

## Review Article

# The Fundamentals of Person-Centered Care for Individuals With Dementia

Sam Fazio, PhD,\* Douglas Pace, NHA, Janice Flinner, MS, and Beth Kallmyer, MSW

Alzheimer's Association, National Organization, Chicago, Illinois.

\*Address correspondence to: Sam Fazio, PhD, Alzheimer's Association, National Organization, 225 N Michigan Ave, Chicago, IL 60601.

E-mail: [sfazio@alz.org](mailto:sfazio@alz.org)

Received: March 15, 2017; Editorial Decision Date: June 19, 2017

Decision Editor: Katie Maslow, MSW

## Abstract

**Background and Objectives:** Person-centered care is a philosophy of care built around the needs of the individual and contingent upon knowing the unique individual through an interpersonal relationship. This review article outlines the history, components, and impact of person-centered care practices.

**Research Design and Methods:** Through literature review, published articles on person-centered measures and outcomes were examined.

**Results:** The history of person-centered care was described, core principles of care for individuals with dementia outlined, current tools to measure person-centered care approaches reviewed, and outcomes of interventions discussed.

**Discussion and Implications:** Evidence-based practice recommendations for person-centered care for individuals with dementia are outlined. More research is needed to further assess the outcomes of person-centered care approaches and models.

**Keywords:** Alzheimer's disease, Dementia care, Individualized care, Recommendations

Person-centered care is essential to good dementia care and the underlying philosophy of the 2018 Alzheimer's Association Dementia Care Practice Recommendations. Person-centered care is a philosophy of care built around the needs of the individual and contingent upon knowing the person through an interpersonal relationship. It challenges the traditional medical model of care that tends to focus on processes, schedules, and staff and organizational needs. It requires commitment from everyone within the organization, especially leadership. Whether referred to as "person-directed," "resident-focused" or something similar, the core principles are essentially the same.

This article will describe the history of person-centered care, outline the core principles of care for individuals with dementia, review current tools to measure person-centered care approaches, and discuss outcomes of interventions. Lastly, this article will outline practice recommendations for person-centered care for individuals with dementia.

## Overview of Person-Centered Care for People with Dementia

### Origins of Person-Centered Care

The term *person-centered care* has its origins in the work of Carl Rogers, which focused on individual personal experience as the basis and standard for living and therapeutic effect. Tom Kitwood first used the term in 1988 to distinguish a certain type of care approach from more medical and behavioral approaches to dementia. Kitwood used the term to bring together ideas and ways of working that emphasized communication and relationships. Kitwood (1998) proposed that dementia could be best understood as an interplay between neurological impairment and psychosocial factors, namely, health, individual psychology, and the environment, with particular emphasis on social context. He believed that the environment has as much effect on the brain as the brain has on a person's abilities. Fundamental

to Kitwood's theory was a rejection of the standard medical approach to dementia, which focused on rigidly treating a disease. He believed that the basic assumption in the medical sciences of dementia carried far too negative and predictable implications for the nature of caregiving.

Kitwood and Bredin (1992) shared evidence from studies of different care practices, suggesting that dementia does not universally progress in a linear fashion, and most importantly, it varies from person to person. They concluded that the person with dementia is in a state of relative well-being or ill-being, and that indicators can be observed through detailed observation. They found a need for high-quality interpersonal care that affirms personhood; one that implies recognition, respect, and trust. The approach that Kitwood and Bredin developed to fill this need was *person-centered care*. Philosophically, they looked at what persons with dementia need and determined that the answer began with love at the center surrounded by the following five offshoots: comfort, attachment, inclusion, occupation, and identity (Kitwood, 1997). Individuals need comfort or warmth to "remain in one piece" when they may feel as though they are falling apart. Individuals with dementia need to feel attachment when they so often feel as though they are in a strange place. Individuals need to be included and involved both in care and in life, and more than simply being occupied; they need to be involved in past and current interests and sources of fulfillment and satisfaction. Finally, people with dementia need to have an identity and their caregivers must help maintain this identity (Kitwood, 1997). As Kitwood (1997) stated, "To have an identity is to know who one is, in cognition and in feeling. It means having a sense of continuity with the past; and hence a 'narrative,' a story to present to others" (p43). Due to declining cognition, persons with dementia need others to "hold their story" and to respond to them as "thou, in the uniqueness of their being" (Kitwood, 1997).

Kitwood (1997) developed a conceptual approach to care that provides staff with a way of thinking about what they do according to principles that guide care and reinforce or support personhood and well-being throughout the course of dementia. Rather than simply providing care in accordance with routines organized for staff convenience, efficiency, or some other criteria, Kitwood (1997) suggested that the focus should be on the person who is the recipient of care. Kitwood's framework encourages staff to focus less on *what* is done and more on *how* it is done. Kitwood's principles assist those who provide care to critically evaluate how programs and communication strategies can be adopted and implemented to support the multidimensional person with dementia.

### Selfhood and Person-Centered Care

At the core of person-centered care is the self—who we are, our values and beliefs, etc. Selfhood is much more than memory and should not be viewed only in terms of

cognitive abilities. Recognizing and maintaining selfhood is key to person-centered care. Researchers have found intact manifestations of selfhood in spite of significant cognitive impairments and that it is not intact autobiographical memory that constitutes self or personal identity (Sabat & Harré, 1992; Sabat & Collins, 1999). Sabat and Harré (1992) revealed through case studies that the self of personal identity persists far into the end stage of AD. Sabat and Collins (1999) suggested that the multiple personae presented in public and in relationships can be lost, partly as a result of how others treat and view the person with AD. Thus, losses in aspects of selfhood might be traced, in part, to dysfunctional social interactions rather than solely the neuropathology of Alzheimer's disease. Based on findings suggesting a connection between self and interactions with healthy others, Sabat (2002) concluded that it is possible—through discourse, or language—to observe intact selves in individuals with AD. He also suggested that a self of social identity could be seen by the attributes or characteristic that one possesses, and a self of personal identity by pronouns used.

Building on Sabat's research, Fazio and Mitchell (2009) quantitatively evaluated the persistence of self in persons with dementia through language use and visual self-recognition. They found that although overall frequency of language usage declined across impairment levels, there were no significant differences in either *rates* or *proportions* of pronoun and attribute usage. This suggests that it is not a loss of self per se that is responsible for a lower frequency of language usage, but more likely a decreased ability to initiate conversation. In addition, when individuals were asked to identify themselves in photographs, cognitively impaired individuals—in spite of forgetting the photographic session only minutes earlier—exhibited unimpaired self-recognition, consistent with a preserved self.

Others are an essential part of maintaining the self in people with dementia. When a person is seen as diminished due a decline in cognitive functioning, they can be treated as if they were no longer a human being and in nonhuman ways (Fazio, 2008). Kitwood and Bredin (1992) state that some of the most disabling effects of brain disease are to be found not in functional impairment but in the threats to one's self and personhood. They believe personhood is dependent on other people. Recognizing that selfhood persists, learning about the complete self, and finding ways to maintaining selfhood through interactions and conversations are fundamental components of person-centered care for people with dementia.

### Relationships and Person-Centered Care

Maintaining selfhood is a key part of building and nurturing relationships. Kitwood and Bredin (1992) discussed how interdependence is a necessary condition of being human. However, due to the Alzheimer's disease, a dependence on others is a necessity for persons with

dementia. The care provider becomes an absolute necessity, both physically and psychologically. This relationship is critical. Kitwood and Bredin (1992) explained that personhood can be ensured only within the context of a mutually recognizing, respecting, and trusting relationship. In his earlier work, Kitwood (1990) described 10 processes and interactions that tend to depersonalize a person with dementia, which include disempowerment, labeling, infantilism, and objectification. Words do matter, as language leads to perceptions, and ultimately approaches to care (Fazio, 1996). Labels depersonalize individuals and can lead them to be treated in ways that do not support their personhood.

Relationships with others do have a great impact on personhood. Kitwood and Bredin (1992) believe that the personhood of individuals with dementia needs to be continually replenished, their selfhood continually evoked and reassured. The other person, the caregiver, is needed to offset degeneration and fragmentation and sustain personhood. The further the dementia advances, the greater the need for “person-work.” The caregiver is needed to hold the pieces together to become the memory (Fazio, 2008). Kitwood and Bredin (1992) believe that this may be understood as the true agenda of dementia care. Care partners need to be the support that maintains the self and structure the environment and interactions within it to effectively do so. Knowing the person is central to care that is based in mutual trusting and caring relationship.

### Key Components of Person-Centered Dementia Care

Researchers have worked to find commonalities among models and practices of person-centered dementia care. Levy-Storms (2013) conducted a literature review and found several commonalities among models and practices including (a) supporting a sense of self and personhood through relationship-based care and services, (b) providing individualized activities and meaningful engagement, and (c) offering guidance to those who care for them. Kogan, Wilber, & Mosqueda (2016) conducted an extensive literature review for definitions of person-centered care. They identified 15 definitions, addressing 17 principles or values. They found that the six most prominent domains were (a) holistic or person-centered care, (b) respect and value, (c) choice, (d) dignity, (e) self-determination, and (f) purposeful living. In all, it was clear that there is a shift in focus away from the traditional biomedical model in favor of embracing personal choice and autonomy.

Brooker (2004), a colleague of Tom Kitwood, has outlined one of the most respected descriptions. Brooker outlined that four key components are integral to a person-centered care approach for people with dementia and can result in a shift in practice and culture. These components are: (a) valuing and respecting persons with dementia and those who care for them; (b) treating people with dementia

as individuals with unique needs; (c) seeing the world from the perspective of the person with dementia, so as to understand the person's behavior and what is being communicated, and validating the subjective experience that is being perceived as the reality of the individual; and (d) creating a positive social environment in which the person with dementia can experience relative well-being through care that promotes the building of relationships.

In *Person-Centered Dementia Care: Making Services Better*, Brooker (2006) expanded upon these components and identified key indicators or practices for each of the four components. Key indicators in *valuing care providers* include having a clear vision, developing practices that value employees, creating systems to support staff development, designing supportive and inclusive physical and social environments, and ensuring quality improvement mechanisms. Key indicators of *individualized care* include developing and regularly reviewing care plans that reflect strengths and needs, allowing use of personal possessions, accommodating individual preferences and daily routines, learning about individual life stories, and offering a variety of activities. Key indicators in taking the *perspective of the person with dementia* include communicating effectively, experiencing empathy, monitoring the physical environment, assessing physical health, uncovering reasons for behaviors, and being an advocate. Lastly, key indicators for the *social environment* include treating individuals with respect, creating an atmosphere of warmth, validating feelings, providing appropriate support and assistance, and fostering a sense of community. Indicators such as these outlined by Brooker are important to consider as providers find ways to implement a person-centered philosophy within every day practices (Table 1).

### Evolution of Person-Centered Care Models

Elements of person-centered care can be seen in the Federal 1987 Nursing Home Reform Act (OBRA '87). OBRA '87 states that each person receives the necessary care and services to attain or maintain the highest practicable physical, mental, and psychosocial well-being, in accordance with the comprehensive assessment and plan of care. Additionally the culture change movement, consisting of models like the Eden Alternative, Wellspring, and Greenhouse/Small House, implemented various elements of what we now call person-centered care. One of the best known of these models is The Eden Alternative, founded by Bill Thomas. Its central mission is to eliminate the three “intolerable plagues” of nursing home life—loneliness, helplessness, and boredom—by following ten Eden principles, thereby improving elders' quality of life (Thomas, 1996). One important strategy in this approach is to transform the physical institutional environment to be more homelike. Plants, animals, and intergenerational programs are included in the homelike environment to enhance the elder's social engagement. The Green House or Small House model aims to provide

**Table 1.** Examples of Person-Centered Care Approaches Throughout the Progression of Alzheimer's Disease or Related Dementia

## Person-centered care in practice

Below you will find examples of person-centered care approaches throughout the progression of Alzheimer's disease or related dementia.

Early

Tom has always been a very independent man. Although he was diagnosed with Alzheimer's disease, he wants to remain as independent as possible. He goes through his day as he always did, although now his wife Joan is always there for support if needed. Joan sometimes has to assist with a task, help with finding the right word, or give a friendly reminder. She also continues to include Tom in decisions, including treatments, future care and finances.

Middle

Frank was a professional musician and played at all of the local and regional clubs. Since he played late night gigs, he was used to staying up late each night as well as sleeping late each morning. When Frank's care needs became too much for his wife, she looked for a memory care center that would support his lifelong schedule. In his new home, Frank stays up late in his room, oftentimes listening to old records. Staff let him wake on his own each morning and include that information in his care plan. Since there is a piano in the reception area, Frank often plays for other residents and visitors.

Late

Emily was an avid gardener. Her yard was perfectly kept with many varieties of plants, which she grew from seed. He loved fragrant bushes, especially lavender. One side of her yard was filled with beautiful bushes. Throughout the progression, she stayed involved in gardening. In the later stage of the Alzheimer's disease, care providers looked through seed catalogues with her, and talked about different varieties. They kept fragrant cut flowers and plants in her room, especially lavender when available. They kept a small satchel of dried lavender under her pillow, and also used a nice lavender lotion to moisturize her hands and feet.

a good quality of life for residents by transforming physical environments, radically revising staff configurations, and emphasizing companionship under normal rather than therapeutic circumstances (Li & Porock, 2014). Person-centered care is also an important component of the 2016 Centers for Medicare and Medicaid Service (CMS) Quality Strategy as noted in "Goal 2: Strengthen person and family engagement as partners in their care." The objectives of Goal 2 are to ensure all care delivery incorporates person and family preferences, improve experience of care for persons and families and promote self-management.

## Tools for Measuring Person-Centered Care Practices

A variety of tools to assess person-centered care practices currently can be found in the literature. Edvardsson and Innes (2010) conducted a critical comparative review of

published tools measuring the person-centeredness of care for older people and people with dementia. The tools were compared in terms of conceptual influences, perspectives studied and intended use, applicability, psychometric properties, and credibility. Twelve tools eligible for review were identified; eight tools for evaluating long-term care for older adults, three for hospital-based care, and one for home care. One tool, Dementia Care Mapping (DCM), was dementia specific. Each tool explicitly aimed to measure forms of person-centered care as perceived by care recipients, family members, or staff. Edvardsson and Innes (2010) did recommend that their validity, reliability, and applicability be further explored. A brief summary of each tool included in their extensive review is provided below. Although most of them have not been specifically designed for individuals with dementia, their focus on knowing the person, interpersonal relationships and individual autonomy makes them relevant for assessing person-centered dementia care.

Specifically for long-term care settings, DCM (Brooker & Surr, 2005, as cited by Edvardsson & Innes, 2010) is an observational tool that uses four predetermined coding frames that aim to make the observer view the world from the point of view of the person with dementia. Coding frames of DCMs are as follows: mood enhancers (6-item scale), behavior categories (23 items), personal detractors (PD, 17 items), and personal enhancers (PE, 17 items). Items are rated on a 2-point scale ranging between "detracting" and "highly detracting" for PD and "enhancing" and "highly enhancing" for PE. DCM was developed through a systematic process of item development.

Also for long-term care settings, the Person-Directed Care Measure (White et al., 2008, as cited by Edvardsson & Innes, 2010) consists of 50 items covering eight domains of person-centered care and is divided into two dimensions: person-directed care and person-directed environment. Another tool, the Person-Centered Care Assessment Tool (P-CAT) (Edvardsson et al., 2010, as cited by Edvardsson & Innes, 2010) consists of 13 items in three subscales: personalizing care, organizational support, and environmental accessibility. In addition, the Measures of Individualized Care (Chappell, Reid, & Gish, 2007, as cited by Edvardsson & Innes, 2010) consists of three tools to measure individualized care. The first tool operationalizes the domain "knowing the person" (13 items). The second tool operationalizes "resident autonomy" (15 items), and the third tool measures "communication" (18 items). Lastly, the Family Involvement in Care (Reid, Chappell, & Gish, 2007, as cited by Edvardsson & Innes, 2010) consists of two measures of family involvement in the care of a relative with dementia in a long-term care setting. The first measure (20 items) measures to what extent family members perceive they are involved in the care of their relative. The second measure (18 items) measures the importance attached to being involved in the care of the relative living in long-term care.



Designed for hospital settings, the Person-Centered Climate Questionnaire (PCQ) (Edvardsson et al., 2009, 2010, as cited by Edvardsson & Innes, 2010) consists of two tools (staff and patient versions) to measure to what extent the psychosocial environment of health care settings is perceived to be person centered. The staff tool (14 items) consists of four subscales: safety, everydayness, community, and comprehensibility. The patient tool (17 items) consists of two subscales: safety and hospitality. Another instrument, the Person-Centered Impatient Scale (Coyle & Williams, 2001, as cited by Edvardsson & Innes, 2010), measures recipient experiences of care and contains 20 items in five dimensions: personalization, empowerment, information, approachability/availability, and respectfulness. Intended for home care settings, the Client-Centered Care Questionnaire (DeWitte et al., 2006, as cited by Edvardsson & Innes, 2010) is 15-item questionnaire that was developed to measure to what extent older people receiving home care experience the care as being client centered.

A few additional tools were found that were developed after the 2010 review of Edvardsson and Innes. Zimmerman et al. (2014) developed the Person-Centered Practices in Assisted Living (PC-PAL) in collaboration with the Center for Excellence in Assisted Living (CEAL) as part of a toolkit for person-centered care in assisted living. The PC-PAL includes one questionnaire for completion by residents, and one for completion by staff. They are research quality, evidence-based questionnaires to help organizations measure their person-centered practices and inform their quality improvement efforts. The Resident PC-PAL (49 items) includes four areas that reflect person-centeredness in assisted living: (a) well-being and belonging (18 items), (b) individualized care and services (12 items), (c) social connectedness (10 items), and (d) atmosphere (9 items). The Staff PC-PAL (62 items) includes five areas that reflect person-centeredness in assisted living: (a) workplace practices (23 items), (b) social connectedness (16 items), (c) individualized care and services (8 items), (d) atmosphere (8 items), and (e) caregiver-resident relationships (7 items).

In addition, the Advancing Excellence in America's Nursing Home Campaign developed a Person-Centered Care Tracking Tool consisting of seven steps to success. The steps include (a) explore goal, (b) identify baseline, (c) examine process, (d) create improvement, (e) engage, (f) monitor and sustain, and (g) celebrate success. This tool includes spreadsheets, forms, links to resources, etc. to help gather data, make changes, and celebrate success. Lastly, Burke, Stein-Parbury, Luscombe, & Chenoweth (2016) developed the Person-Centered Environment and Care Assessment Tool (PCECAT) to assess and improve residential care standards using person-centered principles, while also meeting Australian care guidelines

for older adults. The development included a review of existing assessment instruments and their alignment with person-centered principles and Australian dementia care quality standards—management systems, staffing and organizational development, health and personal care, resident lifestyle, physical environment, and safe systems. The tool successfully moved from concept to development and testing, proving to be valid and reliable. The tool is specific to Australian care standards but can be adapted for use in other countries. As shown, a variety of tools are currently available to measure person-centered care practices but more research and consistency is needed. It is important that tools continue to be developed and tested so we can consistently measure the outcomes associated with person-centered care practices.

### Benefits of Person-Centered Care Approaches

Early research in person-centered care demonstrated measurable results. Epp (2003) highlighted several studies that revealed positive results from implementing person-centered care practices including improved quality of life, decreased agitation, improved sleep patterns and maintenance of self-esteem. More broadly, research in the application of person-centered practices and culture-change principles has shown how they can make life better for residents and improve working conditions for staff (Koren, 2010). Relatively simple interventions have produced measurable results—for example, keeping shower rooms warm can make bathing a more pleasurable experience for residents, reduce staff stress, and save time (Koren, 2010). Koren (2010) also stated that several management studies support the link between strategic human resource management and organizational performance, lending support for the organizational redesign called for by culture-change proponents.

### Effects of Person-Centered Care Interventions on Individuals

Li and Porock (2014) provided a comprehensive review article that synthesized current evidence of the effects of multiple person-centered care models on resident outcomes. Systematic searches were conducted using various databases, using multiple keywords. Searches were limited to articles written in English and published from January 1990 to April 2013. In addition, a manual search of the reference lists of selected relevant articles was conducted.

Twenty-four studies from three countries were reviewed and compared in terms of person-centered interventions, measurement, and resident outcomes. Fifteen culture change studies for residents who were cognitively intact or with minor cognitive impairment and nine studies for residents

with dementia were reviewed. Across the studies, culture change models had some beneficial effects on residents' psychological wellbeing. Person-centered dementia care had significant effects on decreasing behavioral symptoms and psychotropic medication use in residents with dementia in long-term care. The outcomes of these culture change and person-centered care studies outlined by Li and Porock (2014) are summarized in the paragraphs that follow.

### Culture Change Studies

Most of the 15 culture change studies focused on residents with intact cognition or with mild dementia and aimed to test a single component of a culture change model. Nine of the studies were guided by the Eden Alternative, two by Green House/Small House model, one by Wellspring, one by "resident-centered care," one by "Social Care Model," and one was conducted by Pioneer Network to test PCC principles. Across studies, there were challenges with weak designs, threats to internal and external validity, simplistic methods, and small biased sample sizes (Li & Porock, 2014). Residents' cognition, quality of life (QoL), psychological wellbeing, physical wellbeing, and other care-related resident outcomes were measured in these studies. The effectiveness of culture change in terms of QoL, depression, loneliness, helplessness, boredom, and activities of daily living (ADL) was the major focus of all studies. Other outcomes examined included restraint use, pressure ulcers, infections, medication use, falls, and nutrition problems (Li & Porock, 2014).

Three of the five studies that examined the impacts of culture change models on residents' QoL found beneficial effects, including dignity, security, individuality, and autonomy (Li & Porock, 2014). Other studies illustrated impact on depression as shown by a significant decrease in the Global Depression Scale in both cognitively intact and cognitively impaired residents over time, and by lower levels of helplessness, boredom, and loneliness (Li & Porock, 2014). Activities of daily living were examined in four Eden studies and two Green House studies, showing a lower percentage of residents who were dependent in eating and lower incidence of decline in late-loss ADLs than residents in comparison groups (Li & Porock, 2014). In addition, physical restraint use was reported in five studies, with less physical restraint use was found in three studies (Li & Porock, 2014).

### Person-Centered Dementia Care Studies

Li and Porock (2014) reported that eight of nine person-centered dementia care studies were grounded by Kitwood's concepts. Seven of the nine person-centered dementia care studies developed individualized interventions based on understanding residents' needs, histories, and wishes. Dementia care mapping was used to develop the person-centered dementia care interventions in two studies. Studies applied a variety of validated instruments to measure residents' cognitive impairment, QoL, behavioral symptoms, affects, and other physical wellbeing (Li & Porock, 2014).

Behavioral disturbance was observed in eight studies. The five studies that used aggression or agitation as primary outcomes showed that interventions significantly decreased the challenging behaviors expressed by residents with dementia (Li & Porock, 2014). However, three studies that did not primarily target such behaviors nevertheless did achieve significant findings. Integrating results of these studies shows that person-centered interventions seem to be effective in decreasing agitated behaviors in residents with dementia (Li & Porock, 2014). Emotional disturbance, such as depression and affect, was measured in five studies. Overall, these studies showed that person-centered dementia care interventions helped to produce more positive affections but did not reduce depression symptoms (Li & Porock, 2014). Psychotropic drug use was evaluated in three studies, and a reduction of neuroleptic or antipsychotic use by the intervention groups was found in two of the three studies (Li & Porock, 2014). Lastly, four validated QoL measurements for people with dementia were used in two studies. However, the effect of person-centered dementia care on QoL in residents with dementia cannot be determined due to inconsistent findings (Li & Porock, 2014).

In short, of all the culture change studies, the Eden Alternative seemed to have some beneficial effects on residents' psychological wellbeing, including depression, loneliness, helplessness, and boredom (Li & Porock, 2014). Studies also showed positive outcomes for effectiveness of culture change models in terms of QoL, ADL function, restraint use, and other outcomes, however more research is needed. In relation to person-centered dementia care studies, interventions had significant effects on decreasing behavioral symptoms, producing positive affect, and reducing psychotropic medication use in residents living with dementia in long-term care (Li & Porock, 2014). However, the effects of person-centered intervention on residents' living with dementia QoL, depression, sleep, and other physiological outcomes cannot be determined based on the inconsistent results of the reviewed studies (Li & Porock, 2014).

### Effects of Person-Centered Care Approaches on Staff

Barbosa, Sousa, Nolan, & Figueiredo (2015) conducted a review to assess the impact of person-centered care approaches on stress, burnout, and job satisfaction of staff caring for people with dementia in residential care communities. The review was limited to experimental and quasiexperimental studies, published in English and involving direct care workers. Seven studies were included and addressed different person-centered care approaches, including DCM; stimulation-oriented approaches, such as recreational therapy (storytelling) or multisensory stimulation (Snoezelen); emotion-oriented; and behavioral-oriented approaches. Of the seven studies, five assessed burnout, four measured staff's stress, and three measured job satisfaction.

van Weert and colleagues, as cited by [Barbosa et al. \(2015\)](#), investigated the effectiveness of integrated Snoezelen on work-related outcomes of staff in nursing homes. Fritsch and colleagues, as cited by [Barbosa et al. \(2015\)](#), evaluated the impact of a group storytelling approach on people with dementia and care assistants. Finnema and colleagues, as cited by [Barbosa et al. \(2015\)](#), examined the effect of integrated emotion-oriented care (validation in combination with other interventions such as reminiscence and sensory stimulation) on both nursing home residents living with dementia and staff. Schrijnemaekers and colleagues, as cited by [Barbosa et al. \(2015\)](#), studied the effect of emotion-oriented care on staff through a pre-post randomized controlled trial (RCT). Wells and colleagues, as cited by [Barbosa et al. \(2015\)](#), implemented a behavioral approach consisting of training staff through five educational sessions to use an abilities-focused morning care routine with residents. Jeon and colleagues, as cited by [Barbosa et al. \(2015\)](#), implemented DCM through an RCT conducted in 15 care communities assessed the efficacy of DCM and person-centered care on staff stress and burnout.

[Barbosa and colleagues \(2015\)](#) stated that methodological weaknesses and heterogeneity among studies make it difficult to draw firm conclusions. However, five of seven studies reported benefits on dementia care workers, suggesting a tendency toward the effectiveness of person-centered care on staff. Each of the two RCTs that assessed emotion-oriented approaches were successful in reducing direct care workers' stress, burnout, and job dissatisfaction ([Barbosa et al., 2015](#)). However, emotion-oriented approaches were comprised of multiple components (e.g., validation and reminiscence), making it difficult to understand which one was the most effective ([Barbosa et al., 2015](#)). An additional RCT found that DCM positively affected direct care workers' stress and burnout, and a nonrandomized controlled study based on multisensory stimulation showed immediate significant positive impacts on the three outcomes of interest ([Barbosa et al., 2015](#)). Finally, one of two behavioral-oriented approaches, which adopted a nonrandomized design, showed a reduced burnout in direct care workers ([Barbosa et al., 2015](#)). The remaining two studies reported no effects on staff's psychological outcomes ([Barbosa et al., 2015](#)). As a group, these studies provide some of the strongest evidence available as the staff-related benefits of person-centered care models. Additionally, reduction in stress, burnout and job dissatisfaction may also lead to reduced staff turnover—a significant challenge within long-term care.

### Effects of Person-Centered Care Approaches on Residents and Staff

[Brownie and Nancarrow \(2013\)](#) performed a systematic literature review, resulting in nine articles (seven studies) that met the inclusion criteria. There was one randomized, controlled trial, while others were quasiexperimental pre-post-test designs. The studies included in the review

incorporated a range of different outcome measures to evaluate the impact of person-centered interventions on residents and staff. [Brownie and Nancarrow \(2013\)](#) found that person-centered culture change interventions were not homogeneous or single-element interventions. Instead, they incorporated several features including: environmental enhancement; opportunities for social stimulation and fulfilling relationships; continuity of resident care by assigning residents to the same care staff; changes in management and leadership approaches, with the introduction of democratized approaches to decision making that involve residents and staff; changes to staffing models focused on staff empowerment; and individualized humanistic philosophy of care ([Brownie & Nancarrow, 2013](#)). [Brownie and Nancarrow \(2013\)](#) found that the Eden Alternative was the only intervention identified in this review that articulated a framework (incorporating all features) for a person-centered approach to caring for older residents, and improving staff working conditions. In contrast, other types of person-centered interventions were community-specific that focused on one or two features.

Three Eden Alternative studies met the inclusion criteria for this review. Two studies reported improvements in residents' psychological well-being as measured by the prevalence of feelings of boredom, loneliness, helplessness, and depression in Eden Alternative communities ([Brownie & Nancarrow, 2013](#)). These studies found statistically significant reductions in these feelings (except loneliness) for residents in Eden Alternative communities when using validated psychological assessment tools ([Brownie & Nancarrow, 2013](#)). Coleman and colleagues, as cited by [Brownie and Nancarrow \(2013\)](#), found that environmental enhancement was actually associated with adverse outcomes for residents in an Eden Alternative community, compared with residents in a traditional (control) nursing home. They found that residents in the Eden Alternative community had a higher rate of falls (31% within a 30-day period) compared with controls (17%). In this study, the residents in the Eden Alternative community were on average younger than those in the control community (82.6 years of age vs 88 years of age), with fewer impediments in relation to functional status ([Brownie & Nancarrow, 2013](#)).

One Green House model study met the inclusion criteria for this review. This 2-year study compared residents in four 10-bed Green House homes with two comparison sites ([Brownie & Nancarrow, 2013](#)). The aim of the study was to determine the effects of the Green House model on residents' quality of life (via interviews) and quality of care (via MDS data). After controlling for baseline characteristics, there was a statistically significant improvement in Green House residents' perception of their quality of life, compared with the control groups ([Brownie & Nancarrow, 2013](#)).

Three community-specific person-centered care studies met the inclusion criteria for this review. Two of these

community-specific approaches evaluated the impact of person-centered interventions on organizational and workplace characteristics in addition to residents' well-being (Brownie & Nancarrow, 2013). According to Brownie and Nancarrow (2013), one study confirmed that person-centered care positively impacted nurses' job satisfaction and work conditions, as well as improving their capacity to meet the individual needs of residents with dignity and respect. Furthermore, these person-centered approaches improved the continuity of residents' care because they were more likely to be assigned to the same nursing staff and also led to increased social interaction between residents (Brownie & Nancarrow, 2013).

Lastly, Brownie and Nancarrow (2013) described a large Australian study that randomly assigned 289 residents across 15 care communities to receive person-centered care, dementia care mapping, or usual care. The communities were selected because they used a task-focused, rather than a person-centered, approach to care and were similar in terms of management structures, staffing, standards, and size. Agitation was significantly lower with both person-centered and dementia care mapping than usual care. However, the incidence of falls was higher in person-centered care than in usual care (Brownie & Nancarrow, 2013).

Brownie and Nancarrow (2013) concluded that forming accurate conclusions about the impact of person-centered interventions on residents and staff is hampered by the heterogeneity of the interventions and significant methodological differences between studies. However, person-centered interventions are associated with positive influences on staff outcomes (satisfaction and capacity to provide individualized care); improvement in the psychological status of residents (lower rates of boredom and feelings of helplessness); and reduced levels of agitation in residents living with dementia. However, it did appear that some person-centered interventions might be associated with an increased risk of falls in aged-care residents (Brownie & Nancarrow, 2013). While more research into the cause of increased risk for falls is needed, it may be possible that residents are more at risk for falls when they are ambulatory and active as opposed to being sedentary and prone to sitting or laying down for much of the day.

## Shifts in Organizational Culture

As noted, person-centered care exists within the larger movement of culture change, a broad-based effort to transform nursing homes from interpersonal health care institutions into true person-centered homes offering long-term care services (Koren, 2010). After much work in the early 1980s among various organizations and advocates, the Pioneer Network took the lead in fostering the culture-change movement within nursing homes. Koren (2010) stated that culture change movement's overarching goals are to individualize care for residents, making communities more homelike and less "institutional." "It promotes

person-centered care through reorientation of the community's culture—its values, attitudes, and norms—along with its supporting core systems (such as breaking down departmental hierarchies, creating flexible job descriptions, and giving front-line workers more control over work environments)" (p2). In addition, it strives to honor residents' individual rights, offering them quality of life and quality of care in equal measure. Culture change also recognizes the importance of all staff members' contributions to the pursuit of excellence (Koren, 2010).

The culture-change movement espouses a set of principles, instead of offering a prescriptive set of practices or dictating conformance to a model. Early in the culture-change movement, there was a lack of agreement as to precisely how all of these changes would manifest themselves in a nursing home transformed by culture change. A gathering of stakeholders came together to develop a consensus that the "ideal" community would feature the following components: resident direction, homelike atmosphere, close relationships, staff empowerment, collaborative decision making, and quality-improvement processes (Koren, 2010).

Over the years, various models have been evaluated and research has demonstrated results. However, there is still much work to be done to identify outcomes and support the overall business model. Koren (2010) stated that several aspects of the nursing home field, including its workforce, regulation, and reimbursement, limit the initiation of culture-change practices. Culture change requires dedicated leadership over a period of years, a stable workforce, the buy-in of nursing, and funds for environmental improvements (Koren, 2010).

Koren (2010) concluded that "With a policy environment conducive to innovation, and supportive of both initial and sustained adoption of new models, it is possible that—before the baby-boom generation needs long-term care—nursing homes will have become a better value proposition" (p3). The culture-change movement has shown that provision of high-quality nursing home care, individualized to meet each resident's needs in a setting that maximizes self-determination and well-being, can be a vision made real—with person-centered care as the central focus.

## In Closing: Making Recommendations for Quality Care

What this literature review establishes is that there is nothing clear-cut about demonstrating scientific evidence for complicated, individualized, psychosocial interventions such as person-centered care. Overall, the research has limitations including sample sizes, varied interventions within person-centered care models and finally, a paucity of funding and incentives for psychosocial research. Most certainly, more research is needed to continue to understand how to effectively measure person-centered care, what elements are required to make a difference and how does all of this translate into everyday care delivery practices.



However, when examining person centered care through the combined aspects of available evidence (mostly in residential communities), current best practices, expert opinion and common decency, it becomes clear that providing care based on knowing the person within the context of an interpersonal relationship in a way that supports individualized choice and dignity is difficult to argue against. While the evidence in support of person-centered care models and interventions may not be wholly conclusive, there is sufficient evidence to support the following recommendations.

## Practice Recommendations for Person-Centered Care

### 1. Know the person living with dementia.

The individual living with dementia is more than a diagnosis. It is important to know the unique and complete person, including his/her values, beliefs, interests, abilities, likes and dislikes—both past and present. This information should inform every interaction and experience.

### 2. Recognize and accept the person's reality.

It is important to see the world from the perspective of the individual living with dementia. Doing so recognizes behavior as a form of communication, thereby promoting effective and empathetic communication that validates feelings and connects with the individual in his/her reality.

### 3. Identify and support ongoing opportunities for meaningful engagement.

Every experience and interaction can be seen as an opportunity for engagement. Engagement should be meaningful to, and purposeful for, the individual living with dementia. It should support interests and preferences, allow for choice and success, and recognize that even when the dementia is most severe, the person can experience joy, comfort, and meaning in life.

### 4. Build and nurture authentic, caring relationships.

Persons living with dementia should be part of relationships that treat them with dignity and respect, and where their individuality is always supported. This type of caring relationship is about being present and concentrating on the interaction, rather than the task. It is about “doing with” rather than “doing for,” as part of a supportive and mutually beneficial relationship.

### 5. Create and maintain a supportive community for individuals, families, and staff.

A supportive community allows for comfort and creates opportunities for success. It is a community that values

each person and respects individual differences, celebrates accomplishments and occasions, and provides access to and opportunities for autonomy, engagement, and shared experiences.

### 6. Evaluate care practices regularly and make appropriate changes.

Several tools are available to assess person-centered care practices for people living with dementia. It is important to regularly evaluate practices and models, share findings, and make changes to interactions, programs, and practices as needed.

## Funding

This paper was published as part of a supplement sponsored and funded by the Alzheimer's Association.

## Conflict of Interest

None reported.

## References

- Barbosa, A., Sousa, L., Nolan, M., & Figueiredo, D. (2015). Effects of person-centered care approaches to dementia care on staff: A systematic review. *American Journal of Alzheimer's Disease and Other Dementias*, 30, 713–722. doi:10.1177/15333175153520213
- Brooker, D. (2004). What is person centred-care for people with dementia? *Reviews in Clinical Gerontology*, 13, 215–222. doi:10.1017/S095925980400108X
- Brooker, D. (2006). *Person-centred dementia care: Making services better*. London: Jessica Kingsley Publishers.
- Brooker, D., & Surr, C. (2005). *Dementia care mapping: Principles and practice*. Bradford: Bradford Dementia Group, University of Bradford.
- Burke, C., Stein-Parbury, J., Luscombe, G., & Chenoweth, L. (2016). Development and testing of the person-centered environment and care assessment tool (PCECAT). *Clinical Gerontologist*, 29, 282–306.
- Chappell, N. L., Reid, R. C., & Gish, J. A. (2007). Staff-based measures of individualized care for persons with dementia in long-term care facilities. *Dementia*, 6, 527–547. doi:10.1177/1471301207084372
- Coyle, J., & Williams, B. (2001). Valuing people as individuals: development of an instrument through a survey of person-centredness in secondary care. *Journal of Advanced Nursing*, 36, 450–459. doi:10.1046/j.1365-2648.2001.01993.x
- De Witte, L., Schoot, T., & Proot, I. (2006). Development of the client-centred care questionnaire. *Journal of Advanced Nursing*, 56, 62–68. doi:10.1111/j.1365-2648.2006.03980.x
- Edvardsson, D., & Innes, A. (2010). Measuring person-centered care: A critical comparative review of published tools. *The Gerontologist*, 50, 834–846. doi:10.1093/geront/gnq047
- Edvardsson, D., Koch, S., & Nay, R. (2009). Psychometric evaluation of the English language person-centred climate questionnaire—patient version. *Western Journal of Nursing Research*, 31, 235–244. doi:10.1177/0193945908326064

- Epp, T. D. (2003). Person-centred dementia care: A vision to be refined. *The Canadian Alzheimer Disease Review*, April, 14–18.
- Fazio, S., Seman, D. & Stansell, J. (1999). *Rethinking Alzheimer's care*. Baltimore, MD: Health Professions Press.
- Fazio, S. (2008). *The enduring self in people with Alzheimer's: Getting to the heart of individualized care*. Baltimore, MD: Health Professions Press.
- Fazio, S., & Mitchell, D. B. (2009). Persistence of self in individuals with Alzheimer's disease. *Dementia*, 8, 39–59.
- Kitwood, T. (1998). Toward a theory of dementia care: ethics and interaction. *The Journal of Clinical Ethics*, 9, 23–34.
- Kitwood, T. (1997). *Dementia reconsidered: The person comes first*. Berkshire, UK: Open University Press.
- Kitwood, T. (1990). The dialectics of dementia: With particular reference to Alzheimer's disease. *Ageing and Society*, 10, 177–196.
- Kitwood, T. (1988). The technical, the personal, and the framing of dementia. *Social Behaviour*, 3, 161–79.
- Kitwood, T., & Bredin, K. (1992). Towards a theory of dementia care: Personhood and well-being. *Ageing and Society*, 12, 269–287.
- Kogan, A. C., Wilber, K., & Mosqueda, L. (2016). Person-centered care for older adults with chronic conditions and functional impairment: A systematic literature review. *Journal of the American Geriatrics Society*, 64, e1–7. doi:10.1111/jgs.13873
- Koren, M. J. (2010). Person-centered care for nursing home residents: The culture-change movement. *Health Affairs (Project Hope)*, 29, 312–317. doi:10.1377/hlthaff.2009.0966
- Levy-Storms, L. (2013). *Dementia care: The quality chasm. Dementia Initiative*. White paper.
- Li, J., & Porock, D. (2014). Resident outcomes of person-centered care in long-term care: A narrative review of interventional research. *International Journal of Nursing Studies*, 51, 1395–1415. doi:10.1016/j.ijnurstu.2014.04.003
- National Nursing Home Quality Improvement Campaign. *Person-centered care tracking tool*. Retrieved from <https://www.nhqualitycampaign.org/goalDetail.aspx?g=pcc>
- Reid, R. C., Chappell, N. L., & Gish, J. A. (2007). Measuring family perceived involvement in individualized long-term care. *Dementia*, 6, 89–104. doi:10.1177/1471301207075640
- Sabat, S. R. (2002). Surviving manifestations of selfhood in Alzheimer's disease. *Dementia*, 1, 25–36.
- Sabat, S. R., & Collins, M. (1999). Intact social, cognitive ability, and selfhood: A case study of Alzheimer's disease. *American Journal of Alzheimer's Disease*, 11–19.
- Sabat, S. R., & Harré, R. (1992). The construction and deconstruction of self in Alzheimer's disease. *Ageing and Society*, 12, 443–461.
- Thomas, W. (1996). *Life worth living: How someone you love can still enjoy life in a nursing home-The Eden Alternative in action*. St. Louis, MO: Vanderwyk & Burnham.
- White, D. L., Newton-Curtis, L., & Lyons, K. S. (2008). Development and initial testing of a measure of person-directed care. *The Gerontologist*, 48, 114–123. doi:10.1093/geront/48.supplement\_1.114
- Zimmerman, S., Cohen, L., Reed, D., Sloane, P., Allen, J., & Pinkowitz, J. (2014). *Tool kit for person-centeredness in assisted living*. Center for Excellence in Assisted Living Collaborative.