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# Embracing Cultural Diversity: Meaningful Engagement for Older Adults With Advanced Dementia in a Residential Care Setting

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Providing person-centered care (PCC) that focuses on meaningful engagement in residential care settings for older adults with moderate to advanced dementia is an internationally recognized challenge. In this study, we aimed to identify best-practice scenarios for supporting older adults with moderate to advanced dementia from culturally and linguistically diverse backgrounds who lived in care facilities. A mixed-methods study with a concurrent triangulation strategy was adopted. Data collection occurred with care partners by means of a preworkshop questionnaire, an appreciative-inquiry workshop, and an adapted Delphi technique. The findings indicate that care partners valued the care facilities' residents' needs for doing, being, and belonging. Collaborative data generation reflected the setting-specific PCC practices. Leadership team members agreed that enabling inclusion and celebrating cultural diversity were important but that cultural humility needed to be promoted.

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The transition from a biomedical to a social model of care within residential settings for older adults with dementia remains challenging (Love & Pinkowitz, 2013; Low et al., 2015; Thomas, 1996). This difficulty has been attributed to a “chasm” that impedes the implementation of the gold standard of person-centered dementia care (Love & Pinkowitz, 2013). This chasm is perpetuated by an impersonal and fragmented approach to care that deters care partners<sup>1</sup> from promoting dignified lives for residents in care facilities (Power, 2010; Thomas, 1996). Although the emphasis in care settings should be on providing person-centered care (PCC), which focuses on addressing individual-specific needs and promoting engagement in meaningful activities, research indicates that residential care is associated with loneliness, helplessness, and boredom (Edvardsson et al., 2014; Thomas, 1996).

Although some cultures value and revere older adults, this reverence is often not reflected in social experiences (Carr et al., 2015); similarly, organizational culture ideals associated with PCC do not always match the social reality for people with advanced dementia. A systematic review indicated that targeting specific care tasks was more likely to achieve positive care outcomes than was advancing global practice changes related to the organizational care culture philosophy (Low et al., 2015). Similarly, meaningful engagement integral to PCC should not merely involve activities linked to the person's past but should provide connectedness and a sense of belonging to the care environment (du Toit & McGrath, 2017).

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<sup>1</sup>*Care partners* are defined as anyone—staff, family, or otherwise—involved in the day-to-day life of an older adult (Thomas, 1996).

Meaningful engagement becomes more important as dementia progresses (Han et al., 2016). *Meaningfulness* involves embracing the here and now, whereas *engagement* encompasses a sense of involvement, choice, and positive meaning while performing an activity or part of an activity (Townsend & Polatajko, 2007). Meaningful engagement is closely associated with understanding diversity and enabling people to be “immersed in their social and cultural contexts” (Beagan, 2015, p. 273).

The 2015 *World Alzheimer Report* estimated that 46 million people worldwide live with dementia, making it “one of the biggest global public health and social care challenges facing people today and in the future” (Prince et al., 2015, p. 1). Global migration and increased longevity have led to a growing number of people with dementia from diverse backgrounds living in care settings (Kalache, 2013; Martin & Paki, 2012; Prince et al., 2015). Cultural and language differences become important when older people require care (Patel et al., 1998). Although residential care settings may claim to provide PCC and opportunities for meaningful engagement, understanding of these concepts is generally limited (Pate, 2015). Research has also acknowledged that the clinical application of cultural competence is challenging (Engebretson et al., 2008). Even in culturally sensitive care settings, preferences for food, clothing, and communication often are not considered, and cultural identities may easily be lost (Patel et al., 1998). Moreover, statutory regulations create pressure on staff to provide physical care rather than create opportunities for meaningful engagement (Love & Pinkowitz, 2013).

South Africa, with 11 official languages, is renowned for its cultural diversity, but in contrast to the highly regulated residential care practices for older adults in more developed economies, such care is still developing and is not readily accessible to all older adults (du Toit et al., 2014; Hoffman & Pype, 2016; Thomas et al., 2014). Similar to care for older adults in the Sub-Saharan African region, South Africa faces considerable challenges related to a lack of funding and infrastructure (Hoffman & Pype, 2016). In contrast to other Sub-Saharan African countries, where care for older people is provided by families, in South Africa “younger generations see institutional care as viable” (Hoffman & Pype, 2016, p. 8).

Despite South Africans’ growing tendency to access institutional care, organizational culture change movements are in their infancy. In the United States, the Pioneer Network, a leader in the culture change movement, and Eden Alternative®, an international nonprofit organization dedicated to creating quality of life for older adults and their partners, have been promoting PCC for

20 yr; in South Africa, the nonprofit Eden Alternative South Africa has been operational for 6 yr.

Regardless of location, uncovering best-practice scenarios for culturally and linguistically diverse (CALD) residents with advanced dementia should be based on an approach that imagines “a positive future that is meaningful and sustainable” (Better Practice Project, 2014, p. vi). Care partners play a significant role in understanding when residents experience doing, being, and belonging that addresses their needs and their right to meaningful occupational engagement (Hitch et al., 2014; Townsend & Polatajko, 2007; Wilcock, 1998). In this article, we describe the South African perspective on a larger international study that aimed to answer the question, “What is excellent PCC for residents with moderate to advanced dementia from diverse ethnic backgrounds?”

## Method

### Study Design

A mixed-methods design with a concurrent triangulation strategy was used to enable quantitative and qualitative data to be collected concurrently and then compared to “determine if there is convergence, differences, or some combination” (Cresswell, 2009, p. 213).

Two levels of data collection were undertaken: a workshop using an appreciative inquiry (AI) technique, and a consensus process with an adapted Delphi technique that consisted of two rounds.

### Setting

Two care facilities for older adults run by a single organization and located in a predominantly middle-class suburb participated. Because no government subsidies are available, residents are expected to pay to live in the facility. A general manager oversees both facilities, each of which has a nursing manager, senior qualified nursing staff, junior nurses, nursing aides, and assistants. Accommodations range from cottages to assisted living and care for semifrail residents. The organization has an ethos of involving residents and creating an environment that is as uninstitutional as possible. The larger facility has a dedicated dementia unit that accommodates 26 residents with a daily activity program provided by assistants.

### Participants

*Appreciative Inquiry Workshop.* For the AI workshop, we recruited 5 participants from each of these groups: nursing aides, volunteers, relatives of residents with dementia, and residents who did not have dementia. The last

group provided a voice to represent fellow residents' perspectives of living in the facilities. Diversity was represented through primary language (English,  $n = 15$ ; Afrikaans,  $n = 3$ ; isiXhosa,  $n = 1$ ; Setswana,  $n = 1$ ), age (26–45 yr,  $n = 5$ ; 46–65 yr,  $n = 7$ ; >65 yr,  $n = 8$ ), gender (female,  $n = 16$ ; male,  $n = 4$ ), and ethnicity. Ethical clearance for this study was obtained from the Human Research Ethics Committee at the University of Cape Town, South Africa (HREC REF: 318/2015). All participants provided informed consent.

*Adapted Delphi Process.* Five staff members who had been employed at the facilities for >9 mo and who were in leadership positions were recruited and participated in both Delphi rounds. Leadership roles represented housekeeping, nursing, administration, and property maintenance.

### *Appreciative Inquiry Workshop*

Before taking part in the AI workshop, participants completed paper-and-pencil questionnaires developed for the study. The questionnaires contained items on demographics and asked about the respondent's perspectives on PCC and its provision. The cofacilitators used the information to gain greater insight into the facility and workshop participants and to facilitate discussion during the workshop.

We used an AI approach to obtain a consensus on what would constitute excellent PCC for CALD residents with advanced dementia. Unlike traditional problem solving, AI appreciates and envisions possibilities within systems and relationships (Cooperrider et al., 2000). Two AI components (Cooperrider et al., 2000) dominated data generation: (1) discovery—What about the facility should be appreciated and valued? and (2) dream—envisioning possibilities for the future.

Participants were grouped according to their care partner role. The qualitative process initially generated examples of what was considered excellent PCC for persons with advanced dementia from CALD backgrounds. Participants engaged in interviews in pairs to discuss the following topics: exciting and enjoyable experiences with residents with dementia; what created the space for this to happen; what the facility did to create opportunities for residents with dementia; what they appreciated most about residents and staff at the facility; and, finally, three wishes to create an ideal facility. After this discussion, each participant recorded the one best story his or her partner had shared. The process continued to gain consensus on the best examples generated by the group. In the four groups, each person shared his or her best story. Finally, everyone came together to share the stories and vote for the top

five. These steps were based on the nominal group technique embedded in the AI process (Cooperrider et al., 2000).

*Adapted Delphi Technique.* To provide further understanding of information from the workshop, 5 participants were invited to participate in online surveys aimed at building a consensus on what was working well in engaging residents from diverse backgrounds at the facility. Two surveys were conducted. The first was demographic and directional (with Likert-scale and open-ended questions), and the second was a deeper investigation of the qualitative responses from Survey 1 (with items that appeared to have majority support with binary responses, free text fields, and Likert-rated items). Given the small number of participants, the marker of agreement in each phase was qualitative.

### *Data Analysis*

Data were collected and stored using Qualtrics, an online survey software (Qualtrics, Provo, UT). Data documented on flip charts during the AI workshop were typed verbatim and analyzed. Researchers' reflections from the debriefing meeting immediately after the workshop were also used in the analysis. Data were scanned to digital files and kept on a secure institutional research data store. Descriptive statistics were generated for categorical data from the preworkshop questionnaire and Delphi rounds. Likert scale options were collapsed into three categories (the two options on the negative and positive ends of the scale were each combined, and the neutral option was retained) for the analysis because of the small number of responses in some cells.

A content analysis approach was followed to summarize the information conveyed by the open-ended questions and qualitative data from the workshop (Sandelowski, 2000). We looked for distinct concepts in the data that represented units of meaning (codes) related to excellent PCC. These codes were organized into categories and then grouped into themes. We analyzed the data independently and discussed the categories and themes to reach consensus.

## **Results**

### *Opinions of Person-Centered Care*

Despite few participants having received training in PCC, most AI participants, apart from the residents, had good knowledge of PCC. The 5 staff in leadership positions, who participated via the adapted Delphi process, doubted that staff had sufficient time for PCC and were ambivalent about being task focused as opposed to having quality interactions with residents. Tables 1 and 2 show the ratings for items relating to PCC as practiced within the facilities. Noted that although the Delphi survey was distributed to

**Table 1. Perceptions of Person-Centered Care (AI Preworkshop Questionnaires)**

| Items   | Poor | Unsure | Good |
|---|------|--------|------|
| How well does your organization support the use of the different languages known by residents who live here?            |      |        |      |
| Residents   |      | 3      | 2    |
| Relatives   |      | 2      | 3    |
| Carers  | 1    | 1      | 3    |
| Volunteers  |      | 4      | 1    |
| Total   | 1    | 10     | 9    |
| How would you rate your current knowledge of person-centered care?  |      |        |      |
| Residents   | 2    | 3      |      |
| Relatives   | 1    |        | 4    |
| Carers  |      | 1      | 4    |
| Volunteers  | 2    |        | 3    |
| Total   | 5    | 4      | 11   |
| In your organization, how would you rate the opportunities for residents to be involved in individualized activities?   |      |        |      |
| Residents   |      | 2      | 3    |
| Relatives <sup>a</sup>  |      | 1      | 3    |
| Carers  |      |        | 5    |
| Volunteers  |      | 1      | 4    |
| Total   | 0    | 4      | 15   |
| In your organization, how would you rate residents' choice and involvement in daily activities?                         |      |        |      |
| Residents   | 1    |        | 4    |
| Relatives <sup>a</sup>  |      | 1      | 3    |
| Carers  |      | 1      | 4    |
| Volunteers  |      | 3      | 2    |
| Total   | 1    | 5      | 13   |
| In your organization, how would you rate the incorporation of residents' life histories and life stories in care plans? |      |        |      |
| Residents   |      | 4      | 1    |
| Relatives <sup>a</sup>  |      | 2      | 2    |
| Carers  | 1    | 2      | 2    |
| Volunteers  |      | 3      | 2    |
| Total   | 1    | 11     | 7    |

Note. N = 20. AI = appreciative inquiry.

<sup>a</sup>Missing response.

all 5 participants, 1 participant did not complete the items related to PCC. Participants in the AI group seemed more aware of the range of languages spoken by residents and staff than leadership, and more than half (n = 11) indicated that language could be better supported.

### Examples of the Practice of Person-Centered Care

The care that staff identified and appreciated doing well reflected three unique themes: *active engagement*, *enabling belonging*, and *tailoring care*, described in the following sections.

**Theme 1: Active Engagement.** Active engagement encompassed *being involved*, *doing together*, and *taking*

*initiative*. Relatives and residents felt that *being involved* was key, and staff affirmed this by expressing their need to involve families on a more permanent basis. Involvement often occurred through engaging in occupations that encouraged residents to relate and have fun. For example, being involved enabled a resident to *take initiative* in finding a solution for a fellow resident to mobilize safely in the dining room: “A resident was able to assist in finding a solution for a lady who needed her walker close by” (resident).

*Doing together* was important in encouraging active engagement. Opportunities for residents and families to socialize were valued by all participants. Occupations that encouraged *doing together* included music and dancing, making collages, playing games, telling life stories through photo displays, and going on outings. These occupations provided opportunities to relate, get to know others better, and share fun. Celebrating special occasions, such as birthdays, was significant in making residents feel valued and special. After the workshop, a staff member in a leadership position commented, “It was good to see family involved as a group. They have never done something as a group before” (field notes).

**Theme 2: Enabling Belonging.** Enabling belonging encompassed feeling *part of the community*, *creating opportunities to connect*, *understanding and responding to needs and preferences*, and *building relationships*. Family members regarded belonging as a priority. Belonging was often a result of taking part in events that made relatives and residents “feel part of the home.” A volunteer echoed the importance of belonging and felt her role was to “bring life by making [residents] part of the larger community.”

Volunteers, staff, residents and relatives rated *creating opportunities to connect* as key to PCC. Ways of facilitating connections included sharing memories and past experiences, sharing a hug or listening to stories, linking the facility to previous home comforts, enjoying experiences such as outings, and contact with animals. A volunteer told of how operating the “sin trolley”<sup>2</sup> allowed her to connect with residents.

*Understanding and responding to needs and preferences* was another vital aspect of PCC that manifested in several ways. Nursing aides displayed understanding when they responded to personal preferences. For example, a nursing aide realized that a male Polish resident who was grumpy when showered actually enjoyed bathing instead; her

<sup>2</sup>The sin trolley contains items that residents may purchase, such as treats (e.g., candy and cookies) and basic necessities (e.g., toothpaste and deodorant).

**Table 2. Perceptions of Person-Centered Care (Delphi Round 1)**

| Items  | Disagree | Neutral | Agree |
|--|----------|---------|-------|
| Residents are offered individualized activities.   | 1        |         | 3     |
| Staff have the time to provide person-centered care.   |          | 3       | 1     |
| Staff create a homelike environment for the residents.   |          |         | 4     |
| Our physical environment helps residents to function at their best.  |          |         | 4     |
| The quality of interaction between staff and residents is more important than getting physical tasks done. |          | 2       | 2     |
| Our care plans include the life history of the residents.  |          |         | 4     |
| Residents can choose whether to participate in everyday activities.  |          |         | 4     |

Note. *N* = 5. Responses from 1 participant are missing.

recognition of and response to his preference resulted in a positive outcome. A volunteer similarly shared her experience of addressing residents' needs on more than one level. Volunteers took time to understand residents and to recognize their feelings and thus were able to "share a hug or listen to stories" and "give life by making [residents] part of the larger community" (volunteer, AI group).

Nursing aides, residents, and volunteers emphasized *building relationships* as crucial to enabling belonging. Nursing aides went beyond the call of duty to build bonds with residents. For example, a staff member shared how her colleague had compromised her own cultural beliefs by sharing information about her pregnancy with a resident and allowing the resident to feel the baby kicking.

*Theme 3: Tailoring Care.* Categories of tailoring care included *embracing difference*, *taking time*, *seeing the individual*, and *compassionate care*. Participants valued the way in which staff members showed an appreciation of residents' cultures and *embraced difference*. Staff not only were mindful of cultural and religious differences but also created opportunities for residents to be spoken to in their own language and to share religious connections with others from the same faith. "We had a Portuguese-speaking lady who, as her dementia developed, lost the use of English. We asked family members to write down common words and also encouraged Portuguese-speaking volunteers to visit" (staff member, adapted Delphi group).

Participants mentioned examples of how the facility had successfully engaged residents with dementia from different cultures. These activities were often associated with music and eating: "Enjoying music and singing along creates an appreciation for different cultures—fellow residents joined in a sing-along and dancing when a Hebrew song was played for a Jewish resident" (relative, AI group).

A member of the leadership team expressed the importance of finding out more about residents to be person centered: "I think education of the staff is key to the well-

being of that resident. Finding out . . . who they are and what they experienced in the past" (staff member, adapted Delphi group). *Taking time* was seen as critical for getting residents with dementia to join in and become involved in shared occupations, for example, through involving residents with dementia in carol-singing practices.

Tailoring care required *seeing the individual*, which entailed getting to know residents. Staff and volunteers were key in this aspect. Volunteers were able to give time to get to know residents as individuals. This led to a volunteer "collecting and retelling life stories through photo displays on the notice board so that everyone can get to know and respect them for their careers and lives they lead." Staff expressed the importance of finding out about residents' cultures, food and music to "find out who they are and what they experienced in the past."

The stories shared in the AI group clearly demonstrated the *compassionate care* given by staff members. Staff not only showed that they cared; they went beyond the call of duty to care: "Our organization has a vision for these residents. We want to make people's person centered care unique to give them back all the values they had during their lifetime" (nursing aide, AI group).

*Collaborative Research Process.* The AI process encouraged engagement within the smaller peer groupings that preceded joint discussions in the larger group. Participants initially found it challenging to focus on positive examples of excellent care. "One resident voiced an opinion that all her peers agreed to. . . . They need more cupboard space, so why should they find anything to be happy about?" (field notes).

The workshop process changed this perspective, and when each peer group had to decide on a dream for the facility, the same resident voiced, "Cupboard space would be nice, but we need to think of something that would be good for everybody here at [facility]" (field notes). The residents' dream was "consideration for others."

Relatives did not initially interact well within peer groups or the larger group, but the AI process encouraged their participation:

Family members were very withdrawn initially. One person busied himself by completing the workshop handout prior to initiation of the AI process. It appeared as if staff and volunteers were extra generous in encouraging the family participants during the sharing of stories. Could it be why the most votes went to family stories? (field notes)

The stories from the workshop that received the most votes were those presented by the relatives:

- Enjoying music and singing along creates an appreciation for different cultures.
- Opportunities to gather and share memories and past experiences.
- Contact with animals.

Relatives acknowledged their importance in the care partner unit with their dream that merely stated, “Music. Family.”

The nursing aides participated enthusiastically throughout the AI process. “They were very excited and came up with a range of scenarios for each question . . . many examples were quite revealing and personal” (field notes). Their dream for the facility displayed the ideal of unity and development: “One dream! Growth.”

Contrasting with the collective positive focus of the AI workshop, the adapted Delphi data displayed a range of individualistic perspectives. “PCC is the way forward . . . but it is not always carried through because of time constraints, shortcuts and the old attitude of ‘we’ve always done it like this’” (staff member, adapted Delphi group).

Another perspective was that all staff needed training to embrace cultural diversity to support the true essence of PCC: “In our country we have staff from a different ethnic environment who need training to look after our residents. They need to know how our culture works . . . and I think we should have training on their culture” (staff member, adapted Delphi group).

## Discussion

Our findings indicate that PCC for care facility residents with advanced dementia from CALD backgrounds was associated with residents’ perceptions of their individual preferences and feelings of belonging. There was, however, uncertainty about the extent to which residents’ life stories were included in their care plans. These findings resonate well with a recent synthesis of qualitative studies that indicated that meaningfulness is associated with

whether a resident with dementia experiences connections with self, others, and the environment (Han et al., 2016). Connectedness in doing, being, and belonging reinforces the importance of viewing residential care facilities in context. For residents with advanced dementia, aging in the right place emphasizes the importance of caring relationships and roles that provide security and familiarity (Wiles et al., 2012). The residential care context needs to provide functional, symbolic, and emotional attachments that mirror needs addressed by a community—that is, by signifying home, kinship, and a neighborhood, thereby making meaningful engagement inseparable from context (Wiles et al., 2012).

Autonomy associated with meaningful engagement and access relates to both the physical and the social context (Hunter et al., 2016). Care partners and those involved in direct care not only set the tone for belonging but also benefit from it. Wallin et al. (2012) found that staff working in residential dementia care facilities experience general job satisfaction when they see that care standards reflect a caring climate and personalized approach to residents’ well-being.

Vernooij-Dassen and Moniz-Cook (2016) recommended collaborative approaches to support changes to organizational processes to facilitate PCC instead of involving staff only in dementia education. The positive scenarios shared in this study confirmed that excellent PCC was taking place and provided staff ownership and investment in better service delivery; it was a time to stop, appreciate, and be encouraged. Involving care partners as a combined group in the AI process created a reflective space that encouraged cultural humility<sup>3</sup> and enabled participants to collaborate beyond power relations and ethnicity (Beagan, 2015), thereby promoting understanding, affinity, and a shared vision.

The adapted Delphi technique ensured participant anonymity (McMillan et al., 2014) and posed the most convenient and time efficient way to involve leadership. Despite focusing the questions on positive care practices, however, leadership highlighted barriers to PCC. The positive and collaborative focus of the AI process appeared better suited to promote inclusion and caring relationships across organizational roles. Because of time limitations, only the first two steps of the AI process were engaged. Future research should include all steps to facilitate identification of excellent care practices and encourage care partners to consider how to build on them. The high rate of

<sup>3</sup>*Cultural humility* “is a process of openness, self-awareness, being egoless, and incorporating self-reflection and critique after willingly interacting with diverse individuals. The results of achieving cultural humility are mutual empowerment, respect, partnerships, optimal care, and lifelong learning” (Foronda et al., 2016, p. 213).

missing data for the second Delphi round suggests it was too time demanding; a single questionnaire should therefore be designed for future studies.

## Implications for Occupational Therapy Practice

Our findings may be used to inform ways of enabling meaningful engagement for older adults with dementia living in care facilities.

- Advancing the doing, being, and belonging of residents with advanced dementia requires a collaborative approach.
- Collaboration with care partners to identify positive care practices enables ownership and commitment to sustainable PCC practice changes.
- AI appears to be a powerful vehicle for facilitating sustainable PCC practice changes.

## Conclusion

Facility leadership agreed that enabling inclusion and celebrating cultural diversity were important but emphasized promoting cultural humility, respecting residents' culture and acknowledging limited understanding thereof, instead of highlighting gains within the organization. In contrast, AI participants identified positive care practices they felt could lead the way to enhanced PCC. Active involvement was foundational to identifying and enacting excellent PCC as part of the process of reframing dementia as a social and cultural experience.

Although this study focused on a residential care context in which many residents were of European ancestry, it emphasized that gains in PCC were not reliant on an abundance of financial resources or an advanced infrastructure. With a growing number of people from diverse cultural backgrounds accessing care institutions, and the continuing realities imposed by a developing economy, residential care organizations in South Africa are in a unique position to integrate inclusive care practices that reflect the values of a collective society. Organizational culture change ideals should strive to promote a social reality for residents that both enables belonging and tailors care. Key to this approach is not only identifying what meaningful engagement encapsulates but also understanding why it is significant. ▲

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