## Expanding Expectations for Narrative Styles in the Context of Dementia

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This article uses discourse analyses to examine the narrative styles produced by 2 women with a diagnosis of dementia. Because of constrained cognitive resources, people with dementia (PWD) often use alternative strategies to weave their stories into conversations. People with dementia have difficulty in initiating and maintaining a canonical Labovian narrative structure, even with collaboration from an unimpaired conversation partner. For example, they may omit the orientation needed by the partner, or they may not look back, sum up, and achieve a resolution in ways conversational partners traditionally expect. Nevertheless, our data suggest that PWD are persistent in attempting to negotiate the use of narratives as a linguistic vehicle to express their identity and social needs in the face of cognitive decline and that their stories may be presented in different pieces or may illustrate differing perspectives from the story format initially expected by the clinician. Recognizing this can lead to an expanded set of expectations about narratives on the part of clinicians across disciplines. **Key words:** coconstruct, dementia, narrative, scaffold, speaker-position, small stories

S TORYTELLING HAS been an important part of the history of humankind. Although narrative forms may vary considerably across cultures, they share a common function; that is, narratives organize and present information relating to an individual's life experiences and/or beliefs about phenomena in a coherent manner that can be understood and evaluated by an audience. As Scott and

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Lyman (1968) noted, narrative accounts are often statements made by social actors "to explain unanticipated" (p. 46) events that occur in their lives. In addition to providing a context for recalling and sharing the facts of the story, spoken narratives allow speakers to achieve a wide range of tasks aimed at achieving both instrumental and interpersonal goals as part of their communicative function. Narratives are a highly versatile mode of speech that allow a speaker to both style-shift and adopt different perspectives or subjectpositions (Davies & Harré, 2007; Guendouzi & Williams, 2010) when describing an event. The term *subject-position* refers to particular points in a conversation where the speaker's talk reflects different (or conflicting) "voices" within a narrative (Davies & Harré, 2007). Telling stories allows a speaker the opportunity to discursively explore different points of view regarding an event. Thus, oral narratives create an interactional opportunity through which speakers can explore their own and others' feelings or opinions about a life event or problem.

As Labov (2007) noted, "Before a narrative can be constructed, it must be preconstructed by a cognitive process, namely decision making to ascertain that a given event is in fact reportable" and worthy of retelling. Preconstruction involves retracing the event or experience "backwards in time to locate turning points" (p. 47) or other associated factors that the teller deems are causally or affectively linked to each other. Preconstruction is a recursive process that involves sequencing and comparison of the event or experience through linguistic means.

Narrative discourse has some commonly defined structural expectations. Typically, a narrator must provide an appropriate starting point, attempt to frame the story within a particular genre (such as problem solving or everyday gossip about others), and add details to recreate (or reconstruct) the event in line with a particular worldview. In some cases, for example, narrative involves "troubles-telling" and this particular type of narrative may involve the speaker telling a story in a manner that allows the listener to sympathize with, or better understand, the events of the story at hand. Troubles-telling (Jefferson, 1980) narratives also may involve presenting the trouble from different subject-positions. In telling their stories and rehearsing their troubles, narrators have an opportunity to evaluate and work through emotional responses to their problems.

Constructing narratives requires speakers to allocate considerable higher level cognitive, pragmatic, and linguistic resources to the task. However, in the case of people with dementia (PWD), cognitive resources that support language processing are compromised, such as focus of attention, working memory, event sequencing, and access to semantic lexicon. This results in the production of narrative forms that frequently vary from normal expectations for how a story is "supposed" to be constructed, that is, in the canonical Labovian format of abstract, orientation, complications, resolution, and coda. Looking at the function of several formats of narratives from a sociopragmatic perspective lets us better understand that some expectations about wellformedness that clinicians or family member may bring to an interaction are expectations that may not align with the information or style of narrative the PWD can produce.

The fear created by the specter of dementia for both the individuals affected with the disease and other aging people has been noted in the literature for several decades. Indeed, "dementias have been characterized as the diseases that are most feared by older people" (Kristiansen, Norman, Norberg, Fjelltun, & Skaalvik, 2015, p. 2). As Kristiansen et al. (2015) noted, numerous books and articles have titles that reflect this fear, such as those that cite dementia as a "living death" (e.g., Lushin, 1990; Woods, 1989). The fear of a gradual loss of self has been noted in several previous studies (Guendouzi & Müller, 2006; Sabat, 2001). It is a fear that also permeated the responses of participants in a study conducted that involved recording the perceptions of students in health care professions (Guendouzi, Williams, & Manasco, 2010). Nevertheless, as Kristiansen et al. noted, "Having a DD [dementia disease] and living with the disease in its early stages is a highly individual experience" (2015, p. 2).

Persons receiving the diagnosis of dementia may have problems integrating it into their autobiographical selves. As Harré (1998) has noted, the human experience involves discursively constructing the autobiographical self. We typically construct our individual narratives through reference to past and current events, feelings, or beliefs. In the case of cognitive impairment due to dementia, it is difficult to fully access long-term declarative memories that support canonical narratives. As the disease progresses, sometimes only fragments of the stories may be available to the PWD. Without full reference to auto biographical histories, people's current and potential selves are much less stable constructs. The PWD's narratives become discourses that contain only fragments or pieces of the larger narrative and therefore depend on scaffolding and coconstruction from the PWD's interlocutor for making meaning. Harré suggests that people express themselves through three categories. Self 1 is "the person as one experiences oneself as having a point of view, as a singularity in space in time" (1998, p. 75). Thus, Self 1 is marked in discourse interactions through the use of personal pronouns (e.g., "I," "me," "my"). Self 2 is one's autobiographical self; it includes talk that references an individual's personal attributes, skills, and beliefs in relation to past, present, and future events. Finally, Self 3 is how a person shares his or her autobiography with others; it is the socially constructed "self" that manifests in a person's interactions with others. The stories that we examine here are examples of Harré's Self 3: that is, they are linguistic vehicles in which two women with dementia attempt to express what it means to experience dementia.

The goals of this article are to illustrate some of the linguistic strategies PWD may use to narrate their self-identity and remain active social partners and to highlight the range of discursive strategies that therapists can use to scaffold or coconstruct the maintenance and extension of narratives by PWD. By using the same method, discourse analysis, on two different sets of data, we hoped to present a triangulation revealing the range of language strategies presented by those data. As noted previously by Patton (1999, p. 1192; cf. Leech & Onwuegbuzie, 2007), triangulation supports "different aspects of empirical reality" by "examining the consistency of different data sources within the same method." This is what Patton called triangulation of sources (1999, p. 1193). Thus, by using ethnographically collected conversation and the same analytical technique, that of discourse analysis, we found that the two PWD, being two very different persons, presented entirely different repertoires of narrative construction in their efforts to explain themselves, their lives, and their growing awareness of the impact of dementia.

In this discussion, we first outline some of the classic features and forms of narrative. We then use data from examples of interactions carried out with the two individuals with dementia to show examples of how PWD who are no longer able to provide full, canonical narratives, nevertheless, continue to use story to make sense of their worlds. The first case study investigates conversations with Ms. Copeland (an alias) recorded in the 2 years following her diagnosis of dementia and her subsequent disclosure of it to us. These conversations illustrate the range of story schema and story formats a person with dementia may present at any one time during mild to moderate and late moderate dementia. The second case study focuses on Ms. Smith (an alias), a woman in the early stages of dementia. This participant was interviewed by a graduate student in a university speech-hearing clinic. The sample provides examples of two dialectical subject-positions or perspectives that Ms. Smith presented in her account of her diagnosis of dementia.

#### **NARRATIVE ANALYSIS**

One of the most commonly used methods for clinical analysis of narratives is the schema developed by Labov and Waletzky (1967). This method works well for analyzing a full, or canonical, story told predominantly by a single person. Although such a story may have interruptions, overlaps, or other signals from audience members, it is "one way of recounting past events, in which the order of narrative clauses matches the order of events as they occurred" (Labov, 2011). Labov (1972) indicated that the components of the canonical narrative are an abstract that briefly summarizes the whole story, an orientation that identifies the "the time, place, persons and their activity or the situation" (p. 354), complicating action(s) that are in temporal order and answer the question "Then what happened?" a result/resolution that tells what finally happened, and an evaluation that reveals why the story was told. There is often a coda that comes back to the present time and may contain general observations.

Although it is used frequently by narrative researchers, Labov's canonical narrative framework is not the only way to characterize narratives or the story world, and it may not be the most appropriate way to consider stories from PWD. A narrative must include the quality of tellability: As Norrick observes, "Tellability depends not only on the (detached) content of a narrative but also on the contextual (embedded) relevance of the story for the participants involved" (2007, p. 134). People with dementia may depend more on their audience to fill in story gaps. Accordingly, both the ways narratives develop in conversation (Norrick, 2000) and the work of interactional remembering in conversational narrative (Norrick, 2005) are important for understanding how PWD handle storytelling.

Cognitive scientist and narratologist, David Herman (2009), examined how people use stories to make sense of the world. In his review, Herman credited Ochs and Capps (2001) with shifting attention to the "mundane conversational narratives of personal experience" (p. 3), which were described as "small stories" by Bamberg and Georgakopoulou (2008). Narratives and small stories are situated in time, either in the here-andnow or in the there-and-then. For the notion of tellability, we draw on a recent summary by Baroni (2014), who suggested the teller has a reason for telling the story and thinks the hearer will wish to hear it.

In narratives recounted by PWD, the telling of a story is situated within a social context, perhaps even embedded in a conversation with a listener, although the context within and for the story may not be clear to the listener. Order is likely to vary; stance will be fluid; and the story will have some sort of pragmatic force, some sort of rationale for being told, even if (and perhaps especially when) it is a repeated story (Davis, 2010). As the disease progresses, the narratives generally become more fragmented and pauses and extenders become significant. In this phase of the disease, what Bamberg and Georgakopoulou (2008) called "small stories" increase and the narrative needs in some way to be scaffolded. With further progression, the "small stories" eventually begin to act as formulaic chunks, signaling different features of identity. The stories and story-chunks begin to be repeated, at first pointing to specific areas the person wants to emphasize and as the disease increases, they become placeholders, floor-holders, efforts to continue conversation. As discussed elsewhere, repeated small stories are not necessarily perseveration; they may instead be efforts by the speaker to signal different aspects of the context in which the story is being told (Davis, 2010). That is, they have a function, including becoming a way of saying "I'm here—please talk with me and let me know you see me."

In the examples of narratives presented here, we see how two women with dementia, Ms. Copeland and Ms. Smith, retain their interactional skills and continue to practice the language habits of a lifetime. In the case of Ms. Copeland, this includes a need to story that life that is now threatened by the specter of a disease that she sees as stealing her story, and for Ms. Smith, this includes a need to talk about and work through that specter in an unflinching way.

#### PARTICIPANTS AND PROCEDURES

The data from Ms. Copeland and Ms. Smith were collected in two parallel but separate studies that were designed to achieve the same goal, which was to collect conversational samples and stories from PWD using ethnographic methods. Both studies were covered by institutional review board permissions. The data involving Ms. Copeland were recorded in 10 conversations that took place over a 2-year period during 2000-2002, by the second author, as Ms. Copeland moved from independent to assisted living in Pleasant Meadows, a continuing care residence. Ms. Copeland's name and the name of her residence have been changed to ensure confidentiality. She had been widowed for several years and one of her physicians had diagnosed her dementia as she was getting ready to move from her home to Pleasant Meadows, a site where the second author and several colleagues were already collecting conversational interviews with PWD who had consented for the research. Recording of the conversations stopped, although the conversations continued, at Ms. Copeland's request when she moved in late 2002 to the memory care unit reserved for persons with advanced dementia. In each relocation, of whose significance she was well aware, she remained a tiny, elegantly dressed woman in her early 80s: Our last glimpse of her was in the memory unit activity room, wearing stockings and jewelry to match her dress and clutching a purse, as she stared at the activity leader. All interviews with Ms. Copeland were recorded in her room in Pleasant Meadows, first in independent living and then in assisted living, on an Olympus digital recorder DS330. The discourse was transcribed from .wav files without cleaning or enhancements.

The second data set presented in this article involves Ms. Smith, a retired legal secretary who received a diagnosis of Alzheimer's disease a year prior to this particular interview (the first of three) taking place. Ms. Smith had consulted her general practitioner because of an ongoing vascular problem, a condition that her doctor attributed to a lifetime of smoking. Ms. Smith returned to the clinic on three occasions and took part in three interviews over the period of a year. At the time of the interview reported in this article, she had been suffering from back pain for several weeks. She lived at home with her husband, who informed the interviewer that his wife had recently scored quite low on a cognitive screening, although her general conversation in this particular interaction was not marked by noticeable cognitive or linguistic deficits typically associated with dementia.

Ms. Smith was recruited for the narrative research after she came to a local speech-hearing clinic to be interviewed for a study that focused on how families cope with the diagnosis of dementia. The study involved collecting ethnographic interviews with family caregivers and also, where possible, interviews with the family member who had dementia. Ms. Smith was keen to participate in the study and had agreed to be interviewed by the graduate assistant (GA). The GA was en-

rolled in a communication sciences and disorders master's degree program but was not taking the clinical components of the degree because she was interested in pursuing research. On this occasion, she was hired as a paid research assistant for the project. Although the researchers used the speech-language clinic rooms at the university, Ms. Smith was not a client at the clinic, nor did she at any time receiving clinical services.

The particular interview reported here lasted 50 min and was recorded in a small clinic room that was equipped with a commercial video system connected to computer screens in a separate viewing room. The camera was mounted discretely on the wall. Ms. Smith sat across a table from the GA in a cushioned chair. A glass of water and a box of Kleenex tissues were placed in the center of the table. Following recordings, the data were first reviewed and transcribed by the GA. The first author then reviewed the videotapes, making independent notes. The GA and the first author then met to (re)review the videotapes together to discuss and resolve any discrepancies that were noted in the transcriptions. Following this process, a third party researcher, who was a linguist and not involved with the study, reviewed the videos with the finished transcripts to assess credibility of transcriptions.

As the conversations presented in the following test were collected in separate studies and transcribed by different researchers, there are slight differences in transcription conventions but conventions are kept (as much as possible) to a single system.

Transcription conventions:

- italicized and boldfaced = Ms. Copeland's use of constructed dialogue.
- 2. Long pauses (>500 ms) are signaled with indentation.
- 3. In the extracts involving Ms. Copeland, angle brackets < > are used to indicate a researcher is speaking; otherwise, everything is spoken by Ms. Copeland, using the initials for her pseudonym (A.C.).

- 4. In the data involving Ms. Smith, "GA" indicates the graduate assistant and "Ms. A" indicates Ms. Smith.
- 5. [single square parentheses italics] = nonverbal or paralinguistic information
- 6. (*italics*) = contextual information
- 7. \*\*\* or [...] = omitted material
- 8. Bold text is used to highlight features of the extracts (e.g., the **burden** refrain in Section d).
- 9. Asterisk \* = points at which speech overlaps.
- 10. (.) = minimal pause.
- 11. (2 s) = timed pause.
- 12. **BOLD ALL CAPS [comment]** = functional speech act description or narrative component.

#### THE DATA

In both case studies, ethnographic interview techniques were used to pursue questions that might prompt the interviewee to recall and talk about past events and/or experiences (Guendouzi & Müller, 2006). We remind readers, however, that interviewers are "deeply and unavoidably implicated in creating meanings" (Holstein & Gubrium, 1995, p. 3), as are the researchers who analyze the accounts they collect. Thus, the discussion of the participants' stories is the end result of the interactions between the participants of the conversations, the researchers who analyzed and reviewed the data, and the background information provided by caregivers. We are therefore cautious about claiming that the discussion produced here reflects an a priori reality of the two women's lives.

#### Ms. Copeland: Organizing small stories

Ms. Copeland presented us with a monological performance narrative about family members in our first meeting, one containing all the components of a canonical narrative. In general, however, she was much more likely to share what Bamberg and Georgakopolou (2007) call "small stories" in conversation. Her conversational stories, as Norrick observed, were "told for a reason

and they fulfill multiple simultaneous functions: sharing personal news, entertaining listeners, revealing attitudes, constructing identity, inviting counter-disclosure" (p. 127) and were filled with "incomplete elements and extraneous bits ... false starts, repetitions, and digressions" (p. 131). In this analysis, we follow Georgakopoulou (2006) in defining small stories as "an umbrella-term that covers a gamut of under-represented narrative activities, such as tellings of ongoing events, future or hypothetical events, shared (known) events, but also allusions to tellings, deferrals of tellings, and refusals to tell" (p. 122).

Our examples from conversations with Ms. Copeland display how, as the disease increased, as with other persons with dementia with whom we have conversed, her narratives became more fragmented, she developed a repetitive refrain, and pauses and extenders played a more important role in maintaining conversation (Davis & Maclagan, 2010, 2013). Her stories always had some sort of social context. Her use of small stories increased, and they began to act as formulaic chunks, signaling different aspects of her repertoire of identities. At first, her stories and story-chunks pointed to specific areas she wanted to emphasize and, as the disease increased, they became placeholders, floor-holders, efforts to continue conversation, and, ultimately, a way of saying "I'm here-please talk acknowledge my existence." The analysis begins with Ms. Copeland's initial performance narrative, which contains all the elements of a canonical narrative. It contrasts with her later conversationally constructed "small stories" (Georgakopoulou, 2007), repetitive phrases and two different kinds of laments, each going beyond conventional "griping" or "troublestalk" (Ouelette, 2001).

In her performance story about her grandmother, which she shared during our first meeting, only a few signals of possible confusion or forgetting are apparent, although she begins with an apology for possibly not remembering accurately, and continues to say, "I think" until she reaches the core of her memory about herself and signals strong emotion with "I can remember so distinctly" (line 116; see Norrick, 2005). This is a frequently rehearsed story she has told on multiple occasions to her four children and nine grandchildren and to her friends, and she includes a number of techniques to increase its dramatic quality, switching loudness and gestures to indicate key components. As time went on, we found that she was not particularly comfortable performing stories of her past for strangers and wanted instead to discuss what was on her mind.

Our second conversation was minimal, consisting mostly of setting an appointment for our next meeting. It was during our third conversation that she revealed she had been diagnosed with (probable) Alzheimer's disease and was terrified. Those feelings did not diminish but remained quite strong as she expressed them in several conversations; for over a year and a half, she was still grieving and fearful about the diagnosis, and sensitive about reactions of other persons to her. In the following examples, we begin with her performance story about her grandmother, which included one narrative inside another. We annotate the story shown in Table 1, with the terms used by Labov (2007, 2011) and others to identify story components outlined earlier.

In this well-rehearsed narrative, we see one canonical narrative nested within another. The outer narrative does not have an abstract—that was presumably provided by her friend's request to Ms. Copeland to tell the story. Background information is provided in the orientation, which is followed by a series of complicating actions. The resolution of the outer story is delayed by the nested story about the whiskey, which has an orientation, action, and resolution. This is followed by the resolution of the main story and an evaluation that covers both the main and the nested narratives and a coda that comments on the story as a whole and brings us back to the present time. At the time Ms. Copeland told this story, she had already been diagnosed with Alzheimer's disease. Nevertheless, she was able to present a full and complex narrative with all the traditional canonical elements, primarily, we think, because she had told it so often. She shared no other performance narrative with us over 2 years of conversations, and over those 2 years, the story began to fragment. As dementia increases, many speakers lose the ability to understand what information or what context the hearer will need and may present only a few of the components: orientation but no resolution, action without orientation, evaluation without action are all common, and are usually offered as small stories.

Ms. Copeland shared a few small stories about this grandmother in terms of the tricks she played on others, longer stories (coconstructed with the researchers) about a son, and small stories about having attended Catholic schools and being taught by nuns. These latter small stories and chunks, as shown in Table 2, index her emphasis on her faith and her concerns about the lives of her children. By our third conversation, early the next month, she trusted us enough to share her unhappy feelings about her recent diagnosis in a lengthy conversation (559 lines, 414 turn-utterances, of which 190 were by A.C.). She continued to voice fear and sorrow until January of the following year, going beyond troubles-talk, which can range in intensity, to a lament for that which could not be changed. Notice that her story is presented only as chunks of orientation and evaluation chunks; she and her condition embody the complication.

The stigma associated with dementia is still strong among many older persons, including among clinicians, as found in a 2006 study "Perceptions of Stigma in Dementia" by the School of Nursing and Midwifery, Trinity College, Dublin. Garand, Lingler, Conner, and Dew (2009) cited studies showing that people may also internalize the public's stereotypes and back away from obtaining diagnosis, treatment, or social support. This internalization began almost immediately in 2000 with Ms. Copeland, as illustrated in the excerpts in Table 3, and peaked a year later, in January 2001, fading only after she moved

Table 1. Grandmother story: Nested canonical narratives and reenactment January 16, 2000

Speaker	Utterances	Analytical Comment
Ms. Copeland:	My grandmother and my grandfather	ORIENTATION
	She was Irish and he was Welsh She came to this country with her relatives when the Irish Potato famine was in effect	
	[after father's death] continued orientation about living with her grandparents	
	I think my grandmother thought that was a perfect time for her to go back and see her relatives so she did. [sidebar about her grandfather]	ACTION
	So she went and the day she was coming back my mother kept me out of school because this was a big occasion and it was a hot hot day in early September. [tone changes to almost a whisper; big pauses] And I remember	NEW ORIENTATION
	standing at the watching the boat that came in and we watched and the gang plank was put down and all the people came down	ACTION
	and no grandmother and we waited and waited and my mother thought <i>my goodness I bope she's not sick</i> she didn't have enough for one drink left and pretty soon down comes my grandmother all alone and she's got on a black wool coat with a fur collar and a fur hat and it's ninety odd degrees.	ACTION
	[grandmother disembarks] My mother I can remember so distinctly I was only about seven but is everything all right mother (changes tone, slight mimicry)	REENACT
	wait till we get to the car she said (slight mimicry of older person) we got to the car	
	and it seems that my grandpar-	[REPHRASE]
	father's relatives wanted to send my grandfather some Irish whiskey and my grandmother (indistinguishable) said <i>I can't do that dear</i>	ABSTRACT 2 ACTION
	they'll they'll catch me (slight change of tone)	(Continues)

**Table 1.** Grandmother story: Nested canonical narratives and reenactment January 16, 2000 (*Continued*)

Speaker	Utterances	Analytical Comment
Researcher:	and my grandfather's relatives said <i>we've taken care of that</i> they had made her a belt to wear around her waist that had little pockets in it in which they had little glass bottles with caps and they put all the Irish whiskey in this and she was afraid it would show through her dress <oh yes=""></oh>	ACTION 2
Ms. Copeland:	So she put on this heavy coat ( <i>laughter</i> ) which made them all explode	RESOLUTION
	But that was my grandmother She could get away with it She was a funny lady	EVALUATION
	But anyway we told that story through the generations about this Irish grandmother who got away with this and no one else could.	CODA

from her private apartment with kitchenette and a public dining room in independent living into the assisted living section, which had its own small dining room. Interestingly, it was the nursing staff, not her family, who told her in late summer 2000 that she would be moving into assisted living after the first of the year.

#### The burden refrain

A phrase that would become a frequent refrain surfaced for the first time in her conversations with us in February 2000: She did not want to be a burden on her family or friends (see Table 4). The use of this phrase always elicited responses of reassurance from her listeners it is hard to tell whether she unconsciously wanted to elicit some kind of reaffirmation of her previous abilities to manage a family and keep a home. However, by late 2001, she was using a version of the phrase to affirm herself as well as to voice her concerns: She was now proud that she was not a burden to her children, she liked being at Pleasant Meadows, and she had, in general, a more realistic perspective on her situation, which she now called her "ailment."

#### Small stories

Much of Ms. Copeland's conversation was in the form either of nonnarrative accounts or of small stories where she alluded to features of her history that acted as her touchstones or recited events in which she was involved. Mentioning nuns indexed her value system, particularly about the importance of marriage. Grandparents were also important, but her references to her grandmother had shortened considerably a year after her dementia diagnosis (see Table 5).

By the time we stopped recording Ms. Copeland, she was no longer able to produce full, canonical narratives. Nevertheless, as the aforementioned extracts show, she was still able to use small stories and repeated refrains in order to organize information about her life and share this information with others.

In the other case study presented in the following text, we show how the second participant, Ms. Smith, uses different linguistic strategies to tell her story of dementia, maintain the conversation, and also work through the threat dementia poses to her internalized and socially projected identity.

Table 2. Lamentation and apprehension

Speaker	Utterances	Date
Ms. Copeland:	Understand that nothing's changed (.) I just feel (.) what am I living for you know (.) I'm going to become a vegetable (.) let's get it over with (.) I'm not going to commit (.) suicide or anything but I have nothing to look forward to (.) I'm not going to get better.  ***	February 9, 2000
	Thought it would pass (.) but (.) I could look forward and there's nothing nice to look forward to (.) it's going to be bad. ***	
	You know but I (.) (.) it was just last night that I was thinking (.) what's the point in this why don't I just go and it would make it easier on all the children and myself (.) I'm not afraid to die.  Well it is true yes (.) I just don't know how to I keep talking to myself about this and saying you've got to snap out of it and I'm okay for maybe an hour and then all of a sudden it's all back again.	
	That's the hard part of it. It's not like you've got a dreadful disease that you can take medication and get well. I can just see me walking around like a zombie. I see them upstairs.  ***	March 8, 2000
Researcher:	You die of something else beforehand? Many times.	
Ms. Copeland:	I hope I do. I hope I do, because I feel as though my work is done.  And people, my children don't need me anymore.  But I just don't feel like myself. I don't have any friends here.  I think it's because I'm no fun to be with! I don't know, but I never had any trouble and I moved a lot.  Never had any trouble with making friends but nobody calls me and wants to do anything.  Look at me! I'm at a low point!	January 11, 2001
Researcher:	Well, I'm glad we came during a low point because you can climb back up with us.	
Ms. Copeland:	Well, I hope so. That would be nice. I just wish it was all over with.	

# Ms. Smith: Presenting self through dialectical subject-positions in troubles accounts.

Goffman (1959) has noted that social actors present different versions of "self" within

their conversations. That is, as tellers of stories, social actors can discursively align themselves to different perspectives (subject-positions) within the same narrative. Goffman suggested that this allows individuals to assess

**Table 3.** Fear of reactions to her as a person with dementia

Speaker	Utterance	Date
Ms. Copeland:	I I kind of understand because I've moved a lot when my husband was alive we lived in New Orleans and Chicago and Boston and New York so you know everywhere I went (.) we made friends (.) this is kind of an unusual situation for me I don't know quite what to do but I do as I said I'm busy each night which is nice I like the people here (.) it isn't that I'm sure it's my problem.	February 9, 2000
	Oh yes and I you know once that group down in the dining room know what's wrong with me I'll have everyone watching me you know that's what I don't want and talking so I'm trying to hide it as best I can ( <i>trails off</i> ).	
	Now I know what they're talking about—I know it! I'm feeling it! It's scary!	January 11, 2001
Researcher: Ms. Copeland:	How do you feel it? Nobody likes me, first of all. I must be doing something wrong to all of these people. I'm alone a great deal. I have no energy ***	
	Well, I see people that are older than me that have a wonderful time! Nobody here invites me to anything!	
Researcher: Ms. Copeland:	Sometimes you have to invite yourself!  I used to. I used to have friends here. I'm sure that it's me! I feel certain that I feel so mean inside and nasty! I don't mean	
Researcher:	towards other people, but I just don't like what's going on inside. How about calling up somebody that's in the building and	
Researcher.	say, "Can I come visit with you today?" Or, "Would you like to come and have some ice cream with me?"	
Ms. Copeland:	I'm just so afraid that they don't like me that maybe they would say, "No."	
Ms. Copeland:	When I came here, I associated with practically all of my neighbors. The girl across the hall has taken all of the people on this floor and—I don't know if the word is accepted them—and made them into a group and I'm not included! And this hurts, if you can imagine. I don't know what I've done or not done. I go down to the dining room and she's sitting at the table with all of the people from our floor, and I'm not one of them! I don't know what I've done!	

Table 4. The burden refrain

Speaker	Utterance	Date
Ms. Copeland:	Well I have some good friends I'm very fortunate that way.	February 9, 2000
Researcher: Ms. Copeland:	And see those are very very precious moments to you.  mmhmm	
Researcher: Ms. Copeland	and to your friends and to your family (.) yes (.) I just don't want to be a burden to them you know.	
Researcher: Ms. Copeland: Researcher: Ms. Copeland	Grandmothers are the most special people you can have! Don't tell me—tell my children this! They know it! Except that YOU have to see it that way. I feel like now with the condition I'm in, I'm just a burden to them. They are worried about me.	January 11, 2001
Ms. Copeland:	And you know if it goes along with the ailment, then I've got to accept it. I really don't like starting out with a new man that I, you know, but I don't drive anymore, I have to I'm in a bad spot. But I love it here. I can honestly say that I'm very happy to be here. I like the people, there are lots of activities, food's good and I'm not a burden to any of my children, so	November 12, 2001
Ms. Copeland:	Well, I don't have the energy to do things. I don't sign up for trips because I'll be too tired to enjoy them and then <b>be a burden to somebody else</b> .	
Ms. Copeland: Researcher: Ms. Copeland:	This is such a crazy world we're in now. Yes. Just frightening. But I'm not a burden to any of the children, which is something I, I wanted not to be. If I can help them I will, in any way I can, but there isn't much I can do, really.	

their audience's reaction to different view-points and therefore individuals may shift between contrasting, or indeed contradictory, subject-positions within their conversations. Ms. Smith's account of her dementia diagnosis appeared to present two distinct subject-positions when she talked about the disease. The first subject-position reflected a more *neutral* perspective that drew on an *external* source of knowledge, the world of medicine. The second subject-position appeared to represent her *internal emotional reactions to the diagnosis* and her personal fear of her ensuing cognitive decline.

### Framing accounts of "troubles" in the context of dementia

In the example featured in Table 6, the GA greeted Ms. Smith and then initiated the interaction by questioning Ms. Smith about her current health, a conversational politeness move that led into a discussion about the general health problems experienced when growing older (e.g., aches and pains). Although this was not a clinical session, the context of the clinic setting and the GA's attire (a uniform polo shirt with a department logo) may have led Ms. Smith to assume she was in a clinical situation and this may have prompted her

Table 5. Internalizing values at parochial school

Speaker	Utterance	Date
Ms. Copeland:	You know, I went to parochial schools for 12 years and I bet the nuns upstairs are listening to me going, "Tsk, tsk, tsk! That's not what I taught you!"	March 8, 2000
Researcher: Ms. Copeland:	Did they ever smack your hands with a ruler? Never!	
Ms. Copeland:	They're living together.	November 11, 2001 Nuns/schools and values
Researcher:	Well that's a step forward.	
Ms. Copeland:	Well, you see, I was brought up I went to the nuns for 12 years.	
Researcher:	We both know	
Ms. Copeland:	This living together	
Ms. Copeland:	Well, I never thought of it that way, but I went to parochial school for 12 years with the nuns. And boy you just didn't sanction that arrangement at all!	
Ms. Copeland:	and my grandfather was a real Welshman never said boo she ruled the roost physically I mean she was much bigger than he too but she was a funny lady she'd give he built a summer house for her and it only had three bedrooms and my grandmother would invite more people than would fit so she put people out in canoes without paddles in them ( <i>laughter</i> ).	January 16, 2000 Grandparents
Ms. Copeland	See, my Father died when I was 1-month old, and my Mother and I lived with her parents: my grandmother and grandfather. My grandmother didn't get along with her son's wife. So going for holidays was very	May 6, 2001, Short, nonperformance version of grandmother's trip
Researcher:	A lot of tension?	
Ms. Copeland:	Oh, yes! I don't know who was to blame. I was about to start the first grade in school, and my Mother kept me out of school, because my grandmother was returning from a trip to Iowa. We had to be at the dock and drive her home. I can remember standing there to this day, watching the boat come in and then the people come down out of the gate.	

to perseverate on the topic of health issues that became the dominant topic at the outset of this particular interview. Given the context, Ms. Smith also may have assumed that the student was a certified health care professional and therefore she was expected to provide the details of her ailments to the "clinician." The discussion of health issues did, however, provide the GA with an interac-

tional opportunity to introduce a more sensitive topic—the exploration of Ms. Smith's feelings about her diagnosis of Alzheimer's disease.

Because of space limitations, it was not possible to include all 820 turns that comprised the complete 48-min conversation. We have therefore provided a selection of excerpts that all three researchers agreed were indicative

**Table 6.** I don't need this: Coping with dementia

Speaker	Utterance	<b>Analytical Comment</b>
GA:	Oh yeah I can tell you're organized (.) I worked this Medicare study where people had to provide all their records over the past year for any medical visits anything (.) and some people would like (.) hand you this bag.	SIDE STORY 1
Ms. Smith:	(laughs)	
GA:	And other people had it all neatly stowed away.	
Ms. Smith:	Oh lord!	
GA:	Is your doctor mhm an internist (.) general?	SIDE STORY 2
Ms. Smith:	Family practice.	
GA: Ms. Smith:	Family practice.	
GA:	Yeah over in X ( <i>name of town</i> ). Okay.	
Ms. Smith	Yeah he is young enough to be my son (.) he's younger than my youngest child yeah he is young enough to be my son (.) he's younger than my youngest child	
GA:	(laughs) But you like him he's a good doctor.	
Ms. Smith:	Love him.	
GA:	Great *between the pons favored to be removed (.) how's that for doctor talk.	
Ms. Smith:	( <i>laughs</i> ) I'm telling you he is so good he takes his time with you and he doesn't rush out like some doctors (.) uh here it is ( <i>hands copy of medical report to GA</i> )	MAIN STORY EXTERNA SUBJECT-POSITION (impersonal register from voice of medicine/doctor
GA:	Small areas of (.) normal (.) predominantly in the perpendicular white matter suggests you have to know medical terminology to read these things.	
Ms. Smith:	Well I am just lucky that*	
GA:	*I get the general idea (referring to report).	
Ms. Smith:	Ms. A.: Yeah (.) I'm just lucky that my doctor gives me a copy of this.	
GA:	Oh yeah, oh yeah (.) okay and they with this history that's why he sent you in for memory loss.	
Ms. Smith:	Yeah (.) and the thing is he*	
GA:	*Huh interesting (looking at report) okay.	
Ms. Smith:	He mhm when he sent me for the MRI he ordered	
	the MRI and he said now (.) don't I want you to go	
	get uh (.) see (.) uh on the right (.) if you look on the	
	right (pointing to report) so Mr. J. called and made	
	an appointment within the (.) was after the ( <i>laughs</i> ) MRI was scheduled	
	MRI Was scheduled	
		(Continu

**Table 6.** I don't need this: Coping with dementia (*Continued*)

Speaker	Utterance	<b>Analytical Comment</b>
Ms. Smith:	So he said I want you to go to a neurologist anyway he said uh they part of the test (.) you know draw a clock and show it at 3 o'clock (.) or something (.) like that and draw a square and a triangle and a circle you feel like an idiot.	
GA: Ms. Smith:	I bet ( <i>laughs</i> ). And it's part of the reason I hadn't said anything 'cause I know they test with that yeah right.	INTERNAL SUBJECT- POSITION (shift back to Self and use of personal pronoun "T")
GA: Smith:	Yeah they're a little demeaning yeah yeah. Exact the exact word! (.) so (.) so he said I'm a give you three words and I want you to try and remember and then later on I'll ask you for those three words (.) so then we did the rest of the test (.) and he says okay he said what were those three words (.) well the first time I could only remember two of the words (.) so then he kept talking and what not (.) then he goes back there now what were those words again (.) I could only remember one [] then he says you have early stage Alzheimer's (.) I guess er cause I meant Alzheimer's doesn't show on any (.) like any sorta (coughs) X-ray or MRI (.) nothing the only time it def de (.) is they can get a definitive diagnosis is (.) after you die (laughs) and he said you have early stage MRI (.) and I was kinda shook up (.) and cause I (.) I know what it does to people I've s-you know (.) I've seen it (.) but when that was the fourth the next week was September eleventh (9/11).	9/11 SIDE STORY
GA: Ms. Smith:	Oh boy! And I mean I wouldn't even look at it on television (.) I said I don't need this!	
GA:	I remember coming to school and it just happened and we heard it on the radio in the cafeteria.	
Ms. Smith:	Oh yeah.	
GA:	And there is just like.	
Ms. Smith	And there it was all day (.) and the next day and you know.	
Ms. Smith:	They just keep showing it (.) and showing it (2 s) and I (.) I said I don't need that (.) but anyway (.) uh I got to the point where uh (2 s) where if I tried to talk about it the water works (.) and I start crying and crying (.) couldn't control it (.) and uh my husband (.) his first 2 weeks was really in denial ***	MAIN STORY INTERNAL SUBJECT-POSITION (Self 1 use of personal pronoun)
	Cernar	

**Table 6.** I don't need this: Coping with dementia (*Continued*)

Speaker	Utterance	Analytical Comment
	(Ms. A. is searching in her purse for medication	
	lists and the talk is unclear)	
GA:	Yeah.	
Ms. Smith:	So when we went back to the doctor I asked the	SHIFT TO EXTERNAL
	doctor I said uh (.) did you say I said (.) would you confirm to my husband (.) did you say I may have	SUBJECT-POSITION
	Alzheimer's and before I could say or that I have	
	early stage he said (.) he turns to my husband and	
	he says (.) she has early stage.	
GA:	Get used to it buddy right?	
Ms. Smith:	Yes (laughs).	

Note. MRI = magnetic resonance imaging.

of Ms. Smith's dialectical shifts in the way she presented her account of the dementia diagnosis.

Although the GA openly introduces the topic of dementia, her hedges at the end of her opening remark appear to be an attempt to mitigate the potential face threat (Brown & Levinson, 1987) raised by her question. The GA tries to modify her question by adding a qualifying remark that Ms. Smith's dementia is not "full blown" yet. Ms. Smith's use of emphatic intonation challenges the GA's interpretation when she notes that "it" had not only "hit" her but she had noticed the symptoms immediately. Ms. Smith refers to the dementia by the third person impersonal pronoun "it" and uses the active verb "hit" to suggest the disease had an immediate impact on her life. Her account represents an internalized subject-position—It is a description of her emotional reaction to how this diagnosis has affected her life. Her use of the personal pronoun "I" reflects Harré's (1998) Self 1; that is, Ms. Smith's account, at this point in the conversation, relates to her internal concept of self. Having made this claim, Ms. Smith then offers the GA supporting evidence to explain why she had been able to notice the early effects of her dementia. At this point, she draws on Self 2, her autobiographical past, and notes that in her former career as a legal secretary, she had excelled at grammar, spelling, and word finding and therefore when she started to experience difficulties with these language-based tasks, she claimed she knew something was wrong.

Ms. Smith's open acknowledgement of having Alzheimer's disease and her claim of being self-aware of the symptoms differed notably from the first author's prior experience in interviewing other PWD. At this point, as noted earlier, Ms. Smith's story is being told from the internal subject-position of personal and autobiographical experiences, but as is shown later, her narrative stance shifts to an external subject-position that appears to allow her to create a discursive space that distances her from the impact of the diagnosis. Three peripheral but healthrelated side stories also emerged within this conversation and are interwoven into Ms. Smith's story of her dementia diagnosis. As shown in Table 6, the first side story related to the GA's former job as a researcher for a health care company, the second expanded on Ms. Smith's relationship with her doctor, and the third story related to the 9/11 tragedy.

The aforementioned example was typical of the general pattern of exchanges that occurred throughout the longer interview. Ms. Smith's story about her dementia diagnosis does not follow a traditional Labovian structure but rather fluctuates from an internal subject-position to an external subjectposition. The internal subject-position comprises those points in the story where Ms. Smith appears to express her inner feelings as she struggles with the implications of the diagnosis and appears to represent her own voice in the story. The use of the first person personal pronoun reflects Self 1: Ms. Smith was expressing her personal feelings about her experience. At points where her story reflects the external subject-position, she uses a more neutral register that includes descriptions of medical treatments that reflect the "voice" of the world of medicine. This external or neutral voice appears to allow Ms. Smith to talk about this topic with less emotional affect, whereas when there is alignment to the internal subject-position, Ms. Smith's personal fears and her struggle with the diagnosis of dementia are more apparent. The GA twice tries to develop two side stories that emerged, one relating to Ms. Smith's relationship with her doctor and the other the issue of the 9/11 tragedy, but Ms. Smith does not appear to want these to develop beyond a few turns. These side stories are interwoven within the main story and do not disturb the flow of Ms. Smith's primary narrative—her reaction to her diagnosis of dementia.

At the moments in the interaction when Ms. Smith's account is situated within the external subject-position, she physically appeared to be more at ease and laughed more frequently. However, when the incident of the clock test was recalled, her account shifted to the internal subject-position that reflected a more emotional response to her dementia. When recalling how she failed a word memory test, Ms. Smith admits to feeling like an "idiot" and not being able to "stop crying." The side story emerging at this point references the 9/11 tragedy, which co-occurred the week she was given her diagnosis of dementia. Although the GA seemed keen to develop this particular side story, it was difficult to distinguish whether some of Ms. Smith's comments related to the tragedy of 9/11 or to her own diagnosis of dementia. In posttaping discussions of the data, the GA admitted that during the conversation she was unclear which Ms. Smith was referring to because there were no overt linguistic markers reflecting the transition between these two topics. For example, Ms. Smith was referring to the continual media coverage of the 9/11 tragedy when she made the following statement: "I said I don't need 'that'"? Postinterview discussions and a second review of the videotape with a focus on nonverbal behaviors (e.g., face expressions, voice quality, body stance, and paralinguistic features) suggested Ms. Smith was referring to her dementia. In particular, the falling emphatic intonation on the clause final pronoun suggested it referred to an issue of personal importance to Ms. Smith—probably her dementia. After a slight pause, Ms. Smith returned to the topic of her dementia using the contrasting conjunction "but anyway" a phrase iterated with a fall-rise intonation pattern marking the shift from the discussion of 9/11 back to the topic of coping with her oncoming dementia. In this particular conversation, the two events appear to have become conflated and comments that might seem to be directed toward 9/11 are actually displays of Ms. Smith's feelings toward her dementia. In addition, we noted that on other occasions when the GA mentioned the topic of 9/11, Ms. Smith did not appear to have a strong emotional reaction.

In this particular interaction, Ms. Smith provides us with a narrative formulation that is constructed through a dialectic opposition between two subject-positions that fluctuate from talk that reflects a fear of the diagnosis of dementia to talk that reveals a more distanced perspective consisting of detailed reports of the clinical aspects of her dementia. The external subject-position appears to create a discursive space that allows Ms. Smith to distance herself from the distressing personal experience of her diagnosis by describing the assessments and/or treatments of dementia in a clinical manner that portrays the problem as something "other" or separate from her own life. The dementia becomes a health issue she can discuss in detail, analyze, and even laugh about with the GA. However, in the sequences of her account that shift to the internal subject-position of fear, she appears less fluent, producing a greater number of pauses and restarts in these particular utterances. In addition, at one point, she notes that she tried to talk about her dementia and she admits she couldn't "control" her crying during this period.

#### **DISCUSSION AND FINAL COMMENTS**

The analyses of Ms. Copeland's and Ms. Smith's stories help both further the knowledge base of narrative study and explore individual experiences of PWD's reaction to the disease. The analyses show that alternative narrative formats used by PWD may differ from the classic Labovian tradition and indeed from each other. Ms. Copeland's initial story shows that, even after she had been diagnosed with dementia, she was still able to formulate a full narrative with a chronological story line, an abstract, problem/dilemma, resolution, and coda. Her later comments on her "ailment" took the form of "small stories," repetitive phrases, and laments, none of which were canonical narratives but all of which enabled her to present information relating to her life experiences and her beliefs. These later offerings show that there are other formats besides canonical narratives in which people can express their stories.

Ms. Smith's account shows that narratives do not necessarily follow an event-by-event structure or classic narrative format that has a resolution; they can also be constructed in a dialectical manner that involves oscillating from one subject-position to another. Much of Ms. Smith's story is presented through two "voices" that represent different perspectives. Individuals have choices in the ways they present stories (e.g., vocabulary choice, verbal construction, or choice of pronouns) that may reflect their internal emotional or psychological states of mind. For Ms. Smith, it appears that these shifts between opposing

external and internal subject-positions enable her to talk about dementia with others in a manner that is less personal and less distressing.

It is notable that when Ms. Smith shifts alignment to the internal subject-position, she is unable to sustain the discussion of dementia for the same length of time as she does when aligning to the external subject-position. Thus, Ms. Smith can talk about the topic of her dementia in a way that reflects her fears and emotions and then within a few turns she can distance herself from the disease so that she almost becomes a bystander commentating on her own illness.

In the case of dementia, this dialectical story structure is perhaps unsurprising because dementia is a story that typically does not have a solution or resolution. At this point in time, there is no cure or "happily ever after" coda to the story of dementia, which is decline and then death. In this sense, the topic (diagnosis of dementia) is not slotted into a preconstructed narrative framework; rather, the nature of the topic drives the way the story is told

#### Conclusion and implications

What can the analyses of life stories told by two women with dementia add to health care professionals' understanding of PWD? First, caregivers and therapists need to be aware that there are many ways to tell a story and that PWD tell stories in ways that do not always match common, socialized expectations of narrative norms. Next, the content of PWD's narratives may aid researchers to better understand how this disease impacts the individual. Such knowledge will help guide professionals in their interactions with PWD and, in addition, provide the PWD an opportunity to actively contribute to conversations in a manner that allows greater autonomy in the discursive expression of competent self-identity. Indeed, as Ms. Smith noted to the researchers, she performed very poorly on formal language-based assessments during diagnostic medical interviews. Yet, many of the students who later viewed the videotapes of Ms. Smith's interview in a classroom seminar found it hard to believe that she had Alzheimer's disease, and similarly, there were no obvious symptoms of Alzheimer's disease in Ms. Copeland's first performance narrative.

Furthermore, in ethnographic interviews, PWD have often surprised us with their ability to contribute if we allow them to "tell it their own way." The interactions examined here revealed that despite their increasing cognitive difficulties, Ms. Copeland and Ms. Smith strive to be active conversational partners. More important, these narratives reveal a common human behavioral trait that seems unchanging even in the face of cognitive decline. That is, in collaboration with their interlocutors, speakers discursively construct viewpoints about an event or experience that may shift from one subject-position to another without a fixed reference point. Ms. Smith's narrative style reveals a great deal about how she may be reacting to her diagnosis of dementia. Ms. Smith presents a neutral voice that confidently discusses the assessments she has undergone and the medications she is taking. But interwoven throughout her account are moments when her talk reflects her deeper inner fear of the inevitable outcome of having dementia. Throughout all three interviews involving Ms. Smith, there were examples of this shift between subject-positions and it was not surprising to the researchers to find out that her caregivers and family believed that Ms. Smith was coping quite well with the situation. This was in part because she was able to use an impersonal voice of the world of medicine when discussing her condition; however, it was evident from what she revealed through the internal subject-position that Ms. Smith was experiencing a great deal of fear about her future.

Clinicians and therapists are usually adept at identifying canonical or near-canonical narratives presented by their clients. Our analyses of Ms. Copeland's and Ms. Smith's interactions demonstrate that clinicians need to be aware also of the other forms of story that clients may present. These include *small stories* that al-

low them to share their personal news, reveal their attitudes, and construct their identity. Throughout the early stages of the disease, clinicians need to be alert for laments over the diagnosis and the future, and until the later stages of the disease, clients often produce repetitive phrases such as Ms. Copeland's "burden" refrain that indicate the client's current emotional state. All of these noncanonical narratives form ways in which clients can continue to present their stories and construct their identities even when the formulation of canonical narratives is no longer available to them. Rather than presenting core beliefs, speakers fluctuate in their opinions and reactions based on the current interactional context-A communication habit that suggests classic narrative format is not really suited to capturing experiences such as being told one has dementia.

Recording and analyzing narratives can reveal many subtle nuances of speaker meaning that extend beyond samples of a client's linguistic ability. Classic narrative is well suited for stories and accounts that have a resolution and a "happily ever after" coda. It also is well suited for stories that are not "happily ever after" but can be told as self-deprecation. It is a formula that works well when we experience something in life that has an endpoint that, whether for good or bad, we can retrospectively review and account for in our interactions with others. That is, we can talk about an experience that we have lived through and survived. Ms. Smith's narrative and Ms. Copeland's later interactions remind us that PWD are not going to get to that point in their story—the point on the other side where they can look back, sum up, and describe the experience and thus achieve the classic resolution of narrative lore. This point is made explicitly by Ms. Copeland in Table 2: I have nothing to look forward to I'm not going to get better.

The analyses presented here suggest that PWD, like all humankind, discursively construct life narratives from different subjectpositions and a viewpoint may change within the narrative as the story proceeds, oscillating in a dialectical rhythm discursively displaying the shifting perspectives of the narrator. Narrative analysis of data collected from PWD speaks to their persistence in negoti-

ating interactions in an attempt to rationalize and explain their stories to others despite their increasing cognitive deficits.

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