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<https://doi.org/10.1057/s41599-022-01166-9>

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A person-centred problem

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It has become commonly expected that the “personhood” of people with dementia should be recognised, understood in the relational sense that is now widely adopted in healthcare practices. Despite its broad acceptance, however, the concept of personhood remains problematic in dementia care, as a result both of the theoretical challenges it poses and the practices that arise from it. This work employs the technique of ethnographic observation of residents, family members, and care staff of an aged care facility to explore the ways in which various modalities of the “self” are displayed in persons with dementia. The results provide insights into the moral and ontological impact of personhood on the systems that structure and influence interactions involving people with dementia. We conclude that privileging a preserved identity in dementia, and delivering care that conforms to contemporary “person-centred” expectations may limit recognition of the fluid, ongoing selfhood of people with dementia and that a reconsideration of this focus may enable us to expand our understanding of, and our responses to, their changing experiences.

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Background

While a “person-centred” approach to care in dementia may appear intuitively attractive to many it remains theoretically and practically problematic. The idea of person-centred care is conceptually tied to the sense that it is important to recognise that the individual being cared for continues to be a “person”, that is, that they possess “personhood” (Kitwood, 2019). The concepts of personhood and person-centred care arose in response to pre-existing approaches to caring for those with dementia (and other vulnerable groups) in ways that were perceived as disempowering and dehumanising (Kitwood, 1997). Tom Kitwood and Kathleen Bredin, following on from the psychotherapy of Carl Rogers, developed the notion of person-centred care in the late 1980s as an extension of their theoretical work focused on the needs of people with dementia (Kitwood, 2019). This approach to care was considered important because it resisted the devaluing of people with dementia and celebrated their moral worth.

From a commonly accepted vantage point person-centred care makes obvious sense. In dementia care, a focus on personhood, it is argued, is required as dementia robs individuals of their status as persons. Their status is considered diminished because of a loss of, or an “unbecoming”, of self consequent to the progression of dementia (Herskovits, 1995). Changes to cognition and communication, particularly those relating to an autobiographical narrative sense of self, changing relationships to others, and the unclear persistence of values may diminish the unbroken possibility of “selfhood” in dementia. An assumption of ongoing personhood, which recognises the dignified and valued status of persons within their communities, can be seen as reinvesting with respect and dignity the ways in which people with dementia are perceived.

In his key contribution to contemporary views on personhood in dementia care, Kitwood argued in western societies ‘personhood’ had become excessively bound to the concepts of autonomy and rationality. This had a significant and detrimental impact on how people with dementia were recognised (Kitwood, 1997; Higgs and Gilleard, 2016). Such a conception of what constitutes a person has pragmatic, in addition to moral, relevance since how we regard people with dementia influences the support we provide to them to continue their participation in society, and therefore the impact of their condition. Kitwood argued that the loss of self that he considered to characterise dementia was exacerbated by the “malignant social psychology” of those around them, that is, the experience of dementia is in large part shaped by the expectations and behaviour of others (Dewing, 2008).

In describing his approach to defining personhood Kitwood notes that the idea of personhood is explored in three main types of discourse: the spiritual and theological, the ethical and that of social psychology. While Kitwood defends the notion of a transcendent, non-material aspect of personhood, his approach primarily focuses on establishing what he considers its foundational principles of personal and social relationships and moral solidarity. Influenced by Buber, Kitwood argued that in meeting the other as a person we are contributing to an inclusive, genuine human exchange with benefits for both persons involved. This allows us to perceive the unique, rich qualities, and stories of this other person and counter cultural assumptions which regard particular cognitive capabilities as central to personal value. Kitwood’s conception of personhood was therefore a “status” “bestowed upon one human being, by others, in the context of relationship and social being” and implying mutual respect and trust (Kitwood, 2019). From this vantage Kitwood felt that the personhood of people with dementia was “increasingly changed... but not lost” (Edvardsson et al., 2008). Recognising the personhood of those with dementia was thus seen as a just

restoration of status that also acted as “treatment” since it influenced both the experience and course of the disease.

This approach to personhood remains central to the field of dementia care today. However, the underlying concept has also been more extensively applied to other areas of care. Personhood can have metaphysical aspects (e.g. in relation to the notions of self, identity and agency) and moral implications (e.g. the notion of the equal value of all persons) (Higgs and Gilleard, 2016; Hennelly et al., 2021). Through its reliance on the idea of personhood as a “bestowed” status, Kitwood’s focus on a relational conception avoids a need to specify particular components or competencies required of a person to possess personhood. However, it also generates other problems. For example, a focus on a universal threshold of personhood means there is less attention to maintaining capabilities to support personhood seen as continuum. Additionally, personhood becomes the sole responsibility of those appreciating this status and the contributions of the persons themselves become less clear.

The relationship of personhood to constructions dependent on concepts of “selfhood” and “identity”, is relevant here. Our use of these terms within this essay consciously draws upon a rich existing discourse which includes multiple understandings and employments of “selfhood”, “self” and “identity”. These ideas are useful in a heuristic sense for clarifying and distinguishing concepts. Lindemann, in defining her notion of personhood usefully employs the metaphor of an actor on stage to highlight Wittgenstein’s sense of personhood as expression and recognition (Lindemann, 2014). Personhood from this perspective is the character being played, the role recognised and engaged with by the crowd witnessing a performance. Identity emerges within this character role from the interplay between actors. The actors (all of us) “hold on” to these characters we play through our performance adhering to a shared social script and responding to each other’s cues. When an actor denies the cues of another character that identity is “let go” and left to travel without the ongoing support of the performance’s shared narrative. This adheres to a notion of identity based in narrative that’s also socially constructed, that is, something that arises from and is perpetuated by stories where we (in the words of Dan Zahavi) might be the “narrator and the main character, but ...not the sole author” (Zahavi, 2005)(loc 2131). Kitwood’s sense of identity is similarly narrative in nature, a life-story which, in the context of dementia, might be lost if it is not “held in place” by others (Kitwood, 2019, p. 66). Kitwood’s suggestion here is that while the person with dementia remains the main character in their narrative they may no longer be the author or the narrator.

From Lindemann’s account the self is the actor; a locus of “idiosyncratic causation, sensation, and experience” which is shaped by the social practices in which the self participates (Lindemann, 2014, p.16). The discussion of selfhood in dementia is undoubtedly a fecund field of thought with many key contributions, albeit little conceptual conformity (Caddell and Clare, 2010). An important aspect of this is an increasing focus on a self within dementia that is embodied, situated, enmeshed and corporeally and ecologically connected (Hennelly et al., 2021; Kontos and Martin, 2013; Kontos and Naglie, 2007). A key contributor to this has been Pia Kontos. Developing on Merleau-Ponty’s phenomenology of perception and Bourdieu’s theory of the logic of practice, Kontos sees a pre-reflective selfhood arising from the body’s natural capacity to apprehend and convey meaning, and the sociocultural influences which inform performative acts of embodied and their interpretation (Kontos, 2004). She argues that the body is a fundamental source of selfhood in dementia, a view that has significant implications for care provision (Kontos, 2005). For Kontos, notions of relational personhood do not

adequately recognise the significance of the lived, experienced body in the constitution or maintenance of selfhood. Central to this understanding of selfhood is importance of a pre-reflective experience of self as embodied, a “self-giveness”, which underlies self-experience regardless of cognitive capacity or neuropathological diagnosis (Zahavi, 2005; Kontos, 2005). Conscious of these ideas, and to avoid ambiguity, in this paper we take “selfhood” to refer fundamentally to the pre-reflective, embodied experience of self and to other resulting aspects of self-experience such as self-narrative and temporality and occurring within and in relation to lifeworlds of experience.

These concepts are inter-related, and the experiences linked to them inter-reliant. They also depend on, assume and relate to an embodied, experienced subjectivity. The personhood and selfhood of individual actors presuppose their “being-in-the-world”, creating a clear yet dynamic link between lifeworld-influenced notions of personhood and their corporeal, cognitive and social experiences (Fuchs, 2017). Both are affected in complex ways, but not negated or annulled, by the advent and progression of dementia. It is the changes that occur in both domains, and the links between them, that form the focus of this study. Previous studies have investigated both disruptions and continuity in experiences of selfhood (Caddell and Clare, 2010). Likewise, either directly or indirectly, perturbations in the form and content of personhood have been recognised and documented (Higgs and Gilleard, 2016; Hennelly et al., 2021). Critically, attempts to understand both the nature of personhood, experiences of self and self-identity in dementia and the connections between them cannot be conceived in merely theoretical terms but must be empirically grounded. People with dementia are actively engaged in maintaining their own senses of self and their relationships with others, all of which are drawn together—sometimes in a precarious and unstable manner—in the structures and experiences of personhood (Hennelly et al., 2021).

The articulation of relational understandings of personhood in dementia into person-centred care practices and the implications of these practices for the recognition of the selfhood of people with dementia have received limited attention and will be the focus of this study. While personhood is multi-faceted, we contend that the relational approach to its conceptualisation is of key relevance to person-centred dementia care (McCormack, 2004). Kitwood identified a number of principles and practices which could support “positive person work” in person-centred dementia care (Kitwood, 2019). Central to these was an the provision of emotional support that responded to the psychological needs of people with dementia within care relationships that support personhood and encourage the personal growth (Cheston, 2019). These needs included a need for love, comfort, attachment, identity, inclusion, occupation. These formative ideas have to a disparate range of approaches in a variety of care contexts broadly referred to as “person-centred” (Hennelly et al., 2021).

Despite the lack of a unified definition or practice, approaches to dementia care generally regarded as conforming to Kitwood’s concept have become widely accepted, and studies have demonstrated measurable benefits of some interventions in some contexts. Systematic reviews have suggested that increasing use of “person-centred” care in the aged care setting have diminished agitation and falls (Ballard et al., 2018). Similarly, there is evidence for a broader benefit of this approach including improved outcomes for care providers. Approaches to care that seek out and recognise persons with dementia in formal care relationships have been shown to be beneficial for people with dementia and to improve their connections with themselves and others (Hennelly et al., 2021).

Deeper exploration of these practices, however, has also raised concerns and uncertainties. While recognising that the intention

is to empower and value persons with dementia, their reliance on external standards that have not been subjected to discussion has led to concerns of hidden power dynamics (Brijnath and Manderson, 2008; Behuniak, 2010). This is particularly relevant in the aged care context where care staff have the power to determine what behaviour is acceptable—commonly requiring docility and branding disruptive behaviour as pathological—while simultaneously claiming to support the value of persons with dementia and their self-expression (Kontos and Martin, 2013; Brijnath and Manderson, 2008; Behuniak, 2010).

Concerns have also been raised on the basis that the philosophical roots of person-centred care are insufficiently clarified. While undoubtedly dynamic, what is at stake in dementia and the responses to it is invariably influenced by broad contributions from culture, language and nationality (Calia et al., 2019). Individuals and organisations employ widely varying assumptions and beliefs about the meaning of personhood and the provision of person-centred care that are not always consistent (Hunter et al., 2016; Brooke et al., 2018). As a result, what appears under the rubric of person-centred care is highly variable and does not conform to a single accepted definition. It has even been suggested by some that the ambiguity of “personhood” and the difficulty in interpreting this term within healthcare provision should warrant its abandonment in favour of more concrete reference to providing support to enable people’s existing capacities (Higgs and Gilleard, 2016).

While these concerns relate to the translation of personhood into care practices, yet others question the focus on Kitwood’s version of personhood. Dewing notes that Kitwood’s approach to personhood while influential was unfinished, warning us to avoid too simplistic or rigid readings of his work while reminding us that its primary goal was the expression of a moral concern for all others (Kitwood, 2019; Dewing, 2008). Acknowledging the importance of Kitwood’s work, we would note that its construction is open to an interpretation and enactment that supports the status of a continuous person, through viewing aspects of that person as static, within a context of significant change. Kitwood’s personhood extolls us to assume continuity within the constant change of systemic processes of meaning and experience from which the experience of dementia emerges (Chapman et al., 2019). This is further highlighted by the importance Kitwood places on the maintenance of the narrative identity of the person with dementia, an identity which person-centred care seeks to “hold in place” through its contribution to continuing this story unchanged (Kitwood, 2019, p. 75). This focus on the past historical narrative of those with dementia is suggested to support carers better see the “person” rather than the disease process (Brooker, 2001). While this may help amplify moral worth and intelligibility; it also risks translation into care practices which obscure the ways in which continuing and changing experiences contribute to dynamically evolving ideas of self, inadvertently clinging to a static link to who a person with dementia has been at the potential expense of recognising who they have become. This applies with special force to persons with dementia who may experience a vivid, and sometimes troubling, flux of communicative, social and embodied phenomena, in relation to which they struggle to negotiate a continuation of identity through self-reflection and episodic self-narrative (Summa and Fuchs, 2015). In this sense the fabrication of a “person”, with specific assumptions about what can validly contribute, may undermine different modes of experience and expression. This concern—that person-centred care attributable to a relational notion of personhood may negatively impact the recognition of selfhood for persons with dementia—has not been sufficiently explored.

This research aimed to address some of these deep questions by exploring how people with dementia think of ideas of self and

personhood. It does so by examining their expressions and those of their families and close contacts and their care community within an aged care setting.

Research methods

This manuscript reports on a data subset from a larger mixed-methods study. This larger study sought to understand the experience of decision-making for persons with dementia and their carers by in-depth exploration of the perspectives of persons with dementia, their family-carers and their primary health carers through interviews. Engaging with these data requires methods which are embedded and yet critically reflective. Ethnography allows a researcher to be both an observer and participant within the lifeworld of the experience unfolding around them. Contemporary views of ethnography understand this practice as occurring within an epistemic uncertainty, and this postmodern perspective will be explored as an interpretive lens through which to understand the relevance of an ethnography of dementia, and the challenge of its results. Ethnographic work also has particular advantages over methods which rely solely on spoken communication to enable the contribution of participants, such as in this study, where the advanced nature of their dementia led to significant communication difficulties. Furthermore, ethnography enables exploration of people's experiences of and within their environments. For these reasons ethnography has a long-established tradition of being utilised for research involving small numbers of participants with dementia in aged care facility settings (Chatterji, 1998).

Setting and participants. This work was conducted in a psychogeriatric nursing home (PGNH) for residents with behavioural concerns. Bardo house (a pseudonym) is such a facility, situated on a large arterial road in metropolitan Melbourne, Australia. It is a locked unit with staff members being the only persons with free access, while all others need permission to enter and exit the unit.

Bardo House had a cruciform layout. A long main entry corridor, braced by offices, and staff rooms ends in three short corridors. Each of these corridors terminates with a module including a food preparation area, an open dining room-lounge-entertaining area, and 8–10 single bedrooms and several bathrooms. Bardo House has high-fenced grounds containing several small, planned gardens with walking paths, and shaded areas.

Three residents of the psychogeriatric nursing home, Patrick, Nellie and April (not participants' real names), who all had advanced dementia were primary participants in this study. All staff, visitors, and residents at Bardo House were informed of the research being conducted onsite.

Data collection. The data collection was undertaken over a period of 6 months spent in ethnographic assessment at Bardo House including over 70 h in the care facility with Chapman as field researcher. The primary activity during this time was participant observation. The researcher spent the time at Bardo house being and talking with the participants, the staff providing their care, and the family and other people visiting them, and participating in the events and activities that occurred including meals, care episodes, and periods of rest and relaxation.

The time spent with participants was both public and private. Patrick, Nellie and April often spent time in communal areas among others or at community events involving large groups of residents. Private moments with residents usually entailed joining or following what they were engaged in. For Patrick this was usually sitting alone at a two-person table in the dining room next to a large window. Time with Nellie was usually spent walking the

corridors of Bardo house. Spending time with April usually meant sitting in her room among her pictures and her music.

Brief notes were taken during periods of observation to accurately record events, with more detailed reflexive ethnographic field notes subsequently generated. The researcher attended to interactions between participants and others, interactions between the participants and their surroundings. These were informed by transcribed audio recordings of conversations with primary participants. These conversations were unstructured, and fluid attempts to engage participants who all had communicative difficulties. Non-verbal responses were annotated during conversations, and occasionally by de-identified photography. Interpretive engagement with data was deepened through generation of narrative vignettes of participant experience. These were based on the researcher's descriptions of and reflections on elements of interaction physical, or social, and conversation that occurred during the observation using described methods (Spalding and Phillips, 2007; Phinney et al., 2016).

Analysis. In approaching this work a postmodern approach to ethnography was adopted, where the epistemic difficulties implied by recognising categorical distinctions between "researcher" and "participant", or determining a single resolved perspective is acknowledged (Lather, 2011). The ethnographic work was also seen as co-created with participants. This was in two senses, firstly that in engaging in ethnography, novel, interdependent relational connections and sources of meaning are fuelled within the self-organising and social systems involving researcher and participants. Secondly, interpretations of data were also iteratively and organically presented to participants during the ethnographic period to inform further reflection and deepening. Data within this process is understood as the formal, harvested and reflected narratives arising from a focus on the narratives, discourses and behaviour that unfold during the research event (Kuhn and Woog, 2005). This is a vortical process where new ideas (rather than "answers") arise from the engagement with the practice of the "relentlessness and rumination" of ethnography (Lather, 2011; Kuhn and Woog, 2005; Stewart, 1996). This involved a cyclical and reflexive process of data reduction, analysis and interpretation to bring order to the data and expose and explore patterns for interpretation (Brewer, 2000).

Ethical considerations. Approval for conduction of this study was provided by the human research ethics office at St Vincent's Hospital, Melbourne Australia (HREC-A protocol number: 036/13), as a component of a larger body of work (Chapman et al., 2019). This study was conducted with attention to all relevant ethical regulations and guidelines. Thorough consideration of the ethics of enabling the participation of people with dementia and their networks, while minimising risk was maintained throughout this study. For example, a supported consent process was utilised for participants within this study where all persons with dementia were consented along with their person responsible or surrogate decision making ensuring that the required person was involved in this decision making without the use of capacity assessments. Similarly, a responsive dynamic longitudinal approach to consent and was also enacted with these considered as dynamic and ongoing processes throughout the study rather than established by completion of a consent form.

Results

These data exposed expressions of experience and the latent tensions with apparent expression of person-centred care within Bardo House. This is evident within the two themes and seven

sub-themes expressed below. The first theme, *Maintaining the person*, arose from the subthemes of “continuity and stasis”, “working with change”, and “pure theatre: fabricating characteristics”. The second theme, *Self-expression*, arose from the subthemes “choosing involvement”, “performing tasks”, “body memory”, and “fragile connections”. These represent and express the data gathered within this work, highlighting its relevance to the key aim of exploring the experience of persons with dementia and the expression of respect for personhood and care provision. They highlight evidence of the dynamic expression of experience within this setting with reference to the persistence of embodied self-reflection and episodic personal narratives.

Maintaining the person. Care at Bardo House involved a systematic and embedded process of respecting and maintaining the personhood of its residents. These efforts involved staff, and the residents’ relatives and friends in contributing to variety of acts and behaviour.

Continuity and stasis. A focus on what remained “the same” for residents was a clear preoccupation in Bardo House. Residents were perceived as linked to persistent aspects of themselves, including their history, their characteristic reactions, their values and their preferences. April was seen by her daughter through her musical spirit. April was a performer in a family dancing troupe in her early adulthood. Treasured photos of a young April posing with her family in elaborate costumes and the ever-present strains of crooner music filled her room. April remained “a dancer”, and “performer” for her daughter, and the images and melodies seemed designed to remind them both of this link at every opportunity.

Nellie’s family felt that she engaged the world in ways that reflected her continuity. Her “humour” shone through unchanged in the moments between when dementia’s “shutters” were down. In these moments Nellie was hidden from their view. Nellie’s family told cherished stories which echoed qualities which they felt persisted from before her dementia. Bill (Nellie’s son), retold an adventure with Nellie from a few years earlier when her dementia had made a trip to the dentist a major undertaking for them both as Bill needed to carry her up the stairs. He described pausing on the stairwell landing to catch his breath, and Nellie saying, “Phew, that was like climbing Everest.” Bill laughed with triumph and joy while sharing the victory of that moment, before beginning to cry softly. The importance of these moments of being “the same” painfully linked to the evidence that so much was different.

Another aspect of the continuity was that residents were seen as valuable and valued by those around them. April remained a “treasured” and trusted friend and confidant to her daughter even though she was no longer able to communicate with words. Patrick was a loved husband and father whose intelligence and many abilities continued to influence and inspire his family. Similarly, staff at Bardo House expressed how they valued residents’ presence. Some staff had “favourite” residents. It was common for staff to hug residents, smiles and demonstrations of warmth and affection were frequent. Residents were also valued for what they had achieved or represented in a more public sense among staff at Bardo House. Kylie (the nursing team leader) reinforced that residents had contributed to society and deserve respect as much as anyone. They had “fought in wars” and should be assumed to have been instrumental in the lives of those who followed them.

These important aspects of identity were also seen as continuous even if more support was required to demonstrate them. Family and staff members often spoke for residents,

expressing what they felt and preferred. Expressing preferences for residents was seen as necessary and supportive of an assumed and perceived continuity of identity and responses. Nellie’s family felt that they could detect and express her continuing “spark” that was the real her. The “real” Nellie acted and dressed in certain ways, and so advocating for her to remain clothed as she used to, in dresses and not in tracksuits or pyjamas, responded to this real presence. When clothed in this way Nellie was also more recognisable as her past “real” self to her family. The act anticipated her ongoing preferences and preserved an aspect of April whose maintenance remained important to them. April’s daughter identified her mother as persisting within moments of embodied activity. April was herself to her daughter when her activity resonated with these core and persistent elements of her perceived identity, such as when she was dancing, and swaying to the music that she used to play for her daughter when she was younger. In these cases continuity related to aspects of identity which remained recognisable to others despite the unmistakable changes that the progression of dementia entailed. Continuity within the experience, identity and preferences of residents was actively sought, and the perception of continuity was valued regardless of the changes in support required to provide evidence for this.

Working with change. Despite any focus on stasis or continuity reminders of change were a persisting reality in Bardo House. To some extent change was the very reason for residents’ living at the facility. Bardo House provided care for people whose needs exceeded what could be provided elsewhere. Changing behaviours and increasing needs were required for transfer to Bardo House. Simultaneously Bardo House anticipated that further changes would occur for its residents. It was a “short term facility” where residents could “transition” to periods of more predictable care needs and be transferred back to other, less specialist, facilities.

As a psychogeriatric nursing home Bardo House was better resourced. It had reliable and expected access to primary and specialist medical input. Despite this care staff and managers identified that it was their person-centred approach to care, rather than other “clinical” interventions, that were a key ingredient to support residents “improving” and transitioning back to other facilities. It had greater ratios of staff to residents. Staff members had received more training than was usual at an aged care facility. Residents were anticipated to get or be “better” in Bardo house due to these care approaches and many staff were confident that this would occur. Medications that might pacify or sedate resident were thus intended to be decreased over the time at Bardo House due to these improvements. Notably residents getting “better” did not necessarily mean that their health was improving, but referred to the frequency and severity of the behavioural concerns that had led to admission at Bardo House. Residents’ behavioural concerns often improved due to their progressing dementia and frailty, where the advanced nature of these issues meant that the resident was no longer able to be physically aggressive or resist care as they had done previously.

Person-centred care was particularly associated with a continuity of valuing and respect for residents. Senior staff at Bardo House discussed qualities that care staff needed to embody to be person-centred. Staff were expected to demonstrate that residents were appreciated, rather than just cared for, to be treated like persons. Staff needed to be respectful, to encourage and respond positively to the residents. These approaches were considered particularly important as many residents, particularly those with aggression or sexually disinhibited behaviour, were identified as being at risk of not being treated with respect in care environments.

A respectful, person-centred approach was demonstrated not just through the actions of staff but through the construction and the philosophy of the environment itself. Physical spaces were intended to engage residents with their interest and their familiarity. The modules—Topaz, Opal and Jade—each had a colour, and a decorative theme (music, craft and babies and children) to support the orientation of residents. These spaces were bright, interesting and engaging. Activity spots (such as boards covered in knobs and switches) offered familiar and accessible items to visually and physically explore. Exploration was supported and encouraged in Bardo House. While the residence was locked externally there was more freedom inside. The living areas and rooms of the facility were open and residents freely moved about these spaces and the connected gardens. Senior managers considered the allowance of residents' free movement a further gesture of their respect for them. This was also linked to the acknowledgements that resident distress could be worsened by environments and by the actions of others. Kylie (CNC) suggested that allowing residents to move within these areas "such as you would in your home" recognised that residents had "places to be" and that supporting this improved behaviour. Modulating the restrictive aspects of residential care (changing the implicit limitations to freedom within this environment) reflected person-centred care through expressing assumed preferences for residents. In this way these actions instituted a change to enhance an assumed continuity of residents' environmental preferences and enhance the expression of a maintained identity.

Pure theatre—fabricating characteristics. Achieving a person-centred approach for individual residents at Bardo House was made more complex by their cohabitation. Care was provided to individuals and also to groups of people raising the challenge of providing a person-centred approach to many. While staff expressed their wish to identify and respond to the individual needs and characteristics of the residents, the approaches and practices were often unavoidably homogenised into generic and instrumental "person-centred" approaches. An important example of this was revealed through the decoration of Bardo House's resident areas.

Bardo House's resident areas had several major decorative themes. One room's theme was music. This was expressed through decorations with plastic musical instruments, old LP covers from the 1970s and 1980s and sheet music hanging high from the ceiling. Another room, thought to represent "home" or "family", was decorated with plastic baby dolls, and bright infant's toys (such as rattles and blocks) throughout the room. The work and thought on display echoes an increasing focus on care facilities engaging the lived experience of residents through being "places" (rather than the sterile and bland non-places of clinical spaces) (Reed-Danahay, 2001; Kontos and Martin, 2013). At Bardo House additional time and expense were admirably committed to creating rooms' aesthetic themes. However, the choices resolved in unclear messages. No one currently working at the facility remembered why these items were chosen, what they were meant to mean, or who was involved in creating this space. For the current staff Bardo house had always been like this. Similarly, residents (and families) do not choose a specific area and aren't recommended to a themed area because of their history or interests, they are just assigned rooms when they are free. For instance it was notable that some residents in the "family" did not have their own families.

The semiotics of the items used to decorate these rooms were also confusing. The LP covers and sheet music may be familiar references or remind residents of music, but the rainbow of plastic instruments were clearly toys. The sense of child's play

they represent was unlikely to be something that the residents identify with. Residents did not seem concerned by the decorations, and staff assumed that they are no longer able to discriminate between real references to adult experience and the pastiche that was offered. However, some family members were concerned by what was being conveyed. Heidi, Patrick's wife, described her disbelief at the "pure theatre" of Bardo House' decorations. She felt the decorations were unrelated to the resident's past experience, or their current reality. Patrick had been an artist and a talented musician and Heidi felt that he would find little in his environment that resonated with him.

Whether decorations or reminders which were thought to be relevant to a resident's past remained relevant to them now was an open question. Residents' rooms were small and furnished with built-in furniture including a cupboard and a bed. Individual enhancements to these generic rooms were often provided by families and friends through personal elements including small furnishings, photos, precious objects and decorations. These objects were chosen by family and friends and brought in for residents on the assumption of their relevance for that person. However, families also commonly noted that these objects seemed to have altered, limited or variable relevance as the resident's dementia progressed. This was usually interpreted as residents losing these anchors to their past. These items then carried new meanings for those who could connect with their origin, often symbolising loss and grief, rather than what was originally intended as an identity enriching prompt for the resident.

Self-expression. Residents expressed themselves in multiple and sometimes surprising ways at Bardo House.

Choosing involvement. Residents were offered participation in an extensive list of prescribed activities and events at Bardo House. Some activities were frequent such as daily or weekly, such as morning tea, Catholic mass and craft club, and others were more episodic such as holiday celebrations. Negotiations around resident involvement in activities exposed the challenging articulation of person-centred care and self-expression in this context.

Deciding when residents would be involved in activities had underexplored ethical depth. Activities supported the involvement of residents but also assumed a preference for engagement. Whether an activity or event was "liked" or "right for" a resident was determined by staff and family, and this determined whether the resident should be involved. Families had a particularly strong role in knowing whether their loved one "liked" activities (such as attending mass) due to their knowledge of their past interests. If a resident was determined to "like" an activity then it was assumed that the resident's attendance was the best outcome, somewhat regardless of the resident's response to these offers.

Residents' responses to activities were recognised as preferences, but were often given less weight than assumptions of whether an activity was "right for" a resident. For instance, a staff member upon re-gathering April for the third time after she continued to leave "Morning Tea" asked her, "Are you not happy with me today?" The carer interpreted April's behaviour as communication, and yet felt that her attendance at the tea was still required. Staff members' receptivity to residents' preferences regarding activities was also variable. While verbal responses were always polite and courteous to residents, nonverbal communication could be dismissive. In one instance Nellie was asked whether she would like to attend Mass but at each slow attempt to respond the staff member quickly determined an "answer" and asked another question. The interaction ended with the staff member saying goodbye and walking away while Nellie was still engaged with answering a question. Similar interactions where

verbal interactions were undermined by limited eye contact and attention to turn taking were common and suggested the diminished relevance of residents' expression of preferences.

The activities and events themselves, "for" residents as they were, operated on multiple levels and expressed symbolic, and under-appreciated normative practices. A poignant example were the residents' birthday parties at Bardo House. These were joyous occasions, but seemed to hold significantly different meanings for staff and residents. While the performance of birthday parties, within a sociocultural structure that considers this as a near universal celebration, is clearly consistent with considering residents at Bardo House as ongoing persons, many aspects of these events indicated challenges and additional levels of meaning in action. The birthday party at Bardo House was formalised, almost ritualistic, and each instance echoed the others. The only changes tended to be the name of the person being celebrated on the white board, and when "Happy Birthday" was sung.

Staff members were critical to the performance of the party. They would set up the party and lay out hats and balloons in a dining room. Staff would gather residents which, given their variable mobility and enthusiasm could take a significant amount of time, effort, and coordination. Staff also maintained the semblance of the birthday party, ensuring it was recognisably different from other gatherings at Bardo House. If left alone, residents' activities and engagement would resemble any other event or day. The party was nominally for the residents but the staff members were most critical to the ritual of the party.

Residents were described as being "invited" to the party but attendance was expected and mandatory. Many residents seemed indifferent to the parties, or left parties and needed to be regathered. On some occasions it remained very unclear how conscious invited residents were of events. Residents were often provided with repetition of the same greeting and explanation of what the gathering was for by the coordinator. At one party a resident, Susan, was wheeled to the party in her bed having returned from the emergency department in the early hours of the morning. Susan was not observably conscious, and staff members commented that they thought that she might be dying. She was returned to her room during the birthday party prior to it finishing, and without seemingly being aware that she had joined the party or that it had been deemed that she should leave. Residents' engagement with the conventions of the birthday parties was also variable. Most residents did not talk with those they sat with, follow the actions indicated by the coordinator (such as clapping at the nominated times) or sing happy birthday. This was in sharp contrast to the staff who were able to come and go as they wished, but whose roles diminished with all the residents in one place. They stood around the outside of the dining room, chatting happily about their lives outside Bardo House and joining in with the stages of the party as they were requested. After cake had arrived, been cut, and eaten along with cups of tea the staff usually continued to chat for some time standing in groups around the silently sitting residents. Residents were returned to their usual places in Bardo house at times chosen by the staff members, prior to the area being cleaned when all evidence of the event was disposed of, or stowed away.

Performing tasks. A clear contributor to the challenge of "hearing" the preference of residents was the limited time that staff felt that they had to do this. Staff felt uncertain how best to use the time during shifts, and how to translate their time into care for their residents. They described days filled with arbitrary tasks, which were often felt to be more focused on accreditation and satisfying management rather than providing care. Care time in similar facilities is often divided arbitrarily and simplistically into tasks and this kind of categorisation sits awkwardly alongside bodies

and people who respond and require support unpredictably or in ways which are challenged by the needs of the systems that support them (Cohen, 2011; Twigg, 2006). At Bardo House many staff members alluded to a hope that their caring could be embodied through how they were with residents and through "small things", moments of kindness and consideration, within the busy, task-based working days that they lived.

These microethical moments of expression and caring reflected a recognition of the other as a person to be cared for, regardless of the multiple demands on carer's time (Kontos and Naglie, 2007; Komesaroff, 2008). Simple acts like knowing and acting on a resident's preference for tea was a way of honouring that person. Intimate acts such as showing affection through hugging residents or through laughing with them were also seen as important demonstrations of care within the day's activities that helped acknowledge the ongoing person. The manner of acts also demonstrated care that was attentive to a multitude of personal needs. The most skilled expressions of this microethical balance were care acts that attended to needs (i.e. performed a task), while demonstrating and asserting knowledge of residents' preferences and values, and their sociocultural presence within their environment. An expression of this arose when a resident (Tony) had soiled himself while out in the shared dining room space. Tony was sometimes reluctant to go to the bathroom for changing, and moments when staff had insisted that he go the bathroom had created friction and aggression in the past. The staff member, noticing the issue, offered Tony a hand and asked him to dance with her to the music that was playing. Tony's face shone as the staff member slowly led their dance, spinning and smiling, towards a bathroom where he could be helped.

Body memory. Residents at Bardo House who had dementia clearly demonstrated evidence of their selfhood despite these arguable challenges in the instrumentation of person-centred care. Continued evidence of residents' body memory, their lived body in relationship to their perceived and experienced world, were clear.

Evidence of embodied selfhood abounded at Bardo House. Residents asserted their being through their fluid exploration of experience. Their inter-corporeal experience and asserted agency was evident and powerful. Communication changes meant that for many residents, expression was predominantly non-verbal. Non-verbal expression, particularly of emotions, was seen by staff as attempts to communicate preferences, and the nature of Bardo House as a facility intending to "hear" these expressions and diminish problem behaviours meant that these preferences had an impact upon their lived-experience. Some of these expressions were interpreted as rejections of experience. Staff understood residents' communicated preferences for seating arrangements at meals due to how they had reacted previously and planned who would sit where accordingly. Residents asserted their independence by closing doors to their rooms to maintain privacy, and walking away from staff or other residents if they wished to avoid them.

Some expressions also demonstrated attraction towards or belonging with others and experiences including intimacy. April developed a persisting relationship with Bill, a male resident that was publicly intimate. They would stand or sit near each other and hold hands, or hug. Occasionally April would stroke her hand up and down Bill's forearm as they spent time together. Over months they were each other's partners, despite very limited verbal interaction. Bill and April's relationship was commonly perceived and discussed by staff and family members in ways that made clear that this intimacy had a positive impact beyond just the two of them.

Non-verbal expressions demonstrated how residents felt they belonged. Residents would gather with each other and with staff and visitors supported by rich non-verbal interactions. Nellie would physically position herself as a “speaker” within a conversation of a group of people. She would look at each speaker as they spoke, which often resulted in attention being directed towards her in turn, in this way becoming an interlocutor without verbal contribution. Other residents would match and respond to non-verbal communication, such as changes in eye contact and facial expression, including signals that the conversation was over. Nellie and other residents engaged in nonverbal communicative behaviour which influenced their communicative presence within Bardo House and demonstrated their embodied selfhood.

Intriguingly, and despite the acknowledged challenges of assuming the personal significance of this constructed environment, objects within Bardo House also catalysed moments of self-expression. Residents interacted with objects and activity stations, exploring them visually and through touch, and on occasion demonstrating their deep relevance. In the “family” themed room was an antique, heavy, black Singer sewing machine which was a powerful object for Nellie. The machine was a link to her history. Nellie’s mother had used a similar machine to make clothes for her, as had Nellie for her own children. Unlike her hesitancy and limited language fluency elsewhere Nellie was confident around the machine. She stated with conviction that she could show me how to use it, and basked, laughing in that space of her own comfort and surprise, telling me, “Yes, it is true.” The machine was a private but visible catalyst for Nellie’s bodily memory allowing her strong connection with her own episodic narrative, and the enactment of her interpersonal presence. April likewise responded privately to these public prompts. Songs that were significant to her, such as “Unforgettable” by Nat King Cole led her to wave her arms, as if conducting musicians through the tune, or dance in slow circles holding an imaginary partner. April’s responses demonstrated her familiarity with the music but also exposed her self-discovery in association with these self-important experiences. These instances reflected ongoing self-expression and self-discovery linked to these residents’ fragile personal narrative, but accessible due to the deep bodily memories associated with these objects. While this was achieved through choices within a “person centred” approach to care, the objects were not chosen for relevance to these persons, but on assumptions of what might interest people of a certain age and socio-cultural setting. The success of these moments of self-expression was therefore due to the embodied selfhood of these people with dementia, rather than specifically due to the potency or prevailing insight of the person-centred approach to care that was utilised.

Fragile connections. Moments of reflective engagement with experience were fragile and fragmented even while seeming clear and significant. These usually had the character of explorations, of creating or investigating meaning within the experienced moment. The connections evident in some situations suggested the self-reflective awareness of the residents. On one occasion April revealed an old picture of a well-dressed young man in her room. Text on the back of the photo identified the man as April’s now deceased husband but April could not say who he was. Holding the picture of the person that she can no longer name April softly touched his face repeatedly, lightly tapping. Her face was calm and sad. Each tap seemed to acknowledge a sense of the photo’s deep meaning, concealed but still resonant, a sense that this photo belonged with and to her. The interaction with the mysterious depth of the photo seemed to allow a re-emergence of its significance for April, who was additionally tangibly present within her connection to this antinomy.

Explorations of fragile connections to narrative, people and past experiences also revealed moments of insight and creativity within self-reflection. Comments from residents exposed processes of experiential investigation, of reflexively investigating and sharing meaning despite a paucity of verbal communication. Nellie at one point in conversation recalled and described snatches of her experience of sewing for her children. During this Nellie enigmatically explored the personal significance of “doing” this for the children.

Nellie: Yes. The act of doing

I: The act of doing

Nellie: Or the art

Nellie’s comments could be variably thought of as referring to the link between the intent of an action and what and how it is actually done, the relational links in “doing” something for your own children, or the importance of remembering the deeper meaning and aesthetic value underlying making or doing something. The comment may not have or require a clear answer but does suggest Nellie’s self-connection, an experience heightened by her ability to humorously regard her own physical frailty. As with others at Bardo House Nellie’s outward presentation to the world was often one of confidence. On one occasion Nellie responds to a question about her past managing to exert her poise and self-possession despite her uncertainty.

Nellie: Oh I don’t know what... Don’t know what, but I know it

Nellie’s comments suggest a deep self-knowledge. She belongs within this assertion. She is confident in her persistence in this moment in a way that is not specifically related to her memory or knowledge of specific elements of her personal context. In a sense Nellie seems to be saying that the unremembered thing is unimportant compared to her knowing herself.

Instances of the residents exploring experiences un-related to a recognised link to their past were no less powerful, even if they required more effort in interpretation. Such exploration often seemed to contain creativity, a playing with experience to find new possibilities. These environmental explorations were at risk of being described as purposeless, and yet still suggested important possibilities. Patrick’s “art” provided evidence for this (Chapman et al., 2019). He was unable to interact verbally and gave limited non-verbal clues of his connection with others but given the opportunity would interact with the unchanging vista of the table-top where he sat for much of every day. Using objects available to him such as books, cutlery, or blocks Patrick would create arrangements on the table. He would reach out and take an object, regard it and place it very precisely with careful attention to the other objects in front of him which he would also adjust relative to the new object. Patrick’s pictures were not static but a live and dynamic thing. He would place the objects, consider what he had done for a few seconds, and then change something, perhaps rotating it or shifting it in ways which were subtle but definite. In doing this Patrick seemed to be quietly exploring or playing with his sensory environment through creating an image, a tableau that was meaningful to him. The sense of this being meaningful was reinforced by the iterative nature of his activity, he seemed to be working towards something, perhaps something changeable but nonetheless a “right” experience that continued to develop.

Discussion

Recognition of the tensions within the application of person-centred care at Bardo House does not require a rejection of the

relevance of the concept of personhood in dementia. However, it does highlight the challenges that a relational construction of personhood and the person-centred care that stems from it can create in practice. In the performance of instrumental “person-centred” acts of care for people with dementia, implicit attention to a relational support for their “personhood” often depends on deep assumptions about how they were historically understood, or more generically, about the social or ontological “being” of people in our culture. While intending to centre on and support a unique person these practices attribute an unsurprising primacy to a pre-existing set of values and their continuity, and to the relevance of socio-culturally normative experiences, resulting in care which can be both homogeneous and misdirected, and which may be at the expense of an appreciation of the rich, evolving experiences of persons with dementia.

It cannot be claimed that the commitment to these commonly held assumptions is mistaken. However, it is limiting, as it confines the possibilities of understanding a person with dementia to who they were understood to be, and what has come before rather than as one who is capable of new-meanings and fresh experiences. In seeking to recover and respect the identities of those with dementia we do them a disservice if we see and narrate their story as tied to a maintained “real self” (Gillett, 2002).

As can be seen from the experiences at Bardo House some of what is achieved through this performance of personhood most directly benefits those around the person with dementia. Seeking to honour an unchanged value, a focus on “personhood” may support the arbitrary attribution of qualities and identities to the person by others, most notably by families and loved ones who grieve the changes taking place. These choices value the historic “person as experienced” by others over the more obscure contemporaneous, demonstrably challenging lived-experience of the person with dementia. These insights reveal an additional depth to Kitwood’s social psychology, as they demonstrate how the social performance of a response to “personhood” can diminish the interpreted meaning of experiences of dementia that are discrepant from how that person has hitherto been understood.

Understanding the selfhood of people with dementia as enmeshed with their dynamic and embodied responses to their world, regardless of the severity of the dementia, creates rich possibilities. As has been described by Summa, selfhood can be seen as a persisting “mineness” in relation to the world (Summa and Fuchs, 2015), a self-reflective engagement or bodily-memory that does not rely on autobiographical narration but on an episodic and vibrant temporality. Thomas Fuchs describes the elements of bodily memory as including procedural memory, of habituated and meaningful motor behaviour, spatial memory, where the memory of the body interlinks with how we explore and make sense of our environment, and inter-corporeal memory, where our embodied, pre-reflective sense of being with others resides (Fuchs, 2012). These multiple aspects of bodily memory are fundamental to our lived world of experience but are also preserved despite the advancement of dementia (Fuchs, 2020). Evidence of these aspects of bodily memory are therefore key contributors to the self-expression of persons with dementia. Kontos’ description of “embodied selfhood” likewise suggests that the pre-reflective being-in-the-world of people with dementia is continuous, expressed and perceivable within how life is lived in socio-cultural environments (Kontos, 2006). The creation of meaning and exploration of experience of people with dementia is not less valid due to its difficulty to contextualise with our knowledge of their lives. Instead it can be seen as moments of fragile and novel creation in new cognitive and communicative contexts that remains impenetrable to our gaze.

It is important here to acknowledge the systemic nature of these interpretations, and the consequences of dementia within

aged care. Dementia and its interpretations influence systems from systems of cognition and communication within the person with the diagnosis, social systems, and broader systems of culture, language and meaning. While much of the focus on systems in dementia considers systemic influences on the dementia experience less attention is paid to how people with dementia participate in influencing systems around them. Some social systems, such as psychogeriatric nursing homes, come to exist in response to the impact of dementia on people, and the impact of these people on society. The impact of dementia interacts and influences other systems, which give rise to institutions such as the economic, political, and health and social policy realities which define “care” in dementia.

This work itself, and my perceived horizon as an interpreter, is influenced by the presence of dementia and its impact on us all. This provides people with dementia with a formative power. They shape and influence systems of action and meaning even through their own dependence, and despite (as has been described in this work) some resulting system processes being poorly focused and potentially repressive (Dunham and Cannon, 2008). Birthday parties for example were tasks to symbolically demonstrate shared community values and norms, but in fact uncovered tensions between the lifeworld experience of staff and residents. Residents were welcome and valuable in these rituals to the point of their ability to maintain the form of proceedings, while staff were free to subvert these events given their different status.

The lifeworlds of people with dementia may endure—but they also need repair. However, assuming that persons with dementia need support for their contribution to their lifeworlds to be recognised has echoes of Kitwood’s notion of the cultural and social contribution to the dementia experience; in assuming that support is required we may create that necessity (Chatterji, 1998). As has been shown, attempts at repair work by people with dementia may not reliably conform to expectations and these attempts are at risk of remaining unheard and unacknowledged.

Both the risks and rewards of this hermeneutic process are in effect amplified by the vulnerability of those with dementia. As can be seen from Bardo House, fragmented moments of selfhood can be moving and powerful, and it is through recognition of these fragile selves that the potential to repair identities, to “heal”, despite dementia, may be found. This requires engagement from those around people with dementia which resists the notion of a “real self” and nurtures counter-stories that accept those with dementia as changed but present selves that remain morally valuable (Lindemann, 2014). For this to occur our focus needs to encompass the rich expanses of the life that continues to be led by a person with dementia, and the impact that this has had on others, including the potential pain and distress that their current experience may be fostering in those to whom they are close.

The transformative power of dementia is not a positive force. The radical changes that it brings about generate profound and often destructive impacts on large numbers of people. But “accepting dementia... without oversimplifying the lived experience” (Beard, 2017) also reveals new possibilities for us to explore and understand the subtle and dynamic reality of our embodied experience, and its interaction with the world within which it is enmeshed.

Kitwood’s notion of a relational personhood fostered a fecund critical reflection on our understanding of dementia and on how care was provided, ultimately compelling a rejection of a medicalised and reductive paradigm. Person-centred care, arising from this understanding, has improved many aspects of the experience of people with dementia. It has also encouraged a deeper respect for their moral worth and for the potent influence of human relationships on the dementia experience. For all this, however, the lack of attention to the philosophical and cultural biases

inherent in the key concepts have resulted in an uncritical adoption of person-centred care and a failure to recognise the limitations and fixation of this approach. A prevalent focus on valuing and supporting aspects and identities of people with dementia that seem recognisable and continuing diminishes the appreciation of the fragile, altered but fertile, self that may result.

The time has come for dementia care to move beyond an unquestioning assumption of “person centredness” and instead to embrace the possibility of people growing and being with and within dementia. In effect, it is time to learn from dementia and from those with dementia, to seek to continue to develop our responses to its challenge. This is not only necessary but may be the most powerful response to dementia that we are able to make.

Data availability

The datasets generated during and/or analysed during the current study are available from the corresponding author on reasonable request.

Received: 10 February 2021; Accepted: 14 April 2022;

Published online: 03 May 2022

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Acknowledgements

We are thankful for the support of the NHMRC Australia who provided Chapman with a PhD scholarship grant to support this work.

Competing interests

The authors declare no competing interests.

Ethical approval

Approval for this study was provided by the human research ethics office at St Vincent's Hospital, Melbourne Australia (HREC-A protocol number: 036/13). This study was conducted with attention to all relevant ethical regulations and guidelines.

Informed consent

An informed consent process, including use of supported consent for participants with dementia and their surrogate decision-makers, was utilised for all participants in this research study.

Additional information

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