchor and operationalize person-centered dementia care.

Person-centered — Has its roots in humanistic psychology and the seminal work of Carl Rogers and Abraham Maslow based on the understanding that people are multi-dimensional beings and the psychosocial context of health and well-being is as important as the physical/medical aspects.

Personhood — Standing or status that is bestowed upon one human by others in the context of relationship and social being. Personhood implies recognition, respect and trust.

Structural Elements — The eight structural elements constitute the “frame” or building blocks for person-centered dementia care.

Source: Dementia Care: The Quality Chasm, 2013. www.ccal.org/wp-content/uploads/DementiaCareTheQualityChasm_2-20-13-final.pdf.

their lives. The overwhelming response by almost every one of them was that they hoped their lives had a purpose, that they in some way made a beneficial difference having lived.

Experiencing a meaningful life affirms an individual's sense of self, purpose, and self-esteem. Having meaningful things to do adds purpose and enjoyment in daily life, and fosters emotional health and a sense of connection with others. Since people have different needs for solitude and socialization, what is purposeful and meaningful for each individual is unique to them (Love 2013).

Robert Bowles (2014), a wonderful gentleman living with Lewy Body Dementia (LBD), is a terrific role model for all those he mentors. He shares his outlook through blogs and online conversations.

"Even with the changes that have occurred in my life and the increased symptoms, I refuse to be discouraged. For me, a positive attitude is everything. It sets the stage for how I will live with LBD. I know that as I have become socially active and engaged, I have done better. Finding purpose in my life was the catalyst that made all of this possible. Dementia Mentors has an online memory café in the U.S. twice each week and once each week in Europe. This provides social interaction which is the lifeblood of living with dementia."

In the poignant video, *Person-Centered Matters*, Lon Pinkowitz shared his personal perspective honed from years of being his father's caregiver:

"Life is best lived and most fulfilling with a sense of purpose. Starting with memory, Alzheimer's slowly erodes aspects of living. It is important that we don't further diminish the life of someone living with dementia, even if our actions are with the best of intentions. A life lived fully includes the continuing right to give as well as receive; to endure as well as take comfort; to move forward despite the possibility of missteps and errors. Caregiving in its best form means remaining aware of a person's need for self-respect and purpose, especially as the need for assistance grows greater." (Pasternak 2014.)

A Dementia-Capable and Dementia-Friendly Nation

Our nation can and must become dementia-capable and dementia-friendly. The Dementia Action Alliance is a volunteer national coalition engaged in changing our nation's understanding of and attitudes about dementia, by promoting approaches to care and services that are person- and family-centered, and by serving as a trusted source for education, conversations, and advocacy. It affirms, "A nation joined will make the difference."

You can serve as highly effective change agents in your communities by engaging others in meaningful conversations about quality of care and quality of life for their loved ones and themselves. You can emulate Margaret Wheatley's (2002) practical approach to change: "Change begins when a few people start talking with one another about something they care about... We rediscover one another and our great human capacities. Together, we become capable of creating a future where all people can experience the blessing of a well-lived human life." •CSA



Jackie Pinkowitz, M.Ed., is a co-leader of the Dementia Action Alliance and Board Chair of CCAL-Advancing Person-Centered Living, a national advocacy organization. She is a member of the advisory councils of Rutgers University Graduate School of Social Work Gerontology Program where she is also an instructor, and the HealthCare Association of New Jersey. Contact her at jpinkowitz@gmail.com, 732-212-9036, or visit www.ccal.org/tag/jackie-pinkowitz, or www.futurage.com/Leadership.html. Also, see www.daanow.org for additional resources.

REFERENCES

- Alzheimer's Association. 2015. Alzheimer's Disease Facts and Figures. *Alzheimer's and Dementia*. 11(3) 332+.
- Batsch, N. L., and M.S. Mittelman. 2012. World Alzheimer Report 2012: Overcoming the stigma of dementia. London: Alzheimer's Disease International, 75.
- Biggar, A. 2013. "The Philosophy and Powerful Effects of Person-Centered Care for People with Dementia." *Generations, Journal of the American Society on Aging* 37(3) 4-5.
- Bowles, R. 2014. "My Journey with Lewy Body Dementia." Perspectives Newsletter of the Shiley-Marcos Alzheimer's Disease Research Center (Fall 2014-Winter 2015) 20(1) 1-2.
- Bryden, C. 2005. *Dancing with Dementia*. London: Jessica Kingsley Publishers.
- Fazio, Sam. "The Individual is the Core— and Key— to Person-Centered Care." *Generations, Journal of the American Society on Aging* (2013) 37(3) 16-20. www.asaging.org/blog/individual-core-and-key-person-centered-care.
- Institute of Medicine. 2001. *Crossing the Quality Chasm: A New*