Person-Centered Dementia Care and the Cultural Matrix of Othering

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Received February 14, 2013; Accepted June 25, 2013 
Decision Editor: Nancy Schoenberg, PhD

Purpose: The dominant clinical view of dementia and its treatment are through the biomedical lens—an approach to understanding the demen-
tias that focuses on bodily and mental pathology and symptomology. Person-centered care (PCC) represents a shift in focus away from biomedical approach in elder care. The primary objective of this research was to examine how PCC was defined, shaped, and practiced by staff members within a dementia care setting. Design and Methods: Ethnographic data were collected over an 8-month period using participant observation (400 hr) and ethnographic interviews with 20 people with dementia and 25 staff members of Cedar Winds, a dementia-specific long-term care setting that had a strong organizational support for using a person-centered approach to dementia care. Results: The observed cultural matrix of othering is the focus of this article and represents the cultural processes that prevented PCC from being enacted within Cedar Winds. The three main characteristics through which the residents were oth-
ered and PCC was obstructed were (a) dementia as a master status, (b) functional dependence, and (c) aggressiveness. Implications: This article concludes by examining the efforts that could reduce the extent of othering and improve the person centeredness of elder care settings.

Key Words: Dementia, Older adults, Person-centered care, Cultural matrix of othering

Person-centered care (PCC) represents a shift in focus away from a traditional, biomedical approach and toward a more holistic and individualized model of elder care. The application of PCC within dementia care contexts stemmed from early theoretical work that demonstrated that a biomedical approach (focus on mental pathology) could compromise the personhood of people with dementia (Kitwood, 1997; Sabat & Harré, 1992). Kitwood (1997) proposed that the biomedical orientation of many nursing aides fostered a narrow perspective, which did not fully consider the psychological, social, and cultural complexities of the person with dementia.

Since this early research on person-centered dementia care (PCDC), there have been multiple descriptions of the essential components of this approach. Brooker (2003) proposed that in PCDC, the carer must value and respect the resident, regard all individuals with dementia as complete people, attempt to understand the experiences of the person with dementia, and create a positive social environment. McCormack (2004) used a relational perspective of PCDC to capture the central goal of shared experience and empathy within care interactions. According to McCormack, a dementia caregiver must recognize and encourage continued social roles of the person with dementia. In this sense, PCDC includes the biographical, cultural, and social aspects of the person with dementia. Edvardsson, Winblad, and Sandman (2008) concluded that PCDC must be, above all else, based
(a) on a recognition of the resident’s personhood and (b) on emphasizing the relationships between caregivers and residents in daily care tasks.

Ideally, deep and meaningful caregiving relationships will form and enable the caregivers to gather information from the residents and use the knowledge to tailor care to the preferences of the individual with dementia. If caregivers’ perspectives align with those that are socially endorsed, which view the person with dementia as in decline and having lost essential abilities to function, it may be difficult for caregivers to focus on a resident’s personhood or to form strong, person-centered relationships with them. As such, the cultural meanings and definitions these staff members associate with dementia could impede PCDC and will be examined here.

Although previous theoretical and empirical work has been done to describe and measure PCDC, the meanings and uses of PCDC on the ground-level remain nebulous, especially for the nursing aides (Innes, 2009; Innes, Macpherson, & McCabe, 2006). Kalis, Schermer, and van Delden (2005) stated that PCC principles may only be applied in situations where it is most pragmatic for the nursing aides. The nursing aides’ selective application of PCC could lead to inconsistencies between concept and practice (Innes et al., 2006).

The objective of this research was to examine how PCC was defined, shaped, and practiced by administrators and staff members (including nurses, aides, etc.) within Cedar Winds, a dementia-specific long-term care setting that had a strong organizational support for using PCC. This project sought to understand the care culture in this setting and the factors that influenced the use of PCC approaches in this environment. This article examines how the biomedical and other cultural notions of dementia led to situations where the residents were marginalized and “othered” by staff members and, at times, hindered the implementation of PCC principles.

Conceptual Model

Collins’s (1990) sociological usage of cultural matrices and intersectionality underpins the post hoc framework developed to explain the impact of othering on the care culture within Cedar Winds. This theory posits that there are numerous potentially stigmatizing labels linked to a person’s identity. For example, in Cedar Winds, a resident can be linked to multiple marginalized groups: “woman,” “demented,” “incontinent,” “dependent,” “old,” or “aggressive.” These labels and their associated characteristics interact on multiple levels and mutually compound the effects of any one label to profoundly influence the dynamics of social relationships (McCall, 2005). The intersections reflect deep modes of oppression, which stem from such labels, which must be examined to understand the experiences of marginalized individuals (Crenshaw, 1989; McCall, 2005).

The term “cultural matrix” has been applied in various subfields within sociology (Collins, 1990) and anthropology (Alleyne, 1971) to emphasize the complexity of the backdrop inherent in the cultural influences on human life. A matrix implies that cultural patterns and categorical systems interact on multiple levels, such as those of the individual, the institution, and the community. A cultural matrix is most often used to examine how subordinating cultural patterns, such as hierarchy, interact so as to “other” and marginalize categories of people.

Othering is a process that is undertaken by individuals to identify those people who are classified as different in a negative way or categorically both distinct from and of lesser significance than oneself and accepted social norms. The data presented subsequently demonstrate that the othering of people with dementia stems from the broader biomedical and cultural notions of what it means to have dementia. Many notions of “typical dementia behaviors” were prevalent in daily conversations among nursing staff, in meetings, in Cedar Winds’s Model of Care, and in initial staff training for dementia care. The specific context can promote and/or discourage othering. An accurate description of the processes of othering within Cedar Winds can clarify how othering can affect care and how these malignant actions can be minimized.

Data and Methods

This ethnographic research focused on cultural description, which recorded, explained, and interpreted the practices of Cedar Winds and the language people used to explain them. Ethnographic techniques (e.g., observation and formal interviews) are often used to gain knowledge and understanding about the way of life of a difficult-to-access group, person, or institution that is not well understood by outsiders (Berg, 2006). As was described earlier, research has yet to adequately describe the ground-level understandings and practices of PCDC.

The ethnographer (PJD) observed and participated in the daily life at Cedar Winds and recorded
detailed field notes. Observations and informal “off-the-cuff” conversations were focused on the interactions among nursing aides and residents that occurred in the public space. The researcher conducted participant observation 2–3 days a week (average of 5 hr per day) for 8 months (approximately 400 hr total). Observations took place on all shifts and days of the week in order to maximize situational variation. Informal conversations were driven by the social context of Cedar Winds and not preplanned. Single formal ethnographic interviews were conducted with residents and staff members. The ethnographic interviews with residents lasted an average of 41 min and with staff members 56 min. An interview guide was developed before entering the field to elicit detailed responses regarding care and were reflexively adapted based on interviewees’ responses.

Resident interviews began with questions about their general experiences at Cedar Winds and their relationships with others in this setting (including nursing aides). Following this conversation, residents were asked about what the staff members should know about them and what, if anything, the resident thought staff members knew about them. Other questions addressed aspects of the care experience. For example, “How do the people who work here care for you?” and “Tell me what it is like for you when you get ready in the morning?” Nursing aides were asked about their daily care practices, what they believed to be “good dementia care,” and how they provided care. Some of the interview questions for staff members were adapted from the Person-Centered Care Assessment Tool, a measure developed to quantify the person-centeredness of a dementia care setting (Edvardsson, Fetherstonhaugh, Nay, & Gibson, 2010).

Sample

The sample is disaggregated on two levels: (a) the facility that was the site of the research and (b) the individuals within this setting, some of whom served as informants.

Setting

The setting was Cedar Winds, a religiously affiliated home that provided both assisted living (AL) and nursing home (NH) levels of care to people with dementia. The residence was split into two locked areas: one for AL and the other for skilled nursing care. These two areas contained approximately equal numbers of residents and staff members. Cedar Winds was chosen as the study site primarily because of its extensive and established organizational model of PCC. The model of care was detailed in a 60-page document that contained many principles of PCC, including (a) physical design to support autonomy and functioning of residents, (b) determining residents’ needs and preferences, (c) evaluating “challenging behaviors,” (d) individualized care, (e) communication between departments, and (f) continuous training on PCDC.

The frequency and content of training in Cedar Winds were observed during this study. One 8-hr, mandatory dementia training session was provided to all new staff members. There were also weekly care meetings that focused on care approaches to modify problematic behaviors. The impact of these sessions on changing care was limited because few nursing aides attended and PCC ideals were often lacking in this training. The role of training within Cedar Winds will be discussed later in this article as it pertains to the observed care culture.

Individual Level

Sampling on the individual level was done entirely within Cedar Winds and consisted of two types of informants: staff members and residents. Recruitment and consent of individuals were limited to those people who agreed to participate in formal ethnographic interviews. These people were chosen based on their ability to provide the researcher with some specific insight, personal meaning, and experiences surrounding the research topic (Rubinstein, 1992). However, informal conversations and observations were also conducted with people who did not go through the formal informed consent procedure. In total, 20 residents and 25 staff members were interviewed. The exact number of informants was determined by examining the content of the data for repeated patterns (Luborsky & Rubinstein, 1995).

Staff informants were selected from all shifts and care levels (NH and AL) in order to gather diverse perspectives on PCC, reflecting different personal approaches, impact of resident impairments, and effect of times of the day. Nursing aides comprised the largest group of the staff informants (N = 10; 40%) because they were the most numerous in this setting and provided the most hours of care to the residents. Other staff informants included, but were not limited to, registered nurses or licensed practical nurses (N = 5; 20%), activities assistants
(N = 3; 12%), and directors (N = 7; 28%; see Table 1 for additional staff characteristics).

Residents were selected as informants based on their ability to respond to questions, determined through observation, informal conversation with them, and recommendations of staff members. The average Mini-Mental State Exam score for the resident informants was 16/30 (range: 8–27), which according to standard biomedical classifications indicates moderate dementia (see Table 2 for additional resident characteristics). Pseudonyms are used to refer to the setting and informants who participated in this research.

**Analytic Procedure**

This research took an ethnographic approach to the analysis of multiple sources of data (care plans, ethnographic interviews, field notes, activities documents, training programs for staff members, etc.) that were collected over the extended period of time that the researcher spent in the field (Berg, 2006). The most important unit of analysis was the individual (residents and staff members). Similarly, we examined dyadic relations (resident–nursing aide, resident–resident, and nursing aide–directors). Also, as noted, complex organizations such as long-term care settings have intertwined levels that influence the people within the setting and, as such, were strongly considered in data analysis (Bronfenbrenner, 1977; Calkins, 2001)—both in development of coding categories and examination of themes.

This research used a targeted thematic analysis of the data. The goal of this analysis was to identify the robust themes through the use of coding. The analytic procedure also provided contextualized findings, which together are used to describe and

<table>
<thead>
<tr>
<th>Staff informant (N = 25) characteristics</th>
<th>Nursing aide, N = 10</th>
<th>Nurse (RN/LPN), N = 5</th>
<th>Activities assistant, N = 3</th>
<th>Administrator/Director, N = 7</th>
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<tr>
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<tr>
<td></td>
<td>Female</td>
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<td>African American</td>
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<td>2</td>
<td>3</td>
<td>7</td>
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<tr>
<td>Years of experience</td>
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<td>1</td>
<td>2</td>
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<td></td>
<td>3–10</td>
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<td></td>
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<td>5</td>
<td>3</td>
<td>1</td>
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<th>Resident informant (N = 20) characteristics</th>
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<td>45–64</td>
<td>2</td>
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<tr>
<td>Mean = 80 years old</td>
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<tr>
<td>65–74</td>
<td>4</td>
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<tr>
<td>Range = 45–92</td>
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<tr>
<td>75–84</td>
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<tr>
<td>85 and older</td>
<td></td>
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<tr>
<td>Mean = 16</td>
<td></td>
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<tr>
<td>24–30—Slight</td>
<td>3</td>
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<tr>
<td>20–24—Mild</td>
<td></td>
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<tr>
<td>Range = 8–27</td>
<td></td>
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<tr>
<td>13–20—Moderate</td>
<td>7</td>
</tr>
<tr>
<td>Less than 12</td>
<td>7</td>
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<tr>
<td>Level of education</td>
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</tr>
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<td>Advanced degree</td>
<td>5</td>
</tr>
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<td>Some college</td>
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</tr>
<tr>
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<td>Less than 1 year</td>
<td>7</td>
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explain the narratives and experiences surrounding PCC in Cedar Winds. The data were reviewed in ongoing meetings by the researchers during data collection and analysis. The possible understandings of the material were examined, and additional follow-up questions were developed.

At the beginning, an initial codebook was developed. The researchers completed the following steps to build the codebook: (a) we both independently read and descriptively coded three transcripts (two staff members and one resident) that the field researcher (PJD) perceived to encode the meaning of the field notes and interviews; (b) we discussed overall impressions and perceived topics in the interviews; and (c) we discussed the relevance of the codes. Coding of the rest of the data began as soon as the initial coding scheme was established.

This coding procedure was used to help target and validate the themes within the data, develop categories of data, and compare topics discussed by all informants, involving different care levels, or other relevant groupings (Richards & Morse, 2007). The codes were linked to the text content and helped organize the data; the themes represented how these portions of the data were connected to each other within the broader context of the data. A theme signifies an important patterned response or meaning that is related to an aim (Braun & Clarke, 2006). As such, themes were the explanatory tool in this ethnographic analysis of data. Furthermore, like codes, themes were derived from project-specific content areas within the data. For example, through the coding procedure, cultural notions of dementia were consistently linked to PCC practices in Cedar Winds.

The quality of the data and findings was aided by the use of several techniques that are common in achieving accuracy in qualitative research. These included the use of memoing, triangulation of data sources for verification, the achievement of pattern saturation when appropriate, cooperative coding, informant reflection on ongoing findings (member checking), and the active search for disconfirming evidence.

**Results**

The findings demonstrated that the features of the dyadic care relationships among direct-care workers and residents varied and were differentially affected by many organizational (e.g., consistent assignment, task orientation, shift, and house dynamics) and individual-level (e.g., characteristics of the direct-care workers and residents) factors (see Doyle, 2012). These relationships existed in a local culture that included training and education, federal, state and community regulations, relationships, individual and organizational factors, cultural backgrounds, and the preconceived notions that the people in Cedar Winds held about each other. The end result was a cultural matrix of othering.

The initial intent of this research project was not to examine the complexities of othering. Rather, othering was observed as a prominent theme in relation to the barriers to PCC, even in the context of a setting that officially promoted PCC. Observation of othering rose as part of the general examination of activities and meanings in the setting. The data available are used to present evidence that a cultural matrix of othering was a significant hindrance to the implementation of PCC in Cedar Winds.

The concept of othering and its centrality to one’s approach to people with dementia will undoubtedly raise some concerns from multiple stakeholders both within and outside Cedar Winds. As such, it is critical to acknowledge findings regarding the direct-care workers in this environment. It was clear through both the interviews with staff members and observations of interactions that the majority of the caregivers derived deep satisfaction, meaning and salience from their work and the relationships that they had formed with “their” residents. The coexistence of meaningful, sometimes deep, dyadic care relationships that enhanced the selfhood of the residents and, in contrast, the interactions that effectively distanced and marginalized residents from their caregivers and diminished their selfhood demonstrated the power of what is being termed here, the cultural matrix of othering.

**Cultural Matrix of Othering in Cedar Winds**

The cultural matrix of othering described here focuses on the observed care cultures as levels so as to best examine the dynamics of care practices within the dyadic care relationships. Two distinct, yet intertwined care cultures were observed in Cedar Winds: (a) traditional, biomedical model of dementia and caregiving and (b) PCDC. Despite the training staff members received about PCC upon their arrival at Cedar winds, there was a tendency to unconsciously revert clinical practice to the more commonly held biomedical model. That
is to say, the biomedical model of dementia was deeply embedded in the staff members’ everyday practices and the PCC routines, and ideologies were layered on top of this and, on occasion, were pared away for any number of reasons, so that some staff members reverted to an understanding of care work based on the biomedical model of dementia.

This cultural matrix of othering represents the cultural processes that prevented PCC from being enacted within Cedar Winds. It appears, then, that the biomedical model of dementia care was also the operational folk model of dementia care deeply held by both many staff members as part of generic culture. This article focuses on the three main characteristics (axes) through which the residents were othered and PCC was obstructed: (a) dementia as a master status, (b) functional dependence, and (c) aggressiveness.

Dementia as a Master Status

The notion of a master status is used here to denote a negative social label that is assigned to a person by others within a shared environment. This classification shapes a person’s entire social experiences and subverts all other identities the person possesses (Berger, Cohen, & Zelditch, 1972). In addition, when a person is labeled with a negative master status later in life (e.g., diagnosis of dementia), all his or her behaviors that were once independent of this classification are interpreted through the lens of the master status (Goffman, 1961). All of the characteristics associated with the master status are attributed to the labeled individual. In some cases, a master status can empower the labeled individual; however, this article will examine how the master status of dementia disempowered the residents.

Staff members’ use of the dementia label in their narratives of the residents often demonstrated the pronounced distance between staff members and residents and represent a return in their thinking from the learned realm of PCC as a social model that describes the inner core of personhood to the more natural use of a biomedical model. Pam, the Director of Nursing, inserted dementia as the master status of a new group of Cedar Winds’s residents. She used these residents’ type of dementia as the primary marker of their identity: “I mean obviously we’re seeing more FTDs [frontotemporal dementia] . . . And generally speaking, the FTD’ers always went to the [nursing home] side where there were more nursing staff and better environment . . . It’s not just your typical Alzheimer’s person over there now.” The “biomedical speak” contained within this quote created a distance between the speaker and the individual residents, who were portrayed as a “type” or “class” of persons, rather than as individuals.

The training role that Pam had as the Director of Nursing and the respect that many direct-care workers had for her made her perspectives on residents and use of such language prominent in the discourse of care in Cedar Winds. Nursing aides also used the diagnostic labels to discuss their experiences with the residents and to reduce individuals to manifestations of medical typologies. The two brief sections subsequently discuss how the staff members used the master status of dementia in Cedar Winds to (a) interpret the residents’ behaviors and (b) infer the extent of their lost abilities. These common behaviors of staff members will be discussed to establish the master status of dementia and how it othered the residents of Cedar Winds.

Dementia Viewed as the Cause of Behaviors

The data suggested that even “normal” behaviors (e.g., walking) were often interpreted to be a result of a “dementing” process (e.g., decline of cognitive abilities leading to wandering). The attribution of normal behaviors to dementia was most clearly seen regarding residents’ walking behaviors. It was common to see residents walking around their respective sections of the building. As would be expected, the residents who were ambulatory would spend a portion of their day moving around the setting. It was very common that the staff members would call this continuous behavior “wandering” or call the person a “wanderer.” Wandering was most often attributed to the disease process. The wandering label implied an aimless walking that was largely devoid of meaning. So, a wanderer was not a person who walked with a purpose or for pleasure, but rather an individual who walked because of dementia. The characterization of this normal behavior as essentially personally meaningless and driven by disease invalidates the unique subjective experience of the person with dementia and is counter to PCC (Kitwood, 1997). This is a consequence of the multiple potential meanings of these walking behaviors that are independent of dementia. For example, the resident may have always walked as part of their daily routines and continued to value health and fitness.
Although dementia was used as a master status, it was applied differentially based on certain characteristics of the residents. Lesser impairment was a protective factor for the attribution of personal meaning to behavior. The more similarities a resident had to the person interpreting their behavior, the less the interpreter relied on the diagnosis of dementia to explain the behavior. In other words, the habitual walking behavior of a younger resident with strong communicative skills and little noticeable cognitive impairment was less likely to be called wandering and more likely to be explained as a preference or choice of the resident. This demonstrated the differential impact of othering on the assignment of meaning to behavior.

Assumptions Regarding Loss of Abilities and Selfhood

Staff members’ perceptions regarding the residents’ competence and abilities were also an indicator that dementia was a master status and led to othering in this setting. Staff members expected that the residents would be incapable of doing certain actions that were traditionally thought to be lost as dementia progressed. Although some staff members recognized the fault in this assumption when presented with counterevidence, clinical norms of the disease trajectories remained the point of reference to predict what the residents were capable of doing and why they acted as they did. The impact that a dementia label had on staff members’ perceptions of the residents’ abilities is demonstrated subsequently within the context of when residents were ignored as potential contributors during social exchange.

Observations of the social environment showed a strong trend toward intragroup communication outside of the dyadic care interactions. Conversations of staff members during periods not involving care responsibilities most frequently engaged other staff members rather than residents. These conversations rarely incorporated residents even if they were close to the conversing staff members. There were even situations when certain residents would be ignored when they attempted to join a conversation.

The dynamics of staff members’ social interactions positioned the resident as subordinate and other. The field notes contained in Table 3 give a detailed account of an instance where a resident was, among other things, ignored, mocked, banished, embarrassed, frustrated, intimidated, and othered. This situation was an extreme case but not an isolated incident. Malignant actions of staff members toward the residents were common although often less blatant than the interaction described below.

The resident described in the earlier observation had considerable impairment in communicative ability and was highly dependent on staff members for his daily needs. These characterizations of the residents were observed to further distance staff members from the resident. It is unlikely that this type of negative interaction could occur if there was a greater equality and empathy contained within the care relationships with Raúl.

The master status of person with dementia created a situation where these types of behaviors by staff members were acceptable because the resident was in essence less of a person with fewer perceived abilities and less human value as he or she declined. Again, this notion is most likely not a conscious thought held by staff members, but rather a notion that is represented only in their behavior. However, the notion that dementia causes a deselfing process was captured in a statement made by the educator in dementia training at Cedar Winds. She said that in the later stages of dementia “you’ve got this empty shell of a body, but the person who lives inside basically kind of has disappeared, um, through the effects of this disease.” This cultural belief about dementia epitomizes why othering can be so prevalent within long-term care settings.

Functional Dependence as a Category of Othering

The previous sections started to demonstrate the role that residents’ functional limitations had within the cultural matrix of othering in Cedar Winds. As a general principle, the greater the impairment of a resident, the more they were perceived by staff members to be different/other. This contributed to the “us”/“them” distinction between staff members and residents. This section will review the impact that need for continence care had on othering. Incontinence care was a primary care task accomplished within the dyadic care relationships. Liz, an AL nurse, even stated that good dementia care is “for them to be toileted every two hours or so, so they have less incidents of incontinence.” This aspect of the residents’ functional abilities was clearly relevant to how they were perceived and positioned as others by the staff members.

Incontinence was framed as something that the staff members should expect all their residents
Table 3. Interactional Consequence of the Cultural Matrix of Othering—Case of Raúl

Context
- Raúl, a resident, was observed trying to express his care needs to nursing aides.
- Raúl was continuously and purposefully ignored by two nursing aides, Ellen and Jerod, who were completing paperwork.
- Interaction occurred approximately 30 minutes before the end of a weekday first shift in the assisted living.

Field notes of interaction

General observations in field notes
Raúl was coming over to the table and at first, he was complaining about his pants being too tight. He was pulling at his pants and trying to explain his concern, with difficulty. Both the nursing aides told him that they were not too tight. Raúl then asked for a key to get in the room. Raúl was pulling at his pants and was saying that he needed to get in “the room.” It seemed like he was referring to the bathroom. The aides kept telling him that everything was fine. Raúl’s anxiety and frustration grew as he talked to the aides—both were laughing at his persistent pleas.

Documented verbatim interaction

Without addressing Raúl, Ellen got up from her chair, went to the resident who was standing in the middle of the dining room, and leaned down and smelled the front and back of his pants.

After smelling him, Ellen sat down. Both of the aides ignored him standing in front of the table. Raúl was visibly frustrated at them and walked away… Raúl soon came back. Jerod jumped up from the table and harshly questioned Raúl

Raúl had great difficulty responding to this question but said something along the lines that he was working at the university.

Raúl became so flustered with the continual questioning that he could barely get out words. They continue to go back and forth until Ellen interrupted.

Raúl stopped and did not say anything, clearly upset. When he continued to come over, the aides either ignored him or Ellen pointed to the other side and told Raúl to go over there.

Neither of the aides took Raúl to the bathroom. Instead, they had a volunteer take him to an activity.

Consequences of interaction
- When Raúl came back as the shift was ending, there was a clear smell that he had experienced incontinence.
- The actions of Ellen and Jerod had a profound effect on the Raúl’s mood later that evening.
- The evening nurse documented that Raúl was again being combative toward the nursing aides.
to develop. The reliance on nursing aides for this very personal situation seemed to elicit profound embarrassment for many residents. Having to interact with another person to use the bathroom is not something to which physically healthy adults are accustomed. As such, these personal care interactions were often characterized by confrontation and conflict. One potential factor contributing to this conflict was that the interviews with residents demonstrated that the vast majority of residents did not believe they needed help with personal care. This belief could exacerbate the contentiousness in some of these interactions. However, the residents’ embarrassment regarding care needs also reflects semiotic behavior, which is meaning driven and requires complex cognitive abilities to understand adult responsibilities and the meaning of being unable to fulfill those responsibilities.

The physical aggressiveness of the residents during these interactions contributed to othering. The perception that residents’ combative behavior was a symptom of their disease, rather than an acceptable reaction to their environment, compounded the distance between the staff members and those residents who needed this level of care. Laura, an AL nurse who would often assist the nursing aides during this type of care, discussed combative ness during incontinence care. She recalled a situation when:

One resident [was] a behavioral issue and the resident was crying and just pleading ‘no, no, no’ and it would break your heart. And all we were trying to do was render care, and I remember one day, I mean, they weren’t grossly incontinent or anything; they, you know, you could tell that they needed to be changed, but they were so beside themselves . . . I stopped myself and I literally, I like walked away and I like, like cried.

Laura’s account of one of the many situations when a resident resisted incontinence care provided some insight regarding the emotional toll these care interactions had for many residents and care staff. It was not easy to provide the personal care, but, according to Laura, “it needed to get done at some point.” This often required the staff members to provide care against the will of the resident. The residents who did not need assistance with this care were more able to maintain elements of control, choice, autonomy, and dignity—aspects of PCC. Many staff members believed that at a certain point of dependence, it became impossible for the resident to maintain their dignity. Residents became people for whom dignity was not possible.

**Othering Based on Residents’ Aggressiveness**

The final axis of the cultural matrix of othering is aggressiveness. Aggressiveness influenced the provision of PCC in numerous complex ways that cannot be fully described in this article. Rather, this section explains how aggressive residents were othered by staff members and how this process influenced the culture of care. This section will present a case example of an aggressive resident, Marilyn, to illustrate the relationship between aggressiveness and othering.

Marilyn was an 88-year-old widowed woman who lived in the NH section. The field notes did not document any visitors for Marilyn during the study. However, her family gave permission for her to be approached about participating in a formal interview for this research. Marilyn was interviewed once for approximately 45 min. Although the direction of Marilyn’s narrative was not always clear, she was able to communicate her thoughts during the conversation. Marilyn seemed to enjoy the opportunity to talk and she spent time telling jokes and being sarcastic in response to some questions.

Many staff members had warned not to do the interview with her because she had a propensity to become aggressive toward anyone around her. Marilyn was perceived to be capable of violence at any time. This concern was expressed by people in several departments and by the family member who gave consent for the interview. The staff members were surprised that the interview went well and that it did not cause Marilyn to become upset. These perceptions of the staff members demonstrated how past instances of Marilyn’s aggressive behavior were associated with her current identity and were also used to predict her future behavior.

Staff members perceived Marilyn to be relatively high functioning because of her ability to communicate verbally. However, despite this capacity, staff members infrequently engaged Marilyn in social conversations. Marilyn’s aggressiveness acted to reduce attempts of the direct-care workers to gather and use her biographical information for interactions with her. The direct-care workers did not want to interact extensively with Marilyn. This is critical to note, as the formal interview with Marilyn demonstrated that she was able to communicate her current realities and preferences.

Because Marilyn was in a wheelchair that she had limited ability to self-propel, she required
assistance to move around the NH. As a result, she spent most of her time in locations chosen by the nursing aides—either in the television inlet down a hallway, a common room, or the dining room. According to her chart, Marilyn also required full assistance to complete her personal care. Nursing aides documented that she was especially aggressive during care. According to one nursing aide, “She is just a mean lady.” The nursing aides’ general dislike of Marilyn may have been partially caused by Marilyn’s documented verbal abuse toward them.

The direct-care workers created their own solutions to reduce the conflict caused by Marilyn. One solution for the problems during personal care was that staff members gave her physical distance or left her completely alone while she was becoming irate in the bathroom. During meals, Marilyn was seated at a desk facing the dining room wall and separated from all other residents and staff members. These solutions had clear implications for PCC. Marilyn did not have a choice regarding where she could sit during mealtimes. Also, staff members defined Marilyn’s identity and personality by her aggressive behavior, and she was othered based on that characteristic. Finally, observations of staff members’ interactions with Marilyn showed that they displayed little positive regard toward her, which, according to some definitions, is contradictory to PCC.

Conclusion and Recommendations

Observational and interview data presented in this article support the finding that, while PCC principles were discussed and sometimes applied in Cedar Winds, the more traditional approaches to dementia care (task completion and biomedical focus) still dominated this care culture. The predominance of othering was a central barrier to integrating PCC into daily interactions. Through the process of othering, staff members distanced themselves from the residents and, in doing so, created an “us vs. them” paradox. This sociocultural distance contained within the dyadic care relationship hindered many people from forming the “nurturing relationships” required in PCC.

Othering was determined to be one of the most critical processes that affected the care relationships within Cedar Winds. The specific context of care promoted othering through the staff members’ focus on biomedical aspects of dementia, functional decline, regression, and viewing residents’ behaviors as problems. These characteristics of othering within Cedar Winds supported the notion that the othering of people with dementia stems from the broader cultural notions of dementia. The identification of these specific situations that fostered othering and marginalization can be used in future research to attempt to reduce the actions that distanced individuals. The distance created by othering can hinder the caring and compassionate relationships between direct-care workers and residents (Kitwood, 1997).

Significant attempts were needed in Cedar Winds to reduce the distance that was observed between some caregivers and the residents created through the process of othering. This article demonstrated that the process of othering, within the context of the three axes, was a major barrier to the implementation of PCC. Only through the reduction of the distance within the dyadic care relationship can PCC be fully achieved. Data collection and analysis related to the cultural matrix of othering suggested that there are two main avenues that could reduce the extent of othering within Cedar Winds: (a) increasing the amount of social engagement between the residents and staff members and (b) use of training to humanize the residents and dispel the hold the biomedical model had as the default care model. The discussion of these two recommendations will be limited to robust and well-supported patterns in the data.

Engaging the Residents

The residents’ voices were identified as a primary resource to address many of the barriers that existed to the provision of PCC. In the context of othering, having greater mutual exchange of information within the dyadic care relationship has many potential positive effects. By having staff members talk to the residents, gather information about their narratives and perceived realities, and communicate information about the resident’s life to other staff members could, among other things, (a) increase the closeness of the dyadic care relationship, (b) humanize the resident, (c) shift staff members focus to a less disease and decline-oriented model, and (d) improve direct-care workers’ empathic capacity toward people with dementia. Of course, direct-care workers would need more time for care activities, so they could better engage the residents to achieve this goal.

The interviews with residents revealed that it would be challenging to gather information from residents directly and to understand their presented
narratives. Their interviews showed that vast disparities across residents existed in the clarity of their narratives. However, most people with dementia, even in “advanced” stages, communicated a narrative. These narratives included past events, current lived experiences, and future expectations. The residents’ narratives also expressed their preferences, needs, and desires. Regardless of the clarity or accuracy of the residents’ voices, they were able to build personal narratives and realities that were current, dynamic, and often distinct from archival data about the resident contained in their charts.

Having multiple, sometimes conflicting, representations of self for people with dementia is an issue of personhood that can complicate the provision of PCC. Not only did the person with dementia have multiple roles identified in various contexts of the setting, but people within the environment (e.g., family and staff members) also inserted their own perceptions of the person, which were not always based on the realities of the residents’ own perspectives. The multiplicities of views of the resident raise fundamental concerns regarding PCC. Researchers, caregivers, and long-term care organizations discuss PCC as an alternative to the biomedical model but often overlook the problems that exist in identifying the locale of the “person” in PCDC. These multiple representations of the self/person influence the application of PCDC, as they could lead to differentiated approaches and understandings of who that person is. The question becomes, with these multiple representations of self by the resident and differing staff members and family perspectives of the resident’s current self, who is the “person” in PCC? What perspectives of self, if any, dominate within the approach to care? These are fundamental questions that must be addressed in the context of the PCC, as the answers may inform the progress toward a more psychosocially appropriate approach to care.

Asking people with dementia about their lives and their experiences of the world around them was, at times, confusing and removed from others’ realities. But a nonjudgmental, engaged listener could gain a great deal of valuable information about the resident that could be used to inform care. If nothing else, having a chance to talk elicited an appreciation from the residents and possibly improved their subjective well-being. Listening to the residents’ narratives is one potential way to increase a staff member’s empathy and compassion for the resident and reduce othering. This technique also has implications for improving PCDC.

**Training**

Altering the content of the training sessions is another potential way to reduce othering that occurred within this long-term care setting. Training could be focused on the ways to address the axes within the cultural matrix of othering and enhance PCC. A first step could be to work with the educators to acknowledge the underlying strength of the biomedical model and the need to openly foster more creative alternatives to it. A second step could be to make staff members aware of the potential effects that certain language related to dementia has on PCC and the experiences of the residents. The training content could exclude elements that framed dementia as a master status, or that infantilized, stigmatized, objectified, or in some way othered residents, based on their actions or diagnosis. The training could then add sessions about othering and the culturally held notions of people with dementia and the ways that a caregiver can work to combat elements of malignant social psychology in practice. Most importantly, the training needs to clearly explain why it is important that these behaviors be eliminated from the care relationships.

Little is currently known about the extent to which a person’s past training or job experience in direct care influences the likelihood that they will provide PCC. Future research could examine the influence that previous training about dementia and caregiving have on how person-centered a direct-care worker is in daily practice. It is possible that education from previous training, managers, and peers could be difficult to modify substantially. Even if previously held beliefs can be modified, it is unclear how much training would be needed to contest and undo the dominant thinking about dementia that was witnessed at Cedar Winds. Regardless, training will serve as a primarily avenue to reduce the culturally embedded othering that can stymie the person-centered goals of long-term care.

**References**


