Helping Individuals With Dementia Live More Fully Through Person-Centered Practices

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ABSTRACT
Dementia, including Alzheimer’s disease, is a health condition saddled with social stigmas and is widely misunderstood. Person-centered care practices can positively improve the psychosocial experience of living with dementia and have become the gold standard for care because of the resulting beneficial outcomes. The purpose of the current article is to describe four person-centered principles that form the foundation for dementia care practice: (a) the idea that individuals can and do live fully with dementia; (b) quality of life depends not only on the care received but also on the value that others put on their abilities and life; (c) being meaningfully engaged and having purpose are vital to well-being; and (d) respect, dignity, and choice are not only foundational to person-centered care but for basic human rights. Although efforts have been made to mandate person-centered practices, challenges remain that can direct future research and practice efforts. [Journal of Gerontological Nursing, 41(11), 9-14.]

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Dementia, including Alzheimer’s disease, is one of the most significant public health challenges of the 21st century for the United States and globally. A Rush Institute of Healthy Aging report estimates that approximately 5 million Americans older than 65 are living with dementia, including Alzheimer’s disease (Herbert, Weuve, Scherr, & Evans, 2013), and this number could triple to approximately 14 million by 2050. Alzheimer’s Disease International estimates that more than 46 million individuals worldwide currently have dementia and this number is predicted to increase to 131.5 million by 2050 (Alzheimer’s Disease International, 2015). A 2010 analysis conducted by the RAND Corporation (Shih, Concannon, Liu, & Friedman, 2014) estimated that in the United States, the cost of caring for individuals with dementia is between $159 and $215 billion annually. The cost of informal and formal
care is expected to rise dramatically as Baby Boomers continue to age. The RAND report asserts the cost of caring for individuals with dementia as one of the most costly to society, comparable to or higher than the cost of caring for individuals with cancer or heart disease (Shih et al., 2014).

A 2012 public opinion survey conducted by the Marist Institute of more than 1,200 Americans placed dementia as the most feared health condition above cancer, stroke, heart disease, and diabetes (Andersen, 2012). This fear is likely because dementia is a health condition saddled with societal stigmas and is widely misunderstood. The prevailing mindset, including among many health care professionals, is of immediate loss—that an individual living with dementia’s abilities, capacity, and decision-making skills are immediately and irreversibly diminished (Power, 2014). Although no cure or effective treatment is currently available for the neurocognitive physical changes brought on by dementia, compelling evidence has demonstrated that person-centered care practices can positively improve the psychosocial experience of living with dementia (Doyle & Rubinstein, 2013; Dupuis, Gillies, Carson, & Whyte, 2011; Edvardsson et al., 2008; McCance, McCormack, & Dewing, 2011). Expectations about what individuals can or cannot do affect how they are treated, and how they are treated subsequently impacts their overall well-being (Boyle et al., 2012; Dupuis et al., 2011; Edvardsson, Fetherstonhaugh, & Nay, 2010; McCance et al., 2011; Sabat, 2011, 2012).

The World Health Organization (2015) and Institute of Medicine (2001) have deemed person-centered care as the gold standard for care because of the positive and resulting beneficial outcomes. A white paper titled, “Dementia Care: The Quality Chasm” produced by CCAL Advancing Person-Centered Living, a non-profit advocacy organization, contributed to the discussion by forming a consensus definition and conceptual and operational framework for person-centered dementia care (Love & Pinkowitz, 2013a). A condensed version was subsequently published in Generations: Journal of the American Society on Aging (Love & Pinkowitz, 2013b). The framework includes eight structural domains needed to support person-centered dementia care. These domains include (a) relationships and community (sense of belonging), (b) governance, (c) leadership, (d) care partners (workforce), (e) services, (f) meaningful life and engagement, (g) environment, and (h) accountability. Each of these domains represents a building block of person-centeredness, and each has its own unique elements and indicators needed to ensure appropriate practices. The white paper concluded with recommendations put forth and presented as an initial step to changing national perceptions and knowledge about dementia and provided guidance on practices that help an individual live more fully with dementia (Love & Pinkowitz, 2013a). The paper included, among other things, a change in the words used (i.e., “living with” rather than “suffering from”) dementia, person rather than patient, and care partner rather than caregiver; a sampling of personalized practices; and calls for advocacy, research, education, and improved direct care practices.

**PERSON-CENTERED CARE PRINCIPLES**

Few conditions would benefit from person-centered care as much as dementia. As such, the current article focuses specifically on person-centered dementia care and highlights four overarching person-centered principles (Table) that center around the individual’s value and engagement as the starting point for his/her well-being and quality of life. The principles begin with a judgment of society’s moral and ethical responsibility to support individuals living with dementia as holistic, existential beings—seeing them as more than their health care condition and as multifaceted individuals whose lives have meaning and authenticity (e.g., personality, spirit, character). Brooker and Latham (2016) define person-centered care as an aim to “maintain and nurture personhood. Personhood is what makes us essentially human” (p. 18). This belief forms the foundation for person-centered dementia care and is rooted in humanistic psychology and the seminal work of Carl Rogers (1961).

**Principle 1: Individuals Can Live Fully With Dementia**

The Internet has provided a means for individuals living with dementia in the early stages to write about their perspectives of well-being and lived experiences with dementia. The recurring themes in their writing is the dehumanizing effect they experience from others who misperceive the condition and impose stigmas, and a resiliency to live well in the face of a chronic illness and increasing disability. Dr. Sandy Halperin, a self-advocate living with early stage dementia in Florida, reminds people that “I am still living and not dead yet, so please treat me as a living human being” (personal communication, August 15, 2015). Mary Beth Wrighton, newly diagnosed with young-onset dementia, is featured in a five-episode video series produced by the Murray Alzheimer Research and Education Program (2014) in Canada. She sets out to learn how others are coping with the diagnosis and able to live well with the condition. Mary Beth talks to individuals who have taken a positive, proactive approach to dealing with the daily struggles of living with dementia and describes the importance of hearing from the experience of others that her life was not ending. Max McCormick (2014), also living with dementia, wrote on Facebook: “I am living my own life, and sure, there are things I
can no longer do. But there are many things I can do. I will not let what I cannot do stop me from doing what I can do.” Each of these individuals possess hope that they cannot only cope, but also experience personal growth, continue to do interesting and meaningful things, and thrive with dementia. From a theoretical perspective, these sentiments reflect qualities that demonstrate their resilience (Ryff, 2014), which further illustrates the need to transform the thinking of their care network that they are “living with” rather than “dying from” dementia.

Kate Swaffer (2014, p. 1) wrote: ...at the age of 49, health care professionals and service providers all told me the same thing: to give up work, give up study and go home and live for the time I had left.... It was also suggested I put my affairs in order...and to get acquainted with aged care, including selecting a respite day care and residential care facility, sooner rather than later, so I could become used to it.

Other individuals, such as Harry Urban (personal communication, March 2015), were told to take a prescription and come back in 6 months. Had they been diagnosed with any

### TABLE

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<th>Principle</th>
<th>Resources*</th>
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| #1 Individuals can live fully with dementia. | • Video developed by the Murray Alzheimer Research and Education Program (2014): “A New Voice: Living Well with Dementia” (access https://uwaterloo.ca/murray-alzheimer-research-and-education-program/education-and-knowledge-translation/products-education-tools/new-voice-living-well-dementia)  
• Personal blog by Kate Swaffer (2015) who is living fully with young-onset dementia: “Creating Life with Words: Inspiration, Love and Truth” (access http://kateswaffer.com)  
• Personal 5-minute video by Richard Taylor (2014) who was living fully with dementia (died July 2015): “I'm Still Richard” (access https://vimeo.com/95513323)  
• http://www.forMemory.org, a website designed for individuals younger than 60 who have been diagnosed with a cognitive impairment. Available from the website is a book, Pathways of Hope: Living Well with Cognitive Changes (Van Ryzin, Baum, & Milius, 2011). |
| #2 The quality of life for individuals living with dementia is derived not only from the care and support they receive, but also in how others perceive their value. | • Dementia Beyond Disease: Enhancing Well-Being (Power, 2014)  
• “The Experience of Living with Dementia in Residential Care: An Interpretative Phenomenological Analysis” (Clare, Rowlands, Bruce, Surr, & Downs, 2008)  
• “Dementia and Its Influence on Quality of Life and What It Means to be Valued: Family Members’ Perceptions” (Moyle et al., 2014) |
| #3 Being meaningfully engaged and having purpose and value are as vital to well-being as physical health. | • Developing a National User Movement of People with Dementia: Learning from the Dementia Engagement and Empowerment Project (Joseph Rowntree Foundation, 2015)  
• The Enduring Self in People with Alzheimer’s: Getting to the Heart of Individualized Care (Fazio, 2008)  
• http://www.uwaterloo.ca/partnerships-in-dementia-care |
| #4 Respect, dignity, and making genuine choices in daily life are not only foundational to person-centered care to live fully with dementia but for basic human rights. | • Being Mortal: Medicine and What Matters in the End (Gawande, 2014)  
• “Reinvesting in Life is the Best Prescription” (Swaffer, 2014) |

*The provided resources are not a comprehensive list but are some suggested resources for each principle.*
other chronic health condition, health care professionals would have recommended further courses of action, such as rehabilitative therapy, healthy eating, physical exercise, blood thinner medication, insertion of stents, and monitoring of blood pressure or blood sugars to help live with the conditions. Instead, individuals being diagnosed with dementia learn that their brains are broken, and they begin experiencing indignities due to stigmas that break their spirits. They lack guidance to ways to stay meaningfully and positively engaged, which puts them at greater risk for negative psychological outcomes and increased stress (Brooker & Latham, 2016). Swaffer (2014, p. 1) coined the term “prescribed disengagement” as the effect of not being provided with helpful strategies: “This sets up people with dementia to live a life without hope, without a sense of a future and destroys the notion of well-being.”

Principle 2: The Quality of Life for Individuals Living With Dementia is Derived Not Only From the Care and Support They Receive, But Also in How Others Perceive Their Value

A 2013 qualitative study by Moyle et al. (2014) sought to understand the factors that influenced quality of life for individuals living with dementia and how they were perceived and valued by their care network. One-on-one qualitative interviews were conducted with 20 family members whose relatives resided in long-term residential care (e.g., assisted living, nursing home, other dementia-residential care (e.g., assisted living, long-term care, assisted living, etc.) and how they were perceived and valued. Results of the study suggested several important themes: (a) the environment in which an individual lives can either provide comfort and security or make the individual feel chaotic and “out of place”; (b) the daily interactions with care partners can strongly improve quality of life (i.e., when there is a conversation or activities that provide meaning), or quality of life can be diminished (i.e., when the focus is purely task oriented); and (c) family members often misunderstood dementia and associated the condition solely with diminished capacity, which negatively influenced the value they ascribed to the individual (Moyle et al., 2014).

Urban (2015) writes:

Don’t stereotype me or underestim-ate me because I have Alzheimer’s…. So many people see me as a helpless person that needs constant care, when they hear about my diagnosis of dementia…. I don’t want your money for research because my concerns are the here and present. I need to teach you how to help us regain our respect and dignity and give us a better quality of life.

Principle 3: Being Meaningfully Engaged and Having Purpose and Value are as Vital to Well-Being as Physical Health

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 reassurance, hugs, support, a meaning in life. Value us for what we can still do and be, and make sure we retain social networks. (Bryden, 2005, p. 127)

Person-centeredness is at the opposite end of a one-size-fits-all, prescription-based model for physical health and safety. Rather, person-centeredness assumes a need for individualized approaches that are tailored to the individual’s holistic bio-psycho-socio-spiritual needs. These approaches involve changed attitudes and behaviors—from a focus on the loss of abilities to tapping into and supporting existing strengths and abilities.

The current authors’ own research in this area involved the development and evaluation of FIT Kits®. FIT, which stands for Families/Friends Interacting Together, Kits are pre-packaged sets of selected engagement items and informational materials designed to help care partners (e.g., family, friends, long-term care staff) have better interactions with the individual living with dementia through meaningful and purposeful, fun activities (Femia & Love, 2010). The framework behind FIT Kits uses a self-empowerment perspective, providing care partners with tools that make it easy for them to support the psychosocial capacities (e.g., social connectedness, expression of positive emotions) that an individual with dementia retains. The rationale for this focus is the brain’s neurophysiology, specifically the limbic system, where even in late-stage dementia, the individual retains the capacity to perceive and express emotions. Individuals living with dementia can continue to relate to others emotionally, even if they have lost the ability to regulate the triggers of those emotions. In other words, they can continue to experience meaning, a sense of purpose, and a sense of play.

An evaluation performed on FIT Kits showed that 90% of care partners reported that the individual living with dementia enjoyed the FIT...
Kit activities, and the same percentage of care partners reported that they enjoyed the activity as well (Femia & Love, 2010). Findings suggested that the FIT Kits addressed a significant challenge for care partners, which was identifying interesting activities that could increase the quality of the interaction between them and the care recipient (Femia & Love, 2010). Having a means to provide interesting engagement in a convenient and easy-to-use approach made it easier for care partners to promote individuals’ social engagement, improve the quality of their interactions, and stimulate positive expressions of mood. These outcomes result in a dual benefit, improving the well-being of the care partner and individual living with dementia.

Principle 4: Respect, Dignity, and Making Genuine Choices in Daily Life

These elements are not only foundational to person-centered care for dementia but for basic human rights (Australian Human Rights Commission, 2013). Sandy Halperin, Kate Swaffer, Mary Beth Wighton, and countless others are demonstrating that they can live fully with dementia. An example is a person-centered approach devised by Robert Bowles, a retired pharmacist living with young-onset dementia, that he calls ASAP. ASAP stands for acceptance, socialization, attitude, and purpose (R. Bowles, personal communication, March 25, 2015). For him, this acronym encourages him to accept that he has a debilitating neurocognitive disorder, needs to stay socially active because this is important to him, keep a positive attitude about life, and continue to perform activities that provide him with purpose and interesting things to do.

In 2012, a volunteer national coalition of individuals and organizations formed the Dementia Action Alliance (access http://www.daanow.org), whose mission is to change the nation’s understanding of and attitudes about dementia, educate others about person-centered practices, and address the stigmas surrounding dementia. A free, online public-service video, titled “Person-Centered Matters,” produced by CCAL Advancing Person-Centered Living was widely distributed that featured five individuals living with dementia at various stages (access http://www.daanow.org). The video highlights how and, more importantly, why individuals living with dementia deserve to live the fullest lives possible. An evaluation of the video’s effectiveness was conducted with a group of dementia care professionals in a variety of positions, including administrators and direct care providers. Results suggested that the video was effective in changing the attitudes, knowledge, and readiness to adopt person-centered practices by having an immediate effect on participants’ feelings of competence for implementing person-centered care (Love, Femia, Barsness, & Porock, 2014). This positive change was sustained at 1-month follow up, and qualitative findings further supported the emotional and motivational benefits to participants as well as a positive intent to maintain or change their care practices in the future. The positive messaging of the video, as well as the collective work of the volunteer advocates who comprise the Dementia Action Alliance, have spotlighted dementia care as a human rights issue.

As in the case of other conditions, the question is not how individuals are cared for, but who is doing the caring. Person-centeredness is based on a biopsychosocial construct as opposed to conventional biomedicine. Person-centeredness is based on a biopsychosocial construct as opposed to conventional biomedicine. Person-centered care practices include integrating the needs of individuals with those of their care partners and other family members. As such, the culture of care can be changed to reflect the values of person-centeredness.

CONCLUSION

Person-centered values and practices form the gold standard of care for individuals living with dementia. This standard is widely recognized as positively benefiting individuals and, as such, is embedded in federal law in the Patient Protection and Affordable Care Act (2010) and in national initiatives, such as the Centers for Medicare & Medicaid Service's (CMS, 2014a) National Partnership to Improve Dementia Care and Reduce Antipsychotic Use in Nursing Homes.

Efforts have been made to implement person-centered practices, including federal regulatory requirements, such as those enacted by CMS for Home and Community-Based Services section 1915(c) waivers (CMS, 2014b). Despite these efforts, there are continuing challenges, the foremost being changed mindsets and the evidence-base for effective person-centered care practices. The current authors’ research suggests that care providers believe in the values of person-centered care but have difficulty implementing them in practice.

Nurses have a long, storied history of putting the needs of individuals first. They form the backbone of health care across all settings (e.g., home health care, primary care, nursing homes, acute and post-acute care, hospice) and are major influencers in the culture of care. As such, they can be vanguards of change, leading the charge to change mindsets to implementing person-centered dementia care practices. There are, however, practice and research implications. The research to provide evidence-based person-centered practices has not caught up with abundant anecdotal evidence. Research efforts to create the evidence base are hampered by the scientific methodologies of conventional biomedicine. Person-centeredness is based on a biopsychosocial construct as opposed to a biomedical construct. Thus, there are barriers to the methods that are considered rigorous and not designed for measuring person-centeredness.

Until scientifically rigorous methods of research are developed to measure the biopsychosocial nature of person-centered care, making person-centered practices the standard will continue to be a challenge. Nurses are in a prime position to be vocal advocates to move person-centered dementia care from an ideal concept to standardized practices that...
reflect their moral standard and ethical obligation to help individuals live fully with dementia. Some initiatives are underway, such as the Dementia Action Alliance (access http://www.daanow.org) and Dementia Friendly America (access http://www.dfamerica.org), which can be helpful conduits to mobilize momentum.

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