Rethinking sociability in long-term care: An embodied dimension of selfhood

Pia Kontos

Version  Post-Print/Accepted Manuscript


Publisher's Statement  This is the peer reviewed version of the article, which has been published in final form at https://dx.doi.org/10.1177/1471301211421073.

How to cite TSpace items

Always cite the published version, so the author(s) will receive recognition through services that track citation counts, e.g. Scopus. If you need to cite the page number of the TSpace version (original manuscript or accepted manuscript) because you cannot access the published version, then cite the TSpace version in addition to the published version using the permanent URI (handle) found on the record page.
Rethinking Sociability in Long-term Care: An Embodied Dimension of Selfhood

By Pia C. Kontos

© Pia C. Kontos¹, 2011

¹Pia C. Kontos, BA, MA, PhD
Research Scientist, Toronto Rehabilitation Institute
Assistant Professor, University of Toronto

Direct all correspondence to:
Dr. Pia Kontos
Research Scientist
Toronto Rehabilitation Institute
Assistant Professor, Dalla Lana School of Public Health
University of Toronto
11035-550 University Avenue
Toronto, ON M5G 2A2
Canada
TEL: (416) 597-3422, ext. 7609
FAX: (416) 597-7105
Email: kontos.pia@torontorehab.on.ca
Abstract

Sociability, interaction through which solitariness becomes togetherness or a union with others, has largely been explored without reference to the importance of bodily sources of agency. Encapsulated in the theoretical notion of embodied selfhood is the pre-reflective nature of selfhood deriving from the body’s pre-reflective capacity for engaging with the world and the socio-cultural significance of the body. This paper argues for an expansion of the discourse on sociability in dementia to include embodied selfhood as a source of interactive practices. An eight-month ethnographic study of selfhood in dementia was conducted in a Canadian long-term care facility. The findings suggest that social and cultural habits, movements, and other physical cues serve important communicative functions in the course of social interaction. This underscores how sociability is an embodied dimension of selfhood, which not only broadens the discourse on sociability in dementia but also offers important insights to inform person-centred dementia care.
Introduction

Sociability, defined as interaction through which solitariness is resolved into togetherness or a union with others (Simmel & Hughes, 1949), has been found to play an important role in residents’ quality of life (Oleson et al., 1998) and in reducing agitation (Cohen-Mansfield & Marx, 1992; Kutner et al., 2000). Yet institutional care settings have long been described as places where residents spend most of their time in social isolation (Chen et al., 2000; Ice, 2002). Often, limited sociability has been related to bodily impairments of the elderly, including dementia-associated decline in cognition, hearing, speech, sight, and ambulation (Chen et al., 2000; Cook et al., 2006; Hubbard et al., 2003; McKee et al., 1999). While there is increasing evidence that nursing home residents actively seek ways of interacting with staff and relating to fellow residents (Hubbard et al., 2002; Hubbard et al., 2003; Kontos, 2004; Kutner et al., 2000; Surr, 2006), to date, the bodies of those with dementia have failed to be seen as an important source of agency for sociability (Kontos, 2004, 2005).

In this paper I argue for an expansion of the discourse on sociability to include embodied self-expression – encapsulated in the notion of “Embodied Selfhood” (Kontos, 2004, 2005, 2006; Kontos & Naglie, 2006, 2007b) – as a source of interactive practices. The theoretical precepts of embodied selfhood include Merleau-Ponty’s (1962) reconceptualization of perception and Bourdieu’s notion of habitus (1977, 1990). Embodied selfhood provides the theoretical framework for the articulation of the body as a site for the production of sociability. Findings presented here are drawn from an ethnographic study of an Alzheimer support unit. The findings suggest that social and cultural habits, movements, and other physical cues serve important communicative functions in the course of social interaction, underscoring sociability as an
embodied dimension of selfhood. Understanding the embodied nature of sociability has important implications for initiatives to improve care practices.

**Sociability: A Disembodied Discourse**

Research on sociability in institutional care settings suggests that such settings are not total domains of solitude and emptiness. Hubbard et al. (2003) identified important aspects of verbal communication including hostility, humour, and expression of affection and sexuality that produce and reproduce social interactions between residents. Others have similarly focused on the narrative or discursive properties of communication with persons with dementia (Mayhew et al., 2001; Sabat & Harré, 1992; Sabat & Collins, 1999; Tappen et al., 1999). Focus has largely been on language use in conversation, specifically on how the continued use of personal pronouns by persons with advancing dementia is indicative of the persistence of their selfhood.

Despite the fact that social interaction amongst older people with dementia is largely constructed through the use and interpretation of nonverbal behaviour (Hubbard et al., 2002), there is a paucity of research on the nature and meaning of nonverbal communication amongst persons with dementia (for an exception see Hubbard et al., 2002; Kontos, 2004, 2005, 2006; Kontos et al., 2010b; Kontos & Naglie, 2007b). Sociability research shares this oversight, in large part because of the theoretical influence of symbolic interactionism. Key to interactionist social theory is belief that selfhood is socially acquired and sustained, and that the body of the social actor is a largely inconsequential feature of the “self-in-society perspective” (Turner, 1996, p. 62). Thus, the self is understood not as a fixed attribute of an individual but rather as ‘emergent’ and crucially tied to interaction (Cooley, 1972; Goffman, 1963; Mead, 1970). Consequently, the idea that the body might be one component of the continuity of the self is
discarded in favour of the argument that the continuity of the self rests solely on the continuity of others’ perceptions (Turner, 1996).

Embracing a view of selfhood that hinges on social interconnectedness provides a crucial critique of the dominant biomedical paradigm of dementia which associates the onset and progression of Alzheimer’s disease with a complete loss of self (Davis, 2004). It does so by identifying practices which lead to the loss of selfhood that is so widely thought to be caused by neuropathology alone; namely, infantilization, intimidation, stigmatization, and objectification (Kitwood, 1990, 1998). However, to maintain that it is social interconnectedness alone that constitutes selfhood is to deny the significance of embodiment (Hughes, 2001; Kontos, 2005), or more precisely embodied selfhood (Kontos, 2004, 2005, 2006; Kontos & Naglie, 2006, 2007b) – the idea that bodily habits, gestures, and actions support and convey humanness and individuality. Consequently, until now, the body as a source of agency has not been incorporated into the discourse on sociability in the dementia literature.

*Embodied Selfhood*

Embodied selfhood is premised on a pre-reflective notion of agency which resides below the threshold of cognition and is manifest primarily in corporeal ways (Kontos, 2004, 2005, 2006). As an embodied dimension of human existence, selfhood persists even with severe dementia (Kontos, 2004) as demonstrated, for example, in religious and artistic practices (Kontos, 2006; Kontos & Naglie, 2007b), aversion to particular foods (Kontos et al., 2010a; Kontos et al., 2010b), and in bodily dispositions that convey prior vocation (Kontos et al., 2010a; Kontos & Naglie, 2007a, 2007b) of persons with dementia.

Embodied selfhood takes its theoretical bearings from Merleau-Ponty’s understanding of non-representational or basic intentionality (Merleau-Ponty, 1962), and from Bourdieu’s concept
of habitus, which links bodily dispositions to structures of the social world (Bourdieu, 1977, 1990). More specifically, I conceptualize Merleau-Ponty’s elucidation of basic intentionality as providing the corporeal foundation of selfhood evidenced by the existential expressiveness of the body. Merleau-Ponty’s basic intentionality is the body’s concrete, spatial, and pre-reflective directedness towards the lived world. It refers to a field of possible movements, a kind of inner map of movements the body naturally ‘knows’ how to perform without having to reflect upon such movements (Merleau-Ponty, 1964). In Merleau-Ponty’s words (1964, p. 5), “a system of possible movements…radiates from us to our environment”, giving us at every moment a practical and implicit hold on our body, a hold that situates us as subjects perceptually, linguistically, as well as through motor activity. In this “system of possible movements”, the body possesses, according to Merleau-Ponty, a co-ordinating capacity in relation to itself, through what he refers to as the ‘primary perceptual’ level that is prior to explicit intellection. I understand the primacy of perception as providing the foundation for selfhood, and therefore argue that selfhood, at the most fundamental level, must be understood as inhering in the existential capacity of the body to engage with the world (Kontos, 2004, 2005, 2006).

In Merleau-Ponty’s discussion of basic intentionality, he makes no reference to socio-cultural modes of expression because his exclusive concern is with capacity per se. However, clearly there is a socio-cultural style or content to bodily movements and gestures, the source of which is not attributable to a primary level of signification. Bourdieu’s concept of habitus is pertinent here because it foregrounds the socio-cultural sources of bodily practices.

Bourdieu’s sociological approach to understanding the embodiment of social structures further informs my articulation of embodied selfhood in that I conceptualize habitus as instilling at a pre-reflective level the socio-cultural dispositions of selfhood. Our social being derives from
habitus, what Bourdieu defines as socialized inclinations, associated with membership in a particular cultural group, which instill in individuals dispositions and generative schemes for being and perceiving (Bourdieu, 1977, 1990). Habitus comprises dispositions and forms of know-how that are learnt by the body but cannot be explicitly articulated. It is a form of knowledge that does not pass through consciousness for it is enacted at a pre-reflective level. As Bourdieu states, “the schemes of the habitus…owe their specific efficacy to the fact that they function below the level of consciousness and language, beyond the reach of introspective scrutiny or control by the will” (1984, p. 466, emphasis in original). Just as dispositions are embodied and materialised in practice, so is selfhood embodied and manifests in socio-culturally specific ways of being-in-the-world (Kontos, 2004).

Research on embodied selfhood (Kontos, 2004, 2005, 2006) has identified this pre-reflective form of agency as providing an important foundation to how persons with dementia interact meaningfully with the world through activity and engagement. This research has challenged in a significant way the widespread presumption of the loss of agency with cognitive impairment (Davis, 2004; Fontana & Smith, 1989). To date, embodied selfhood has not been extended formally to the discourse on sociability. Embodied selfhood thus brings a new approach to understanding sociability than has yet been considered in studies of dementia, selfhood, and embodiment.

**Method**

*Ethnographic Setting*

Chai Village is an Orthodox Jewish long-term care facility that accommodates 472 residents and is located in an urban region of southern Ontario. The majority of the residents suffer from probable Alzheimer’s dementia with a minority diagnosed with vascular dementia.
Approximately 80 residents reside on each floor. Their average age is 88 years with the average length of stay being 1510 days. On the unit where I conducted participant observation, there were 79 residents (11 men and 68 women). All were Jewish of Eastern European descent. The level of cognitive impairment amongst the resident population ranged from moderate to severe, as measured by the Mini Mental State Examination (MMSE) (Folstein et al., 1975).

There are richly diverse social activities at Chai Village, with the following among the regular weekly programmes: creative arts including ceramics, silk-scarf painting, drawing, knitting, crochet, weaving and beading; ‘sing-a-long’ where residents are encouraged to play musical instruments such as tambourines and sing popular Yiddish as well as English songs; and the celebration of Jewish High Holidays including *Rosh Hoshanah* (the Jewish New Year), *Yom Kippur* (the day of Atonement), *Sukkot* (the pilgrimage festival for the completion of the harvest), *Simchat Torah* (the completion of the cycle of *Torah* readings), and *Hanukkah* (the festival of lights).

*Participants*

University-based ethics approval was obtained for the study. Following study introductions, informed consent was obtained by proxy for 13 residents (3 men and 10 women). Eligible participants met the following criteria: medical diagnosis of probable Alzheimer’s disease; moderate or severe level of cognitive impairment as measured by the MMSE (Folstein et al., 1975); 65 years of age or older; and two times more women than men. These criteria were selected in order that the sample be representative of the larger Canadian profile of probable Alzheimer’s disease (Canadian Study of Health and Aging Working Group, 1994). Among the study participants, the mean MMSE score at the time of recruitment was 11.38, standard deviation was 4.82, the range was 1–19 (mild 19-24, moderate 10-18, severe 0-10) (Jones *et al.*
2004), with 38 percent being severely cognitively impaired (see Table 1). To ensure that the identity of study participants is protected, all names of the residents are pseudonyms.

Conducting the Ethnography

The ethnographic study was conducted during 2001-2002. Participant observation is fundamentally naturalistic; it is conducted in the natural context of occurrence, amongst the actors who would normally be participating in the setting, and thus follows the natural stream of everyday life. As such, it has the advantage of drawing the observer into the phenomenological complexity of a particular social and cultural world (Jackson, 1996). Participant observation was conducted over eight months for approximately eight hours per day, three days per week. Observation sessions occurred during scheduled programme activities, Jewish holiday celebrations, meal times, and when participants engaged in unscheduled activities such as walking in the hallways or sitting in the living room. All these activities provided a field of experiential possibilities to observe and explore the ways in which individuals with probable Alzheimer’s disease inhabit their life-world.

Detailed and descriptive field notes were recorded during the observation sessions whenever possible and elaborated afterwards. Field note descriptions included the following: the physical location, its layout and how the space was used; and the social environment, what people were doing, how they were relating to one another, how their activities were organized, and the sequence or pattern of events. In my observations I specifically attended to embodiment: locomotion, posture, eye contact, facial expression, gestures; maneuvering the body; balance; social mores, social graces, etiquette; and mannerisms, clothing, accessories, hair.
Analysis

For purposes of the present article, I reexamined my ethnographic findings with a more explicit focus on the various aspects of resident-resident sociability captured by the data. My analysis reveals a strong affinity between interactional dimensions of social life and the pre-reflective sources of selfhood. As such sociability is here conceptualized as an embodied dimension of selfhood.

Field notes were analyzed using thematic analysis techniques (Denzin & Lincoln, 2000). Descriptive coding was first conducted wherein segments of text were assigned a code reflecting the original statement. Codes were then clustered as categories of emerging themes. Through an inductive, iterative process, categories with similar content were investigated for inter-relationships, and further refined and formulated into fewer analytical categories through an inductive, iterative process of going back and forth between the data and the conceptual framework of embodied selfhood.

The data are organized by the thematic categories of ‘empathy,’ ‘social etiquette,’ and ‘the power of gesture’, which disclose a narrative about caring, codified behaviour premised on particular likes and dislikes, and gesticular communication. It is a narrative that captures the embodied nature of sociability, emanating from the pre-reflective sources of selfhood.

Findings

Empathy

There was a great deal of empathy expressed between residents, as when a resident touched another’s arm very tenderly, offering comfort to ease agitation. The giving of attention through an open and gentle presence, and looking at, and listening to each other were additional ways that empathy was expressed between residents. Whether residents expressed their
sentiments to each other verbally or otherwise, there was no uncertainty in these gestures and expressions - they communicated affirmation of one another as human beings. Residents expressed empathy through kind words, touch, attentiveness, and responded to others’ presence and feelings of sadness, loss and fear. In many instances residents responded to a perceived vulnerability or weakness in another resident, displaying a sensitivity that flowed from what Merleau-Ponty (1968, p. 143) refers to as the common bond of embodied experience. 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. Shared corporeal existence gives us an understanding of the experience of others (Merleau-Ponty, 1968), such as hunger, fear and sadness, and thereby facilitates connection to the selfhood of another person (Kontos & Naglie, 2007a):

Having finished her breakfast, Anna stood up and made her way towards the hallway, no doubt to see if by chance the door to the exit had been left open. In doing so, Anna noticed another resident seated alone at a table and stopped abruptly. The woman had oxygen tubing protruding from her nose and which was attached to a portable tank hanging on the back of her wheelchair. She was withdrawn and remote, as if she had faded away leaving behind only a vague form. Her breakfast had been served but, unable to feed herself, she was waiting for assistance. Her private sitter had gone to the kitchen momentarily.

Anna’s preoccupation with the exit doors was suddenly on hold. Looking at the woman’s untouched breakfast, Anna eagerly pushed her walker up to the table and pleaded, “You have to eat!” Her tone expressed a genuine maternal worry. Releasing her hands from her walker, Anna leaned her right forearm on the table for support. She began to peel a boiled egg from the woman’s plate. This was no small effort given her crouched posture that afforded little leverage. Anna placed the peeled boiled egg on a napkin in front of the woman and said, “You must be hungry. Eat!” The woman looked up at Anna and a faint smile appeared beneath the deep creases of her face. She took hold of the egg, and continuing to gaze into Anna’s eyes, her head fell forward gently, then back, blinking her eyes slowly. Anna nodded in approval and smiled proudly.

***

Bertha was extremely agitated. She walked into the living room and sat down next to Ethel who was sleeping. Bertha’s cries woke up Ethel who watched her for a moment and then turned to get the attention of a personal support worker (PSW) who was attending to another resident. Ethel pointed to Bertha’s shaking leg and
said “Oye, look at the leg running. She is sick”. Ethel paused to hear what Bertha was saying; with a distressed look on her face she said to the PSW, “She is crying ‘oye mamma’”. The PSW told Ethel not to worry and that Bertha would calm down. Ethel asked, “She is in pain?” and the PSW assured her that she was not. Ethel, now with tears in her eyes, said, “Maybe she is hungry?” The PSW told her that Bertha is probably a little frightened. Ethel immediately put her hand on Bertha’s knee and leaned close to her body, looking at her face. Bertha’s cries quieted to a gentle moan. Ethel sat with her for most of the afternoon, eventually falling asleep with her hand still on Bertha’s knee. Bertha too had fallen asleep.

Following Merleau-Ponty (1968), 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.

Anna and Ethel need not reflect on whether discomfort is experienced in the above noted observations since their own aggregate bodily experiences inform them about the discomfort of hunger or pain. These shared bodily experiences are important dimensions of selfhood that facilitate connection and inform empathetic caring.

Social Etiquette

Bourdieu argues that the conditioning associated with membership in a particular social class tends, through the relationship to one's own body, to instill in the individual dispositions and generative schemes for being and perceiving (Bourdieu, 1977, 1990). Dispositions are corporeal in that they are embodied in human beings, which, in practice, predispose individuals to move, behave, and to make lifestyle choices characteristic of their habitus (Bourdieu, 1984). There is a socio-cultural style or content to bodily movements and gestures that was evidenced by the regularity of social practices, such as residents adhering to proper etiquette. Manners prescribed by social convention for interaction with others are, for the most part, observed by the residents. For example, when Florence compliments Edna on her pink beaded necklace and string of pearls, Edna replies “thank you”. Bertha, the study participant with the most profound cognitive
impairment, always says “thank you” when her private sitter wipes food from her mouth or chin. Dody routinely will say “good morning” when she sits down at the dining table for breakfast; Florence will in turn say “good morning” and Molly smiles and acknowledges Dody with a nod. “Bless you” can always be heard after a resident sneezes. When Molly uses a Kleenex tissue she softly wipes the tip of her nose. Covering one’s mouth when yawning, coughing, or belching is common. Frances always holds her napkin over her mouth while she attempts to remove a stubborn piece of food from her back dentures. Florence will never leave the dining table without first pushing in her chair. The following instance is exemplary:

The kitchen was short staffed so there was no PSW readily available to feed Molly. I decided to lend a hand by buttering her slice of bread, spreading a generous amount of jam, and cutting it in half. Molly looked at the bread for several long minutes. Then, she picked up one of the halves from her plate, carefully holding the crust so as not to get any jam on her fingers. She slowly placed a small bit between her teeth, not allowing her lips to touch the bread. Leaning slightly forward she took a tiny bite, as if to allow the expectant crumbs to fall on her plate. Leaning back in her chair, and then placing the piece of bread back on the plate, she chewed very slowly while keeping the lipstick on her lips perfectly in place.

Awareness of, and respect for such conventions can also be inferred from the strong reaction of residents to those who lack manners. The following examples are noteworthy:

Molly took a bite of her buttered bread and as she chewed, she looked up at Dody, who sat directly across from her. Dody was using her napkin to clean her nostrils - twisting the corner of the napkin and inserting it into her nostril, turning it several times and then pulling it out. As Dody inspected the napkin after pulling it from her nose, Molly frowned and abruptly put her bread down on the table. She looked at the PSW with a scrunched up nose, the corners of her lips curved downwards, and furrowed brows. It was an expression of disgust.

***

Abe belched very loudly in the dining room. Anna, who was seated just one table over, held her hands over her ears and shouted, “I can’t take that. Tell the ‘messhuggener’ [Yiddish for crazy person] stop it”.

***
As Edna left the living room Ethel looked at her and, covering her mouth with her hand in a gesture of shock, she said to Anna, who was sitting next to her, “oh, look! She has her ‘toches’ [Yiddish for buttocks] hanging out”. Edna’s skirt was hiked up well above her knees, and the excessive swing of her hips revealed her bottom. Ethel then said, “she doesn’t understand even to pull the skirt down”. Anna shook her head in disapproval.

***

Hanukkah jelly donuts were served to the residents during a Hanukkah party. Dora ate her donut as she continued to listen to the music. Licking the jelly from her fingers she moved her head from side to side and said to herself, “Ooh, is this geshmak!” [Yiddish for delicious, fabulous taste] while smacking her lips together. Florence, who was watching Dora, turned to the resident seated next to her and said, “look how she puts her fingers in her mouth” and shook her head in disapproval. The resident similarly shook her head in disapproval as she looked at Dora, and then said to Florence, “that’s not right”.

The residents’ responses to observations of poor etiquette are reflective of how ‘habitus tends to favour experiences likely to reinforce it … to protect itself from crises and critical challenges by providing itself with a milieu to which it is as pre-adapted as possible’ (Bourdieu, 1990, p. 61, emphasis in original).

The Power of Gesture

Gesture is “a phenomenon that often passes without notice” (McNeill, 2000, p. 1) and yet in face-to-face interaction it is an important resource for communication. Situated meanings emerge out of a complex relation between language, gaze, gesture, and bodily attitude (Keating, 2003) and thus attention to the kinds of information the body encodes, as well as how gesture and speech work together are critical.

Residents did not communicate with each other with words alone. There is a “physiognomy beneath the dictionary sense of words” (Kisiel, 1974, pp. 228-229), a “generative grammar” that finds its locus in the expression of the face, the play of the eyes, the movement of other parts of the body and the tone of voice. Gestures, movements of the body, limbs, hands, head, feet, and legs, facial expressions (smiles, frowns), eye behaviour (blinking, winking,
direction and length of gaze, and pupil dilation) and posture carried implication and meaning at Chai Village. Constantly and everywhere this gestural resource was employed, often serving the purpose of conveying praise, blame, thanks, support, affection, gratitude, disapproval, dislike, sympathy, greeting, farewell, and so forth. Slight head nods, eye and small lip movements, chin thrusts, shoulder nods, hand and finger movements, as well as leg and foot shifts were intentional, informative, communicative and interactive. A brief series of acts, for example, would signal for another resident’s attention: the direction of gaze towards another person, a smile, eye-brow-lift, a wave, and a head nod.

Residents’ direction of their gaze was of central importance, specifically where they looked, what they looked at, and for how long. Such direction of gaze allowed one to start interaction because mutual gaze provided the structure for these interactions. Simply looking at another resident could initiate an encounter:

Bertha and Anna were seated across from one another in the lounge. Suddenly their eyes met and Anna smiled. Anna’s smile triggered a smile in Bertha, making her resonate with animation. The sudden appearance of a smile on Bertha’s face was extraordinary because it transformed her usual expressionless face. Bertha’s smile seemed to reanimate Anna’s fading smile. Several moments ensued of linked smiles back and forth.

This resonates with Merleau-Ponty’s argument (1964) that communication dwells in corporeality or, more specifically, the body’s capability of gesture. Even when speech is incoherent, seemingly void of linguistic meaning, there is a smooth and appropriate alternating pattern of vocalizing back and forth as well as gesticulating back and forth. In the following example, with only “Bah”, “Shah”, “BRRRRRR”, and “Bupalupah” uttered, Anna and Abe communicate without any recourse to intellectual interpretation:

Abe sat down in the dining room and shouted “Bupalupah”. Anna twisted around in her chair so that she could see Abe (his table was behind hers). Abe’s face opened up. His eyes grew wider, his mouth eased into a broad smile and he shouted “BRRRRRRR!” with a rising and then falling pitch. Anna imitated him shouting back “BRRRRRRR!”
following the same change in pitch. Abe then shouted “Bah” and paused while looking at Anna. Anna shouted “Shah” and then waited for Abe’s response. Abe shouted “Bah!” and Anna, “Shah” establishing a repetitious pattern of exchange.

Because of the fact of Abe’s speech impairment and Anna’s mimicking of him in jest, the force of their speech acts derived not from their semantic content but rather from the meanings that their bodies directly indexed.

Merleau-Ponty’s claim that speech is a gestural system is illustrated by instances where word finding difficulties led residents to replace aspects of utterance content with gesture. Referred to as an intrinsically coded gesture (Harper et al., 1978), in the following examples the meaning of the gesture is seen in the gesture itself, and though it has a direct verbal translation, the gesture effectively replaces speech:

Anna and Goodie were seated in the living room together side by side in two armchairs. Anna turned herself in her chair so that she was facing Goodie and began telling her about Abe’s daughters who frequently come to visit: “They always wear those things….big….nice”. Goodie knotted up her face apparently confused about what Anna was trying to convey. She shifted herself slightly so that she was leaning in towards Anna. As Anna continued, “Beautiful, they are so big and nice”, Goodie said “Oh yes”, lifting her eyebrows with her eyes wide open as she followed Anna’s gestural illustration of the large hats Abe’s daughters wore. Anna lowered her hands and said “Beautiful” and Goodie said “mmmmhhmm” as she sat back in her chair and then replied, “Yes, beautiful”.

***

Florence was seated in the living room eating a piece of bread with jam. She watched as an immensely overweight PSW passed by and then turned to Edna and said, “It’s terrible” chin-pointing at the PSW. Edna looked at the PSW and then leaned in closer to Florence and said “What?” knitting her brows and lowering her eyelids. Florence filled her cheeks with air so that she looked like a chipmunk and, holding her hands way out to her sides, repeated, “It’s terrible”. As Florence continued to eat the bread Edna said “Oh! She’s fat!” and then pulled herself back in her chair. Edna paused for a moment and then, leaning in extremely close to Florence, she said in a whisper, “There’s a lot of fat people here” and Florence replied, “That’s right” in a matter-of-fact way. Edna shifted back into her chair and Florence continued to eat her bread.

Gestures and bodily movements derive further meaning from their distinct socio-cultural style or content. When the residents of Chai Village interact with one another, so identifiably
Jewish are their intonation patterns and nonverbal forms of communication that a person of Jewish heritage need not know that Chai Village is a Jewish facility to instantly recognize that the residents are Jewish. Following Bourdieu, we could say that their Jewishness is actually embodied in their arms, hands, feet, and head underscoring the essence of habitus, which is the embodiment of culture-specific conditions of primary socialization. For example, in the exchange between Abe and Anna where only “Bah”, “Shah”, “BRRRRRR”, and “Bupalupah” were uttered, Anna signals her desire to terminate the exchange and to resume eating her breakfast with a typical Yiddish gesture:

Anna eventually turned back around in her chair seated with her back to Abe. Abe shouted “Bupalupah!” as if wanting to initiate another exchange with Anna but she instead raised her right forearm keeping her elbow close to her body and pushed her hand in a swift downward motion with a sharp flick of her wrist. With this dismissive gesture, she terminated their interaction and they each began to eat their breakfast quietly.

The sharp flick of the wrist is a characteristic gesture of Eastern Jews for whom most gesticulation is restricted to the vertical and the frontal planes of the body (Efron, 1972). Because the elbows typically stay close to the body the wrist becomes a commonly used pivot for manual gesture with the angle formed by the hand being quite pronounced. It is a verbally inexpressible form of physical motion that carries emphatic weight with its force and punctilious form. Residents not only demonstrated understanding of what the gesture encodes and how it correlates with the structure of discourse, but also grasped the multiple meanings and innuendoes that could be derived from this gesture. This was evidenced in how its usage was adjusted according to the social circumstance and micro-organization of the given occasion of interaction.

Abe watched the resident across the table from him as she refused the food that a PSW was trying to feed her. Abe began to eat his lunch. As he put a spoonful of soup in his mouth he yelled “AHH-AHM” looking directly at the resident. She looked at Abe and again pushed away the PSW’s hand as she tried to feed her
soup. Abe yelled “AH-BABABABABA-AHM!” as he put another spoonful of soup in his mouth. Anna and Edna were shouting “shut up!” and “meshuggener” [Yiddish for crazy person] while each pushing both of their hands in a swift downward motion in front of their bodies with a sharp flick of their wrists signaling disapproval. Abe glanced at Anna and Edna but continued nonetheless. Abe then looked at the PSW and asked, “You know why I do that? Say AHM? Because my neighbour”, pointing to the resident across from him, “doesn’t eat”.

***

Edna was in a terrible state of agitation. She walked along the hallways calling out for her son Ernie. As she passed the living room she saw Florence sleeping on the sofa. She immediately sat down next to her and placed her hand on Florence’s forearm. Florence jolted slightly as she opened her eyes. Edna quickly said to her, “I want to know when I’m going home. I don’t know anyone here”. Florence took her free hand and placed it on top of Edna’s hand which was still resting on Florence’s forearm, and replied in a reassuring tone, “You know me”. Still agitated, Edna said, “I’m completely lost”, holding her hands out in despair. Still very calm, Florence replied, “I’ve been there” pushing her hands in a swift downward motion with a sharp flick of her wrists as if to say “don’t worry about it”.

**Discussion**

There is considerable debate whether selfhood persists with advancing dementia. Much of the literature on Alzheimer’s promotes the view that individuals with dementia experience a steady erosion of selfhood to the point at which no person remains (Cohen & Eisdorfer, 1986; Davis, 2004; Fontana & Smith, 1989). Davis (2004, p. 375) concurs: “what is so devastating about the relentless nature of dementia is the very splintering of the sedimented layers of Being”, until ultimately “there is nothing left”. However, social scientists and health science scholars have challenged in a significant way the presumed loss of self that is so widely associated with the cognitive deficiencies which lie at the core of dementia (Downs, 1997; Golander & Raz, 1996; Herskovitz, 1995; Kitwood, 1990, 1997; Post, 1995; Sabat & Harré, 1992; Vittoria, 1998). The findings reported here contribute to this important challenge to presumed existential loss by focusing on various dimensions of sociability that persisted despite advancing cognitive impairment by virtue of their grounding in embodied selfhood.
At Chai Village, residents demonstrated their mutual recognition of one another as persons. This is a quality that has been identified as an essential component of empathetic care (Hamington, 2004). Literature on the nature of empathy stresses the importance of the imagination (Hamington, 2004; Nussbaum, 2004) – referred to by Hamington as “caring imagination” (Hamington, 2004) – for facilitating such connection with others. This notion of caring imagination has been further expanded with the introduction of embodied selfhood as pre-reflective sources of the body that enrich the imagination of dementia care practitioners, which, in turn, further facilitates their empathetic connection with residents with dementia (Kontos & Naglie, 2007a). In the present study, imagination as an act of cognition must be presumed impaired given the cognitive dysfunction amongst the study participants. The emergence of empathy despite such dysfunction raises the possibility that, to a significant degree, caring imagination is itself embodied and thus residents were able to connect to the humanity of their fellow residents despite their cognitive impairment. Exploration of empathy in relation to embodied selfhood offers an important direction for future inquiry amongst persons with dementia and their care providers to better understand how and the extent to which the pre-reflective sources of selfhood sustain and impel this dimension of sociability.

Sociability amongst persons with dementia has largely been explored in terms of the narrative or discursive properties of communication with focus on the constitutive role of language in the formation of selfhood (Sabat & Harré, 1992; Sabat & Collins, 1999). Language certainly has an inner content but the findings presented here illustrate how the meaning of words is not contained in the words themselves such that their intelligibility is finitely self-subsistent; rather, the meaning of words emerges from “generative grammar” (Merleau-Ponty, 1962, p. 205) that finds its locus in facial expression, gaze, movements of the body, and
intonation and tone of voice. Yet contrary to thinking of gesture as a product of reflexive thought, what Enfield refers to as a “geography of cognition” (Enfield, 2005, p. 1490), embodied selfhood highlights the existential and pre-reflective expressiveness of the body. Sociability, in this sense should not be understood in an intellectualist fashion associated with the activities of a reflexive subject. As the findings presented here illustrate, in the presence of cognitive impairment, words assume their meaning through deduction from gestural communication, underscoring the primacy of embodiment in speech itself. Even where no linguistic meaning at all is conveyed by speech itself, or where there is an absence of any verbal exchange, it is bodily manifestations of selfhood that encode meaning.

Embodied selfhood in the context of sociability is further visibly manifest in the dispositional character of the residents that emerges from the internalization of a socio-cultural environment through the primary experiences of the body. For example, the Yiddish language has an expressiveness that manifests itself in the rhythm of speech (Newman, 2000). There is a great deal of emotion in the highs and lows of the residents’ voices. As the sounds go up and down in melodious directions one can feel the words as much as hear them. The expressiveness of Yiddish is further reflected in how the sounds of the words and how they are spoken match their meaning. For example Dora used the word *geshmak*, which means delicious, which is said with a smacking of the lips. The residents also demonstrated a grasp of the multiple meanings and innuendoes that could be derived from the typical Yiddish gesture of flicking one or both hands in front of the body in a swift downwards motion with elbows close to the body (Efron, 1972), as is evident by the role that such gesture plays in relation to what was being said or in relation to the interactive situation. This is most apparent where the same gesture is made in vastly different contexts – a gesture that in one context can be used as a dismissive gesture such
as when Anna terminates her interaction with Abe in the dining room; in another it can express disapproval, as when Anna and Edna became angered by Abe’s loud utterances in the dining room; and in yet another context, it can be used to express the sentiment “don’t worry about it”, as when Florence employed this gesture while saying “I’ve been there” in order to persuade Edna that it would be okay.

One is not born with language or a culturally distinct intonation pattern or gestural language, but acquires it “by the childhood learning that treats the body as a living memory pad” (Bourdieu, 1990, p. 68). The innovative ways the residents spoke and used their bodies to express themselves are cultural aspects of embodied selfhood that are determined by their cultural heritage. Such innovation renders visible how selfhood emanates from the body as a generative spontaneity which asserts itself in sociability as an improvised engagement with the world. While the study of cultural difference in gesture and language is not new to linguistic anthropology (Efron, 1972; Herzfeld, 2009; Keating, 2003; Kendon, 1997) similar in situ investigations have yet to be taken up in dementia care settings. Consequently, research on sociability in dementia has largely overlooked the socio-cultural significance of gesture and verbal discourse, and the creative ways in which older people with dementia tacitly draw upon their history and culture according to the social circumstance and micro-organization of the given occasion of interaction. This is an area that warrants further research.

Adherence to social etiquette offers another example of the embodiment of history and culture. Respect of a common code of social behaviour was evident not only where there was a regularity of social practice, but also when something happened that deviated from or contradicted regularity such as when a resident who failed to adhere to the proper etiquette was met with the disapproval of the other residents. The determinations attached to primary
socialization and one’s cultural environment give selfhood its socio-cultural specificity by virtue of being embodied and materialized in habitual states, tendencies, and inclinations to act in a particular way (Kontos, 2004, 2005, 2006). Socially and culturally distinct dimensions of sociability at Chai Village were thus regulated not by any conscious obeisance to external rules but because the taken-for-granted, pre-reflective nature of the residents’ interactions.

**Implications for Practice**

Rethinking sociability as an embodied dimension of selfhood is not merely a theoretical exercise, but one that also has important practical implications. Hubbard et al. (2002) argue that care practitioners need to develop ways of both interpreting and encouraging the use of nonverbal communication. While there is some attention to body language in educational interventions for dementia care practitioners, nonverbal expression is most often understood in terms of emotion (Magai et al., 2002; Ruckdeschel & Haitsma, 2004) or physical discomfort and pain (Williams et al., 2005) rather than meaningful communication or expression of selfhood such as previous vocation (Kontos et al., 2010a; Kontos & Naglie, 2007a, 2007b), affection or attraction (Kontos et al., 2010a), and personal preferences (Kontos, 2004; Kontos et al., 2010a; Kontos et al., 2010b). Approaches to person-centred care that fail to address the breadth of bodily movements and gestures for self-expression may contribute to the misreading of behaviour as symptomatic of dementia, and the consequent misuse of pharmacotherapies (Kontos & Naglie, 2009b).

The prevalence of agitation and resistance to care amongst those diagnosed with dementia (Volicer & Hurley, 2003) creates an inordinate burden on staff who are challenged to provide care in a time efficient way while still meeting the demands of best practice (Kitson, 1996). The incorporation of the notion of embodied selfhood into educational initiatives (Kontos
et al., 2010b) has enormous potential to facilitate a shift from viewing behaviour as a problem to be controlled, to understanding the breadth of meaning underpinning self-expression in dementia. An evaluation of an educational program premised on the importance of embodied selfhood for person-centred dementia care (Kontos et al., 2010b) demonstrated that by broadening the current conception of selfhood to include non-verbal communication, practitioners who otherwise prescribe drugs or use physical restraints for seemingly aberrant behaviours consider the possibility that these behaviours are indicative of meaningful self-expression. When the trigger of behaviour is accurately identified, the appropriate tailoring of care has the potential to reduce agitation by addressing the need expressed, thereby improving the time efficiency of practice in the absence of pharmacotherapies and other forms of restraint (Kontos et al., 2010b). Since agitation and resistance to care make the provision of care onerous in terms of time and have been correlated with increased psychological morbidity and stress/burden in caregivers (Brodaty, 1997; Cummings, 1997), reduced behaviour disturbance could also lead to optimizing practice (Kontos et al., 2010b; Kontos & Naglie, 2007a, 2009a) through reducing care time and hence improving efficiencies and reducing the costs of care.

Quality of care in residential and nursing homes is in need of radical improvement (Ballard et al., 2001). Given the significance of bodily expressions of selfhood, particularly in the context of severe cognitive impairment, their recognition and support should be a priority in dementia care. Not only is this crucial to the achievement of person-centred care, but in the context of fiscal constraints and the restructuring of health care, it also has the potential to improve the quality of care for people diagnosed with dementia and their caregivers alike, and is thus worthy of further study and evaluation.
Acknowledgements

The research presented here is based on my doctoral research undertaken in the Dalla Lana School of Public Health, University of Toronto, 1999-2003. This research was supported by the Alzheimer Society of Canada and the Institute of Aging (Canadian Institutes of Health Research) (Award #03-07, 2002-2004). I am presently supported by a Canadian Institutes of Health Research New Investigator Award (MSH – 87726, 2009-2014) which facilitated the writing of this article. I wish to express my thanks to Ann Robertson, Stephen Katz, and Gail Mitchell whose constructive and insightful comments were invaluable to the development of this research. I extend warm thanks to Karen-Lee Miller for her constructive and insightful comments.

Notes

1. The methods employed in this study are fully detailed elsewhere (Kontos, 2004, 2005).
2. The name of the study site is a pseudonym.
3. All names of study participants are pseudonyms.
4. Some findings have been earlier published (Kontos, 2004, 2005).
5. Characterized as un- or semi-skilled (Anderson et al., 2005), personal support workers (PSW) provide assistance with delegated nursing tasks, ambulation, and activities of daily living (Health Professions Regulatory Advisory Council). For a more detailed account of the training, regulation, and decision-making of personal support workers see Kontos et al. (2010a).
References


