

**Embracing cultural diversity – leadership perspectives on championing meaningful engagement for residents living with advanced dementia.**

**Abstract:**

**Introduction:** Resource constraints and high staff turnover are perceived as substantial barriers to high quality residential aged care. Achieving relationship-focused, person-centered care (PCC) is an ongoing challenge. This paper reports on an international project that explored how residential care leadership understand meaningful engagement for residents with dementia from culturally and linguistically diverse (CALD) backgrounds.

**Method:** This paper critically appraises the process, and outcomes, of an adapted Delphi method. Participants were the residential care leadership (i.e. staff in supervisory capacity) from four international facilities.

**Findings:** Participation in the Delphi process was limited even though surveys were designed to require minimal time for completion. No participants opted for the alternative option of being interviewed. Findings indicate that residential care leadership recognised the importance of meaningful engagement for residents from CALD backgrounds. Limitations of time, resources and policy infrastructure were cited as barriers to achieving PCC.

**Conclusion:** These findings suggest that facility leadership understand the importance of PCC, but identify multiple barriers rather than enablers for delivering PCC. Alternative methods, such as collecting data in interactive sessions allowing real-time discussion should be initiated to more effectively engage residential care leaders for a collaborative approach to explore PCC practices.

**Key words:** Adapted Delphi technique; culturally and linguistically diverse residents; meaningful engagement; person-centered care; residential aged care

## Introduction

Provision of person-centered care (PCC) in residential facilities is broadly endorsed and espoused (Brownie & Nancarrow 2013). However, many obstacles to the achievement of PCC persist due to the complex range of needs of residents and diverse local factors. The impact of global migration and geographic mobility in dispersing support networks (Baldassar et al 2017), while an increasing prevalence of dementia within residential care populations, as well as staff retention issues (Low et al 2015), add to these challenges.

Challenges arise when trying to meet the needs for PCC among people of diverse cultures in residential care. Within the Australian context, for example, language is arguably one of the biggest issues. Increasingly, aged care staff in Australia are enlisted from diverse linguistic backgrounds (Beer et al 2009; Jones et al 2013) who speak English as their second language and to varying degrees of proficiency. Similarly, the proportion of speakers of English as a second language living with dementia and entering aged care is also increasing (Goodall et al 2014). Moreover, the cultural and linguistic backgrounds of people living with dementia entering aged care often differ from those of staff (Peri & Cheung 2016). In many parts of Australia residents increasingly represent people of southern European linguistic and cultural backgrounds (Goodall et al 2014); while staff increasingly represent African and Asian backgrounds (Montague et al 2015; Jones et al 2013).

In recent decades older people are entering residential aged care facilities much later in life and potentially with more substantial cognitive impairment and physical health problems. This has been a trend seen in most developed economies. For example, in the United Kingdom (UK) a survey conducted in 2008 found that fewer women over 65 were entering residential care permanently, but the population of those aged 85 years and over had increased substantially between 2001 and 2011 (Lievesley et al 2011).

The proportion of residents with dementia is also increasing (Prince et al 2015). It is estimated that over half of all people with dementia in the UK live in care homes (Office for National Statistics 2014). An international survey that included all BUPA facilities in the UK, New Zealand and Australia found that the proportion of residents receiving 'dementia care' had increased from 14% in 2001/2002 to 23% in 2010 (Lievesley et al 2011). Over half the

permanent residents in Australian facilities in 2011 had a formal diagnosis of dementia (Australian Institute of Health and Welfare 2012). The 2008 BUPA survey of residents in Auckland, New Zealand, also found that just over 67% had some form of cognitive impairment ranging from occasional memory loss to forgetfulness, requiring constant supervision. In South Africa the 2011 census report stated that more than 50% of older people live in extended multigenerational households (Statistics South Africa 2014). However, due to a growing ageing population, recent reports (Department of Social Development, Republic of South Africa 2010; World Health Organization, 2017) noted that more aged care facilities are being funded for older people with memory, vision and mobility difficulties.

As a result, different countries have developed varied models of assisted living, reflecting the culture and policies of that country. The dearth of studies from some regions may reflect the cultural practice of filial piety caring for older people at home and the limited availability of long term care settings (van Malderen et al 2013). Residential care services in countries such as Australia, New Zealand, the UK and South Africa, are provided by a range of providers including private, government, not-for-profit or charitable organizations. In each of these countries, difficulties persist for staff in leadership positions who are ultimately responsible for matching the PCC needs of CALD residents with the capabilities of staff. This occurs within the framework of government and organizational policies, and often within substantially constrained human and financial resources. The difficulties of managing dynamic care needs and staff is exacerbated by high staff turn-over (often referred to as “staff churn”) within residential aged care (Chenoweth et al 2009; Low et al 2015).

Residential care settings may claim to provide PCC and opportunities for meaningful engagement, but the understanding of these concepts can be variable (Eaton et al 2015; Du Toit et al in press). Diverse backgrounds, as well as cultural and language differences become particularly relevant when older people with dementia require formal care. Even in care settings where the workforce is acculturated to care practices that accommodate the cultural background of residents, incorporating preferences for food, clothing and communication is often overlooked, and cultural identities are easily rendered invisible and neglected (Brooke et al 2017). Over the past decade important work to establish CALD guidelines in Australia

(Australian Government Department of Health 2017) and more recently New Zealand, has supported the notion of improving cultural identity (Peri & Cheung 2016; Nare et al 2017). With an emphasis of ensuring that culturally appropriate meaningful engagement is relevant to each resident, South Africa has recently reported the need for a more inclusive culturally appropriate model of care for the older black population living in residential aged care (Department of Social Development, Republic of South Africa 2010).

Staff shortages and staff churn are barriers to PCC as time limitations make it difficult for nursing assistants to individualize their approach to older persons. Care delivery models are not dissimilar across developed and developing economies with most care being delivered by care staff who are unregulated, time poor and under resourced. In most residential care settings, the regulated health care workforce provides a supervisory role relying heavily on a diminishing workforce (Chamberlaine et al 2016; World Health Organization 2016).

In Australia, cultural diversity training and resources have most commonly been developed on the premise that culture is a set of diversities that emphasize differences between people (Australian Multicultural Foundation 2010). Language barriers and cultural misunderstandings between staff, residents, and family and friends can cause psychological stress to each group, and operational inefficiencies for management (Uzun & Sevinc 2015; Etherton-Beer et al 2013; Baldassar et al 2017). Thus, solutions are required to address the language and cultural barriers in the PCC of dementia residents as well as the language and cultural barriers increasingly evident, but largely unexamined, among care staff (Hawthorne 2011).

Few studies describe the role of residential leadership staff in facilitating a person-centered approach although the importance of resident participation and workforce training is emerging as a cornerstone of PCC (Jangland & Guningberg in press; Smythe et al 2017; Thomas et al 2014). Key issues for leaders and managers in care home settings include resident participation in governance of the facility as well as staff development through training and ongoing support. As such, clear leadership policy and a well-trained and motivated workforce appear to be pivotal in creating an environment that fosters PCC and an enabling attitude (Smythe et al 2017; Moore et al 2017). Managers as leaders are crucial intermediaries between

governance and care, placing them in a strong position to take PCC forward. However, barriers have been identified that have challenged leaders to practically advance the standard of PCC in their facility. Traditional practices and stereotypical attitudes require a strong vision to innovate, inspire and challenge staff to move toward a more PCC model of practice (Moore et al 2017). Training needs to be supported as an ongoing community of learning and practice to transform expectations of staff, decentralize organizational hierarchy and focus on the resident's narrative (Moore et al 2017; Backman et al 2016). Several studies have identified strong leadership engagement as a pre-requisite for PCC, however, the strategies identified earlier are difficult to implement alongside the growing demand for residential care, a changing political landscape and increasing pressures on service provision (McCormack et al 2010; Brownie & Nancarrow 2013).

Questions arise as to how standards and guidelines for CALD PCC can be developed in ways that are workable for residential aged care facilities – especially those providing dementia care. Furthermore, it is unclear to what extent policies and procedures that seek to accommodate ever-changing CALD among staff and residents in one national setting, might be generalizable to different countries. A pilot study was undertaken in the aged residential care sector in South Africa, the UK, New Zealand and Australia to explore how meaningful engagement is supported within facilities where diverse groups of older people with advanced dementia were living. This paper reports on a component of this study that focused specifically on exploring the perspectives of leadership staff on PCC for residents with advanced dementia from CALD backgrounds, because, ultimately, it is facility managers who are held responsible for matching resident needs with staff capabilities.

In our study we examined and compared the practices and challenges of PCC associated with meaningful engagement across these four countries and from diverse perspectives. Meaningful engagement becomes more important as dementia progresses (Du Toit & McGrath 2017). Meaningfulness is interpreted as embracing the 'here and now', while engagement encompasses a sense of involvement, choice, and positive meaning while participating in an activity (or part of an activity). In this study, we explored how residential care leadership staff understood PCC for residents from culturally and linguistically diverse (CALD) backgrounds who

are living with dementia. Leadership positions were defined as entailing direct or indirect supervisory roles and/or responsibilities.

## **Method**

An adaption of the Delphi technique (Hsu & Sandford 2007) was used to attempt to determine consensus on the delivery of PCC for CALD residents with advanced dementia. This approach was selected because of its strong history of use in detailed examinations of specific issues for goal setting, policy investigation, or predicting the occurrence of future events. “Delphi is a widely used and accepted technique for gathering data from respondents within their domain of expertise ... The Delphi technique is well suited as a method for consensus-building by using a series of questionnaires delivered using multiple iterations to collect data from a panel of selected subjects ... The aim of the Delphi research is to derive consensus about the facility’s organizational culture and diversity within care partner/staffing settings.” (Hsu & Sandford 2007: 1). Our study also tested the Delphi method as a feasible means for effective and ethical deployment of surveys, and data collection, management and analysis across international field sites. While the immediate aim was to gather and compare data from four facilities, the long-term goal was to expand the study to more field sites. The appropriateness of the Delphi method was thus piloted with this long-term goal in mind.

### **Study settings**

The study was conducted in residential facilities across four countries. One facility was included in each country. Although each site was under different management, all provided residential aged care including, but not only for, CALD residents ageing with dementia. Please note: Job titles for staffing in the different countries were not altered and therefore different terms may be used for the same staffing levels. Authors have attempted to group these according to levels (starting with leadership staff with most responsibility for management) or provided a description where needed (see Table 1).

**[Table 1: Job titles for staffing across countries]**

The UK facility selected was a Southampton-based Social Services Care Home. Social Services is a government led organization providing social care support across the life span for UK residents. Care homes are provided by the government Adult Social Care sector, although it is becoming more limited as private care homes increasingly take responsibility for assisted living needs of older people. Hampshire Social Services had 20 care homes that offered support for people living with dementia at the time of the study (2017). The care home selected for this study had 74 beds offering residential and nursing care to older people with and without dementia. The home was rated 'good' by the Quality Care Commission (independent regulator of health and social care provision in the UK).

The New Zealand care organization comprised 33 rest homes (long-term care facility) and 54 private hospital beds located in a lower socioeconomic area of Auckland. The organization was part of an international chain of residential aged care providers in over 190 countries. It purported to provide a leading role in shaping dementia services in aged care. A facility manager supervised the operational components while a clinical manager and a registered nurse (RN) were responsible the clinical and social care of residents. The residents were supported by RNs, caregivers, an occupational therapist and activities coordinator. This facility had a designated wing providing CALD care and services including a cultural menu.

In South Africa, two care facilities run by a single organization and located in a predominantly middle-class suburb of Cape Town, participated in the study. As there are no government subsidies, residents fund their own accommodation and care costs. A general manager supervised both facilities, and each had a nursing manager, nursing sisters, staff nurses, nursing aides and an activity coordinator. The facilities housed approximately 175 and 83 residents respectively with accommodation ranging from cottages to assisted living and semi-frail care. The organization involved residents in the day-to-day running of events and in creating a home-like environment. However, the inherent hierarchical system in the nursing profession created an authoritarian structure that posed potential barriers for resident-direct care within the setting. The larger facility had a dedicated dementia unit accommodating 26 residents with a daily activity program provided by nursing aides.

The Western Australia site was one of 19 metropolitan and regional care facilities in Perth owned by a not-for-profit service provider. The host facility was in a riverside middle-class suburb. The facility was opened 15 years ago and provides residential care for 65 people (including high dependency dementia care), with an additional 35 independent living residences on an adjoining property. Residents paid to live there but means-tested government subsidies were available. A director of nursing supervised the facility, and staff include nursing, physical therapists, social support professionals, operations staff, and volunteers. A Dementia Services Team was centrally-based within the organization, providing a range of support for individualized PCC across all sites – including education and support to staff, people living with dementia, their families and carers. The team assisted with assessment and care planning to maximize individuals' potential.

### **Participants**

Participants employed in formal leadership positions at each facility were invited to participate. Participants must have worked at the facility for more than nine months and had to provide consent to participate in the survey. To ensure a range of responses, leadership staff in different types of work, such as nursing, operations, and human resources, were included. The initial goal of recruiting a minimum of three leaders from each site was established and met.

### **Recruitment strategy**

Canvassing for participants was arranged through the organization to prevent perceived coercion by researchers. Those who met the inclusion criteria at each site were invited to participate and provided with the Participant Information Form (PIF), which included the anticipated length of time involved for each step of the process, and informed participants that although participation for all three rounds was sought, they could withdraw at any point.

### **Delphi survey methodology**

An iterative process was used to gain consensus among the participating group at each site. A baseline electronic survey also invited participation in an interview at the end of the survey.



The survey development process involved drafting and redrafting by an expert panel to create items and a response structure (See Table 2). The adapted Delphi survey was piloted by volunteers within the aged care workforce in South Africa and New Zealand. Qualtrics, a secure online survey engine was used to develop and deploy the electronic questionnaire, which was provided by and administered at the University of Western Australia (UWA). Survey responses were also collected and stored using Qualtrics. Data entry from all sites were cross-checked by team leaders at each research institution to ensure anomalies were identified before the results were consolidated.

The survey rounds consisted of: (1) a first round with Likert scale items and open-ended questions; and (2) a second round containing items that appeared to have majority support with binary (yes/no) responses, free text fields, and agreement on Likert items. Provision was made for a third round if final consensus items would be needed.

#### **[Table 2: Delphi Survey fields]**

##### **Agreement criteria:**

Given the small number of participants at each site, the marker of agreement in each phase was qualitative. Free text sections in the survey was in support of identified priorities, as it provided opportunities to include examples for these selected items, and inherently verified findings.

##### **Data collection**

Maintaining uniformity in data acquisition methods proved a challenge. While sites in South Africa, the UK and Australia were comfortable with completing the Delphi questionnaire using a centrally-managed online survey engine, the New Zealand site preferred paper-based surveys. Hyperlinks were provided for electronic surveys. Regular reminders, follow-up emails and telephonic contact with facility managers were used to encourage participants to complete the survey during the first and second Delphi rounds.

### **Ethical considerations**

Gaining ethics approval from four universities in four different countries required considerable attention to detail to ensure protocols particular to each setting were observed, while maintaining research integrity across all sites. Sensitivities arose around matters such as terminology to be used in the survey and methods of dissemination. Uniformity in terminology and meaning was eventually found across all sites, with ethics approval first granted by UWA in April 2015. The University of Southampton (SOTON), University of Cape Town (UCT) and University of Auckland (UA) followed soon after. Participants undertaking the online survey agreed to the opening statement “by clicking on the link to take this survey, you are providing consent to participate in the study” while those completing hard copies provided written informed consent.

### **Data management and analysis**

Hard copy survey data were entered verbatim on the online survey engine by an investigator (AM) who was responsible for building, managing and generating reports from the online survey and database. No alteration was made to data content in the transfer from paper to digital format and contents were checked by the chief investigator (CI, SdT) after the transfer.

Data were analysed descriptively by calculating frequencies and proportions for demographic data and narrative data was also tabulated and categorised according to similar themes, or in some cases quantified, as it was mostly presented as single-word answers.

### **Results**

There were 18 respondents in total to Delphi Round 1 – five each in South Africa, Australia, and New Zealand, and three in the UK. Only eight of these respondents participated in the second and final Delphi round. In the second round, the most respondents were from South Africa (5 of 5), in contrast to the UK (2 of the original 3), Australia (1 of 5), and New Zealand (none). Despite this limited sustained participation, the adapted Delphi results revealed some helpful insights. No participants requested individual interviews.

### Participant demographics

A total of 18 staff from the four residential care facilities completed the initial Delphi survey. The occupational roles of the 18 staff were facility manager (2, 11.1%), clinical manager/administrator/coordinator (8, 44.4%), nurses (4, 22.2%), non-clinical supervisor/manager (3, 16.7%), and human resources officer (1, 5.6%). Their duration of employment ranged from 10 months to 28 years (median = 65 months). Ten (55.6%) of the staff were born in the same country in which they worked at the time of survey. The staff who were born outside the country of their workplace came from India to the UK; Indonesia and England to Australia; Zimbabwe, India, and the Philippines to New Zealand; and England to South Africa. Their duration of living in the new country ranged from two to 39 years (median = 10 years). Cultural groups/languages represented by staff and residents other than English are shown in Table 3.

### [Table 3: Cultural/language groups represented by staff and residents]

#### Staff Training

Nine leadership staff members (52.9%) across all 4 facilities had received in-service or other training in caring for culturally/linguistically diverse residents with advanced dementia. A range of training was described: equality and diversity training, dementia training on cultural background, understanding dementia, PCC, challenging behavior. External PCC-focused culture change training providers included The Eden-Alternative, an international organization driving PCC as the core to culture change (Brownie 2011; Thomas 1996), and Spark of Life, an Australian based organization that promotes dementia care through rehabilitation in areas of mental abilities, language, self-esteem, and social and emotional wellbeing (Lee, 2008).

Evidence of comprehensive training to the care facility as a collective was provided by staff,

*“Every member of the staff is trained including the maintenance staff,*

*domestic staff and kitchen and dining room staff as*

*everybody is considered a carer in the home which is the residents’ home and we work in their home.”*

Table 4 shows the 5-point Likert-scale responses to PCC practices in the facility. It indicates that residents’ choice about whether to participate in activities was the practice likely

to be most indicative of PCC as 17/18 participants affirmed this (n=11 strongly agreed; n=6 agreed). Seven participants strongly agreed and eight agreed that care plans, which include the life history of residents, is an invested PCC practice present in the facility. The PCC practice that was least supported was the quality of the interaction between staff and residents being more important than getting physical tasks done. Although 13 participants consented (n=2 strongly agreed; n=11 agreed) that staff have time to provide PCC, four remained neutral. Neutral responses are difficult to interpret but often indicate a degree of tension around what is perceived to be the “best” or “right” response compared to actual practice (Edwards & Smith 2018; Krosnick et al 2002).

**[Table 3: Responses to person-centred care by 17 out of the 18 staff, n (%)]**

In support of their nominations on the Likert Scale, respondents were also asked to provide written examples of how their facility had successfully engaged residents with dementia from different cultures. The three main categories evident in these examples were (i) involving people; (ii) ways in which language barriers had been overcome; and (iii) specific actions to foster engagement.

- (i) Engagement through people was supported by fellow residents and/or their shared cultural and religious communities, staff members, family, activity and diversional staff; or volunteers who spoke the same language as the resident with a CALD background.
- (ii) Practical examples of how language barriers were overcome included:
  - cards with pictures or words in the residents’ language;
  - family assisting with translation either in person or by phone;
  - staff speaking the same language acting as translators;
  - care plans translated into residents’ language; and
  - using body language as a means to communicate.
- (iii) Leadership staff recognized various actions that were employed to foster engagement. These actions focused on specific information about residents that

directed care plans to be more individualized based on the availability of residents' life stories (e.g. by using Maps of Life to store information). Communal living was another area that was specifically highlighted, whether it was by fostering greater insight into residents' cultural and religious practice (including end of life practices) through staff education; creating events to share and celebrate different cultures (e.g. through food, music, singing, dance, decorations, religious practices); and creating new memories of shared community through photographs of cultural events hosted by the facility.

### **Person-centred care practice**

Other comments, excerpted below, from the first Delphi round included a focus on training and education to support staff from other cultural/ethnic backgrounds to learn about the mainstream culture, learning about different cultural beliefs and values and cultural perspectives of ageing and dementia. Suggestions were also made to place residents of a similar cultural background in proximity within the home, and to encourage interaction between staff and residents who speak the same language.

The second round of the adapted Delphi survey (see Table 5) highlighted several enablers for PCC. All participants valued practical training and the importance of locality for face-to-face mentoring/demonstration of PCC principles,

*'Staff need a to have a manager who is present and practices what they preach.'*

Most participants suggested that participating in this research project reiterated awareness of the importance of PCC and encouraged on-going implementation. This was more evident when they were affiliated with a body that promoted culture change,

*'It is a reinforcement of our commitment to the Eden Alternative and brings some focus back to what we do in every day life for the residents. Sometimes we need to stop, step back, think, evaluate and regroup our thoughts and actions... and perhaps find a different angle or idea to make it work even better as we get 'bogged down' quite often with the other necessities of life within a home.'*

In contrast to participants from South Africa and the UK, the Australian participant was very aware of training associated with national policies and guidelines (see Table 5), although items specified were not directly associated with PCC,

*'I can't think of specific policies for person-centred care.'*

*The Act has some very unreasonable guidelines e.g. staffing which is not attainable in South Africa'*

The second round of Delphi did not reveal any examples of staff not in leadership positions, such as staff from allied health, operations or caregivers, as potential role models/mentors to promote PCC practices. External educators, residents, but mostly staff in leadership positions were considered best role models. Qualities other staff lacked or viewed as potential barriers to PCC were highlighted,

*'It's either in the person (naturally) or its not...'*

*'...we need help in our carers understanding our residents' cultural needs. Not the other way round...E.g. Our carers prefer to eat with their hands and our residence eat with a knife and fork. I'm sure the carer would rather pick up the food with their fingers and put it in the resident's mouth...'*

However, included as examples of activities that acknowledged the ethnicity of residents, some very superficial connections were made – for residents who were classed as 'English' the suggestions for activities were,

*'Decorating the facility to reflect the specific holiday – ie St Patricks Day or Easter'.*

## **Discussion**

This section will initially focus on insights derived about PCC from an international perspective. However, due to the low response rate by staff in leadership positions in three of the four participating organizations, careful consideration is also given to the processes associated with data collection.

### **International leadership perspectives on person-centered care**

Acknowledging resident choice and identities were the two practices regarded as most supportive of PCC in the care facilities. Both these practices could support individuality and autonomy of residents. Allowing residents the choice of whether or not they want to participate in everyday activities may appear to provide a real sense of freedom that is not necessarily associated with care institutions. Including life histories in care plans is an observable attempt at acknowledging residents' individuality (Du Toit et al 2013; Edvardsson et al 2014). These practices demand staff time, as highlighted by four leadership participants who

did not agree that staff have time to provide PCC. Time demands and staff shortages force staff to prioritize their duties which could explain the fact that seven staff members did not agree that the quality of interaction between staff and residents is more important than getting physical tasks done.

The examples of how facilities engaged residents with dementia from different cultures mainly centered around human interaction and addressing language barriers. A wide range of opportunities for human interaction involved people outside the facility including family, volunteers, residents' cultural and religious communities, in addition to people inside the facility including activity staff and fellow residents.

Cultural differences were mostly interpreted as different languages being spoken which serve as a barrier to human interaction. It was suggested that residents' engagement could be enhanced by low-cost and engaging actions, such as developing cards or pictures in the residents' language by employing the help of family members or staff with translation, or translating the care plans into residents' preferred language. The use of body language for communication was perceived to be especially powerful as it promoted engagement and reassurance for individuals who could be vulnerable to social isolation. Although the danger of social isolation was identified, the use of technology as a pragmatic option to connect CALD residents with family or friends abroad, was not suggested.

A commonality across all four countries were that leadership did not trust others/subordinate staff to promote and expand PCC. Moreover, the fact that employees' personal cultural preferences (e.g. eating habits) were disregarded could be a possible barrier to PCC. Empathy for cultural preferences should extend to all levels of the collective – staff and residents alike – where the ethnicity of the micro-community's members is honoured. Engaging residents with dementia from different cultures is, apart from the focus on human interaction and addressing language barriers, also evident from activities that focus on valuing and encouraging the expression of cultural diversity. Awareness of cultural diversity is related to learning and experience, where staff receive not only education, but also share in and experience cultural practices through culture-specific events hosted in the organization (Mikelyte & Milne 2016).

### **Data collection method**

The low response was largely because staff were time-poor and the case of the New Zealand and Australian participants, research-fatigued (as indicated by verbal feedback from participating facilities post project). Field notes indicated that leadership staff would have preferred to be involved face-to-face data collection during interactive sessions, such as using a technique like Appreciative Inquiry for data collection. In contrast to the Delphi method, where multiple iterations are needed to build consensus, Appreciative Inquiry could provide an opportunity to identify the positive PCC practices of an organization, in one session of at least two hours (Cooperrider & Whitney 2001).

It may be possible that Appreciative Inquiry's emphasis on the co-evolutionary and collaborative search for the best in people and their organizations energizes participants and enhances their engagement as they are inspired by each other's contributions, whereas the Delphi method could be experienced as more individualized and, in a sense, more isolated especially during the first round.

The fact that no participants requested individual interviews, contrasts with the fieldnotes which indicated that most leadership staff expressed an interest in being included in interactive face-to-face activities. This finding could indicate a degree of ambivalence about their leadership role in delivering PCC and may reflect limitations in time, resources and policy infrastructure to participate in research.

### **Multiple ethics processes**

Administrative processes associated with this research project, impacted data collection. Contemporary research is enriched by collaborative projects undertaken by researchers in different jurisdictions. Such projects are shaped by the input of the partner institutions, their respective human ethics research committees, and the involvement of local stakeholders and participants (Tan 2016; Paulos & Frago 2017). Although there is no universal conceptualization of research ethics (Youtie & Bouzman 2014), human research ethics



committees utilize a common set of “secular principles” when assessing research proposals (General Assembly of the World Medical Association 2014). Therefore, although committees approach their task from a consistent base, the interpretation of the principles, and concerns about how best to ensure the protection of study participants may vary depending on prevailing views in a particular jurisdiction.

This project required ethics approval from four universities in different countries. The UWA’s ethics application which was the first to be completed and submitted was *intended* to serve as a guide for the other universities to follow. The UWA application proposed that qualitative fieldwork in Western Australia be undertaken by the UWA team only. The non-UWA researchers would undertake qualitative research within their own respective regions. All data gathered by each respective research team was shared for analysis by the full research team collectively. Data were stored in a central repository and were shared among all the researchers for analytical purposes, before collaborating on publications and oral presentations of our combined work. While there is no room in this paper to discuss these issues in detail, the process did serve to highlight how understandings of ethics related to research in residential care facilities differs across countries. For example, achieving uniformity in data acquisition methods and reaching agreement on the meaning of key terms, including ‘culture’ and ‘culturally diverse groups’, proved a challenge.

The SOTON ethics committee requested a definition of what was meant by ‘culturally and linguistically diverse’. CALD is an acronym used in Australian academic and service circles in relation to multicultural interests. It tends not to include Aboriginal and Torres Strait Islander interests, as these demographics are usually served by other legislation, policies, representative bodies, and community organizations that recognize their particular interests (as traditional custodians). So CALD may not be a universally recognized term. This also raises the ethically fraught matter of semantics – even within one language there may be different meanings. Semantics are informed by local histories and contemporaneous social concerns. Other concerns were raised regarding terms such as ‘aged care facility’ rather than a ‘care home.’

## **Limitations**

The results reported in this paper are drawn mostly from the first round of the adapted Delphi method and therefore allow for only a preliminary discussion

Trying to understand why the sustained participation in the Delphi method was limited is an important outcome of this research project that can inform future research directions. At least one research site indicated that none of the initial staff was available for the second Delphi round, indicating staff turnover as a potentially important barrier (Boyd et al 2011). Additionally, we found that several of the individuals in nursing leadership roles had not received adequate leadership training and were appointed based on their clinical skills. They may have felt daunted by the Delphi questionnaire due to a lack of knowledge and training in the leadership of PCC in their workplaces. These are all important issues, worthy of further research and analysis, that will inform the redesign of our approach in subsequent studies following this pilot.

## **Conclusions**

Leaders of aged care facilities are aware that meaningful engagement is a key enabler of PCC, especially for CALD residents who are ageing with dementia. However, in practice limited time, resources and policy infrastructure are perceived to hamper the capacity to provide PCC holistically. The proportional increase of CALD residents with dementia is growing internationally as a result of historical increases in global migration, increased longevity, and increased diagnosis and reporting of dementia. The specific types of PCC required for CALD groups are also changing over time in response to historical changes in global migration patterns. Training staff to identify needs specific to one CALD group does not prepare them to identify needs for all CALD groups. CALD demographics change over time, as do care staff demographics. The CALD groups that make up present-day resident populations are those that historically migrated into a given area. The CALD groups that make up present-day staff populations are those who migrated more recently.

Care leadership are aware of the CALD gaps and that they need to build flexibility into PCC to accommodate the required changes in CALD PCC through time and in practice. However,

government, industry, and in-house policies that are developed in response to the needs of dominant domestic populations appear to be a barrier to delivery of CALD PCC dementia care.

Our research indicates that there is limited and often inconsistent provision of staff training in PCC for CALD residents with dementia.

Developing accredited CALD PCC training in every country would require aligning health systems to the constantly changing needs and demographics of older populations, and developing sustainable and equitable systems of care in which caregiver demographics are also changing.



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**Table 1: Job titles for staffing across countries**

Facilities manager, director of nursing, nursing administrator, nursing coordinator.
Clinical manager, nursing sister.
Allied health staff, occupational therapist, physical therapist.
Registered nurse, staff nurse.
Caregiver, nursing aide.
Activities coordinator, social support professional (referring to health & wellness staff offering personalized support plans, staff who work to provide entertainment, social activities, outings, aromatherapy, massage, music therapy, and a designated “Pastoral Care” support area).
Operations staff – e.g. cleaning, catering, administration, security, maintenance – including human resource officers, non-clinical supervisors.

**Table 2: Baseline Delphi Survey fields**

<b>First round</b>		
<b>Domain</b>	<b>Field</b>	<b>Item</b>
Demographics of participant and initial open ended exploration of attitudes about cultural groups	<ul style="list-style-type: none"> <li>• Role</li> <li>• Period of employment</li> <li>• What is your own cultural background?</li> <li>• What do you think is the impact of having older people from diverse cultural backgrounds living in your facility?</li> </ul>	Free text
Training of staff	<ul style="list-style-type: none"> <li>• Please tell us about the in-service training opportunities for your staff during the past year: what were the topics and what did the training comprise of?</li> <li>• Please add any further thoughts about training opportunities for your staff.</li> </ul>	Free text
PCC practices in the facility	<ul style="list-style-type: none"> <li>• Residents are offered the opportunity to be involved in individualised everyday activities.</li> <li>• Staff simply do not have the time to provide PCC. (Followed by reasons why: Ratio between staff and residents; quality/standard of physical care required by organizational guidelines?)</li> <li>• Staff have to get the work done before they can worry about a homelike environment.</li> <li>• It is hard for residents in this facility to find their way around.</li> <li>• The quality of the interaction between staff and residents is more important than getting the tasks done.</li> <li>• The life history of the residents is formally used in the care plans we use.</li> <li>• The care practice at this facility encourage engagement, through promoting a sense of involvement, choice for participating in daily activities.</li> </ul>	5 point Likert scale



<b>First round</b>		
<b>Domain</b>	<b>Field</b>	<b>Item</b>
	<ul style="list-style-type: none"> <li>• Please provide an example/s of how one of your staff adapted/ altered their work routine to include a resident with advanced dementia's preference.</li> <li>• Please provide an example/s of how you encourage your staff to ensure that residents with advanced dementia are involved in activities, including smaller aspects of that activity. It may be helpful to think about examples such as how your staff would support residents with advanced dementia to be involved in an activity like a birthday party hosted in a large room? It may also be helpful to think about your activity offerings: what other examples of staff supporting involvement for residents with advanced dementia come to mind?</li> </ul>	Free text
Questions related to cultural sensitivity and competence	<ul style="list-style-type: none"> <li>• Please tell us about how your staff work with residents from diverse cultural backgrounds. Think about what things help your staff to provide an ideal service, and the barriers they face.</li> <li>• Please provide any example/s of how a formal team meeting assisted to ensure that a resident from a diverse cultural background was supported to experience a sense of belonging in the facility.</li> <li>• Provide an example/s of how an individualised care plan was adapted to ensure that a resident from a diverse cultural background was supported to do their preferred everyday activities.</li> </ul>	Free text
	<ul style="list-style-type: none"> <li>•</li> </ul>	

<b>Second round</b>		
<b>Domain</b>	<b>Field</b>	<b>Item</b>
Events supporting culturally diverse practices	<p>Please rate how important these events are in your setting. If you feel it would assist others, we would appreciate if you can describe specific examples relevant to your setting.</p> <ul style="list-style-type: none"> <li>• Cultural events - e.g. music, songs, dancing</li> <li>• Culturally specific food that is on the menu</li> <li>• Other leisure or group activities related to culture - e.g. decorating communal areas for specific events such as St Patrick's Day, Diwali (the festival of lights), the Rio carnival, or 4th of July celebrations)</li> <li>• Significant family events are facilitated/supported by staff members - e.g. weddings, anniversaries, births and funerals</li> <li>• Other types of social events related to culture</li> </ul>	<p>10 point Likert scale</p> <p>Free text</p>
Culturally relevant activities	<p>Please tell us more about:</p> <ul style="list-style-type: none"> <li>• any culturally relevant activities for individual residents in your setting</li> <li>• specify the ethnicity/language of the resident and provide examples of any culturally-relevant activities that the resident is participating in or has participated in.</li> <li>• give examples of activities could be helping a resident prepare a traditional food they enjoy or supporting a resident to attend culturally relevant events in the local community.</li> </ul>	Free text
Factors that can support and promote a Person-Centred Care approach	<p>Please rate how important these factors are in your and provide specific examples relevant to your setting:</p> <ul style="list-style-type: none"> <li>• National policies and guidelines</li> <li>• The organization's own policies, guidelines, job descriptions and expectations</li> <li>• Affiliations/registrations with specific bodies or programs</li> <li>• Leaders in the organization and the examples they provide through their care practice</li> <li>• Training and/or education</li> <li>• Staff members find time-efficient ways to individualise everyday care routines to ensure that residents' cultural backgrounds are honoured Other forms of support that may promote</li> <li>• Person-Centred Care in your s/etting</li> </ul>	<p>10 point Likert scale</p> <p>Free text</p>

Collaborative research impact	How has participation in these research activities (i.e. the survey and the workshop) impacted the leadership, residents, relatives and/or volunteers within your setting?	Free text

**Table 2: Cultural groups/languages of staff and residents other than English**

	<b>UK</b>	<b>Australia</b>	<b>NZ</b>	<b>South Africa</b>
<b>Staff and residents</b>	Polish, Dutch	Chinese, Burmese, Italian, Indian	Maori, Tongan, Samoan, Niuean, Cook Island Maori, Indian/Hindi/Fijian Indian, Gujarati,	
<b>Residents only</b>	Swedish, German	Dutch, German, Croatian	Cambodian	German, Dutch
<b>Staff only</b>	Romanian, Filipino/Tagalog, Malayalam/Goa/Tamil/Indian, African.	Filipino, Africana, Nepalese, Sri Lankan	Fijian, Filipino	Xhosa

**Table 3: Responses to person-centred care (n=17)\***

	<b>Strongly disagree</b>	<b>Disagree</b>	<b>Neither agree or disagree</b>	<b>Agree</b>	<b>Strongly agree</b>
	<b>No. (%)</b>	<b>No. (%)</b>	<b>No. (%)</b>	<b>No. (%)</b>	<b>No. (%)</b>
<b>Residents are offered individualised activities</b>	0 (0)	1 (5.9)	1 (5.9)	13 (76.5)	2 (11.8)
<b>Staff have time to provide person-centred care</b>	0 (0)	0 (0)	4 (23.5)	11 (64.7)	2 (11.8)
<b>Staff create a homelike environment for the residents</b>	0 (0)	0 (0)	2 (11.8)	11 (64.7)	4 (23.5)
<b>Our physical environment helps residents to function at their best</b>	0 (0)	0 (0)	2 (11.8)	12 (70.6)	3 (17.6)
<b>The quality of interaction between staff and residents is more important than getting physical tasks done</b>	0 (0)	2 (11.8)	5 (29.4)	8 (47.1)	2 (11.8)
<b>Our care plans include the life history of the residents</b>	0 (0)	0 (0)	1 (5.9)	9 (53.9)	7 (41.2)
<b>Residents can choose whether or not to participate in everyday activities</b>	0 (0)	0 (0)	0 (0)	6 (35.3)	11 (64.7)

\* Missing response from 1 staff member

Table 5: Examples of identified factors that could support and promote Person-Centred Care

ITEM	<b>SOUTH AFRICA</b> [Examples per item provided by at most 3/5 participants]	<b>UK</b> [1/2 participant provided all examples]	<b>AUSTRALIA</b> [Only one participant]	New Zealand [No participants]
<b>National polices and guidelines</b>	Older Persons Act (2006) Basic Conditions of Employment Act	Equality and diversity, The social care act, Health and safety Act. Safeguarding Vulnerable adults	Corporate Governance & Regulatory Compliance	
<b>Organization's own policies/guidelines/expectations</b>	House rules Grievance procedure Code of conduct	As above Specific job descriptions for staff	Multi Skilled Carer Privacy and Confidentiality Policy.	
<b>Affiliations/registrations</b>	Eden Alternative	CQC - Care Quality Commission (independent regulator of all health and social care services in England) NMC - Nursing and Midwifery Council (regulates nursing registration and nursing standards)	Programs are not significant Staff member (naturally) has the ability for PCC or not	
<b>Leadership examples</b>	Encourage residents to take initiative Trainers/Educators as mentors	Support plan devised from the past history, the information gathered from family and the current needs.	Management who is present and do what they expect from others	

		Risk assessments to maintain safety		
<b>Training and/or education</b>	Hands-on training and leading by example	Month long induction Practical dementia training	Fire Safety, Manual Handling, Food Safety, Infection Control, Documentation and PCC	
<b>Key features for being person-centred</b>	Let residents choose what they want to wear Admission forms to include a questionnaire for background/life history of resident Involving family and volunteers to host events	One-on-one sessions with resident by member of staff having coffee/other drink, Namaste, Nail care Assisted with bath as per the resident's preferred time. Choices of meals - menu to choose	Know resident's nick name Remember names of family members/ people who important to the resident	
<b>Collaborative research impact</b>	Reinforcement commitment to Eden Alternative philosophy Refocus on what is done in everyday life for the residents Assist carers to understanding residents' cultural needs	Rethinking care Motivation to do better	No impact	

KEY:  Ranked first as most the important priority  Ranked second as an important priority