

Dementia, Embodied Memories, and the Self

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EMBODIED MEMORIES, DEMENTIA AND THE SELF

Abstract

Researchers in cognition and linguistics have the last couple of decades argued that more complex memories of the kind often called episodic memories are embodied and are multimodal. This is something that is interesting in the field of persons living with for example, neurodegenerative dementia. In this article the interest is on how bodily gestures can be used to make sense of episodic memories that cannot be verbally communicated by persons with dementia. Empirical examples are discussed with a focus on the use of bodily gestures and how the stories are connected to identities and a sense of self. A key conclusion is that embodied resources like bodily gestures can be used to construct and communicate a sense of self. It further indicates that modal aspects of memories are central in the communicative sense-making process. Finally, the examples demonstrate how embodied episodic memories can be used to present and sustain a sense of self.

Introduction

A growing number of researchers have argued that both identity and self are narrative: a person's self develops and changes through a constant narrative elaboration and revision (see Brockmeier, 2015, for an overview). The stories that form and define selves also function as guidelines for action and, as psychologist Jerome Bruner writes, "in the end, we become the autobiographical narratives by which we 'tell about' our lives" (Bruner, 1987, p. 15). Others have argued that over time the individual's life story will include new elements and connections, but also more coherence, "depth" and wisdom as a result of revisions (Randall & McKim, 2008).

Dementia conditions like Alzheimer's disease as well as many other brain disorders challenge the idea of such a deep connection between self and stories. The reason for this is that brain disorders like dementia change not only the storyteller but also the story. When pathological processes affect the brain, the kind of autobiographical stories people tell generally tend to deviate from most of the cultural narrative norms and expectations (Ehrlich *et al.*, 1997). The stories told by persons with acquired brain injuries or dementia are often at best characterized as *broken stories* (Hydén & Brockmeier, 2008). The stories, the storyteller, and the listeners become *entangled* in broken stories: beginnings and endings are twisted together, interwoven with repetitions of the same event, resulting in shared states of narrative perplexity (Hydén, 2018). Ultimately the person with dementia will lose the ability to tell stories in conversational interaction, no longer giving voice to or authoring those stories where he or she features as a main character, and thus it is left to others to continue the telling (Lindemann, 2014). Thus, the question dementia — as well as other brain disorders — raises is whether it is possible for a person to have a self, without being able to remember and tell stories about what he or she has done and experienced in the past. Are they persons without “such a thing as selfhood”?

A problem with the argument about the close connection between stories and self put forward by narrative researchers, is that it rests on two assumptions that have questionable empirical support. First, that selfhood primarily is based on episodic memories. In contrast, in the following it will be argued that the self can be expressed in all kinds of bodily actions not just verbal actions like storytelling based on episodic memories. Rather, it is also possible to communicate a sense of self through embodied actions, from ways of moving to knitting. This notion favors a different kind of memory system, namely procedural memories. Second, that episodic memories consist of abstract (amodal) representations of events rather than on sensomotoric experiences. By arguing that episodic memories rather are based vision, taste,

etc., it becomes possible to understand how people with dementia make creative use of language, from figurative expressions to gestures, in order to communicate a sense of self.

Dementia and memory

Dementia is an overall term describing a broad spectrum of symptoms, which can be caused by a multitude of diseases and/or injuries to the brain. As such, dementia is a syndrome in which there is deterioration in cognitive function (Hughes, 2011). Alzheimer's disease, one type of primary degenerative dementia, accounts for 60-70% of all cases of dementia. A central problem in especially Alzheimer's disease is the challenge to various memory functions: from working memory to episodic memories (Morris & Becker, 2004), and autobiographical memories, that is, memories of unique personal events and experiences (Conway, 2005; Cohen-Mansfield *et al.*, 2006). For some individuals living with Alzheimer's disease also linguistic functions become challenged, resulting in word-finding problems, problems with understanding words and phrases, etc. (Macoir & Turgeon, 2005).

The loss of autobiographical memories has led narratively-inclined researchers to argue that a person with dementia cannot have an identity or a self, as he or she cannot remember and tell autobiographical stories. In arguing against this an increasing number of researchers have stressed that dementia does not rob the person of a self or an identity; nor does it turn persons into non-persons (see for instance the arguments in Hughes *et al.*, 2006). At the same time, living with dementia means that both the identity and the self of the person will be affected in various ways (Sabat, 2001). As the link between memories and linguistic expression and communication become problematic due to the progression of the disorder, several researchers have started to look for conceptions of memory functions that try to avoid understanding memory primarily in terms of abstract representations of for instance events (as in the case of episodic memories). For some researchers, an alternative would be to look

for *embodied memories*, that is, understanding memory as based on bodily experiences of various kinds. In doing this they have gone back to philosophers like Maurice Merleau-Ponty (1962) that stresses the role the body in experiencing the world, and to linguists, cognitive and neuroscientific researchers that have argued that both cognitive and linguistic processes are grounded in bodily experiences (Bietti & Castelló, 2013; Gallese & Lakoff, 2005; Gibbs, 2006). By stressing the bodily ground for memory processes, it becomes possible to understand some of the activities and behaviors of persons living with dementia as part of active attempts to sustain a sense of self.

I will discuss two such cases. First some of the work of the Canadian anthropologist Pia Kontos, who has stressed the importance of the embodied selfhood and what I would call embodied procedural memory processes. The second, is my own work around the use of episodic memories in storytelling.

Procedural memories and self

From a phenomenological background it could be argued that self, identity and subjectivity, is not something inner that is expressed openly (Matthews, 2006). Instead of just investigating the use of discursive tools for expressing subjectivity, personhood, identity and self, it can be argued that the philosopher Maurice Merleau-Ponty's concept of *embodiment* is important in order to understand dementia as a special way of being-in-the-world (cf. de Jaegher, Pieper, Clénin & Fuchs, 2017). The British philosopher Eric Matthews writes that subjectivity exists "in speech, in gesture, in behaviour, in interactions with [...] environment, both human and natural" (Matthews, 2006, p. 173). Subjectivity, like identity and self, is embodied, that is, found in all the different practical, bodily ways persons engage with the world: how they talk, move around in a room, and in their preferences and dislikes.

This is a notion that is central to Pia Kontos in her work with people living with dementia in a later stage (Kontos, 2004, 2005). Referring to Maurice Merleau-Ponty and the embodiment concept, Pia Kontos (2005) have suggested that the concept of “*embodied selfhood*” is central in understanding the selfhood in connection to dementia. She argues that the “embodied selfhood” can be seen as,

a complex interrelationship between primordial and sociocultural characteristics of the body, all of which reside below the threshold of cognition, grounded in the pre-reflective level of experience, existing primarily in corporeal ways. (Kontos, 2005, p. 559)

Thus, Pia Kontos argue that the person is a “body-subject”, rather than an “inner” cognitive self. The embodied selfhood has a special existence in the form of “the body’s concrete, spatial and pre-reflective directedness towards the lived world” (Kontos 2004, p. 837). In other words, in the ways that a person integrates her bodily movements into a coherent pattern that express fundamental ways of being. Pia Kontos gives an example from her ethnographic fieldwork at a care home for persons living with dementia. She writes about two old women with dementia — Anna and Molly:

when Molly reached behind her neck to pull her pearls from beneath her bib, she ‘knew’ where her hand was, and how far and at what angle she had to reach to grasp the pearls. When Anna applied lipstick while leaning for support against the hallway wall, she not only knew where her hand was but also mobilised all the postural adjustments required to execute the action while maintaining her balance. Molly and Anna intended a certain outcome by their actions, and the enabling actions were spontaneously distributed amongst the appropriate parts of their bodies. (Kontos, 2004, p. 838)

To Pia Kontos, these small bodily movements are not accidental, meaningless or without connection. On the contrary, they are part of the very central core of the person. Thus, these mundane actions are indications of a subjectivity and a continuation of movements these women established a long time ago. The movements constitute parts of their selfhood, their individual beings-in-the world; their typical ways of doing things. This is an argument that connects with Eric Matthews' view that

There survives something of their adult individuality in the habits of behaviour (...) These characteristic gestures and ways of doing things are what keep alive the sense of the individual they once were, even if the more sophisticated levels of the individuality have been removed. (Matthews, 2006, p. 276)

Pia Kontos' argument can be connected to the discussion about embodied memory by arguing that the memories that constitutes selfhood in this case are *procedural memories*; that is, bodily procedures, especially habits, that resides in the way the body interact with the world, with coherence and purpose and meaning. The everyday habits turn into sedimented layers of habits and individualized ways of engaging with the world, expressing a self that survives in the body and its movements, rather than in verbal stories.

Thus, following the phenomenological approach, a person living with dementia is not in a position to either have or not have a self. Persons living with dementia — especially in the late stage — have a self and subjectivity that is manifested in different embodied ways rather than in the elaborated narratives that have become impossible due to the dementia. It could further be argued that these embodied procedural memories are part of their life story, although this story cannot be told verbally. This indicates that the ability to use language and to tell stories is less important following the phenomenological perspective.

So, in this case, a conception of embodied procedural memories, would help us to understand how a person with dementia can sustain her sense of self. Instead of focusing on verbally told stories, our focus will be directed to the small everyday actions and bodily movements, in order to see these as meaningful actions, directed toward and being part of the life-world and life story of the person.

Gestures and lost words

One challenge that persons living with dementia face, is that their linguistic resources become less available as the disease progresses. This often results in word-finding problems, problems with understanding words, and increasing difficulties in constructing utterances. Thus, taking part in conversations and especially in storytelling becomes difficult. Persons with dementia tend to deal with the fact that over time they can use less of their linguistic resources by using other semiotic resources, in particular gestures (Hydén, 2013). My argument is that by thinking of episodic memories, not as amodal representations of events stored in the brain, but rather as consisting of modal, embodied, experiences that are part of networks in the brain, it becomes possible to understand gestures and bodily enactments as part of complex cognitive processes.

From a psychological perspective, it is possible to argue that in order to tell about an event it is necessary to remember and transform some kind of multimodal memory of the event so it can be expressed in spoken language; at least the first time the story is told. Linguistic constructions are based on a *linear* and *sequenced* rendering of an event: it is necessary to identify the subject, the characteristics of the subject as well as the context, add an action, its characterization, etc. This entails analyzing the various multimodal memory fragments of the event into its constituent parts so these can be transformed into linguistic constructions (McNeil, 1992).

One of the challenges many persons with dementia face is to be able to perform this analytical task, as well as to identify appropriate linguistic constructions, from single words to more syntactically complex constructions. Thus, although a person with dementia may in some sense be able to conjure various types of modal memory fragments of an event, it may be difficult, sometimes even impossible, to communicate this event through verbal means. One possibility in this situation is to use *gestures* and *bodily enactments* either instead of linguistic constructions or as a complement. Gestures — as well as the bodily enactment — have an advantage over linguistic expressions as the gesture is iconic in nature, that is, gestures have a direct relation to the events they represent (McNeill, 1992). It can be perceived as an immediate, synthetic whole and does not need to be analyzed into constituent parts.

In other words, there is less need for the transformative steps between the various modal memory fragments and the linguistic expression. It is also less an individual word that is substituted for a gesture, but rather a complex experience that corresponds to more complex linguistic constructions. Thus, for a person living with dementia it is possible to use words and when these fail, to add gestures, implying that the persons with dementia are free to make use of two (or more) different semiotic means as their main “channel” in communicative situations.

An example: using gestures

One example of the use of gestures together with verbal utterances in storytelling may be seen when a woman I call Laura told about her son in a research interview. (For more information about this research project, see Hydén, 2009; Hydén & Nilsson, 2015.) Laura is at the time of the interview 52 years old and has early onset Alzheimer’s disease, diagnosed when she was 48 years old. She has two children, one daughter in her early 20s who is

married and a son, 16 years old. Laura and her husband separated in connection with her receiving her diagnosis. She also stopped working and she is currently living in an apartment on her own with daily support and help. This interview was part of pilot study for study of couples living with dementia (see Hydén & Nilsson, 2014). The interviews were video-taped and then transcribed. In the analysis, special emphasis was on gaze, gestures and other bodily movements (added as two separate lines besides the verbal transcription in the examples below). In the transcription in the examples, every line roughly represents an “idea unit” (Chafe, 1994) almost always delimited by the teller with a brief pause, and then next segment is introduced, and so on. This segmentation of the telling of a story allow listeners to either accept or request clarifications before the story incrementally proceeds. Thus, a common ground is created between the participants consisting of a shared version of the story (for further discussion about this, see Hydén, 2018).

As Laura lived alone, she wanted her social support person to be present during the interview. The interview was conducted in Laura’s home and videotaped by two interviewers (I₁ and I₂). In the interview Laura was asked to tell about her diagnosis, her life story, and her present life. In this example Laura is telling about the divorce from her husband and relation to her son. Doing this she has severe problems finding words.

Example 1.

- | | | |
|---|------------------|--|
| 1 | Laura: | well my son ehh (1,5s) |
| | Gestures: | ((hands resting in lap - default)) |
| | Gaze: | ((gaze directed towards I ₁)) |
| 2 | Laura: | lives with his father (2s) |
| 3 | | and w-we all lived there (0.7s) |
| | I ₁ : | mm |
| 4 | Laura: | w-we separated |
| | Gestures: | ((raises both hands in an outward movement)) |
| 5 | Laura: | and then (0.7s) |
| | Gestures: | ((join hands)) |
| 6 | Laura: | we had different (2s) |
| | Gestures: | ((outward hand movements - keeps hands separated)) |
| 7 | Laura: | he came to me (0.8s) |

		Gestures:	((right hand in to the body midline))
8	Laura:		and then it was empty (0.5s) ((small laugh))
9	I ₂ :		yes
	Laura:	Gestures:	((left hand in to body midline))
		Gaze:	((shifts gaze to I ₂))
10	Laura:		and then (2s)
		Gestures:	((right hand outward and then to midline))
		Gaze:	((shifts gaze to I ₁))
11	I ₂ :		[alternate residence]
12	Laura:		[we did this for a while]
		Gaze:	((shifts gaze to I ₂))

The interviewers ask Laura to tell about her son who had been staying with her for some time after the separation. As already mention, in the transcription every utterance is represented by one line. Laura talks slowly, one “idea” at a time with pauses between; most pauses are quite long, around two seconds. Some of her lines are used to indicate a continuation of the ongoing events in the story rather than to indicate new ideas (Lines 5, 10).

When the example begins Laura’s hands are in a default position while she talks; her hands are in her lap and her gaze directed towards the first interviewer, who is presenting the question. She goes on to say that her son lives with his father and that they all used to live there together (Lines 1-3). She pauses slightly between the three utterances and speaks slowly. Laura then says that she and her husband separated (Line 4). She has some problems producing this utterance indicated by her stumbling when saying “we” and as if she is sensing a problem with her words. She simultaneously raises her two hands from her lap in an outward movement, as if demonstrating and illustrating the notion of “separation”. She then returns her hands to their default position in her lap. This outward movement of her hands also establishes a *gestural space*, a space placed before her body and between the four participants sitting around a low sofa table.

She continues by saying that as a consequence of their separation (“and then” in Line 5) the spouses had “different” — but she cannot find the word she is searching for (probably “homes” or “apartments”). Instead she again uses an outward movement of her hands, but

this time she holds them separated when she utters the word “different”, as if she wants to underline that their separation was not temporary.

After establishing their permanent separation in this way Laura continues by shifting her focus to her son — although without indicating this in any other way than by a shift in pronouns from “we” to “he” (Line 7). When Laura says that her son came to stay with her she moves her right hand, still outstretched, in towards her body midline, as if showing her son’s movement from his father’s home to hers. She uses very few words in describing both the separation and her son’s coming to live with her. This is even clearer when she then says, “and then it was empty” (Line 8). This expression is probably a proxy for a linguistic expression of the idea that her son then left his mother in order to move back to his father. She then says “and then” (Line 10) and at the same time moves her hands from her lap outward and then moves her right hand again in toward her body midline. A possible interpretation is that it is as if the whole concept of her son alternating his living between his parents is impossible for Laura to express in words. She uses words just to indicate the sequence of events and gestures to capture her son’s moving back and forth between his parents. This interpretation of what is going on is corroborated when the second interviewer fills in the abstract word that can capture the notion she is trying to express, “alternate residence” (Line 11), and Laura implicitly accepts this suggestion by continuing her story (Line 12).

It is obvious that Laura’s speech is truncated by a number of pauses. These rather lengthy pauses are placed at what could be seen as an idea unit, to use Chafe’s term (Chafe, 1994). This indicates that what she wants to contribute to her story in the conversation is fairly well-structured around a number of ideas. At the same time, it is obvious that Laura has problems with finding individual words (names of places, instead she uses for instance pronouns like “there”) and making linguistic constructions corresponding to more general

and abstract ideas (“separation”, “alternate living”, etc.). Her linguistic constructions have a basic agentive structure (“we separated”, “he came to me”) but lack all further descriptions by adding, for instance, auxiliary verbs that help to specify the mood of the actions, or adjectives that add information about the setting and characters.

Some of the words Laura uses are quite interesting: it is words like “separated”, “different”, “came to me”, “empty”, etc. All these words or constructions have one thing in common: they represent a more complex conceptual notion. What is lacking is a linguistic elaboration of the concepts. For instance, the word “different”, could probably linguistically be expanded into something “separate apartments” or “lived at different places”, etc. That is, the words “separated”, “different” etc. are dense words, full of further meaning — at least to Laura. Normally this meaning should have been expanded into a more elaborated linguistic structure and thus contributed not only to more linguistically complete utterances, but also to utterances that had more meaning and thus were less vague. Instead of a linguistic elaboration, Laura uses gestures.

Thinking with gestures

It is obvious that Laura’s gestures take on a special meaning as she is challenged in producing the required linguistic elements. A number of researchers favoring an embodied perspective indicate that an essential part of our cognitive activity is based on everyday bodily experiences (Gibbs, 2006). In the field of telling stories that would imply that we make use of actual experiences (bodily and otherwise) of events (actions, activities, experiences), both when we tell stories and when we listen to stories (Bolens, 2012). This also opens up the possibility to “tell” by enacting part of the story, that is, to perform actions that are central to the story. Although much conversational storytelling entails enactment — showing rather than telling — this becomes of special importance when people for some reason have lost either the ability to use verbal language or lost partial command of spoken language.

Enactment may assume a greater role, as is the case with persons with acquired brain injuries like dementia.

Many phenomenological philosophers from Maurice Merleau-Ponty to Maxine Sheets-Johnstone (2011) have argued that the lived bodily experience is crucial in forming concepts and an understanding of world as well as communicating in and about the world. As has been pointed out by several researchers recently, gestures can also involve other senses besides visual perception. One of the researchers proposing this approach is Jürgen Streeck, who writes:

Although speakers utilize a variety of methods to depict objects, including drawing their shapes or performing schematic acts of making them, the most common method for depicting things by gestures is to perform some schematic act of handling them: lifting them, putting them down, or performing a characteristic motion that identifies the object more specifically. (Streeck, 2013, p. 72.)

What Jürgen Streeck points out in this quotation is that it is not only visual drawing of shape that matters in constructing a gesture, but also motor, kinesthetic, tactile, haptic, and other experiences that can be used to inform a gesture. Jürgen Streeck also writes:

hand gestures are performed by lived bodies, that is, bodies that have accumulated tactile and haptic experiences and skills in their owners' life-worlds. What the hands contribute to symbolic communication are motor schemata that construe content and/or perform social actions. (Streeck, 2013, p. 73)

Enacted gestures in this sense would involve performing and showing some multi-modal actions that are central to the story and that are similar to the actions in the story. Thus, the

enactment of action is a gesture that has an iconic relation to its referent; that is, the performed action looks and feels the same as the referent action.

As a consequence of this, it must be added that the gestures Laura used in the example above actually were iconic, multi-modal enactments of embodied meanings. Although Laura had severe difficulties with finding words and other linguistic expressions, she at the same time obviously had embodied conceptual ideas about what she wanted to tell: the separation, the spouses living at different places, the son moving back and forth between his parents, and the emptiness when he was gone. The gestures she forms — separation, coming and going, emptiness — are all synthetic enactments, capturing in a general and thus abstract way the basic relations and coming and going of the persons close to her. It would thus be possible to think of her gestures as a kind of abstract enactments of her embodied experiences. What Laura remembers is less an abstract representation, and more an embodied pattern of relations that she then can use because she does not need to “unzip” these synthetic, gestural signs to fit them into a linguistic, sequenced structure. Laura thus creatively resolves the problems her declining semiotic resources present to her.

An argument in favor of this interpretation is that Laura sometimes evidently cannot remember either what happened once or stories told about events in the past. In these cases, she doesn't use gestures. In the section of the interview just after the one discussed above, Laura is requested to tell about circumstances around how she got her diagnosis. Laura starts to tell but cannot remember anything about meeting the doctor, going through the medical and psychological examinations and eventually receiving the dementia diagnosis. In contrast to the first example she does not use gestures when she doesn't remember.

Example 2.

- | | | |
|---|--------|---------------------------|
| 1 | I: | what happened after that? |
| 2 | | did you contact |
| 3 | Laura: | SHE |

4 Monica
5 my sister
6 eh
7 she had some
8 something in on
Gesture: ((raises right and makes circle movement with right index
finger; stops and moves finger to lips))
Gaze: ((unfocused gaze turned downward))
9 ((pause 3s))
10 damn I don't know
11 but I came directly to XXX the right person
12 I did see
13 yes hmmm
14 but I cannot remember who it was
15 I.: do you remember what happened
16 Laura: ((pause 5 s))
17 noo
18 eh well I was to do certain things
Gaze: ((gaze turned downward))
19 and I should
Gesture: ((circle movements with both hands; puts both hands in her
lap))
Gaze: ((gaze down))
20 yes in
21 well
22 ((pause 3s))
23 these pills
24 they just fall straight down here
Gesture: ((right arm and extended hand moves from head and downward;
her upper body follows this movement))
25 In order to talk
((moves body into default position; her arm makes a circle
movements and then back to default position in lap))
26 ehh
27 I'm not that old
28 I'm not that old
Gesture: ((small circle movement with left hand))
Gaze: ((gaze down))

In this example, it is obvious that Laura has a less clear memory about what happened, and she doesn't remember stories that might have been told about what happened. A guess is that Laura is attempting to tell about how her sister Monica helped Laura to contact a doctor her sister knew (Lines 3-8). When Laura is trying to find words and expressions that would work she raises her right hand and makes a circle movement with her index finger. This gesture is

used again twice (Lines 19 and 25). It is not obvious from the situation what the circle movement refers to, although it is faintly similar to a somewhat conventionalized gesture indicating that the person is seeking for something in her mind. Laura stops her gestures and is quiet and unmoving for three seconds, then says, "I don't know", thus confirming that she cannot find what she is trying to remember. Slightly before and during the pause, she is not making gestures. Then she clearly moves on to the next event sequence in the story, what happened at the doctor's. She again tries to remember something—whom she met. During her search (Lines 11-14) she is not using any gestures, just words. The interviewer asked what happened then (Line 15), and Laura is quiet for 5 seconds, doubtless because she cannot remember what happened. She doesn't make any gestures during this sequence but sits in a default position with hands in her lap. Then (Line 18) she suddenly remembers that she was asked to do certain things and when she tries to tell about this she makes gestures, using the circle movement, this time with both her hands. Laura turns her gaze downward, indicating that she gives up and seems to move on to a new event having to do with taking pills (Lines 23-25). (From other parts of the interview it can be conjectured that she is referring to the prescribed dementia medication that is supposed to help her to function better.) In trying to find the linguistic expressions she again gestures, mimicking something falling down. Then again, she probably gives up (Line 26) and says, "I'm not that old," as if commenting on her own situation and inability to find words and memories.

In the sequences when she was at a loss finding linguistic expressions and probably did not have a clear idea about what she wanted to say, Laura doesn't make any gestures. At other places, she only seems to be making a gesture when she talks about the pills. The other gestures (especially the circle movements) seem to refer to her ongoing search for memories and words; that is, they are signs to the listeners about what is going on in the situation. This is something that might indicate that it is important to recognize that gestures have different

functions. Some gestures are referring to events in the storyworld, others to what is going on in the conversational situation. Still other gestures are part of the transformative process from idea to semiotic sign.

To sum up, it can be argued that the gestures Laura used in the first example were iconic, multi-modal enactments of embodied meanings. Although Laura had severe difficulties with finding words and other linguistic expressions, she at the same time obviously had embodied conceptual ideas about what she wanted to tell: the separation, the spouses living at different places, the son moving back and forth between his parents, and the emptiness when he was gone. She also told about these in a temporal sequential order that obviously corresponded to the referent events.

The gestures she forms — separation, coming and going, emptiness — are all synthetic enactments, capturing in a general and thus abstract way the basic relations and coming and going of the persons close to her. It would thus be possible to think of her gestures as a kind of enactments of her embodied experiences. What Laura remembers is less an abstract representation, and more an embodied pattern of relations that she then can use because she does not need to “unzip” these synthetic, gestural signs to fit them into a linguistic, sequenced structure.

An argument in favor of this interpretation is that Laura sometimes evidently cannot remember either what happened once or stories told about events in the past. In these cases, she doesn't use gestures. This is what happens in the section of the interview just after the one discussed above, Laura is requested to tell about circumstances around how she got her diagnosis. Laura starts to tell but cannot remember anything about meeting the doctor, going through the medical and psychological examinations and eventually receiving the dementia diagnosis. In this sequence Laura doesn't make any gestures.

Concluding discussion

It is obvious that persons with Alzheimer's disease are extremely memory challenged, especially concerning what is generally classified as voluntary episodic memories. Anna and Molly in Pia Kontos' example do not tell stories, but by using their still functioning procedural memory, they can sustain and communicate their sense of a self. The examples with Laura show that she is able to recall certain events while others are beyond her ability to recall — at least in this situation. (In no way are we allowed to conclude that she has “lost” these memories; more probably they have become involuntary memories.) Further, it seems that Laura was severely challenged at a certain point in her storytelling: namely in analyzing dense meanings into words and then to expand these words into a more elaborated linguistic utterance. Laura's use of gestures and enactments seemed to be based on the use of embodied memories of events, and implied that she could use these to enact or recreate aspects of the events. Thus, by using both procedural memory as well as embodied episodic memories, it becomes possible for persons living with Alzheimer's disease to sustain a sense of self in interaction with other persons. A first conclusion is that it is at least possible to argue that persons living with dementia can communicate and express a sense of self.

A second conclusion is that although autobiographical stories communicated in interaction are important for conveying a sense of self and identity, it is obvious that sense of self also can be communicated and expressed in embodied actions. This indicates that also procedural memories are of importance and that episodic memories can be seen as drawing on modal experiences. What connects the procedural and modal, embodied episodic memories is that the person's bodily actions that are at the center. It is what persons are able to do rather than their discursive presentation that is of interest. In that sense, their self is communicated beyond words.

Finally, it is clear that the linguistic challenges that persons with dementia encounters also restricts their possibilities of communicating a sense of self. The possibility of placing oneself in one or several autobiographical stories makes it possible to express and communicate several different aspects of oneself, to point to changes and development, etc., something that become more problematic for persons living with dementia. As the disorder progresses this means that other persons in the social network of the person with dementia become the bearers and tellers of his or her autobiographical stories, and in this sense become the keepers of at least parts of the self of the person with dementia (Lindemann, 2014).

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