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Version Post-Print/Accepted Manuscript

Citation (published version) Kontos, P., Naglie, G. Bridging theory and practice: Imagination, the body, and person-centred dementia care. *Dementia: The International Journal of Social Research and Practice* 2007; 6(4):549-569

Publisher's Statement This is the peer reviewed version of the article, which has been published in final form at [dx.doi.org/10.1177/1471301207084394](https://doi.org/10.1177/1471301207084394).

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**Bridging Theory and Practice:
Imagination, the Body, and Person-Centred Dementia Care**

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Abstract

As a corrective to the depersonalizing tendencies of some caregiving practices and treatment contexts, the principles of person-centred care have been widely espoused. However, proponents of person-centred care often fail to acknowledge the fact that the body is a fundamental means of communication and, as such, the body is essential to the expression of personhood. Using a qualitative research design, we explored with health care practitioners how an embodied notion of personhood could enhance person-centred dementia care. Our findings indicate that the communicative capacity of the body enriches the imagination and connects health practitioners to the personhood of their care recipients, thereby fostering sympathetic care. Our findings further indicate that health care practitioners perceive that when care is premised on the communicative capacity of the body, this may improve the time efficiency of clinical practice, and may reduce, in certain instances, the need for drug therapy as chemical restraint. Further research is needed in order to evaluate the outcomes of an embodied selfhood approach to person-centred dementia care.

Keywords

Dementia
Embodied selfhood
Focus groups
Person-centred care
Research-based drama

Introduction

Budget constraints, increasingly complex clinical care requirements, and a growing elderly population have resulted in major reforms in national health care systems (Bergman et al., 1997). These reforms have generally fallen short of expectation (Ham, 2003) and may even be having a negative impact on both recipients and providers (Aiken, Clarke, & Sloane, 2000) of care (Donelan, Blendon, Shoen, Davis, & Binns, 1999). With significant reductions in the number of health care practitioners, workloads are inevitably increasing and there is a corresponding reduction of care to the most basic of physical tasks such as eating, toileting, bathing, and walking (Armstrong & Armstrong, 2003; Twigg, 2000). Care time is defined in terms of tasks that can be measured easily with written standards pertaining to how much time can be spent on a given task and how it should be done (Twigg, 1997). The rationale of economic efficiency creates a system wherein the measure of care lies with the physical task rather than the quality of human interaction and, as a consequence, the relationship between the care provider and recipient is not quintessentially one of caring (Crawshaw, 1996).

Staff shortages, increasing workloads, and the related insufficiency of time are commonly cited as the sources of the deficiency in quality of care (Hall & Kiesners, 2005; Mark, 2002). While the consequences of inadequate staffing are not to be disputed, there are factors in addition to staffing ratios that influence the quality of care provided. Dementia care is a case in point. Consider the following account of a care practitioner working on an Alzheimer Support Unit, who, after feeding a resident her lunch went to see if any assistance was needed elsewhere on the unit:

This was a large room with four beds, four chairs and four commodes; it was home to four ladies with dementia. As I entered, the door was wide open; all four ladies were sitting on their commodes, and the smell of feces permeated the air. There were no curtains or partitions to screen the ladies from each other or anyone else walking past. My colleagues Sandra and Mary

were feeding two of the ladies, and talking about the night out they had just spent together. Sandra was feeding Mrs. T. As soon as there appeared a little room in her mouth, more food was inserted. Her cheeks were bulging with food she hadn't had a chance to swallow. Mrs. T started to gag; food began to spill from her mouth; then she coughed and sprayed Sandra with half-chewed food. Sandra proceeded to clean herself up, while leaving Mrs. T with food debris all over her clothes and exposed thighs (Kitwood, 1997, p. 45).

Reducing those afflicted with dementia to dehumanized units of work, as depicted in the above example where feeding is combined with toileting, cannot be a function solely of the preoccupation with quantitative considerations of economy over qualitative issues of caring. Clinical practice reflects both systemic values as well as the individual values of practitioners (Frank, 2004). As Frank argues, in the interpersonal moment of practicing medicine almost invariably there is the possibility of acting with compassion. Though Frank is speaking specifically about the practice of medicine, his argument can be extended to include nursing and allied health care practices as well. Hoagland similarly states, 'caring is a choice we make' (1988, p. 283).

This is not to suggest that there were any malicious or deliberate intentions on the part of the caregivers to mistreat or neglect the women with dementia in the above quoted account. On the contrary, interactions that dehumanize and demoralize the person with dementia can be a consequence of a deeply embedded cultural assumption that with advanced dementia there is a corresponding loss of selfhood (Davis, 2004; Fontana & Smith, 1989). With cognition and memory upheld as the sole guarantors of personhood in Western culture, the dementing process is likened to a dismantling of the person (Davis, 2004), a state that in the later stages of the illness is believed to resemble that of infancy or even death itself (Kitwood, 1993). Kitwood (1997) has described a host of ways in which persons with dementia are depersonalized, invalidated, and treated as dysfunctional. Treatment contexts and caregiving relationships that

foster practices such as infantilization, intimidation, stigmatization, and objectification create what Kitwood (1990; 1998) refers to as a ‘malignant social psychology’ that damages care recipients’ fragile self-esteem, leading ultimately to the loss of selfhood that is so widely thought to be caused by the neuropathology alone.

Assuming a loss of selfhood with advanced dementia implies that there is no affront to human dignity in treating those who are cognitively impaired as though they are unable to experience humiliation. Such an assumption can influence negatively the care provided to individuals with dementia in that they are treated as objects rather than as persons worthy of dignity and respect (Kitwood, 1997). Thus in the case of dementia care, resources alone are insufficient to ensure the provision of humanistic care if such resources are deployed in an organization where the prevalent assumption underpinning care practices is that with advancing cognitive impairment there is a corresponding loss of selfhood. Although more staff can be crucial to providing quality care, increasing staff alone will not resolve the deficit in the quality of care if the additional staff are providing depersonalizing care.

We advocate a new care ethic that underscores the importance of the communicative capacity of the body to enrich our imagination and connect us to the personhood of others, thereby fostering sympathetic and person-centred dementia care. Using a qualitative research design that combines research-based drama with focus groups of health care practitioners, we explored with study participants the breadth and importance of nonverbal self-expression by persons with severe cognitive impairment and how the recognition and support of such self-expression could improve person-centred dementia care. Drawing upon Hamington’s notion of ‘caring imagination’ (Hamington, 2004) and Kontos’ notion of embodied selfhood (Kontos, 2004b, 2005, 2006), we argue that achieving person-centred dementia care is dependent upon

health practitioners' imagination to recognize that selfhood persists despite the presence and progression of cognitive impairment. We further argue that when health practitioners' imagination is informed by shared bodily experiences with their care recipients and the ways in which selfhood is expressed through social habits, gestures and actions of the body, even greater sympathetic connection can be made.

Methods¹

Six focus groups were conducted in three different academic health care facilities, located in an urban region of Ontario, Canada. The participating facilities provide a range of programs and services including acute inpatient care, outpatient care, complex continuing care, long-term care and rehabilitation, and were chosen because they specialize in the care of persons with dementia. Each group was led by the same moderator who had experience facilitating focus group discussions and a theoretical understanding of the topic for deliberation; qualities deemed necessary for the success of focus groups (Krueger, 1998; Krueger & Casey, 2000). A research assistant with qualitative research training was also present for each focus group to operate the tape recorder and document key points of the discussion.

Each focus group began with a live performance of a research-based dramatic production, entitled *Expressions of Personhood in Alzheimer's*. The production itself consisted of five separate vignettes, which were thematically connected in that all featured bodily expressions of selfhood by severely cognitively impaired residents of an Alzheimer Support Unit. These were actual observed occurrences drawn from ethnographic research on an Alzheimer Support Unit (Kontos, 2004b). The following five instances of actual observed occurrences served as the basis for the scripts of the vignettes: 1) a female resident struggles to pull out a string of pearls from underneath her bib so that they could be seen by the other residents seated at her table without

the staff ever responding to her display of her pearls; 2) a resident who has no recollection of her ability to weave repeats ‘I cannot’ as a program instructor brings her a canvas to weave, but once a threaded needle is placed between her fingers she proceeds to weave with proficiency; 3) a resident who sees another resident seated at the dining table alone with her breakfast untouched gestures for her to eat as she peels for her the hard boiled egg and removes the foil lid of her juice; 4) a resident believes that her deceased husband to whom she was married for 65 years has just died, and she gestures to a nurse who tries to console her to ‘sit Shiv’ah’ with her (the Jewish ritual of prescribed mourning following the death of a parent, spouse or child), and the nurse does; and 5) on the eighth day of Hanukkah a party is organized for the residents and following the celebratory lighting of the Menorah, when staff begin to take the residents back to the unit, one resident resists and, while staff are busy tending to other residents, she slowly makes her way across the room in her wheelchair to where the Menorah stands, and she covers her eyes and whispers a prayer to herself.

The production served as a springboard for discussion about the breadth and importance of non-verbal self-expression by persons with severe cognitive impairment and how the recognition and support of such self-expression could improve person-centred dementia care. Our rationale for choosing drama to convey Kontos’ ethnographic research findings was that it would provide the focus group participants with a more vivid depiction of the manifestation of selfhood in habits, gestures and actions of the body than could be achieved with traditional dissemination strategies (e.g. academic discourse) (Kontos & Naglie, 2006).² Further to this rationale, *Expressions of Personhood in Alzheimer’s* is a production that not only re-presents embodied expressions of selfhood in Alzheimer’s disease, but also critically exposes depersonalizing tendencies of some caregiving practices that are a consequence of either an

assumed loss of selfhood that is widely associated with severe dementia, or a narrow perspective on personhood that does not account for the role that the body plays in its expression. The dramatic portrayal of interactions between staff and individuals with Alzheimer's disease was intended to facilitate the focus group participants' recognition of opportunities for health care staff to respond to and support the selfhood of persons with cognitive impairment in its embodied manifestations.

The focus groups were each approximately ninety minutes in duration; thirty minutes for the dramatic performance followed by sixty minutes for discussion. The discussion was based on a series of semi-structured questions about participants' reactions to the production, specifically their understanding of self-expressions by persons with severe cognitive impairment through bodily habits, gestures and actions, and the response or lack of response by the care practitioners depicted in the production. Participants were invited to compare and contrast the above with their own experiences in order to explore self-expression by persons with severe Alzheimer's in the context of their practice, and the implications of recognizing, or not recognizing such expressions for dementia care.

Participants

A purposive sampling strategy (Denzin, 2000) was used to select the participants involving the following criteria for participant eligibility: 1) a nurse, health care aide, occupational therapist, physiotherapist or recreational therapist; 2) experience in providing direct care (e.g. bathing, dressing, feeding, rehabilitation) to patients or residents diagnosed with dementia; and 3) practice in accordance with a person-centred approach to care. The rationale for eligibility was that including nurses and allied health care practitioners would bring a diversity of clinical experience that would broaden and enrich the focus group discussions. Also, the practice

of these particular health care practitioners focuses on the body as the primary site of care work.³ It is precisely the physical nature of their clinical practice that provides them the experience that would be crucial to the body-based perspective on personhood that we wished to explore. Recreational therapists were included given that in the activities they organize (exercise, music, social tea, etc.) they would have close proximity to residents which would provide them opportunities to observe residents' bodily habits, gestures and actions. Finally, those practitioners who adopt a person-centred approach to their dementia practice would be more likely to recognize that the recipients of their care, irrespective of their degree of cognitive impairment, are persons. Such recognition would be indispensable for a discussion about self-expression in Alzheimer's disease and how the recognition and support of such expression is critical for person-centred dementia care.

The appropriate administrators (manager, clinical nurse specialist, advanced practice leader, etc.) of each institution identified participants who, in their assessment, met all three eligibility criteria. Those participants deemed eligible and who agreed to be contacted by the principal investigator were contacted by telephone, informed of the purpose of the focus groups and were asked if they were willing to participate. Informed consent was obtained from all participants who were contacted. Ethics approval was obtained by the ethics review board of each of the three health care facilities involved in the study.

Each focus group consisted of six to eight practitioners on staff at the given facility with two focus groups conducted per facility (see Table 1 for summary of participant characteristics). Forty-three female practitioners participated; sixteen nurses, ten occupational therapists, eight physiotherapists, seven recreational therapists, and two health care aides.⁴ Fewer health care aides were recruited because two of the three facilities do not staff this category of practitioner.

Participants were recruited from long-term care (67%), behavioural management (26%), and geriatric rehabilitation (7%) units that varied in size (10-bed to 79-bed units) and client/staff ratio (3:1 to 7:1).

All focus groups were audio-taped and transcribed. All data were analyzed according to standard thematic analysis techniques (Denzin & Lincoln, 1998). Descriptive codes of analysis were first attached to segments of the text (Kuckartz, 1995). The descriptive codes were then grouped into broad topic-oriented categories and all text segments belonging to the same category were compared (Kuckartz, 1995). Ultimately, the topic-oriented categories were further refined and formulated into fewer analytical categories through an inductive, iterative process of going back and forth between the data and our conceptual framework of ‘caring imagination’ and ‘embodied selfhood’. Emerging themes were identified independently by the focus group facilitator and the research assistant, and agreement on these themes was reached through discussion by both. Data analysis was conducted concurrently with data collection, a process referred to as interim analysis (Miles & Huberman, 1984), which allowed for confirmation, modification, or rejection of emerging themes as new transcripts were analyzed (Pope, Ziebland, & Mays, 2000). Five major themes were identified and are presented in the following section according to a logical progression whereby each theme follows from the previous one.

Findings

Theme #1: Sympathetic Connection

Explicit in the discussions with our participants was the importance of the belief that personhood persists irrespective of advancing dementia. As one physiotherapist commented: ‘It’s often forgotten that they are actually people with a history and a life and that they have wishes

and desires'. Other participants addressed the life history and the individuality of persons with dementia, as exemplified in the following comment by a nurse:

There's a person behind the diagnosis, somebody with a past, somebody with, you know, history. I think one of the main things, to me, to look at is that there's a person behind that disease or diagnosis. It's not just the disease, you know. You don't treat everybody the same way if they all have the same diagnosis. So recognizing the individual needs of each person is so important, regardless of the fact that they have dementia.

An occupational therapist similarly commented:

Sometimes I think we don't even--shouldn't even think about the person being cognitively impaired; you should just think about them as a person and put all that aside, and see who they are and learn about them from a person perspective, not from the perspective that they are severely impaired.

Reflecting on the connection between the recognition of personhood and the quality of the caregiving relationship, a recreational therapist noted, 'I think it just comes down to seeing beyond the difficult behaviours and respecting them as a person. I think when you respect the person, you're going to have a better relationship'. A physiotherapist similarly commented, 'the residents here are like anyone one of us; they respond more positively when treated with respect, and that is the same as we are. The fact of their dementia doesn't change that'. Even in instances of severe cognitive impairment, treating individuals with dementia as persons is deemed crucial.

As one nurse insightfully reflected:

For us, we get bathed and dressed in order to get on with our day but for these residents, and especially those who are confined to bed, bathing, dressing and eating *are* their day so these become those vital opportunities to bring them comfort and dignity [emphasis in original expression].

The importance of dignity mentioned in the above statement of a nurse was further endorsed by other participants as the following remarks of a health care aide demonstrate:

You know, one lady I know never goes without her stocking [sic] so that's important to never ever dress her without her stockings on. It might seem like a small thing, but for this lady,

it is important for *her* because she probably never left the house without her stockings on [emphasis in original expression].

For some participants, recognizing personhood involves personal identification with the care recipient. This is aptly captured in the following statement of an occupational therapist:

You know, I mean if it were your mother, if it were you, how would you like to be treated? Would you like to have your own things around? You know, would you like people to tell you the truth, would you like people to validate who you were in life? Everybody would say yes. There's no one who would say no. This is a tool I sometimes use. I think it could be my mother.

In imagining that either she or her mother could share the same fate as her cognitively impaired clients, the occupational therapist bridges the gap between herself and her clients and is able to act with compassion. Other participants were critical of such personal identification with their clients. As one nurse commented:

To think that it could be you in that situation tomorrow, or your mother, that requires a lot of willingness and introspection, and I think many of us don't want to go there. I think there are times where one does distance oneself as a staff person, and to a degree one has to because if you took it all in at such a personal level, you couldn't cope. It would be immobilizing.

While there was a lack of consensus about the virtue of personal identification with clients as a tool to provide quality care, many agreed that even in the absence of such personal identification, one could still recognize and support personhood. A nurse aptly captured this point in the following statement:

Sure you could think that it could be me, it could be my father, it could be my mother, it could be my grandparents, and that makes it more personal. But I don't do that, I can't. But that doesn't mean that I don't still *see* the humanity in a person and provide good care [emphasis added].

The above quotations highlight the importance of the recognition of personhood, but that recognition does not determine or demand a single approach. Some approach personhood via

personal identification while others do so via a recognition of the humanity of the care recipient. Irrespective of the approach, both recognize personhood which is fundamental to sympathetic connection with care recipients. In the following theme of ‘shared bodily experience’, study participants discuss how bodily experiences of theirs create further potential for sympathetic identification with their care recipients.

Theme #2: Shared bodily experience

The idea that bodily experiences of health practitioners further facilitate connection to the personhood of those under their care was powerfully captured by the focus groups participants, as exemplified in the following quotations:

I had just finished my shift and I was on my way out when I saw [Mrs. B] standing in the dining room with feces on the floor. She was crying out for a nurse to help. I could have just left seeing that my shift was finished and all, but I couldn’t bear to let her wait another minute to be cleaned up. I mean I could feel her embarrassment and discomfort when I looked at her standing there. So I took her to her room right away and I changed her clothes thinking all along ‘I bet that feels much better’ [nurse].

I have to crush pills for some residents who can’t swallow them whole. But for many it’s really difficult to get them to take it. I mean, *I* know how bitter it can taste when you crush a pill and just mix it with juice. So I try to find out what the resident likes that I can mix the crushed pills with. I noticed that one resident loves jam with her toast so I got the idea to mix the crushed pills with a teaspoon of jam for her. It makes a huge difference. She doesn’t notice the pills at all (emphasis in original expression) [nurse].

In the winter I feel the residents’ cold when I take them out of the bath. So I wrap them in a towel quick and rub their back and arms just as I do myself because I know how it feel [sic] to be wet and cold [health care aide].

One resident who really enjoys the social programs was very upset one day but she couldn’t articulate why. She was disrupting the program but instead of asking her to leave I gave her a hug and she calmed down...I know how the warmth of a hug feels when I’m sad or down [recreational therapist].

In the above quotations the response of practitioners to their care recipients is rooted in a connection and understanding that comes from shared bodily experience. The nurse knows from

experience about embarrassment and discomfort. Similarly, another nurse knows the bitter taste of crushed pills, the health care aide knows from experience about being wet and cold, and the recreational therapist knows from experience about the warmth of a hug. These shared experiences facilitate connection with their care recipients, a connection that clearly informs their sympathetic approach to caring.

Theme #3: Socially acquired habits of the body

In the above theme of ‘shared bodily experience’ we see the significance that experiences of the body have for practitioners’ caring habits. However, such experiences alone are not in all circumstances sufficient to facilitate sympathetic connection with others. The importance of recognizing and responding positively to social modes of expression by persons with dementia was discussed by focus group participants. For example, many participants recounted instances where persons’ previous vocations instilled in them bodily dispositions to move and act in particular ways, and, with some knowledge of the life history of those persons, the meaning of such expressions could be recognized.⁵ For example, a nurse spoke of a resident who was previously a farmer:

In the middle of the night, 3:00am, he gets up and goes in the middle of the hallway, and he’s doing like this [demonstrating the motions of planting] because he is thinking that he is still a farmer and has to wake up early to plant the rice, or whatever.

When asked about her response to the resident’s behaviour, the nurse replied, ‘so long as he isn’t harming anyone I think it is important to support and encourage this because he is expressing himself in the way that he knows’. Another example of how selfhood is manifest in social habits of the body was provided by an occupational therapist:

One of our residents was a cleaning person or superintendent I think it was, and his whole life he did cleaning. So he spends much of his time now rearranging the furniture, stacking chairs, and that sort of thing. It’s who he is.

In these cases, as well as in similar examples where residents' previous vocations instilled in them bodily dispositions to move and act in particular ways, some degree of knowledge about their life history was necessary in order for the health care providers to recognize such expressions as meaningful. However, even in the absence of such knowledge, it is nonetheless assumed that behaviour has an underlying meaning. As one recreational therapist said 'there's always a reason that person has a behaviour. There's a reason for it, and we just need to stop and figure out what it is'. A nurse similarly commented 'I just find that as nurses we need to look a little bit deeper; like try to respond to the 'why' of the behaviour'. Echoing these comments another nurse stated:

Sometimes their behaviour is so difficult to figure out, but I think whether it's a large unit or a small unit, just spending a few minutes just to investigate what's going on, sometimes we can learn a lot from that, like what this behaviour is telling us about this person.

The focus group participants also spoke of how selfhood is expressed through social etiquette. The following incident recounted by an occupational therapist is exemplary of how social etiquette is manifest:

There's another gentleman...he'll often stand by the door of the dining room blocking the residents from going in and out. But, you know, talking to him will not help, you know. I say 'come this way', and things like that. What I found, and I just found this out by accident, I just put my hand out like this [motioning the gesture of putting one's elbow out for another to take hold of], kind of like when an older couple walk together arm-in-arm, and he took it.

The gesture of walking arm-in-arm was evidently something the resident recognized and was able to respond to. Similarly commenting on embodied expressions of social etiquette, a recreational therapist recounted the importance of hats for the residents of a Veterans' facility:

Hats. I find that hats, because I do a lot of outings, you know, it's like, 'oh, we got to wear a hat'. They're used to wearing a hat to go out, and then we enter a building, off comes the hat, you know. And I used to do a lot of Legion trips. If anyone wore a hat to go into a Legion, they had to buy everybody a round of beer. So you see, once they're coming in, oops, there goes the

hat, you know. So some of those things that they've grown up with or have done their whole life stay with them.

Awareness of, and respect for such conventions can also be inferred from the strong reaction of some residents to other residents who fail to adhere to proper etiquette. Referring to the scene of the play where a cognitively impaired woman pulls a string of pearls from beneath her bib so that they can be seen by the other residents at the dining table, a health care aide comments:

We have a resident like the woman with her pearls who is so nice and proper. I remember one time at breakfast, or maybe it was lunch, I can't remember, but what happened was a man burped so loud and a woman seated at his table was disgusted. She gave him a look I'll never forget and just like that she got up and left the table. She know [*sic*] you don't behave like that at the table. I said to myself 'what a proper lady'.

Awareness of, and respect for social conventions was clearly inferred by the health care aide from the reaction of the female resident to the improper behaviour of the male resident seated at her table.

Theme #4: Time efficiency

Participants agreed that taking time to figure out the reason for specific behaviours that they interpreted as bodily expressions of personhood, and how to respond positively to such expressions, can render the provision of care more time efficient in the long term. As one occupational therapist indicated, 'I find if I take more time initially to meet that underlying need, even if I have like six other clients to take care of, it saves time in the long run. Take one extra minute, you'll save five, kind of thing'.

These sentiments, as exemplified in the following statements, were echoed by many participants, even among those whose work setting had the highest patient/staff ratio:

I have a gentleman who always was resistive when I tried to remove his pants during care. He would keep pulling them back up or just push my hands away. So I took some time to speak to the wife to figure out what was happening and she says he always was a very private

man, always closing the bathroom door and covering himself when he would bathe. So I came up with the idea to attach Velcro to the towels we use so I could get his pants off without him being exposed. So we use that around him, you know, during care, and because you have him covered, he's less resistive, and it's much easier and less time consuming to get his care done [nurse].

I took the time to find out from the wife about a resident of mine who I can't get to stay seated on the toilet. He resists and resists and I couldn't understand why. It turns out that this man loved cars, and next to their toilet in their washroom they always had a basket of magazines about cars. So if he always read a magazine about cars when he was on the toilet no wonder I could never get him to stay seated. Now I bring him car magazines and he stays until he's through. It's really amazing actually that something so simple can make such a difference in terms of the time saved during care and for the quality of care I can provide. There's no fight anymore so he's happy and so am I. There's no stress anymore when providing his care [health care aide].

As indicated in the above quotations, where expressed personhood is identified as the trigger of behaviour, the appropriate tailoring of care has the potential to reduce 'aberrant' behaviour thereby improving the efficiency of practice and the caregiving interaction for both care provider and recipient.

Theme #5: Nonpharmacologic behavioural management

Practitioners who recognize and support bodily expressions of personhood of those in their care suggest that such recognition and support can reduce the use of pharmacotherapies for the management of behaviour attributed to symptoms of dementia. As one nurse describes:

Treating the person as a real person cuts down on the need for medication. Like, you know, sometimes we give medication for restlessness, agitation, but it's not needed. We usually have our minds on carrying out the task in hand, rather than listening to and observing what the person is communicating. But if I go deeper, beyond, you know, my tasks, and interpret it you know, I can often come up with a plan that doesn't require medication and that succeeds in calming the resident.

A recreational therapist recounts how, through the discovery of the meaning of a resident's aggressive behaviour towards other residents, she was able to reduce the resident's aggressive actions without the need of prescriptive drugs.

The gentleman who would knock the hats off of other residents' heads in the dining room, well, when we realized the reason for his aggressiveness towards the other residents, we were able to manage his behaviour simply by reassigning the seating. By seating him with other residents we reduced the times he was confronted by those who insisted to wear a hat in the dining room.

Resistance to personal care was also identified as being amenable to nonpharmacologic strategies as exemplified in the theme of 'time efficiency' (see above), by the example of the nurse who introduced Velcro-strap towels to accommodate a resident's need for privacy during care and the health care aide who provided car magazines to accommodate a resident's habit of reading such material while on the toilet.

Discussion

In the account quoted in the introduction about the female residents with dementia being fed while being toileted, there was a failure on the part of the care providers to respect the human dignity of the women, a failure to regard them and treat them as persons. The care providers' lack of awareness and sensitivity points to a more fundamental lack of sympathy for these women. This of course raises the issue of the origination of sympathy, and what precisely allows and/or encourages such sensitivity. Following philosophical insight, most notably that of Hume (1978 [1739]), Smith (1976 [1759]), and more recently Nussbaum (2004), it is the imagination that allows and encourages sympathetic connection with others. As Smith (1976 [1759], p. 9) argues in his theory of moral sentiments:

By the imagination we place ourselves in [a sufferer's] situation, we conceive ourselves enduring all the same torments, we enter as it were into his body, and become in some measure the same person with him, and thence form some idea of his sensations, and even feel something which, though weaker in degree, is not altogether unlike them.

Referring to this sentiment as 'moral imagination' (Nussbaum, 1995), Nussbaum argues that with imagination it is possible to 'think what it might be like to be in the shoes of a person

different from oneself, to be an intelligent reader of that person's story, and to understand the emotions and wishes and desires that someone so placed might have' (1997, pp. 10-11).

Because sympathy is an integral component of care, Hamington (2004) advocates the notion of 'caring imagination'. In our conceptualization of a care ethic premised on an embodied notion of personhood we draw upon Hamington's epistemology of care. Hamington (2004) argues that it is our imagination that allows us to make the connection that facilitates sympathetic care for people unrelated to us. Imagination is capable of traversing physical distance, such as when natural disasters in distant parts of the world activate our sympathy towards the victims of such disasters. The distance to which Hamington refers also includes socially constructed distance (e.g. differences between ethnic groups in a given community). However, here we wish to broaden the notion of distance to include the distance between a care provider and recipient with advanced cognitive impairment. Just as Hamington argues that imagination allows us to bridge the gap between ourselves and unknown others, our focus group data suggest that in order to sympathize with a care recipient, the recognition and acknowledgement that selfhood persists irrespective of one's degree of cognitive impairment is central. It is the imagination that transcends assumptions about the diminishing humanness of persons with Alzheimer's disease and only then can care providers act with compassion. In other words, in the context of dementia care, it is the recognition that selfhood persists despite the presence and progression of cognitive impairment that facilitates sympathetic care.

The theme 'sympathetic connection' highlights the importance of the recognition of personhood for sympathetic care, fundamental to which is the imagination. For some participants recognizing personhood involves placing themselves or a close relative in the shoes of their care recipients. Thus in these instances it is the act of the imagination that bridges the gap between the

care provider and care recipient which then enables the provider to act with compassion.

Through this imaginative gesture, the identification of the care recipient with oneself or with a close relative transforms the care recipient into a person whose closeness to oneself naturally incites a compassionate disposition.

Not all participants agreed that such personal identification with their clients was necessary in order to ‘see the humanity in a person and provide good care’. Some maintained that personalizing care in this way can be immobilizing and not all practitioners are willing to make such an emotional investment and to place themselves in such a vulnerable position. However, the ability to ‘see the humanity in a person’ does not entail a self-evident awareness for the practitioner. Indeed if it were self-evident that individuals who are severely cognitively impaired are ‘persons’ then instances such as that described in the introduction where residents are fed while being toileted would never occur. What allows the care recipients to enter into the view of the care provider as persons is their humanity; humanity as a larger category becomes the means of identification and it is the imagination that broadens one’s perspective and facilitates this connection. In other words it is the imagination that allows the care provider to entertain a degree of speculation as to what the care recipients’ existence is like.

This is not to suggest that speculation of this kind must be entirely accurate. It is not accuracy that guarantees the connection but rather an imaginative understanding of the care recipient’s humanity. For example, in reference to the nurse who commented on the importance of bathing, dressing and eating as activities that can bring comfort and dignity to those who are confined to an Alzheimer Support Unit, though she may not herself have an actual experience of being institutionalized and unable to bathe, dress or feed herself, she does recognize the dignity

that bathing, dressing and eating accord to a person with dementia precisely because such dignity is fundamental to being human.

Hamington (2004) draws upon Merleau-Ponty's (1968) philosophy of the body to argue that the shared nature of fundamental bodily experiences with other beings enriches the imagination thereby providing further potential for sympathy.⁶ According to Merleau-Ponty (1968) we share a corporeal existence with other beings and thus, to some extent, we immediately have a level of shared knowledge of sensory experience that is both tacit and explicit. Hamington (2004) illustrates this point with the example of our response when a knife accidentally cuts another's body; he explains that we don't have to reflect on whether or not pain was felt since our own aggregate bodily experiences inform us that pain comes with such an experience. The idea that the intertwined nature of bodily experience gives us an understanding of the experience of others and thereby connects us to the personhood of the other, is powerfully captured by the focus groups participants. The examples provided under the theme 'shared bodily experiences' demonstrate how the response of practitioners to their care recipients is rooted in a connection and understanding that comes from what Merleau-Ponty (1968, p. 143) refers to as the common bond of embodied experience. Given this common bond, to a certain degree these practitioners know of their care recipients' bodily experience, knowledge that clearly informs their approach to caring. As Hamington argues (2004, p. 56), 'there is an internal 'logic' to caring habits. They make sense for others because they would make sense for me and my body given similar circumstances'.

However, it is important to bear in mind that it is the imagination that facilitates the connection between the embodied experience of the practitioner and that of the care recipient. In the theme 'shared bodily experience' we see that health practitioners know from experience

about embarrassment and discomfort, the taste of bitterness and sweetness, being wet and cold, and the warmth of a hug. However, it is an act of the imagination that connects their own experience to that of their care recipients. It is in this sense that the shared nature of bodily experience enriches the imagination, which, in turn, further facilitates sympathetic connection to the personhood of another and, by extension, sympathetic care.

The focus group data indicate that shared bodily experiences alone will not in all circumstances be sufficient to facilitate sympathetic connection with others. For example, in the theme ‘socially acquired habits of the body’, many participants recounted instances where they recognized self-expression not through shared bodily experiences but rather through their care recipients’ expressions of socially acquired behavioural habits. Tendencies and inclinations to move and behave in a particular manner were linked for example to the residents’ previous vocation. This is consistent with the notion of embodied selfhood (Kontos, 2004b; 2005), which asserts a socio-cultural dimension of selfhood that derives from the socio-cultural specific conditions of one’s socialisation and cultural environment. Such culture-specific conditions give selfhood its socio-cultural specificity by virtue of being embodied and materialised in our habitual state, tendencies and inclinations to act in particular ways. Additional examples of how propensities and movements of the body are socially qualified were provided by the focus group participants in their discussion of residents’ awareness of and respect for social etiquette. The examples provided by the study participants of proper table etiquette, and the social conventions of walking arm-in-arm and wearing a hat in a Legion illustrate socio-culturally specific ways that selfhood is expressed. Thus, it is not basic bodily experiences alone to which sympathetic identification gives us a connection; social and cultural habits, movements, and other physical cues disclose significant information about a person and only when the imagination of health

practitioners is informed by both social expressions of the body and more fundamental bodily experiences can they fully empathize and contextualize their caring efforts.

Conclusion

The findings of our study suggest that, in the context of severe cognitive impairment, practitioners can better achieve person-centred dementia care by engaging their imagination to recognize that selfhood persists despite the presence and progression of cognitive impairment. Using their imagination allows them to sympathize with their care recipients, thus providing the necessary foundation for person-centred care. Where imagination is informed by shared bodily experiences with their care recipients, there is even greater potential for sympathetic care. Yet even when the imagination is informed by shared bodily experiences, this is not in all circumstances sufficient to facilitate sympathetic connection with others. This is so because in circumstances where selfhood is manifest in socially acquired habits of the body (e.g. social etiquette and bodily dispositions which convey one's previous vocation), sympathetic connection is dependent upon the recognition and support of such manifestations.

Our findings further suggest two potential implications of practitioners integrating an understanding of bodily expressions of personhood into their clinical practice: first, it may improve the time efficiency of clinical practice in the long run; and second, it may reduce in certain instances the need for drug therapy as chemical restraint. Recognizing bodily expressions of personhood is not by any means a panacea for managing the behavioural symptoms associated with dementia. However, when specific causes of the behaviour such as pain are excluded, and when expressed personhood can be identified as the trigger, the appropriate tailoring of care has the potential to reduce 'aberrant' behaviour, thereby possibly improving the time efficiency of practice in the absence of pharmacotherapies. These findings underscore the need for an

empirical exploration of the outcomes of an embodied selfhood approach to person-centred dementia care.

In exploring the relevance of the theoretical notion of embodied selfhood for clinical practice, we discovered that there are care providers who are finding their way intuitively to a person-centred approach that recognizes and supports selfhood as manifest in the body's habits, gestures and actions. Yet, the intuitive practices of a select few and the concomitant experience that derives from such practices will not be sufficient to change practice more broadly. Giving theoretical voice to these intuitive practices is a necessary first step towards the development of a more systematic approach to care that recognizes and supports bodily expressions of selfhood. For those practitioners who are already intuitively engaged in such an approach to care, theoretically grounding their intuitive and experiential knowledge would effectively reinforce their approach.

Quality of care in residential and nursing homes is in need of radical improvement (Ballard et al., 2001). However, resources by themselves are likely to be insufficient to ensure the provision of high quality care if such resources are deployed in an organization where practitioners assume a loss of personhood in the advanced stages of dementia. Given the communicative capacity of the body to inform and enrich our imagination and connect us to the personhood of others, thereby fostering sympathetic care, it is imperative that this capacity be further explored as a means of improving person-centred dementia care.

Acknowledgments

This study was generously funded by the Collaborative Research Program: Rehabilitation & Long-Term Care, the Canadian Nurses Foundation, and the Nursing Care Partnership. Dr. Kontos is supported by the Canadian Institutes of Health Research Fellowship Program, and the Health Care, Technology, & Place (HCTP) CIHR Strategic Research & Training Program (supported by CIHR Institutes of Health Services and Policy Research, Gender and Health, and Knowledge Translation Secretariat). Dr. Naglie is supported by the Mary Trimmer Chair in Geriatric Medicine Research, University of Toronto. Toronto Rehabilitation Institute receives funding under the Provincial Rehabilitation Research Program from the Ministry of Health and Long-Term Care in Ontario. The views expressed here do not necessarily reflect those of our supporters or funders.

Notes

¹ The methods employed in this study are similarly described in an article of ours that describes an evaluation of health practitioners' perceptions of a research-based theatre presentation as a pedagogical tool (Kontos & Naglie, in press).

² For a more detailed discussion of our rationale for choosing drama as a knowledge translation strategy, and the methodological process of translating Kontos' ethnographic research into dramatic form see Kontos and Naglie (2006).

³ Though physicians deal with the body, medical practice is constructed in such a way as to confine direct bodywork to the activity of diagnosis or to mediate it by high-tech machines (Twigg, 2000).

⁴ In the focus groups where the health care aides were present, there was no discernible power dynamic. All participants were fully engaged in the discussion and ideas and experiences were shared freely. We can only speculate that the participants' full commitment to the issue of person-centred dementia care rendered their status differences insignificant.

⁵ The study participants are clearly driven by a desire to impute meaning into various behaviours of their care recipients, however, it is important to note that it is not just any meaning that is being imputed but rather a meaning that corresponds to a particular reality (e.g. previous vocation, social etiquette, etc.).

⁶ Hamington, in referring to Merleau-Ponty's notion of the shared nature of corporeality, does not explicitly articulate the centrality of this notion to personhood. However, the logic of his argument that the shared nature of corporeality creates the potential for sympathetic care is dependent upon the idea that shared bodily experiences allow us to make a connection with the personhood of another being. Kontos (2004a; 2004b; 2005) explicitly argues that the body's inherent ability to convey meaning provides the corporeal foundation of selfhood.

TABLE 1: Participant Characteristics (N = 43)

Gender	No. (%)
Female	43 (100)
Professional Background	
Nurse	16 (37.2)
Occupational therapist	10 (23.3)
Physiotherapist	8 (18.6)
Recreational therapist	7 (16.3)
Health care aide	2 (4.7)
Area of Practice	
Long-term care	29 (67.4)
Behavioural management unit	11 (25.6)
Geriatric rehabilitation unit	3 (7.0)

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