

# **Unveiling the Concept of Person-centered Dementia Care within Occupational Therapy in Residential Aged Care Facilities: A Critical Interpretive Synthesis**

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## STATEMENT OF AUTHENTICATION

I, Xizi Shen, hereby declare that this submission is my own work and that it contains no material previously published or written by another person except where acknowledged in the text. Nor does it contain material which has been accepted for the award of another degree.

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Signed \_\_\_\_\_

Date 12/01/2017

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## THESIS ABSTRACT

**Background:** The current environment within residential aged care facilities is likely to deprive residents with moderate to advanced dementia of opportunities for engagement in desired occupations, thus may place them at risk of experiencing social and occupational injustice. Occupational therapists' position as experts for enabling meaningful engagement and as advocates for occupational justice can play a significant role in assisting residents with moderate to advanced dementia in defending their occupational rights and enhance their wellbeing. The link between occupational therapy and meaningful engagement of residents with moderate to advanced dementia has been established. Concepts regarding person-centered dementia care are adopted as the guiding principle for service providers in this field. However, it is unclear how occupational therapists embrace the essence of person-centered dementia care when promoting meaningful engagement of residents with moderate to advanced dementia.

**Aim:** The aim of the current study was to explore how theoretical underpinnings of occupational therapy practice in residential dementia care have influenced the implementation of core concepts of person-centered dementia care.

**Method:** A critical interpretive synthesis was conducted to critically consider the power structure underpinning occupational therapy practice in residential dementia care. Thirty peer-reviewed articles were used as the source sample for this study. Evidence pertaining to occupational therapy practice was integrated and analyzed using concepts regarding occupational justice and themes of doing, being, becoming, belonging and co-occupation to generate synthesis.

**Results:** Six themes were identified in the current occupational therapy practice within residential dementia care. Collaboration, referring to involvement of the resident and key stakeholders in the occupational therapy process, and tailored practice, referring to the process of individualizing occupational therapy practice to meet resident's specific needs, are the two themes that underpin the other four themes: enabling doing, being, belonging and becoming of residents with dementia.

**Discussion:** This synthesis indicates that occupational therapists enhance occupational justice in residential dementia care by increasing access to meaningful engagement and enabling participation of residents with moderate to advanced dementia in doing, being, and belonging at the level of co-occupation, where interdependence between residents and care staff members is fostered. However, the becoming domain of occupation has not been comprehensively addressed. Thus the needs of residents for continued growth and development as occupational beings need to be further investigated and expanded to ensure that occupational therapy practice within residential dementia care remains at the forefront to ensure occupational justice for this vulnerable population.

**Implications:** The findings expose shortcomings in how occupational therapists address person-centered dementia care. This study suggests that occupational therapists should advance their person-centered practice within residential care settings by moving beyond the scope of recognizing personhood to focusing on enabling interdependence between residents and all significant role players in their everyday lives.

## **SECTION 1**

### **REVIEW OF THE LITERATURE**

#### **Unveiling the Concept of Person-centered Dementia Care within Occupational Therapy in Residential Aged Care Facilities: A Critical Interpretive Synthesis**

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# **Unveiling the Concept of Person-centered Dementia Care within Occupational Therapy in Residential Aged Care Facilities: A Critical Interpretive Synthesis.**

## **A Critical Review of the Literature**

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### **1. Definition and consequences of moderate to advanced dementia**

Dementia, more specifically Alzheimer's disease and related dementias, is defined as a neurodegenerative clinical syndrome characterized by the deterioration in cognitive functions and ability to perform daily activities (World Health Organization, 2012). As dementia progresses, people become increasingly dependent on others for daily living activities (Chenoweth et al., 2009). In middle to late stages of dementia, people significantly rely on others for daily functions and basic needs (Chenoweth et al., 2009). In addition, behavioral, emotional and motor impairments also accompany the deterioration in cognition of people at later stages of dementia (NICE and SCIE 2006). These symptoms and outcomes can result in institutionalization and decreased quality of life for people with moderate to advanced dementia (NICE and SCIE 2006; Brodaty, 2009).

#### **1.1. Prevalence and incidence of dementia**

Dementia is becoming an increasing concern in the aged care sector due to its prevalence and projected growth (Prince et al., 2013). The incidence of dementia increases exponentially with age. From a global perspective, in 2015, 13% of people aged 65 and older had dementia and the incidence rose to 43% for those 85 and older

(Prince et al., 2013). As a result of growing and aging global population, it is estimated that the number of people living with dementia will double every 20 years, with 35.6 million people in 2010 to 65.7 million in 2030 (Prince et al., 2013).

## **2. Culture change movement in residential dementia care**

The growing prevalence of dementia among elderly populations is creating significant demands for long-term residential aged care facilities throughout the world (Prince et al., 2013). One great challenge facing the aged care sector is to ensure acceptable standards of care with limited staff and the complex needs of people with dementia especially those at later stages of the condition (Chenoweth et al., 2009). Responding to this challenge, many residential aged care facilities have adopted the concept of culture change in care delivery systems, replacing the biomedical model of care with a social model that emphasises person-centred care as the guiding standard for practice (Koren, 2010).

## **3. Biomedical model of care and hospital-like environment**

For the past decades, residential dementia care had been dominated by the biomedical model of care that values consistency, efficiency and hierarchy of decision-making (Robinson & Rosher, 2006). In residential aged care facilities guided by this model of care, doctors, nurses and health professionals play significant roles in developing the care plan for residents and aim to address residents' medical conditions and functional deficits (Thomas, Du Toit & Van Heerden, 2014). Thus in this environment, residents with dementia are more like patients in hospital where the focus of care is on their symptoms of dementia and physical features of daily activities, rather than on their psychosocial needs (Brooker, 2007).

### **3. 1. Consequences of hospital-like environment**

#### *3.1.1. Malignant care and excess disability*

The hospital-like environment within a traditional aged care facility can lead to malignant dementia care and excess disability. In this hospital-like environment, the person is objectified and their subjective experiences are not adequately acknowledged and valued (Robinson & Rosher, 2006). This depersonalisation can lead to what Kitwood termed malignant social psychology in dementia care settings. Malignant social psychology can be defined as a range of interactive processes that is driven by good intentions of care staff members but undermines the sense of self of people with dementia (Kitwood, 1997). Harmful outcomes of this malignant residential dementia care include loss of dependence in daily activities, reduced social engagement, exclusion from decision-making, and increased social alienation (Robinson & Rosher, 2006). As a result, the person's sense of self and dignity are undermined. In addition, many service providers cling to the attitude that people with dementia are well taken care of when things are done for them (O'Sullivan & Hocking, 2006). Preconceived ideas regarding the decreased capacity of people with dementia to make decisions and retain control of their own lives are also prevalent among service providers (Swaffer, 2015). These perspectives can result in greater disability that reduces the person's ability to do things for themselves, reinforcing their dependence on others (Robinson & Rosher, 2006; Kitwood, 1997). According to Swaffer (2015), Prescribed Disengagement™ eventually results when care staff members take over from people with dementia and inhibit them from engaging in meaningful activities.

#### *3.1.2. Occupational deprivation*

Within a hospital-like environment, residents, those with moderate to advanced dementia in particular, are institutionalised and at high risk of experiencing occupational deprivation. Due to the progressive deterioration in cognitive abilities (WHO, 2010), people at later stages of dementia have severe cognitive deficits that significantly reduce their abilities to participate in daily activities and socialize with others, placing them at risk for isolation and withdrawal from occupations (Kolanowski, Litaker, Buettner & Yu, 2006; Chung, 2004; Zimmerman et al., 2003). This withdrawal is often reinforced by the malignant dementia care and excess disability described above. Lacking opportunities for engaging in meaningful occupations can negatively impacts on wellbeing of residents with moderate to advanced dementia (O'Sullivan, 2013). Engagement in occupations, which are defined as activities people want or need to do every day (Fisher, 2009), by older adults living with dementia are associated with a number of positive outcomes including giving purpose to their lives, enhancing physical and mental health, promoting self-confidence, and offsetting the sense of hopelessness and frustration associated with dementia (O'Sullivan, 2013).

The system of care delivery guided by the biomedical model of care is thus associated with poor life satisfaction of people with moderate to advanced dementia (Brooker, 2007). Evidence shows that in traditional aged care facilities, many people with moderate to advanced dementia spend a significant amount of time alone and are emotionally distressed (Brooker, 2007). To improve the quality of life and to address the needs of residents with dementia, especially those at later stages of dementia, a more humanistic care approach is needed (Brooker, 2007).

#### **4. Person-centered practice as the gold standard in dementia care**

Person-centred care (PCC) is considered a holistic alternative to the conventional care approach in dementia care, due to its beneficial impact on wellbeing of people with dementia (Cohen-Mansfield, Libin & Marx, 2007; Brownie & Nancarrow, 2013). Person-centered dementia care values the person's experiences and make them the focus of care delivery not their condition (Edvardsson & Innes, 2010). Researchers have identified numerous benefits associated with the use of person-centred approach in residential dementia care. Decreased levels of boredom and feelings of helplessness, and increased level of sociability are observed among people with moderate to advanced dementia in nursing homes adopting PCC as the guiding standard of practice (Brownie & Nancarrow, 2013).

Over the recent years, PCC has become the best practice in dementia care (Brooker, 2007). Government departments around the world are becoming increasingly committed to ensure that the aged care facilities are person-centred. The movement towards person-centred care started in the UK and then moved across the world more than a decade ago (Dewing, 2004). For instance, in 2003, the Victorian Department of Human Services in Australia produced a policy to promote PCC in aged care sector (VDHS, 2003). As a result, since the 2000s, many residential dementia care settings have adopted PCC as the guiding principle (Koren, 2010). The underlying concepts thus have been used to guide service providers in this field (Koren, 2010).

#### **4. 1. Concepts of person-centred care for people with dementia**

##### *4. 1. 1. Personhood*

A substantial amount of effort has been devoted to the development of person-centred dementia care philosophy. The concept of person-centeredness in dementia care originated with Kitwood in 1997. In response to a lack of theories guiding the person-

centred dementia care, Kitwood made personhood at the heart of this approach (Kitwood & Bredin, 1992, p.270). He asserted that the sense of personhood is associated with recognition, respect and trust that are bestowed on the person by others in social relationships (Kitwood, 1997). From his perspective, personhood is a product of social relationships where people around those with dementia take the responsibility to maintain the person's personhood (Kitwood, 1997). For decades, the concept of personhood has been acting as the foundation for developing models and care for people with dementia. Building on Kitwood's work that emphasised the centrality of personhood in dementia care, Brooker (2007) created the VIPS framework to describe four core themes of person centred practice in dementia care: (1) Valuing people with dementia and their caregivers; (2) Using an Individualised approach to recognise and value uniqueness of the person; (3) Using the Perspective of the individual with dementia; (4) Creating a Social environment that supports psychosocial needs of the persons with dementia. The concept of person-centred dementia care has been further expanded by considering perspectives of people with dementia and their care partners regarding PCC. With a deep understanding of key stakeholders' perceptions regarding person-centred practice, Edvardsson et al. (2010) encourage care staff members to incorporate personal knowledge of those with dementia into the caregiving process, provide the person with opportunities for making decisions, and increase positive interactions with the person. Building on Edvardsson's work, Byrne and his colleagues (2012) suggest that the person-centred dementia care should focus on preserving autonomy of the person with dementia and promoting positive interactions characterised by recognition, validation, collaboration and negotiation.

#### *4. 1. 2. Valuing agentic self and supporting agency*

The most recent development of person-centred dementia care concept is extending the scope of care to supporting the citizenship of people with dementia within their care community, so that they can have stronger voice of their own. Higgs and Gilleard (2016) challenges the use of personhood grounded in Kitwood's work as the foundation for developing person-centred dementia care. By relating Kitwood's conceptualisations of personhood to metaphysical and moral philosophy of person, Higgs and Gilleard (2016) claim that agentic self, a key component that may make a person, is not considered by Kitwood, making people with dementia into objects of moral concern and their caregivers take the full responsibility to sustain the individual's personhood. Higgs and Gilleard (2016) then call for a need to study individual agency and the agentic self of people with dementia in order to support their retained capacities and current strengths (Higgs & Gilleard, 2016). Agreement on supporting agency of people with dementia is quickly achieved among leading scholars in dementia care. In order to support agentic self of people with dementia, Poland and Birt (2016) suggest service/care providers to develop interdependent relationship with people with dementia and perceive them as partners in co-constructing the care relationship. In this way, people with dementia are empowered to enact their agency and thus their citizenship is supported.

#### *4. 1. 3. Essence of person-centred dementia care*

Although a substantial amount of effort has been put into the development of person-centered dementia care concepts and philosophy over the past thirty years, there appears to be a lack of worldwide consensus on unified terminology and the core concepts of person-centered dementia care. Various terms are used for person-centered practices in dementia care, including client-driven, client-centered, resident-

directed and relationship-centered (Hughes & Bamford, 2008). By integrating common themes of these different types of person-centeredness with the major concepts of person-centered dementia care described previously, the following seven common themes are identified and may be used as a guiding framework for person-centered practice in dementia care: (1) addressing the person's social environment to support their personhood; (2) acknowledging the uniqueness of the person; (3) respecting autonomy, dignity and rights of the person; (4) focusing on the person's strengths and positive aspects rather than deficits and weaknesses; (5) valuing the person's perspective and subjective experiences; (6) valuing and supporting care staff and other stakeholders to co-construct a caring relationship; (7) enabling the person to enact and build on continuing opportunities for agency.

## **5. Delay in transitioning to person-centred dementia care**

In spite of worldwide efforts to promote PCC, there is a delay in transitioning to this standard of care in many countries' residential dementia care settings (Love & Pinkowitz, 2013). This delay is partly resulted from a persistent strain between the biomedical model of care and PCC. Medical model has permeated the residential dementia care for decades and continues affecting the current care system (Kolanowski, Haitsma, Penrod, Hill & Yevchak, 2015). Considerable efforts have been contributed to studying etiology and symptoms of dementia (Kolanowski, Haitsma, Penrod, Hill & Yevchak, 2015). Up to now, the majority of government funding is put into research that focuses on behavioural and psychological symptoms of dementia (BPSD), a term that is derived from the biomedical model (Kolanowski, Haitsma, Penrod, Hill & Yevchak, 2015).

Another possible reason behind the delay in providing PCC in residential dementia care settings is associated with care staff members' beliefs and knowledge level. With limited expertise and preconceived ideas regarding the capacity of people with dementia to make decisions and retain control of their own lives (Bennett, Shand & Liddle, 2011), care staff members tend to make decisions do everything for them, inhibiting them from engaging in meaningful activities (Swaffer, 2015). Therefore Prescribed Disengagement<sup>TM</sup> occurs and places residents with dementia at a high risk of experiencing occupational deprivation and occupational injustice. This care practice also reinforces dependence and results in passivity of residents with moderate to advanced dementia. Literature shows that many people with dementia, those in later stages of dementia in particular, spend most of their time in states of disengagement, waiting for care staff to provide routine care and generate occupation and social engagement (Perrin, 1997; Holthe, Thorsen & Josephsson, 2007; Morgan-Brown, Ormerod, Newtown & Manley, 2011).

## **6. Occupational therapists have a role in dementia care**

Occupational therapy is a person-centred health profession aimed at enhancing wellbeing through occupations (WFOT, 2010). In addition, the Position Statement on Human Rights issued by the World Federation of Occupational Therapists (WFOT) in 2006 asserts that occupational therapists have a specific responsibility to support people in accessing their right to live meaningful lives. Occupational therapists thus have specific expertise and responsibility to enable engagement of residents with moderate to advanced dementia in meaningful occupations, and address the occupational injustice in residential dementia care. The professional practice of occupational therapy is grounded in and supported by occupational science. Within

residential dementia care, occupational therapy practice is also supported by concepts regarding occupational justice.

### **6.1. Occupational justice**

Advancing occupational justice is an integral part of occupational therapy practice (Hammel, 2015; Whiteford & Townsend, 2011; Townsend & Wilcock, 2004). The World Federation of Occupational Therapists (WFOT, 2006) issued a Position Statement asserting that all people, regardless of their age and condition, have the right to participate and be supported to participate to their potential in their desired and valued occupations. This statement also asserted that this human right to occupational engagement should be ensured by equitable access to participation. To guide practice of occupational therapists doing justice, concepts and framework regarding occupational justice have been developed.

From occupational therapy perspectives, humans are occupational beings (Townsen & Wilcock, 2004). Therefore, all people have the right to engage in meaningful and balanced occupations throughout their lives, to enrich and grow through occupational engagement, and to maintain autonomy and take control around occupational engagement (Townsen & Wilcock, 2004). Occupational justice occurs when there is a fair and equal opportunity for meaningful engagement regardless of ability, age, gender or other factors (Townsen & Wilcock, 2004). With equal access to meaningful engagement, people are able to flourish to their greatest potential within their communities (Townsen & Wilcock, 2004). In light of these theories, Townsend and Polatajko (2007, p101) suggest occupational therapists promoting occupational justice to apply enabling skills grounded in deep understanding and valuing of client's

perspectives, experiences, interests, strengths and capacities. The process of enablement is well in line with the core concepts of person-centered dementia care – acknowledging the uniqueness of the person and respecting and valuing their autonomy, rights, perspectives and strengths.

In addition to the concepts regarding occupational justice, the Participatory Occupational Justice Framework (Whiteford & Townsend, 2011) was developed to provide a practice guideline for occupational therapists doing justice. This framework highlights the participatory and collaborative aspects of enablement process. It suggests occupational therapists promoting justice to share responsibilities for decision making by working in partnership with clients and engaging key stakeholders. It also emphasizes the need to consider the impact of social conditions and structures when occupational therapists facilitate different opportunities and resources to enable meaningful engagement (Whiteford & Townsend, 2011; Townsend & Polatajko, 2007; Whiteford & Wright, 2005). The enablement process guided by the POJF aligns nicely with the essence of person-centered dementia care which involves creating a supportive social environment, valuing care staff and other stakeholders.

Providing practice grounded in occupation justice theories, occupational therapists have the potential to support PCC and promote occupational justice in residential dementia care.

## **6.2. Doing, being, becoming, belonging and co-occupation**

The professional practice of occupational therapy is grounded in and supported by the discipline of occupational science. Occupational science proposes that humans are

occupational beings and argues that occupational engagement and occupational balance can influence a person's health (Hitch, Pepin & Stagnitti, 2014; Pickens & Pizur-Barnekow, 2009; Robeiro, 2001). To support a person's health, leading theorists in occupational science contends that a dynamic balance between five dimensions of human occupation, namely, 'doing', 'being', 'becoming', 'belonging' and 'co-occupation' needs to be achieved (Hitch, Pepin & Stagnitti, 2014; Pickens & Pizur-Barnekow, 2009). By enabling engagement in these five dimensions of human occupation, occupational therapists have the potential to address complex needs of people with dementia for meaningful engagement.

#### *6. 2. 1. Doing*

Doing refers to the process of engagement in occupations that are personally meaningful, but not necessarily purposeful, to the person (Hitch, Pepin & Stagnitti, 2014). Doing occurs when people are actively engaged, either mentally or physically (Hitch, Pepin & Stagnitti, 2014). Literature shows that physically doing and being present at the scene of action without physically participating are equally important to promote the sense of participation of residents with dementia, especially those in later stages of dementia (Hitch, Pepin & Stagnitti, 2014). Enabling participation in meaningful occupations is the central feature of occupational therapy (Molineux & Baptiste, 2011), thus occupational therapists have the expertise to enable occupational engagement of the residents and promote their sense of participation.

#### *6. 2. 2. Belonging*

From occupational therapy perspectives, belonging refers to a sense of connection to other people, places, culture, communities and times (Hitch, Pepin & Stagnitti, 2014).

Central to belonging is the relationship between the person and their living environments that can elicit a sense of reciprocity, mutuality and sharing (Hitch, Pepin & Stagnitti, 2014). Thus for residents with dementia, belonging is associated with their interpersonal relationships with others within their communities in dementia care, including their care staff members and other residents, as well as a sense of connectedness to the physical environment within residential aged care facilities. The senses of inclusion and belonging to the living environment can enhance feelings of wellbeing and promote mental health of residents with dementia (Bailey & McLaren, 2005). With a specific focus on the belonging domain of occupation, occupational therapists have the knowledge and set of skills to promote a supportive environment where residents with dementia are feeling connected. This area of practice also reflects the PCC's emphasis on facilitative social environment.

### 6. 2. 3. *Becoming*

Occupational science defines becoming as the perpetual process of development and change that is driven by the person's goals and aspiration arising through choice or necessity (Hitch, Pepin & Stagnitti, 2014). Becoming resides within a person throughout the life and allows the person to continue to grow and be exposed to new experiences and challenges (Hitch, Pepin & Stagnitti, 2014). As occupational beings, residents in later stages of dementia have the right to express their aspirations, to continually grow and to live a desired and purposeful life. Occupational therapists who enable continued development (becoming) of the residents with dementia have the potential to assist the residents to defend their human rights, thus promoting justice in residential dementia care.

#### 6. 2. 4. *Being*

Within occupational science, being refers to a sense of self as an occupational being (Hitch, Pepin & Stagnitti, 2014). Being links to people's roles (Hitch, Pepin & Stagnitti, 2014). It encompasses the meanings people invest in life and their unique capacities. For many people, being can be expressed through consciousness and the roles people hold in life. Although being can exist independently during self-discovery and reflection, for people with moderate to advanced dementia who are dependent on others for basic functioning (WHO, 2012), occupational engagement supported by others may provide a valuable opportunity to elicit and maintain the sense of self of the residents with dementia. Therefore, occupational therapists addressing this domain of occupation are likely to support the sense of self of the residents with dementia and promote their wellbeing.

#### 6. 2. 5. *Co-occupation*

Leading theorists in occupational science suggest that human beings may also possess needs for 'co-occupation' which refers to occupational engagement that requires participation of two or more people and shared investment of all parties involved (Van Nes, Runge & Jonsson, 2009; Pierce, 2009). This dimension of occupation is characterized by interdependent relationships of all people involved and occurs when they perform shared 'doing' physically, emotionally and intentionally (Pickens & Pizur-Barnekow, 2009). This emphasis on shared-doing and interdependence implies that co-occupation can be perceived as the level of agency for doing, being, belonging and becoming. In consideration of the concept regarding agentic self in person-centered dementia care, co-occupation of residents with moderate to advanced dementia is fostered when interdependence is present during doing, being, belonging and

becoming.

Older adults may have a specific enquiry of co-occupation because of its impact on their wellbeing. Literature shows that engagement in co-occupation assists to maintain older persons' identities and therefore may contribute to their wellbeing in later life (Van Nes, Runge & Jonsson, 2009). In addition, the co-occupation, when people are involved with active agency, echoes the recent extension of person-centered dementia care concepts to valuing and supporting individual agency and promoting interdependence in care environments (Poland & Birt, 2016; Higgs & Gilleard, 2016). Therefore, occupational therapists can support person-centered care and promote wellbeing of the residents with moderate to advanced dementia by enabling engagement in shared-occupations.

In summary, the definitions of these five domains of occupation describe above imply that, in order to facilitate engagement in desired occupations of residents with dementia, occupational therapists should facilitate the person to: 1) engage in personally meaningful occupations (doing); 2) maintain the sense of self (being); 3) continually grow and develop (becoming); 4) nurture belonging to and build connections within the residential aged care facility as a micro-community (belonging); 5) foster interdependence when performing occupations (co-occupation).

## **7. Issues arising from literature review and research aims**

Supported by framework of doing, being, belonging, becoming and co-occupation as well as concepts regarding occupational justice, occupational therapists have the

expertise and set of skills to enable meaningful engagement and promote wellbeing of residents with dementia, those with moderate to advanced dementia in particular.

There is strong supporting evidence for occupational therapist' contributions to improving quality of life for people with moderate to advanced dementia. Literature shows that occupational therapy in residential dementia care is associated with improved cognitive and physical functioning, increased level of independence and enhanced social connection of residents in later stages of dementia (Arbesman & Lieberman, 2011; Gitlin et al., 2008; Graff et al., 2006;). Furthermore, a recent scoping review, conducted by Shparber, Du Toit & Lovarini (2016) reported that occupational therapy practice is associated with meaningful engagement of residents with moderate to advanced dementia. As stated earlier, PCC has been adopted as the guiding principle in residential dementia care, the underlying concepts should be used to guide service providers this field, including occupational therapists. However, it is unclear how occupational therapists incorporate concepts of person-centered dementia care into their practice when promoting meaningful engagement of residents with moderate to advanced dementia.

In order to bridge this gap in knowledge, this study explored how theoretical underpinnings of occupational therapy practice have influenced the implementation of the core concepts regarding person-centered dementia care. This study analyzed relevant documents to examine how person-centered dementia care is presented from an occupational therapy perspective. In this study, the framework of doing, being, becoming, belonging and co-occupation described above as well as concepts

regarding occupational justice are considered as the major theories influencing the occupational perspective of person-centered dementia care.

### **7.1. Implications for practice**

By exploring assumptions and the power structure underlying occupational therapy practice in residential dementia care, this study determined gaps and shortcomings of the professional practice in this field and discussed possible areas for improvement to advance person-centeredness and address occupational injustice in dementia care.

### **7.2. Statement of research question**

The guiding question of this study was as follows:

*What do occupational therapists consider to be person-centered practice when working with elders with moderate to advanced dementia residing in residential aged care facilities?*

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## SECTION II

### JOURNAL MANUSCRIPT

**TARGET JOURNAL:** **Scandinavian Journal of Occupational Therapy**

**TITLE:** **Unveiling the Concept of Person-Centered  
Dementia Care within Occupational Therapy  
in Residential Aged Care Facilities: A critical  
Interpretive Synthesis**

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## **Unveiling the Concept of Person-centered Dementia Care within Occupational Therapy in Residential Aged Care Facilities: A Critical Interpretive Synthesis**

### **Abstract**

**Background:** People with dementia living in residential aged care facilities are at risk of being deprived of occupational engagement. The link between occupational therapy and meaningful engagement of residents with moderate to advanced dementia has been established. Concepts regarding person-centered dementia care are adopted as the guiding principle for service providers in this field. However, it is unclear how occupational therapists embrace the essence of person-centered dementia care when promoting meaningful engagement of residents with moderate to advanced dementia. This study thus aims to explore how person-centered dementia care is presented from an occupational therapy perspective.

**Methods:** Thirty peer-reviewed articles were used as the source sample for this study. A critical interpretive synthesis was conducted to critically consider the power structure underpinning occupational therapy practice in residential dementia care. Evidence pertaining to occupational therapy practice was integrated and analyzed using concepts regarding occupational justice and themes of doing, being, becoming, belonging, and co-occupation to generate synthesis.

**Results:** This synthesis indicated that occupational therapists enhance occupational justice in residential dementia care by increasing access to meaningful engagement and enabling participation of residents in doing, being and belonging at the level of co-occupation where interdependence between residents and mainly staff members is

fostered. However, the becoming domain of occupation has not been comprehensively addressed. Thus, the needs of residents for continual growth and development as occupational beings have not been fully addressed by the current occupational therapy practice in residential dementia care.

**Conclusion:** This finding suggests expanding the role of occupational therapists to empower people with moderate to advanced dementia to enact and build on continuing opportunities for agency.

**Key words:** Agency; Doing, being, belonging, becoming; Co-occupation; Meaningful engagement; Moderate to advanced dementia.

## **Introduction**

There is strong evidence that engagement in meaningful occupations can enhance the wellbeing of older adults with dementia<sup>1, 2, 3</sup>. Occupations are defined as activities people want or need to do every day<sup>4</sup>. Engagement in these occupations by older adults living with dementia gives purpose to their lives, enhances physical and mental health, promotes self-confidence, and offsets the sense of hopelessness and frustration associated with dementia<sup>5</sup>. However, people with moderate to advanced dementia living in residential aged care facilities have unique challenges and limitations regarding occupational engagement. Due to the progressive deterioration in cognitive abilities<sup>6</sup>, people at later stages of dementia have severe cognitive deficits that significantly destruct their ability to participate in daily activities and socialize with others, placing them at risk for isolation and withdrawal from occupations<sup>7, 8, 9</sup>. This withdrawal from occupations is often reinforced by the environment of residential aged care facilities. These institutions are typically characterized by monotonic routines, offering limited personally meaningful activities to the residents<sup>10, 11</sup>. In addition, limited expertise of care staff members, and their preconceived ideas regarding the capacity of people with dementia to make decisions and retain control of their own lives<sup>12</sup> result in what Swaffer<sup>13</sup> termed Prescribed Disengagement™. This sets up care staff members to take over from residents with dementia and inhibit them from engaging in meaningful activities. Although the person-centered approach has been widely adopted in dementia care as a gold standard of care<sup>14</sup>, current environments in residential aged care facilities are likely to deprive residents with moderate to advanced dementia of opportunities for engagement in desired occupations, which may place them at risk of experiencing social and occupational injustice.

Occupational therapists can play a significant role in assisting residents with moderate to advanced dementia in pursuing social justice and defending their occupational rights. In adherence to the World Federation of Occupational Therapists (WFOT) Position Statement on Human Rights<sup>15</sup>, occupational therapists have a specific responsibility to support residents in accessing their right to live satisfying and meaningful lives. This responsibility involves enabling participation in occupations and increasing access to opportunities for meaningful engagement<sup>16, 17</sup>. A recent scoping review reports that meaningful engagement of residents with moderate to advanced dementia is in fact associated with occupational therapy practice<sup>18</sup>. As stated earlier, person-centered care (PCC) has been adopted as the guiding principle in residential dementia care, and the underlying concepts should be used to guide service providers in this field, including occupational therapists. However, it is unclear from the scoping study how occupational therapists incorporate concepts of person-centered dementia care into practice when promoting meaningful engagement of residents with moderate to advanced dementia. Thus, this study aims to bridge this gap in knowledge by reviewing studies included in the scoping review to examine how the essence of person-centered dementia care is presented from occupational therapy perspectives.

#### *Core concepts of person-centered dementia care*

Person centered care is prevalent in residential dementia care due to its beneficial effects on wellbeing and quality of life for residents with dementia<sup>19</sup>. Person-centered care values the person's experiences and make them the focus of care delivery, not their dementia<sup>20</sup>. A substantial amount of effort has been put into the development of person-centered dementia care concepts and philosophy over the past thirty years.

However, there appears to be a lack of worldwide consensus on unified terminology and the core concepts of person-centered dementia care. For the purpose of this study, a review of the most influential works in concept and theory development regarding PCC was conducted. The core concepts of PCC were summarized<sup>20-24</sup> (see Appendix Table 1) to provide a conceptual framework of the ethos supporting this social model of care. Table 1 highlights the following common themes which can be used as a guiding framework to consider occupational therapy practice within residential dementia care context: (1) addressing the person's social environment to support their personhood (defined by Kitwood<sup>21</sup> as a sense of self based on positive relationships with others); (2) acknowledging the uniqueness of the person; (3) respecting autonomy, dignity and rights of the person; (4) focusing on the person's strengths and positive aspects rather than deficits and weaknesses; (5) valuing the person's perspective and subjective experiences; (6) valuing and supporting care staff and other stakeholders to co-construct a caring relationship; (7) enabling the person to enact and build on continuing opportunities for agency.

### *Occupational justice*

Advancing occupational justice is an integral part of occupational therapy practice<sup>16, 25</sup>. The World Federation of Occupational Therapists<sup>15</sup> (WFOT) issued a Position Statement asserting that all people have the right to participate and be supported to participate to their potentials in desired and valued occupations. This statement also asserted that this human right to occupational engagement should be ensured by equitable access to participation. To guide the occupational therapy practice, concepts of occupational justice and the Participatory Occupational Justice Framework<sup>26</sup> have been developed, see Appendix Table 2<sup>16, 25-34</sup>. These concepts imply that when

enabling meaningful engagement of residents with dementia, occupational therapists should do the following: (1) work in partnership with the person; (2) identify the person's strengths, abilities, and relevant resources (personal and environmental); (3) discern the impact of institutional and social conditions/structures within a residential aged care facility and seek to engage key stakeholders; (4) facilitate different opportunities and resources while considering social conditions/structures within residential aged care facilities. In addition to concepts regarding occupational justice, the professional practice of occupational therapy is also supported by theories from occupational science.

*Doing, being, becoming, belonging and co-occupation*

The professional practice of occupational therapy is grounded in the discipline of occupational science. Occupational science proposes that humans are occupational beings and argues that occupational engagement and occupational balance can influence a person's health<sup>30-32</sup>. To support a person's health, leading theorists in occupational science contend that a dynamic balance between 'doing', 'being', 'becoming' and 'belonging' needs to be achieved<sup>30, 31</sup>. Building on this premise, Pierce<sup>33</sup> suggested that human beings might also possess needs for 'co-occupation' which refers to occupational engagement that requires the participation of two or more people. Older adults may have a specific enquiry of shared doing because engagement in co-occupation helps maintain their identities and therefore may contribute to their wellbeing in later life<sup>34</sup>. We propose that occupational therapists working for older people with moderate to advanced dementia living in residential care facilities need to focus on the synthesis of these five dimensions of occupation. The definitions of these dimensions<sup>16, 25-34</sup> (see Appendix Table 2) imply that, in order

to facilitate engagement in desired occupations, occupational therapists should facilitate the person to do the following: (1) engage in personally meaningful occupations (doing); (2) maintain the sense of self (being); (3) continually grow and develop (becoming); (4) nurture belonging to and build connections within the residential aged care facility as a micro-community (belonging); (5) foster interdependence when performing occupations (co-occupation).

The link between occupational therapy and the meaningful engagement of residents with moderate to advanced dementia has been established in the scoping review conducted by Shparberg et al.<sup>18</sup>. However, this study did not examine how theoretical underpinnings of occupational therapy practice have influenced the implementation of the core concepts of person-centered dementia care. Therefore, the present study analyzes documents identified in the scoping review<sup>18</sup> to examine how person-centered dementia care is presented from an occupational therapy perspective. In this study, the framework of doing, being, becoming, belonging and co-occupation described above as well as concepts of occupational justice are considered as the major theories underpinning occupational therapy practice that promotes justice and meaningful engagement of the residents with moderate to advanced dementia. This study aims to determine gaps and areas for improvement in occupational therapy practice to reflect the essence of PCC, and address occupational injustice in residential dementia care. The guiding question of this study was as follows:

*What do occupational therapists consider to be person-centered practice when working with elders with moderate to advanced dementia residing in residential aged care facilities?*

## **Methods**

### *Research design*

An integrative and interpretive study design using critical interpretive synthesis (CIS) was selected for this study. Critical interpretive synthesis is a form of systematic review that aims to provide a fundamental critique to the examined topic by critically considering diverse studies and taken-for-granted assumptions influencing associated conceptualizations<sup>35</sup>. Therefore, CIS is well suited to areas where existing assumptions and power structures of a topic need to be examined.

### *Search strategy and inclusion criteria*

Shparberg et al.<sup>18</sup> used a scoping review methodology to investigate occupational therapy practice and the occupational therapist's role in relation to meaningful engagement for people with dementia living in residential aged care settings. Eighteen databases were searched. After extensive screening processes, 36 articles were included in the scoping review. These included articles adhered to the inclusion process in the CIS that aims to identify relevant material to provide a sampling frame<sup>35</sup>. Thus the documents included in the scoping review were used in the current study to generate synthesis. All grey literature was excluded to decrease resource bias and improve reliability of synthesis<sup>36</sup>.

### *Data analysis and generating synthesis*

Included articles were reviewed and categorized according to their focus. The full text related to occupational therapy specifically was analyzed and coded because of its high relevance to the research topic. An inductive thematic analysis was applied to generate synthesis. This open coding approach was employed to identify all passages

of text relevant to at least one of the following areas of occupational therapy practice: attitudes, knowledge, skills, conceptualizations, roles, practice, rationale for practice, interventions, assessments, and evaluations.

The current study adopted steps for inductive thematic analysis described by Braun and Clarke to facilitate synthesis<sup>37</sup>. This involved a six-step process where (1) each article was read thoroughly and understood in relation to both itself and the research question; (2) passages of text pertinent to both occupational therapy practice and person-centered care were extracted and then coded by the first author; (3) the codes and relevant data extracts were displayed in an excel table and independently checked by the second and third author; (4) similarity in codes was identified; (5) themes were then constructed and reviewed.

Relationships between the generated themes were then explored to generate explanatory accounts. Integration of evidence in this way thus allowed new interpretations of data which is grounded in existing evidence<sup>35</sup>.

This synthesis was based on publicly available publications, thus ethics approval was not required.

## **Results**

### *Overview*

The 30 included studies were categorized into theoretical papers and empirical research focusing on assessment and intervention<sup>8, 10, 38-65</sup> (see Appendix Table 3 for summary). Five conceptual articles, including opinion pieces and editorials, presented

the theoretical understanding of ways to promote meaningful engagement. Fourteen research articles focused on occupational therapy assessment of factors contributing to meaningful engagement. Eleven articles described and evaluated intervention to enable meaningful engagement.

Fifteen categories were generated and combined into six themes (Table 4). Collaboration and tailored practice are two themes that underpin the other four themes, that is, doing, being, belonging, and becoming of the residents. The themes are interrelated but, for the purpose of clarity, will be presented separately in the following section.

**Table 4. Summary of themes with supporting subthemes and quotes**

<b>Doing of residents</b>	
<b>Ensuring activities are suitable for the resident</b>	<p><b>Using familiar daily activities as an intervention approach.</b>  <i>'...these daily activities are simple and do not require new learning...'</i><sup>59</sup></p> <p><i>'...because they are performed repetitively over decades by the resident and hence are better retained as procedural memory until late in dementia.'</i><sup>43</sup></p> <p><b>Tailoring activity to residents' current ability range to support performance and create just right challenge</b>  <i>'...after a client's interests and physical, cognitive, and sensory abilities have been evaluated, the occupational therapist prescribes three activities tailored to his or her specific interests and abilities, with the activities meant to be completed before a difficult ADL task.'</i><sup>38</sup></p> <p><b>Providing prompts and cues according to residents' abilities and preferences</b>  <i>'Taking account of the resident's cognitive impairment, verbal explanation of the activities is replaced with visual demonstration and multi-sensory cueing.'</i><sup>64</sup></p> <p><i>'...a hand-under-hand approach if R prefers contact with the palm, rather than on the dorsal surface.'</i><sup>64</sup></p>

	<p><b>Adapting the rule and equipment to engage all participants in group activities.</b>  <i>'The entire group was engaged at various levels of baking and all enjoyed the end result of cupcake.'</i><sup>61</sup></p> <p><b>Considering residents' preferences regarding the way of doing.</b>  <i>'...older people may appreciate being at the scene of action without having to do anything themselves ... Being present without participating leads us to believe that some residents want entertainment rather than wanting to participate.'</i><sup>52</sup></p>
<p><b>Altering residents' immediate environment to promote participation in activities</b></p>	<p><b>Educating care staff members about how to adapt daily activities and facilitate participation according to the residents' individual needs and ability.</b>  <i>'...occupational therapists should mentor frontline caregivers, teaching and modeling strategies for designing and implementing activity situations that optimize the interests, capacities, and participation of residents with dementia.'</i><sup>55</sup></p> <p><b>Adapting physical context to compensate for residents' unique limitations and meet their abilities.</b>  <i>'... placing label on drawers and closet doors, setting up the workstation with items visible, removing distracting items from workspaces before tasks were initiated and providing ADL equipment.'</i><sup>48</sup></p> <p><b>Promote interdependence between care staff members and residents to facilitate participation in activities.</b>  <i>'...bridging, using a hand-held object, often enables a shared feeling of participation, and can be used...at mealtimes, dressing, and during hygiene and exercise.'</i>  64</p> <p><i>'...independence in ... eating could be facilitated...by establishing an interdependence between staff and persons with dementia, even if a person can take only a few bites on his own during meal times.'</i><sup>50</sup></p>
<b>Being of residents</b>	
<p><b>Using residents' life story to promote a sense of continuity with their previous identities</b></p>	<p><b>Incorporating residents' former interests and previously enjoyed activities into therapy</b>  <i>'...activities become meaningful, motivating and pleasurable for the individual if they are related the person's individual values, unique past life experiences, life roles and routine.'</i><sup>59</sup></p>

<p><b>Facilitating spontaneity of residents</b></p>	<p><b>Promoting spontaneous activities where residents are permitted to take control of their own actions.</b>  <i>'...responded to their (residents') mood, catered to different levels of function...and allowed residents to engage in familiar pastimes as opposed to unfamiliar tasks.'</i><sup>47</sup></p> <p><i>'...playing games following the participant's lead rather than existing rules.'</i><sup>57</sup></p> <p><i>'...only interject(s) to ensure resident safety or to present sensory items when the residents were lethargic.'</i><sup>41</sup></p> <p><b>Involving care staff members in promoting spontaneous activities</b>  <i>'... caregivers to welcome the help of a resident who enjoys setting up table at mealtime.'</i><sup>38</sup></p> <p><b>Advocating for changes in institutional and physical environment to enable choices and empower residents to initiate activities independently</b>  <i>'...resident choice is facilitated in important issues such as when to get up in the morning, when to have a meal and participation in activities.'</i><sup>59</sup></p> <p><i>'It is thought that the presence of familiar objects, combined with some clients engaged in their use, helps other clients to self-initiate their own participation in a task.'</i><sup>38</sup></p> <p><b>Providing options to stimulate residents to make choices.</b>  <i>'...offering options in stimulating the resident to make choice and maintaining their autonomy.'</i><sup>47</sup></p>
<p><b>Belonging of residents</b></p>	
<p><b>Educating care staff members about adapting care practice to residents' retained capacities and needs for interaction</b></p>	<p><b>Teaching care staff members about how to stimulate and maintain conversation with residents</b>  <i>'...care staff members need to be aware that the over-learned daily activities provide topics for conversation and thereby initiate spontaneous interactions.'</i><sup>56</sup></p> <p><b>Educating the care staff members about the knowledge of dementia and its unique impact on different residents</b>  <i>'...knowledge of the disease and consequences for the resident, and analysis of remaining capacities, must be used as the basis for how daily occupations are adapted to meet the residents' needs.'</i><sup>51</sup></p>

<p><b>Creating opportunities for group activities built around shared interests to enable social interaction</b></p>	<p><b>Grouping people by cognitive levels and common interests to promote a sense of connectedness</b>  <i>'... intervention works best in a peer-to-peer living environment where people are grouped in living spaces by care and cognitive levels.'</i><sup>38</sup></p> <p><i>'...group reminiscence session where participants all have crafting as their former leisure activity...hearing other people's recollections triggers one's own half-forgotten memories and generates a collective sense of shared experience.'</i><sup>44</sup></p> <p><b>Using residents' life story to inform share activity.</b>  <i>'... understanding and success are expanded when the person's life story is known and used for the implementation of shared activity.'</i><sup>68</sup></p>
<p><b>Becoming of residents</b></p>	
<p><b>Exercising retained capacities and upholding current strength</b></p>	<p><b>Building activities around the residents' previous skills and former interests help maintain their retained capacities</b>  <i>'...building these activities around the person's earlier skills and interests may elicit preserved capabilities and concealed remaining strengths.'</i><sup>44</sup></p> <p><i>'...the familiarity and repetitive aspects (of lifework activities) enable the person with dementia to actively engage with a focused and/or increased span of attention.'</i><sup>64</sup></p>
<p><b>Using meaningful occupations to improve current abilities.</b></p>	<p><b>Using tasks related to residents' past life to restore lost occupational skill</b>  <i>'...task-specific and meaningful occupations (e.g., using chopsticks to eat, cooking, knitting) are used during training to acquire occupational skills.'</i><sup>43</sup></p>
<p><b>Collaboration</b></p>	
<p><b>Including residents in decision making and goal setting</b></p>	<p><b>Observing residents' behavior and consulting with key stakeholders to formulate therapy goal</b>  <i>'Individual interview was conducted with residents to formulate an individualized and realistic occupational performance goal.'</i><sup>43</sup></p>
<p><b>Involve and collaborate with key stakeholders in occupational therapy process</b></p>	<p><b>Involve family and care staff members in data collection and decision making process</b>  <i>'...family members were asked to provide factual information about the participant, including their crafting activities.'</i><sup>44</sup></p> <p><i>'... caregiver for each resident in the assisted living facility was also present during the interview to confirm the appropriateness and familiarity of the chosen</i></p>

	tasks. <sup>48</sup>
<b>Tailored practice</b>	
<b>Understanding the resident to inform practice</b>	<p><b>Using standardized assessment to identify residents' current level of ability</b>  <i>'...Mini-Mental State Examination... Dementia Rating Scale-2 was administered to understand the resident's current level of cognitive function.'</i><sup>45</sup></p> <p><b>Obtaining information regarding residents' past life experiences and roles.</b>  <i>'...family members were asked to provide factual information about the participant, including their crafting activities.'</i><sup>44</sup></p> <p><i>'...medical and social histories and previous driving experiences were collected from the medical record.'</i><sup>45</sup></p> <p><b>Using observation as an approach to understand residents' subjective experiences and understanding the cause of residents' negative behaviors to determine their desire and volition.</b>  <i>'Multidimensional Observation Scale for Elderly Subjects were conducted to determine self-care functioning, disoriented behavior, depression/anxiety, irritability, and withdrawn behavior.'</i><sup>43</sup></p> <p><i>'....Activity in Context and Time (ACT) to record the resident's occupational patterns and their affect throughout a typical day in the long-term care facility.'</i><sup>54</sup></p>
<b>Use knowledge regarding the person to tailor practice</b>	<i>'....one must perceive the person's emotional tone and understand any contradictory or confusing behavior in order to recognize desires and preferences.'</i> <sup>57</sup>

### *Theme 1: Collaboration*

Collaboration refers to the involvement of the resident and key stakeholders in the occupational therapy. The resident is included in the process of decision-making and goal setting<sup>43, 45, 48</sup>. Individual interviews with the resident are conducted to determine meaningful occupations and prioritize issues to be addressed<sup>45</sup>. Care staff members

and family members are also involved in the process of data collection and decision-making. For instance, in consideration of the resident's cognitive deficits, behavior observation and consultation with care staff members are performed to validate information from the interview and formulate an individualized occupational performance goal<sup>43, 45</sup>.

### *Theme 2: Tailored practice*

Tailored practice describes the process of individualizing occupational therapy practice to meet the resident's specific needs. Two subthemes are included.

*Understanding the resident.* Understanding the resident refers to the process of obtaining factual information to appreciate the resident's circumstances and subjective experiences. It is the first step of occupational therapy practice in promoting meaningful engagement. The body of knowledge regarding the residents' current competence level and life story is obtained through administering standardized assessment<sup>43, 45, 57</sup>, consulting with key stakeholders<sup>44, 45</sup>, and referring to medical notes<sup>45</sup>. Observational tools are also commonly used to understand residents' occupational patterns, social interaction and affect throughout a typical day in the long-term care facility<sup>43, 52-54, 59</sup>.

*Knowledge of the resident informs personalized practice.* Knowledge of the resident is then used to inform personalized practice, and thus serves as the foundation of personalized occupational therapy practice. This knowledge is integrated to identify the cause of negative behaviors<sup>41, 57</sup> and help recognize desires and preferences of the resident<sup>43, 52-54, 59</sup>, unveiling the challenges facing the individual resident<sup>43-45</sup>. Knowledge regarding residents' interests, volition, strength, and ability range also enables therapists to determine personally meaningful occupations and make resident-

specific adaptations<sup>41, 44, 45, 57</sup>. This approach is driven by the fact that in-depth knowledge about the resident provides a basis for planning a personalized and appropriate intervention<sup>41, 44, 45, 57</sup>.

### *Theme 3: Doing*

The theme of doing is focused on engagement in meaningful occupations by residents and is supported by two subthemes.

*Ensuring activities are suitable for the resident.* Efforts are devoted to ensuring that the occupations used as the intervention approach match residents' retained capacities and interests<sup>8, 38, 41, 49, 61, 64</sup>. Given the communicative and cognitive impairments of the residents, simple and repetitive routine activities and lifework activities mastered by the residents in their earlier life are perceived as valuable opportunities to engage them in doing as they *do not require new learning*<sup>59</sup> and are retained as *procedural memory until late in dementia*<sup>43</sup>. Based on the knowledge regarding residents' physical, cognitive, and sensory abilities<sup>8, 38, 51, 62, 60</sup>, the chosen activities are adapted and tailored to enable participation and challenge residents at the just-right level<sup>8, 38, 55, 51, 62</sup>.

To engage residents in group activities of their interest, performance expectations are alternated to fit the individual members' abilities so that *members participate at their own cognitive levels and abilities*<sup>38, 61</sup>. In order to support participation, personalized prompts according to individual competence levels are provided<sup>38, 48, 60, 61, 64</sup>. For instance, considering the resident's cognitive impairment and to support the resident in integrating information<sup>64</sup>, verbal explanation of the activities is replaced with visual demonstration and multi-sensory cueing.

The resident's preferred way of doing also receives broad consideration. Levels of mood, engagement, and preferences regarding occupational forms of their desired activities are unveiled via administering assessments that involve observing the resident's behavior (e.g., Behavior Category Code<sup>50</sup>), their subjective experiences of care (Dementia Care Mapping (DCM)<sup>50</sup>), and their occupational pattern (e.g., Assessment Tool for Occupation and Social Engagement (ATOSE)<sup>56</sup>). Resident-specific modifications are made accordingly, such as letting the resident present at the scene of action without physically participating<sup>52</sup> or following the resident's lead during an activity rather than established rules<sup>57</sup>.

*Altering the resident's immediate environment to promote participation in activities.*

The physical, social and institutional environments in which residents live are considered as interrelated influencing factors in terms of the level of engagement in occupation, and thus are addressed as a whole to increase the potential for occupational engagement. Physical context is modified to compensate for residents' personal limitations and fit their abilities<sup>8, 38, 41, 45, 48</sup>. For instance, in consideration of the residents' level of cognitive function and stimuli tolerance, distracting items are removed from the workplace before activities start<sup>48</sup>. Furthermore, residents' social environment, their relationship with care staff members in particular, is addressed to promote resident participation in more constructive activities<sup>39, 55</sup>. Training is provided to care staff members to facilitate a deep understanding of occupation and dementia<sup>8, 51, 56, 63, 64</sup>. Care staff members are also taught strategies for modifying occupational forms of routine activities to optimize the resident's interests and maximize participation in daily activities where their retained capacities are tapped<sup>8, 51, 55, 56, 63, 64</sup>. Furthermore, care staff members are educated on forming

interdependence with residents ('working with' rather than 'working for') to enhance resident engagement in daily routine activities. For instance, the application of the 'bridging' (e.g., using a hand-held object) approach at mealtimes is recommended to promote a *shared feeling of participation*<sup>50, 64</sup>. Changes at the organizational level are also emphasized to support the development of interdependence between care staff members and residents, thus indirectly facilitating engagement in desired occupations. This approach is grounded in the belief that care staff members treated by the organization in a person-centered way will serve residents through PCC<sup>49</sup>. Servant leadership is therefore proposed to substitute authoritarian leadership style to enhance the knowledge level of care staff members regarding PCC, empowering them to take initiative and be creative<sup>49</sup>.

#### *Theme 4: Being*

The theme of being is focused on maintaining a sense of self and is supported by the following two subthemes.

##### *Using the resident's life story to promote a sense of continuity with previous identity.*

A sense of continuity with previous identity is supported by incorporating the residents' former interests and previously enjoyed activities into therapy<sup>8, 64, 41, 44, 59</sup>. Activities are believed to be personally meaningful, motivating, and pleasurable if they are related to residents' individual values, unique past life experiences, life roles and routines<sup>59, 63, 64</sup>. For instance, reminiscence based on residents' experiences and mastered skills in the past is used as a means of connecting residents to their past identities<sup>39, 44</sup>.

*Facilitating spontaneity to maintain autonomy.* Spontaneous involvement of residents is valued in occupational therapy practice as it *responds to their mood, catered to different levels of function*<sup>49</sup>, and allows them to take control of their own actions<sup>47</sup>. To promote spontaneity, occupational forms of activities and therapy intervention are modified. For instance, the therapist acts as a facilitator and follows the resident's lead<sup>41</sup>. Environment is also addressed to enable spontaneous involvement. Care staff members are encouraged to facilitate spontaneous activities of the resident's choice<sup>38</sup>,<sup>47</sup>. Changes in operational environments, such as adopting a flexible daily routine, are recommended to respect the resident's individual preferences. Resident-specific modifications are also made to the physical environment. Placing personal belongings in residents' rooms is recommended in order to set up a home-like environment, where residents' sense of control is nurtured<sup>38, 43, 44, 57</sup>. Familiar objects are also commonly used in reminiscence sessions as a means of triggering residents' memories, spontaneous involvement and interaction<sup>38, 43, 44, 57</sup>.

#### *Theme 5: Belonging*

The theme of belonging is focused on building connections between residents and their immediate environment and supported by two subthemes.

*Educating care staff members about adapting care practice to resident's retained capacities and needs for interaction.* In response to poor quality of social engagement identified among residents with dementia<sup>47, 56, 63, 64</sup>, staff training regarding stimulation and maintenance of conversation and meaningful interaction with residents is highlighted<sup>47, 56</sup>. Spontaneous conversation is considered more meaningful than conversation around typical care tasks as it *gives a sense of aliveness to*

*conversation*<sup>56</sup>. To initiate spontaneous interactions, strategies such as basing topics for conversation on activities that are important and familiar to the resident, are provided to care staff members<sup>56</sup>. Education on the consequences of dementia and the impact of social engagement on wellbeing is also emphasized because it facilitates deep understanding and valuing of meaningful interaction<sup>51</sup>.

*Creating opportunities for group activities built around shared interests to enhance social interaction.* Group activities are carefully structured to provide opportunities for facilitating a sense of connectedness<sup>38, 44, 51, 64</sup>. To promote a sense of shared experience, residents are grouped by their level of competence, life experiences, and common interests<sup>38, 44, 51, 64</sup>. For instance, older female residents with dementia who had crafting as a former leisure activity are invited to a group reminiscence session around crafts<sup>44</sup>.

#### *Theme 6: Becoming*

Central to the theme of becoming is facilitating re-engagement in daily activities by exercising residents' retained capacities and restoring their lost occupational skills<sup>43, 57</sup>. To achieve this, activities built on residents' previous skills and former interests are used as the intervention approach to elicit their preserved capabilities, such as procedural memory<sup>43, 44, 57, 64</sup>. Owing to the familiarity and repetitive aspects, routine tasks, such as using utensil to eat or knitting<sup>43</sup>, are used to exercise the residents' retained cognitive capacities and acquire lost occupational skills. Topics for reminiscence are set around lifework activities, such as crafting, enjoyed and mastered by the residents in their earlier life, to recall memory and trigger relevant motor movements<sup>44</sup>.

## **Discussion**

The purpose of this synthesis was to explore occupational therapists' perspective of person-centered dementia care when facilitating meaningful engagement of people with moderate to advanced dementia living in residential aged care facilities. This study critically considers assumptions underlying occupational therapy practice in this field. Through this, we can discuss possible areas for improvement in professional practice to enhance person-centeredness and address occupational injustice in residential dementia care.

The findings indicate that enhancing functional independence is a major drive in occupational therapy practice to promote resident autonomy and spontaneity and to facilitate the interaction between residents and care staff members. Limited efforts appear to have been devoted to fostering interdependence between residents and others that helps support residents' social standing within their communities. Residents with moderate to advanced dementia need to be empowered to express their aspirations for future and their own voice. The current study indicates that occupational therapists promote meaningful engagement in doing, being and belonging at the level of co-occupation, where interdependence between mainly care staff members and residents is fostered. Therefore the development of social interdependence can be expanded to involving other care partners such as family members and volunteers.

Additionally, becoming as a dimension of occupation has not been comprehensively addressed. Thus residents' needs for continual growth as occupational beings appeared to have not been fully addressed in current occupational therapy practice in

residential dementia care. Humans need the opportunity for experiencing continued development throughout life to develop a sense of control and experience purposeful lives<sup>66</sup>. Therefore older people with dementia have the right to be supported and to continue to develop as individuals, even when their abilities decline and they reside in residential aged care facilities.

Our findings show that occupational therapists work in partnership with residents to promote engagement in meaningful doing, being and belonging. Knowledge regarding the resident's life story, interests, volition, current capacities and strengths are obtained to personalize activity options. Simple routine activities that are familiar and meaningful to the residents in their earlier life are chosen and adapted to match residents' retained capacities and current strengths. This resident-specific adaptation to familiar routine activities grounded in the resident's life story not only enables participation (doing) but also promotes a sense of continuity with their previous identity (being). The resident's sense of self (being) is further supported by the provision of opportunities to exercise agency and choice in their expression of being. Residents are included in decision making and goal setting processes, where they are given opportunities to show their current interests and motivation. Furthermore, collaborating with residents in decision-making facilitates the development of positive and respectful therapeutic relationships, which in turn improves the resident's interpersonal relationships with the therapist, and thus promotes a sense of connectedness (belonging). In addition, the resident's sense of control and autonomy is supported by providing options for activities to participate in and materials to be used (being). Moreover, spontaneous involvement is promoted and valued by permitting the resident to take control of their own actions and following the resident's lead during intervention. In addition, residents' subjective experiences are

attended and responded to by adapting action and/or intervention accordingly. In this way occupational therapists look to the residents to lead them to an understanding of what action and activities are appropriate and meaningful.

In addition, findings of this synthesis also indicated that engagement is supported through addressing residents' environment and increasing access to meaningful engagement. Residents' social environment is addressed by educating and empowering care staff members to increase interaction with residents and encourage residents to participate in routine care tasks. By engaging care staff members, the key stakeholders involved in dementia care, an enabling environment for interactive occupation is created where residents not only have more opportunities to participate in doing, but also develop a sense of connectedness to their environment as a result of increased social interaction (belonging).

Furthermore, this synthesis also shows that occupational therapists focus on the experiences of participation or the process of doing, rather than the product or outcome. Viewing the process of doing as the therapeutic goal rather than the outcome, attending to the resident's subjective experiences, and adjusting action accordingly suggest that occupational therapists value the 'here and now' of the residents.

However, this synthesis reveals that *becoming* of the residents has not been fully supported. Becoming is rarely the consequence of an individual's pure vision, rather, it relies on the stimulation and support from others<sup>30</sup>. Within the context of residential dementia care, the interdependence between residents, those with moderate to

advanced dementia in particular, and their social environment and support from especially care staff members, are essential to achieve the sense of becoming. This synthesis indicates that although occupational therapists engage care staff members in supporting the doing, being, and belonging of the resident, the resulting relationship between care staff members and the residents could unintentionally inhibit the becoming of these residents. Findings indicate that occupational therapists encourage care staff members to engage residents in daily care tasks through stimulating conversation and/or involvement in simple steps of a task. These findings imply that care staff members direct and instigate the activities providing opportunities for participation and social engagement, while residents react with the passive acceptance of an act. Therefore, although co-doing is occurring, co-occupation which is based on the interdependence and shared investment of all the participants is not achieved. In this stance, the residents are deprived of opportunities for enacting their agency.

This synthesis also indicates that occupational therapists appear to put little effort into empowering residents with moderate to advanced dementia to develop authorship of change to exert influence within their own lives. Therapists provide residents with options to make choices and opportunities for spontaneity once involvement has been established. However, the resident's active agency has not been enacted. In other words, they are still the subject rather than the active agent of their experiences.

Therefore, the current practices of occupational therapists could result in suppressed agency of the residents, and in fact do not support the preserved capabilities of residents with moderate to advanced dementia. Recent developments in concepts associated with PCC emphasize that interdependent relationships between care staff

members and the residents, where the residents are positioned as partners in co-constructing the care relationship, need to be nurtured<sup>23</sup>. Given the deterioration in cognitive capacities and daily functioning, residents at later stages of dementia rely on others for basic needs and care<sup>67</sup>. This creates opportunities for supportive interdependence between the residents and their care partners<sup>67</sup>. Development of interdependence between care partners and residents, where residents are the active agent and creator of the care relationship, will ensure the residents have continuing opportunities for enacting agency and having a stronger voice of their own within their care community<sup>23</sup>. Therefore, this study suggests that occupational therapists may expand the scope of practice to develop a positive interdependence with residents to empower and support them to continually enact their agency. This would allow for therapists to recognize the resident's aspirations and emerging interests, and provide them with opportunities for experiencing novel challenges and learning new things. In this way the residents are facilitated to continually grow and develop as occupational beings.

### **Limitations**

This study included only peer-reviewed articles to generate synthesis. Grey literature, such as PhD and master thesis, that focus on occupational therapy practice promoting meaningful engagement of residents with dementia were not included as data and therefore may deflate effect size estimates.

Although this study exposes shortcomings in how occupational therapists address PCC practice, it is still not sufficient to advance becoming or agency of residents with dementia. Future research is required to examine the possibility and efficacy of this area of practice.

## **Conclusion**

The current occupational therapy practice within residential dementia care promotes meaningful engagement in doing, being and belonging at the level of co-occupation where interdependence between mainly care staff members and residents is fostered. The becoming domain of occupation has not been comprehensively addressed. This study suggests that occupational therapists should support and facilitate a sense of agency for residents with moderate to advanced dementia. Promoting ongoing development of residents as care recipients and occupational beings should counteract Prescribed Disengagement™. This implies that occupational therapists should advance their person-centered practice within residential care settings by moving beyond the scope of recognizing personhood to focusing on enabling interdependent relationships between residents and all significant role players in their everyday lives.

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## Appendix

**Table 1<sup>20-24</sup>. Core conceptual components of PCC in dementia care.**

<b>The essence of person-centered care in residential aged care facilities</b>	
<b>Authors</b>	<b>Central elements of person-centered dementia care</b>
<b>Kitwood, 1997<sup>21</sup></b> - Dementia-specific	<ul style="list-style-type: none"> <li>- Support the personhood of people with dementia by facilitating positive interactions and mutually empathetic relationships between people</li> <li>- Focus on the strengths/abilities of the person rather than on deficits and diminished/lost capabilities</li> </ul>
<b>Brooker, 2007<sup>22</sup></b> - Dementia-specific	<b>Four core themes of person-centered dementia care – VIPS framework</b> <ul style="list-style-type: none"> <li>- Value people with dementia and their care providers.</li> <li>- Use Individualized approach to recognize uniqueness.</li> <li>- Understand the world from the Perspective of people with dementia.</li> <li>- Create a Social environment that supports psychological needs.</li> </ul>
<b>Edvardsson et al., 2010<sup>20</sup></b> - Dementia-specific	<b>Components of person-centered dementia care defined by people with dementia and their family members and care staff</b> <ul style="list-style-type: none"> <li>- Promote a continuation of self and normality</li> <li>- Know the person</li> <li>- Welcome and involve family</li> <li>- Provide activities that are meaningful to the person</li> <li>- Create a personalized environment</li> <li>- Experience flexible routines and continuity of care partners</li> </ul>
<b>Poland and Birt, 2016<sup>23</sup></b> - Dementia-	<ul style="list-style-type: none"> <li>- Support citizenship of the person within residential dementia care settings with stronger voice of their own.</li> <li>- Consider the person with dementia as a partner in co-contracting the care relationship, in order to empower the person to enact and build on continuing opportunities for agency</li> </ul>

specific	
<b>Hughes et al., 2008<sup>24</sup></b> - Different types of person-centeredness - General practice	<b>Nine common themes of different person-centeredness (client-centered, family centered; client driven):</b> - Respect for individuality and values - Meaning: accepts unique perspective reflecting the subjective nature of the person's - Social context and relationships: recognize family and the person's needs, as is the relevance of roles and life stages; seeing social network of relationships as a whole - Inclusive model of health and well-being - Expert lay knowledge: the person's and family's knowledge and experiences are valued. - Shared responsibility: share power; mutual agreement on plans - Communication: Sensitive dialogue; observational skills; - Autonomy: make choices - Professional as a person: value and support staff

**Table 2<sup>16, 25-34</sup>. Theories underpinning OT practice in dementia care settings.**

<p><b>Theories influencing OT's perspective when promoting ME</b></p>	<p><b>Core ideas</b></p>
<p><b>Occupation justice</b> (POJF<sup>26</sup> and relevant concepts):</p>	<p><b>People are occupational and social beings.</b></p> <p><b>Occupational justice<sup>25</sup></b></p> <ul style="list-style-type: none"> <li>- Enablement of fairness and equal opportunity</li> <li>- No discrimination based on ability, age, or other factors</li> <li>- Social commitment to universal design and accessibility</li> <li>- Enabling everyone to flourish to their greatest potential individually or as members of communities</li> </ul> <p><b>Occupational rights<sup>25</sup></b></p> <ul style="list-style-type: none"> <li>- Rights to meaningful occupational engagement,</li> <li>- Enrichment and growth through occupational engagement,</li> <li>- Choice, control and autonomy around occupational engagement</li> <li>- Balanced occupational engagement with neither too much nor too little to do over a lifetime and in particular circumstances</li> </ul> <p><b>Enabling<sup>27</sup></b></p> <ul style="list-style-type: none"> <li>- Promote shared responsibility and client participation</li> <li>- Respect and value client views, experience and interests</li> <li>- Recognize clients' strengths and experiences</li> </ul>

	<p><b>Occupational justice participatory</b><sup>28</sup></p> <ul style="list-style-type: none"> <li>- Promote meaningful engagement in desired occupations</li> <li>- Enable different opportunities and resources, meanwhile considering social structures</li> <li>- Enable difference for social inclusion</li> </ul> <p><b>Collaborative</b><sup>27, 29</sup></p> <ul style="list-style-type: none"> <li>- Working in partnership with clients</li> <li>- Sharing of responsibilities and risks</li> <li>- Engaging key stakeholders</li> </ul> <p><b>Critical OT practice</b><sup>16</sup></p> <ul style="list-style-type: none"> <li>- Identify and value client’s abilities and resources;</li> <li>- Identify environmental resources and barriers</li> <li>- Discern the impact of institutional and social conditions/structures on wellbeing</li> </ul>
<p><b>Framework of being, doing, becoming, belonging and co-occupation</b><sup>30-34</sup>;</p>	<p><b>Five dimensions of occupation</b></p> <p>1. <b>Doing</b>: process of engaging in occupations.</p> <p>(Key words/concepts: Physically and/or mentally doing)</p> <ul style="list-style-type: none"> <li>- Involves engaging in occupations that are personally meaningful, but not necessarily purposeful.</li> <li>- Involves being actively engaged, either mentally or physically.</li> </ul> <p>2. <b>Being</b>: is the sense of self is as occupational beings.</p> <p>(Key words/concepts: Promote a sense of self as occupational and human beings; Being as essence, entity, and existing; Being links to people’s roles)</p> <ul style="list-style-type: none"> <li>- Encompasses the meanings people invest in life, and their unique abilities.</li> </ul>

- Occupation may provide a focus for *being*,
- Can exist independently during reflection and self discovery.
- Expressed through the roles people have in life.

3. ***Becoming***: perpetual process of growth and change

(Key words/concepts: Change and development; Goals; Managing and maintaining; Opportunity to experience novel changes)

- Reside within a person throughout their life.
- Driven by goals and aspirations

4. ***Belonging***: a sense of connectedness to other people, places, cultures and communities

(Key words/concepts: Sense of connectedness; Associated with interpersonal relationships; Physical E (e.g., sense of home))

- Relationships are essential to *belonging*.
- Characterized by a sense of reciprocity, mutuality and sharing

5. ***Co-occupation***: interdependence of the occupations of two or more people

- Occur when participants have shared physicality, emotionality, and intentionality
- Described as ‘doing with’, ‘doing alongside’, ‘doing for’ or ‘doing because of’

**Table 3<sup>8, 10, 38-65</sup>. Summary of included article for synthesis (n=30)**

<b>Author and year of publications</b>	<b>Focus of study</b>	<b>Aims of the study</b>
Chabot, 2013 <sup>38</sup>	Intervention	Describe OT treatment programs to improve occupational engagement of people with dementia
Du Toit & van der Merwe, 2013 <sup>39</sup>	Intervention	Examine impact of adaptations to an environment on meaningful engagement
Edvardsson et al., 2014 <sup>40</sup>	Intervention	Determine effects of implementing national guidelines for PCC on people with dementia and staff
Lape, 2009 <sup>41</sup>	Intervention	Examine effects of the Snoezelen room
Nagayama et al., 2016 <sup>42</sup>	Intervention	Evaluate the impact of interventions driven by occupation-based goal setting and use of ADOC on quality of life and independence of people with dementia
Nakamae et al., 2014 <sup>43</sup>	Intervention	Examine the effectiveness of productive activities with reminiscence in occupational therapy (PAROT)
Pollanen & Hirsimaki, 2014 <sup>44</sup>	Intervention	Determine benefits of crafts as memory triggers in older women in residential dementia care settings
Wang et al., 2009 <sup>45</sup>	Intervention	Evaluate the effect of an anti-collision power wheelchair on social participation of an older person with dementia living in a residential aged care facility.
Wenborn et al., 2013 <sup>46</sup>	Intervention	Evaluate an OT programme aiming to facilitate care staff members to improve activity provision
Richards et al., 2015 <sup>47</sup>	Intervention	Compare non-traditional and traditional residential care facility and their impact on resident occupational engagement

Chard et al, 2009 <sup>48</sup>	Intervention	Evaluate the effect of environmental modifications and care staff training in verbal prompting.
Chung, 2004 <sup>8</sup>	Assessment	Assess occupational pattern, states of wellbeing and time use of residents with dementia
Thomas et al., 2014 <sup>49</sup>	Assessment	Assess care staff members' pre-conceived ideas regarding PPC and occupational engagement
Du Toit & Surr 2011 <sup>50</sup>	Assessment	Determine whether DCM can be used in South Africa
Holthe et al., 2007 <sup>51</sup>	Assessment	Assess occupational patterns of residents with dementia
Morgan-Brown et al., 2011 <sup>10</sup>	Assessment	Assess the time use of residents with dementia
Morgan-Brown & Chard, 2014 <sup>52</sup>	Assessment	Compare pre and post conversion from traditional to household model in residential aged care facilities
Perrin, 1997 <sup>53</sup>	Assessment	Assess extent of occupational need in residents with severe dementia
Wood, 2005 <sup>54</sup>	Assessment	Describe the use of ACT.
Wood et al., 2009 <sup>55</sup>	Assessment	Assess the impact of social and physical environment on quality of life of residents with dementia
Morgan-Brown & Brangan, 2016 <sup>56</sup>	Assessment	Describe the use of ATOSE.
Raber et al., 2010 <sup>57</sup>	Assessment	Assess and understand volition in people with moderate dementia
Morgan-Brown et al, 2011 <sup>58</sup>	Assessment	Assess how time is used by care staff members in residential dementia care settings
Morgan-Brown	Assessment	Assess and compare the social engagement of residents with dementia, before and after

et al., 2013 <sup>59</sup>		conversion to a household model in two residential aged care facilities.
Wood et al., 2005 <sup>60</sup>	Assessment	Assess the association between routine activity situations and meaningful engagement of residents with dementia.
Ridge & Robnett, 2009 <sup>61</sup>	Conceptualisation	Value the emotions of people with dementia.
Wenborn, 2005 <sup>62</sup>	Conceptualisation	Describe the need for meaningful occupation in residential dementia care settings
Harmer & Orrell, 2008 <sup>63</sup>	Conceptualisation	Explore concepts of meaningful activity, as defined by older people with dementia living in care homes, staff and family carers
Hellen, 2000 <sup>64</sup>	Conceptualisation	Describe SUCCESS acronym and its effects on quality dementia care
Warchol, 2006 <sup>65</sup>	Conceptualisation	Describe an interdisciplinary model for dementia care