Telling Stories

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Interaction and Narrative Structure in Dementia

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TELLING STORIES involving ourselves is one of the most important ways we have of telling others who we are—and of who we want to be. Listening to this type of autobiographical story generally makes it possible to infer something about the storyteller, both in the present and in the past.

During their lives most people frequently tell this kind of story, in various settings and to different audiences. They are stories that generally have the storyteller as the main protagonist, and the point of the story has to do with the teller and his or her handling of those events that in some way deviates from what is expected. Generally they are also stories with an “extended reportability”; that is, they can be “told and retold over the course of a long period of time” (Linde 1993, 21). Put differently, people tend to have sets of stories about themselves that function as resources for telling stories at various times to different audiences.

People with Alzheimer’s disease (AD) experience a slow loss of linguistic and cognitive skills. Persons with AD are challenged first by having to remember new things and later on by also having to retrieve memories about the past. As a consequence they face an increasing number of challenges in using language and remembering things from the past, something that also especially affects their ability to tell stories. Losing cognitive functions makes it difficult to organize stories temporally, and the same stories tend to be told repeatedly during the same speech event. Losing linguistic functions also results in word-finding problems, and eventually in problems with constructing meaningful linguistic units, which makes it difficult to tell stories at all.

Although much of the research on AD has focused on the loss of skills, several researchers have recently pointed out that people with AD also make attempts to use their remaining cognitive and linguistic resources (see especially Sabat 2001). What have traditionally been viewed as symptoms of decline and lessening skills could be regarded from this perspective as creative attempts to present a positive self-identity. To tell and retell the same autobiographical stories may be a way to show important aspects of the teller’s self and identity. Several researchers have pointed out that rep-
etition of stories or fragments of stories may capture something important in the way the person makes sense of his or her life (Ramanathan 1997; Mills 1997). The repetitions and the way these stories are organized may thus be approached as creative solutions rather than as mere symptoms.

Several researchers have shown that persons with mild and moderate AD actually are able to both participate more or less fully in conversations and to tell stories—if they receive support from other participants, especially those without AD. In this case persons without AD can act as vicarious voices (Hydén 2008) scaffolding the telling of the story—to use a concept from Jerome Bruner (Wood, Bruner, and Ross 1976)—by helping to organize both the story and the telling by using for instance speech support or small questions.

In the following we use storytelling events where a woman with AD tells the same story to two different audiences. We do this in order to discuss the different ways the audience, and more specifically the interaction between teller and audience, affect the organization of the narrative and hence the various identity functions of the stories. We also argue that at least some of the difficulties in telling stories by persons with AD can be handled by using smaller ready-made narrative units.

Language and Alzheimer’s Disease
Persons with AD have declining cognitive and linguistic functions that make it more difficult to do things like telling stories (Hamilton 1994). Much of the research on the way people with AD tell stories is either experimental in nature, measuring for instance their performance in retelling a story just heard, testing comprehension by answering questions about a story (Welland, Lubinski, and Higginbotham 2002), or telling a story about given pictures (see Ehrlich, Obler, and Clark 1997; Duong, Tardif, and Ska 2003). Other studies draw on interview material where the interviewer prompts the interviewee to narrate stories about his or her life, either to the interviewer or to a spouse (see Usita and Herman 1998).

In these studies it is generally found that persons with AD have problems producing stories and telling stories about topics that others suggest (Usita and Herman 1998). They need a lot of interactional support in order to produce a narrative (Ramanathan 1995). Usita and Herman (1998) also found that narratives told by persons with AD tended to be less chronologically organized. Events were repeated, fewer salient events were mentioned in telling life stories, and certain life stages were nebulously represented. A problem with most of these studies is that the way these experiments are organized and conducted makes it difficult for persons with dementia to tell stories. In a review of language function in AD, Sabat (1994) pointed out that much of the relevant research is hampered by an experimental design, which precludes an analysis of the interaction between researcher and subject. Furthermore, in experiments the subject must talk about topics outside his or her everyday contexts, making the task psychologically unfamiliar and hence artificial. As a result, in these situations, persons with AD tend to perform less well than they would in familiar everyday situations. Researchers tend to ascribe this lower performance to the disease and hence assume that the person is suffering from AD’s malignant properties (Kitwood 1998).
For persons with AD, the ability to tell narratives is affected by the deterioration of linguistic and cognitive skills. Several researchers have pointed out that the effects of the loss of cognitive and linguistic abilities are not absolute but depend on the social context, and especially on the attitude of other conversational partners without AD (Sabat 1991; Kitwood 1998). Sabat has pointed out that persons with AD are actually able to pursue conversations and tell narratives if they get interactional support.

The Driver’s License Story

In an attempt to avoid some of these methodological limitations, data were collected in one care unit at an elder care facility in Sweden. This care unit served eight residents, seven of whom were diagnosed with some form of dementia, mostly AD. For a period of five months, video recording was done in communal areas at the elder center (data collection by L.Ö.). In total about 150 hours of recording were collected. All these residents had consented, together with their next of kin, to taking part in the study. (All the data are in Swedish and have subsequently been analyzed in relation to Swedish language use. Only the examples used in this chapter have been translated into English.)

Storytelling between persons with AD without staff present was observed mainly between two female residents, Martha and Catherine, diagnosed with AD four to five years ago and seven to eight years ago, respectively. Both have midrange AD, although Martha is distinctively more inclined to hold the floor in conversations and generally less impaired in linguistic capabilities. In small talk and in commenting on other persons’ stories, Catherine’s difficulties are sometimes negligible, but they become more evident as she tries to construct a story of her own. In spontaneous storytelling situations, Martha is almost always the teller of the story while Catherine is her confidante. Martha’s stories, told spontaneously to her friend Catherine, often are autobiographical, are emotionally involved, and contain evaluative statements.

We have identified one story that is told several times by Martha on different occasions, in various contexts, and with shifting audiences. The story is organized around a set of reportable events. The actual story is then adapted to these different contexts and audiences and is therefore told in different ways (cf. Linde 1993; Norrick 1998). We call this “The Driver’s License Story.” It is about how Martha in her past, perhaps as a young person, decided to learn to drive and to get a driver’s license, and then to buy her own car. Her husband questioned her ability, both to learn to drive and to save up for a car by herself, but he was proved wrong. In the summer Martha and her family went for a long car ride, visiting relatives in various places. Martha surprised her sister and mother by being able to drive, and she later on discussed with her sister about being a married woman and learning to drive.

In one sense this is a story about the different reactions encountered some decades ago by a woman wanting to be able to drive and to have her own car. It is a story that portrays Martha as not only challenging the values of her generation about what women could and ought to do but also overcoming them, going her own way, and making a statement about herself.

In the following we analyze this story and the way it was told in two storytelling episodes. Episode 1 takes place within the framework of reading from the day’s
newspaper and conversing together. This group activity involves one assistant nurse, Martha, her friend Catherine, and four other residents. Martha’s story lasts for almost six minutes. Episode 2 occurs about a month later. Martha and Catherine are on their own, commenting on their surroundings. This time the storytelling goes on for over 25 minutes.

The Structure of the Story
During the two storytelling episodes, Martha basically tells about her decision to learn to drive and buy a car, and about her first vacation with her car, driving with her husband to see her family. Analytically, some aspects of Gee’s (1986) model for the production of narrative discourse were used. Gee suggested a way of transcribing and analyzing oral narrative, taking its point of departure in the prosodic organization of the narrative. He argues that stories are organized around some basic units that are marked by changes in prosody, like raising the voice, stressing, pauses, and the like. A narrative is divided into main parts, strophes, which are organized around happenings or events, and finally lines, which are the basic elements expressing ideas. The teller prosodically marks various elements in a narrative, helping the listener to follow and understand the story as he or she hears it; this makes it possible to identify what the teller thinks important, funny, noteworthy, or connected.

Using this model, it could be argued that the stories about getting a driver’s license are organized around a set of strophes, for instance “deciding to learn to drive,” “the driving instructor encouraging Martha to learn to drive,” “Martha decides to buy a car,” and so on (table 12.1). The strophes generally have a clear beginning, some sort of complicating action, and an evaluation (Labov and Waletzky 1997). The strophes are variations of more general themes that could be considered parts of the story; for instance, “getting a driver’s license,” “buying a car,” and “driving on vacation.” Taken together, the strophes and the parts constitute a set of temporally progressive events.

The strophes are nested together into stories, and in this way the stories that are told on the two occasions emerge. It is unclear whether the stories that emerge from the nesting process are supposed to be heard as continuous stories—although it is possible to listen to the narrations in that way. The strophes could most probably be thought of as a set of autobiographically reportable events. They are also apparently events to which Martha has access. From the fieldwork we know that Martha had problems accessing memories in general and that she tended to use a small number of stories in different types of situations as a way of creating meaning (Örulv and Hydén 2006).

The strophes are made up of lines that are often organized around certain phrases. Quite often Martha uses the same line (or phrase), although in two different contexts. This is especially true about lines that express some important emotional or moral content. Some of these phrases can be found in both storytelling episodes.

It turns out that Martha organizes the nesting of the strophes into a larger story in different ways, depending on the storytelling setting. When she is telling the story without staff present, the emerging story lacks a temporal progression of events. As a consequence, strophes can be told several times without comments, or events can be told in reverse order or without any temporal order at all. When Martha tells her story with a staff member present, the assistant nurses support Martha’s storytelling,
resulting in a temporally well-organized story. The relationship between the interactional setting and the structure of the story will be analyzed further.

Table 12.1
The Units of the Driver’s License Story

<table>
<thead>
<tr>
<th>Part I: Martha’s Getting a Driver’s License</th>
</tr>
</thead>
<tbody>
<tr>
<td>1:1 Martha decides to learn to drive</td>
</tr>
<tr>
<td>1:2 The local driving instructor encourages the young Martha to learn how to drive</td>
</tr>
<tr>
<td>1:3 Martha’s husband questions her ability to learn to drive</td>
</tr>
<tr>
<td>1:4 Martha passes her driving test easily</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Part II: Buying a Car</th>
</tr>
</thead>
<tbody>
<tr>
<td>2:1 Martha decides to buy a car (VW)</td>
</tr>
<tr>
<td>2:2 Martha’s husband questions her ability to save up for a car</td>
</tr>
<tr>
<td>2:3 What the car looks like (VW)</td>
</tr>
<tr>
<td>2:4 Getting help to buy a car</td>
</tr>
<tr>
<td>2:5 Martha plans how to pay for the car</td>
</tr>
<tr>
<td>2:6 Making a down payment to get the car right away</td>
</tr>
<tr>
<td>2:7 Martha buys a car</td>
</tr>
<tr>
<td>2:8 Getting the car (right away)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Part III: Driving on Vacation and Meeting the Family</th>
</tr>
</thead>
<tbody>
<tr>
<td>3:1 Practicing before going away</td>
</tr>
<tr>
<td>3:2 Making a detour (700 kilometers)</td>
</tr>
<tr>
<td>3:3 Surprising her sister (later: mother): the absent husband/driver</td>
</tr>
<tr>
<td>3:4 Advising her sister about learning to drive: never drive with one’s husband</td>
</tr>
<tr>
<td>3:5 Competing with her husband for the driver’s position</td>
</tr>
<tr>
<td>3:6 Stopping along the road, picking berries and flowers</td>
</tr>
<tr>
<td>3:7 Driving for several days, visiting other relatives on the way</td>
</tr>
</tbody>
</table>

Storytelling Activity in the Absence of Staff

After lunch the two women are moving along the corridor talking, and eventually they sit down on a bench. Quite early on in the stroll, Martha starts to reminisce and gradually starts to tell a story about her driver’s license. Catherine goes along and sits close to Martha on the bench. Martha tells her story for about 30 minutes. At that time the staff starts to move around, and the two women hear snatches of the conversation between the staff. The storytelling comes to an end, resulting in a long pause (nearly 2 minutes). After some brief comments about the staff, the two women start to comment on the lights in the corridor. The storytelling episode is over.

Example 1 is from near the end of the episode—that is, after some 25 minutes. It is a typical example of the way the storytelling is organized and of the kind of
stories Martha tells. This is the third time during the episode that Martha tells the story about her decision to buy a car. Just before the example starts, she has been telling about making a down payment on a car. In line 1, Martha makes a general comment about that summer, followed by an “and then” (line 2) indicating that new events will be added to the story. On line 4 Martha repeats the “and then” and the new story part organized around a new theme starts:

Example 1

1 Martha: it was it was such a lovely summer
2 [and then —]
3 Catherine: [yees you] were lucky
4 Martha: =and then I got and then I ( . . . )
5 the instructor he asked me (. . .)
6 "would you like me to accompany you looking for a ( . ) car — "
7 ’cause he did understand [(xx)]
8 Catherine: [yes]
9 Martha: “’cause they won’t cheat you then” he said
10 and then he said
11 “I can accompany you and ( . . ) look for a car ’cause I could pick
the best one”
12 Catherine: yes that’s true
13 Martha: yes “If you want to” he said
14 “yes I would like that” I said
15 “I’ve got—my brother has got a driver’s license but ( . . . )
16 but he eh (. .)
17 it’s better I get to learn from eh someone who’s a real instructor”
18 Catherine: yes that’s true
19 Martha: =yes “You are really careful, you really are” he said
20 ([(takes hold of Catherine’s arm, leans forwards towards her and
looks in the eye)])
21 “so you’ll get along okay” he said
22 [([(leans back and laughs)])]
23 Catherine: [well that was a nice compliment]
24 Martha: ((laughs)) *yees*
25 ((laughter in her voice; points to Catherine))
26 Catherine: she got a nice compliment!
27 Martha: *yes
28 ((makes a pointing gesture toward Catherine again and keeps it
during the rest of the utterance))
29 he said that
30 yees*
31 Catherine: yes I believe so (xx xx)
32 Martha: =yes
In general the telling of the story in the example is interactionally well organized. Both women position themselves in the turn taking as tellers and listeners, changing positions so as to leave room for comments. Catherine frequently supports Martha’s storytelling with small interjections or comments (lines 8, 12, 18, 23, 26, 31). There are no gaps in the turn taking, or long pauses or outright misunderstandings that cannot be solved. In the telling there are some small pauses generally having to do with word-finding problems (most notably in lines 15, 16). Thus, there is little indication of problems in the organization of the interaction.

From line 19 and onward to line 31, an evaluative section of the story can be identified. During this stretch of talk, it is noticeable that simultaneous talk appears. The simultaneous talk underlines that both participants have recognized and appreciated the evaluation of the events in the story. In this way closeness between the two women is displayed around some points in the story (for a further analysis of this aspect and its relevance, see Hydén and Órulv 2009). The simultaneous talk is further supported by bodily display of closeness and hand gestures; Martha puts her hand on Catherine’s arm, leans forwards, gazes at Catherine, points, and so on (lines 20 and onward).

Discursively the telling is organized around a dialogue between two of the story’s main protagonists, Martha and the driving instructor. The dialogue is replayed and dramatized. The quotations are generally prefaced or followed by expressions like “he said,” “and then he said,” “I said,” and the like. Martha’s narrative voice is found only at the beginning of the story (lines 1, 2, 4, 5) and in the small comments in the evaluative part of the story (lines 21, 24, 25).

There is a problem with unclear word references and sometimes confusing pronouns. In line 4, for instance, Martha says, “and then I got and then I,” and in line 6 she quotes her driving instructor. What she probably meant to say is that she got her driver’s license and then considered buying a car. In lines 15 and 16, Martha evidently has problems finding words. She resolves this problem by using a phrase that she has used several times previously: “It’s better I get to learn from eh someone who’s a real instructor.” This solution introduces a third problem, namely, the fusion of two storylines.

In line 15, Martha introduces a circumstance that probably is important to her: the fact that her brother has a driver’s license. Potentially, he could help her select and buy a new car. When she has talked about her brother previously, it had to do with her not letting him teach her how to drive. It is this storyline she continues in line 17, that she wants the professional instructor to teach her how to drive. She then continues the storyline by quoting her instructor’s approval of her choice. The fusion of two different storylines in this ways happens several times during the storytelling episode.

In general, during the whole storytelling episode when Martha nests the strophes together she does not organize her telling around a temporal progression of the events. Normally it would be expected that this type of autobiographical story would be organized around a set of events that are temporally ordered; the order of the events in the telling corresponds to the order in which it is told (cf. Labov 1972). This would
make it possible for the listener to pose the question “What happened then?” to the unfolding narrative, and to listen for the next. What happens when Martha tells her story is that she changes the order of the events and repeats certain events and parts of the story several times, making certain that events appear again and again without relating them to the temporal sequence of events.

Normally, a storyteller has to indicate very specifically if new information and events are added to the story told so far. This happens if the teller has forgotten to mention some important information, making subsequent events unintelligible or pointless. The reason for the teller to indicate the addition of new information is that the listener then has to reinterpret what has been going on in the story because there will be a new answer to the listener’s ubiquitous question “and then what happened?” Martha does not indicate that she is adding new events, and Catherine as a listener does not signal any problems with understanding the unfolding story. One possible reason for adding the new events and strophes could be that they are in some way thematically connected to something in the preceding strophe.

**Telling the Story with Staff Present: Scaffolding**

In the video-recorded material, the driver’s license story is told twice when staff is present. Generally the story is organized as a number of narrative units organized around strophes that are then nested into a larger story, similar to what happened without staff present. The main difference has to do with the fact that the assistant nurses actively support the telling of, and help to organize, the stories through questions and other means.

Example 2 is from an episode where six of the persons with AD and a nurse are sitting around a table while the assistant nurse reads aloud. The assistant nurse has just been reading an article involving cars, and one of the participants asks the assistant nurse if she has a car. This starts a more general discussion among the participants about cars, different types of cars, and so on. After some further discussion, the assistant nurse turns to Martha and Catherine and asks them if they used to have driver’s licenses. (Unfortunately we do not know whether the assistant nurse in this particular case knew about Martha’s story and hence wanted her to tell the story, although this is a common strategy in the data and occurs in relation to this very story later on with another assistant nurse.)

In response to the assistant nurse’s question, Martha tells about acquiring her driver’s license and how she and her husband went for a vacation (example 2). They went north from their home, on small roads, in order to visit Martha’s sister and her family and other relatives, and Martha was eager to be at the wheel.

**Example 2**

1 Martha: and then we drove up to eh
2 X-county an’ an’ [further up] ((1))
3 Catherine: [X-county?] ((1)) [(xx xx)] ((2))
4 Martha: [to X-county and further up] ((2))
5 I drove 700 kilometers then
6 [(xx xx)]
Asst. nurse: [wow]
Martha: I was so afraid Edward ((her husband)) would get ahead of me to the wheel
so I eh was in an awful hurry whenever we were to drive off ((laughter in her voice at the end of this line))
((laughter))
Asst. nurse: but did you drive all the way by yourself?
Martha: =yes I did
Asst. nurse: =wow
Catherine: =you were stubborn
Asst. nurse: yeah
Catherine: but then you managed [that]
Asst. nurse: [but] then you made many rest stops?
Martha: =well we stopped here and there and had berries an’
and there were lingonberries and bilberries too
Asst. nurse: =ye:ah
Martha: •yeah
Asst. nurse: and then we had relatives along the route too
yes, okay ((nodding))

As we can see in this example, the assistant nurse actively supports Martha in her telling in various ways. She uses sustainers prompting Martha to go on (lines 14, 20, 23), evaluative utterances (lines 7, 12), and she requests further information (lines 10, 16–17). When further information has been provided, she signals understanding (line 23).

When Martha drives home a point (line 9) about hurrying to get behind the wheel before her husband, she laughs. At this point the assistant nurse requests further information when she asks what happened next: “But did you drive all the way by yourself?” This request helps Martha to present some more information about her driving—and she gets appreciation from both Catherine and the assistant nurse. The assistant nurse again requests more information (lines 16, 17), and in response to this Martha continues her story.

The intervention of the assistant nurse helps Martha tell the events in a progressive order and also to avoid repetitions. In this way it is easy to follow and understand what once took place and what events Martha wants to tell about. The assistant nurse’s requests underscore Martha’s accomplishment, giving her fellow participant Catherine the opportunity to affirm Martha as both stubborn and capable (lines 13–15). They also put the events in order. Having clarified the fact that they had relatives along the route, Martha is then able to move on to tell about meeting her sister (subsequent to the excerpt) and surprising her by being able to drive, and the parts of the story are linked together in a smooth and unproblematic way.

When a staff member is present, it also seems that the active support from the assistant nurses is a very effective way of helping Martha in her storytelling. They scaffold Martha in her storytelling (Wood, Bruner, and Ross 1976), in two ways. The first way is providing a framework to enable Martha to tell a shorter anecdote that
fits into the conversation, and the second is helping Martha tell the events in a progressive temporal order. In the first episode the small story illustrates a point already made by the assistant nurse, and Martha does not need to explain why she tells this story. Nor does she need to establish its relation to other events over a longer period of time, which would be more problematic, but can stick to this single anecdote, embracing only one situation.

In the example, Martha is given the opportunity to present herself in a certain way to an audience. That is, she presents herself without having to establish on her own all the contextual information that the listener is usually provided with in autobiographical storytelling (cf. Moore and Davis 2002; Usita and Herman 1998).

The Story Told Twice
In these examples it is evident that for Martha, telling about getting a driver’s license, buying a car, and getting to drive on her own—and being capable of doing so—is a way for her to remember events that are somehow central to her identity. This is probably true even if she is only able to tell parts or fragments of the story on her own, that is, in a sequence that makes sense logically. A constantly recurring theme is her ability to do things on her own and follow her own mind, even if other people are critical or might disapprove of her actions. Apparently, retelling these memories is a way for her to sustain her identity as an independent and capable woman who knows her own mind.

Although combined differently, there is an overall similarity between the two versions of the driver’s license story as to what units are included. The parts seem to fit together in more than one way, some of which notably diverge from the chronological structure but still add up to a recognizable story—even with instances of almost identical linguistic phrases. Taken together, this indicates that Martha is using a number of kindred themes, closely related to getting a driver’s license and to the consequences of this. In this respect her way of telling has a close resemblance to traditional oral storytelling. In the 1960s Albert Lord pointed out that traditional storytellers did not so much recite lengthy stories from memory as they—in their “reciting”—composed the tales, using traditional verbal formulas (Lord 1960). Gee (1986) argues in a similar fashion. Stories that stand out from standard patterns, he claims, become comprehensible when viewed as oral stories rather than as literary stories.

In previous articles (Örulv and Hydén 2006; Hydén and Örulv 2009) we have argued that the frequent retelling of stories organized around a common overall theme—often used to make sense of the current situation even when not quite applicable—could have to do with having limited access to certain cognitive themes, resulting in a reuse of those accessible themes. We used the term “story lines,” that is, genres of narrative plots that organize the stories and render them meaningful as being part of that particular genre and often of a certain moral theme. These genres are also connected to certain ways of presenting a positive self-identity.

In line with this, it can also be argued that difficulties in telling autobiographical stories can be handled by (re-)using smaller ready-made units that somehow illustrate a meaning-based connection between events (Ramanathan 1997, 115). That is, one reuses more or less flexible resources that can be combined in a variety of...
ways, although still in line with the same moral theme, to compose autobiographical stories. In this way the referential aspects of the composed story do not quite add up as comprehensible when scrutinized, but the point or the moral theme remains intact (see Örulv and Hydén 2006). As a consequence it becomes possible to use these moral themes to sustain the teller’s identity.

One important finding in this study is that it is possible for a person to relate actively to a loss of memory by using his or her remaining narrative elements in creative ways, and with some support. Thus, Martha is capable of combining a set of narrative events, characterized by their tellability and evaluative points, into a storytelling event. That is, memory loss is not a simple loss of memories but a loss of a possibility to combine and use memories in telling stories that are recognizable by others.

It also turns out that the most important thing is not necessarily the progressing temporal organization but the tellability of the story and its evaluative points. As long as this works, the teller with AD can use the telling of stories to present and negotiate his or her identity.

Transcript Key

(1) Line numbers are organized so as to reflect the rhythm of the speech and actions.

((italic text)) nonverbal actions and clarifications

underlining emphasis

[text] Brackets indicate the start and end points of overlapping speech (numbered within double parentheses when two such instances occur next to each other).

: elongated syllable

= following previous utterance in immediate succession

•hh audible inhalation

•yeah inhalation speech

“text” reported speech, marked explicitly or with paralinguistic measures such as change in voice quality

— interrupted speech

? question intonation

(xx xx) inaudible speech

(text) unclear speech

REFERENCES


