Storytelling as a Model of Conversation for People With Dementia and Caregivers

**Deborah I. Fels, PhD, P.Eng[1] and
Arlene J. Astell, PhD, BSc, ClinPsych[2]**

Abstract

Storytelling is an important method of communication at all stages of life. Sharing narratives about lived events and experiences provides topics of conversation and opportunities for connecting with other people. In this article, we apply a conventional model of storytelling to the verbal reminiscences of older people with a dementia diagnosis. Their stories retain the conventional structure, suggesting that storytelling, which is an enjoyable and engaging social activity, can provide a conversation model for people with dementia.

Keywords

storytelling, conversation, dementia, reminiscing

Introduction

> To study personal narrative is to value the mundane, everyday, private, informal and often conversational use of language by diverse and ordinary people. In so doing, we also listen on the margins of society and give voice to muted groups.[1(p272)]

Storytelling is a common and everyday part of human existence. It is recognized in many fields of study (eg, folklore, sociology, communication studies, nursing research, and human–computer interaction) as a major driver of human communication.[2,3] Storytelling emerges early in life and is a social activity that occurs across cultures. Stories can take on different forms such as myths, folk tales, legends, fictional, autobiographical, and so on.[4] The focus of this article is on telling autobiographical stories, that is, personal narratives, and unless otherwise indicated, the word "story" is used interchangeably with personal narrative. This article is an expansion of the materials presented by the authors in ref 5.

Personal narratives are those stories people tell about their own lives or lived experiences.[1,6] These narratives usually comprise everyday occurrences and events as lived by the individual and then organized, reconstructed, recounted, and reviewed at some later date. The telling and sharing of memories plays an important role in making and maintaining relationships within families[7] and social groups. We make connections with other people by sharing our experiences and finding points of similarity or things that we have in common. Storytelling has an important social function for people of all ages and at all stages of the life span.[8]

Personal narratives proceed without restriction on topics and expectations of truthfulness.[6,9] Examination of the narrative form of stories has identified 4 components relating to form and function.[4] These are (1) a story text, (2) the context and socio-cultural setting, (3) the audience or listener contribution, and (4) performance, ownership, and control of the story.[1,10]

We have applied this normative framework of storytelling to the narrative recollections provided by older people with a dementia diagnosis. Our aim is to examine the resilience of storytelling in the face of progressive cognitive loss and to explore the potential for storytelling to continue to fulfill a social function for people with dementia. By applying a normative framework that is not specialized for or tailored to people with dementia, we hope to see how much of the normal processes are retained and consider this as a model for supporting conversations with people who have dementia.

Reminiscing in Dementia

Dementia is a progressive neurological condition that primarily affects older people. Alzheimer's disease (AD) is the most common cause of dementia[11] and typically starts with people

[1] Ted Rogers School of Information Technology Management, University of Ryerson, Toronto, ON, Canada
[2] School of Psychology, University of St. Andrews, Fife, Scotland, UK University of Saint Andrews, UK

Corresponding Author:
Deborah I. Fels, University of Ryerson, 350 Victoria Street, Toronto, ON M5B 2K3, Canada
Email: dfels@ryerson.ca

noticing that their memory is not as good as it used to be. As the illness progresses, people have increasing difficulty participating in everyday activities, including conversation and other social interactions. This can put a strain on existing relationships and makes it difficult to form new ones, for instance, with staff in dementia care facilities.

While people with dementia have difficulty recalling and discussing current events, they find it easier to speak about memories from earlier in their lives. The benefits of reminiscing for people with a dementia diagnosis are clearly outlined in existing research.[12-15] For example, authors of ref 12 identified 3 specific functions for people with dementia provided by engaging in reminiscing: "social," "skills," and "self," where social refers to the social benefits of engaging with and sharing memories with other people, skills alludes to the benefits for people with dementia of using their existing social and cognitive skills, and self applies to the opportunity reminiscing affords to people with dementia to participate as equals in a social situation, feel positive about themselves, and be successful.

Storytelling can take place in one-to-one or group settings. Many dementia care facilities provide an activity called reminiscence as part of a weekly program. Interestingly, this has come to be regarded as a dementia-specific activity, as opposed to a normal human pastime in which we all engage. As such, a separate body of literature (see refs 16 and 10 as examples) has developed about reminiscence as used in dementia care, but it is beyond the scope of this article to review this relatively unrelated topic.

In the limited number of studies concerned with storytelling with people with dementia, evidence is drawn from both one-to-one[17] and group settings.[2] For example, the authors of ref 2 used a formalized storytelling and dramatic workshop process to involve caregivers and people with dementia in conversational activities. They used generic prompts relating to (i) everyday life, such as the seasons, nature, and love, and (ii) categories fitting Erikson's[18] model of the life cycle, such as childhood, adulthood, marriage, and so on.[2] The dramatic workshops involved formal elements of performance where people could sing and dance as well as narrate their stories. They found that people with dementia were stimulated to tell personal stories that were engaging and encouraged greater interaction and understanding between people with dementia and their caregivers.[2]

Generic prompts, in the form of photographs, have also been used successfully to stimulate recollection of personal narratives in a one-to-one setting.[12] In this study, older people with dementia generated as many personal autobiographical stories as an age-matched group of older adults without dementia.[12] In this comparison, stories were loosely defined as a series of connected text that were analyzed in respect of the total number of words produced and turns taken in telling the story.

Building on the work of Astell et al. (2010), this article explores whether the stories told by people with dementia retain the conventional form and function of stories as told by people who do not have dementia. This is not an exploration of reminiscence as an intervention for people with dementia. Rather, we present a qualitative examination of the responses of people with differing levels of dementia severity to generic photographs provided as conversation prompts in a one-to-one situation using a normative model of storytelling. The data reported here are taken from a larger study into the impact of dementia on autobiographical memory.

Method

Twenty-seven older adults with a dementia diagnosis were recruited from a day care center and a social work department care home. They were approached through the care facility and provided with information about the study, which was also sent to their relatives. Each participant was encouraged to discuss the study with his or her family before agreeing to take part.

The participants ranged in age from 57 to 98 years, with a mean age of 82.4 (standard deviation [SD] = 10.6). Each participant had been given a diagnosis of probable AD by an old age psychiatrist. Their level of dementia severity as assessed by the Mini-Mental State Examination (MMSE: Folstein et al[19]) ranged between 4 and 24 out of 30 (mean MMSE 14.9, SD = 5.1). Based on their MMSE scores, the participants were classified into 3 levels of dementia severity: mild (MMSE 20-24) n = 4, moderate (MMSE 12-19) n = 17, or severe (MMSE <12) n = 6.

Materials

Photographs. Six sets of 6" by 8 photographs were assembled, each comprising 1 photograph of each of 6 different annual events selected for their relevance to the age, culture, and geographical location of the participants: "Christmas," "Easter," "Burns Night," "New Year," "birthdays," and "holidays," Each event was depicted in 3 forms—"scenes," "food," or "people." For example, the Christmas scene was a decorated Christmas tree; Christmas people showed a family opening presents and the same event represented as food showed a Christmas pudding. Each image was presented in either black and white or color formats. Thus, the total set of 36 photographs comprised 18 black and white and 18 color.

Each set of 6 photographs comprised 1 depiction of each annual event. Half of these were in color and half were black and white to examine the impact of content type (scene, people, and food) and color format on stimulating reminiscing (reported in ref 12). Each session was recorded using a Sony Walkman Professional, WM-D6C, and a Sony Mini DV Video camera, supplied by McMichael Bros, Sony Centre, Clackmannanshire, UK.

Procedure

Each participant was seen individually. The MMSE (Folstein et al[19]) was carried out first then each participant was shown a series of 6 photographs one at a time. The participants were shown black and white and color photographs alternately. Each participant saw each of the 3 types of representation—that is,

food, people, and scene—twice during the session. As each photograph was presented, the participants were encouraged to discuss their memories of each event and were allowed to talk for as long as they wanted or until their discourse ended. The interviewer provided guidance if the participants became confused, asked for more information, or indicated that they had forgotten what was being asked of them.

Personal Narrative Analysis

All recordings were transcribed verbatim. For the present study, a subset of 13 participants was selected to examine story properties as outlined by Langellier[1] and Labov et al.[4] Five participants (2 in the moderate dementia group and 3 in the severe) did not tell any identifiable stories (either linear or nonlinear). All the remaining participants told at least 1 story; however, not all the photographs elicited stories. Of the 22 participants who told stories, 4 "mild," 6 "moderate," and 3 "severe" were selected to reflect the distribution of participants. One story from each of the 13 participants was randomly selected for analysis using the storytelling model.

Components of Personal Narrative

The first of the 4 components of personal narrative[1] identified is "story text."

Story Text.. First described by Labov et al[4] as a result of work carried out with street youth, story text consists of 5 basic characteristics: progression, evolution, contextualization, meaningfulness, and presentation of self.

The first characteristic—progression—is the telling or accounting of an action or event from the past that unfolds in a linear sequence from beginning through middle and an end. A time line can be identified through the use of time-oriented words such as "then," "in the past," specific time references such as date or time of day (eg, "every Sunday"), use of the past verb tense, and phrases that set a time context at the beginning of the story such as "when I was young" or "at the First World War." A time line could be easily identified for each story in our data set from the use of such time-oriented words. For example,

1. Interviewer: Does it remind you of any time of the year MF?
2. MF (participant with severe dementia): Well, when I was in, in the school I remember$_1$ remembering so much er trying to capture, catch these things$_2$. And we had done, done it once$_3$, quite, quite often. But er, but er, not for many, no.
3. I: Right.
4. MF: ... and then it just goes away among, among the fields
5. I: Hard to catch?
6. MF: That's it, yeah, yeah. Uh-huh. That's it.

This excerpt is from a longer story produced in response to a photograph containing an image of an Easter rabbit. It has 5

story phrases as indicated by the subscripted numbers shown the end of a story phrase. The use of words such as "when I was in, in the school" in line (2), and "then" in line (4) are time line indicators, which provide a time context and flow to the story. The phrase "that's it" indicates the end of the story.

Labov and Waletsky's[4] second characteristic of a story text evolves from and captures the experience, events, and emotions associated with that event. Mills[20] suggests that a strong emotional connection, memory, or context elicit stories from people with dementia for as long as they retain speech. The use of nouns, verbs, and adjectives describing the event and emotions associated with it, such as "go to the dance," "we had a party," and "a nuisance" provide evidence of evolution. An example of this is in the following excerpt from a very long story about camping holidays as told by person whose dementia was classified as moderate, in response to a picture of people on a holiday:

1. BM: And er, we used to have a sing-song.
2. I: Hmmm
3. BM: And cars coming down used to join in. And we had a great time. And then, we used to invite the girls that we had picked up in the dancing
4. I: Hmmm
5. BM: To come and get a meal. And they came. And we gave them a good meal$_7$. And then er, we sat and blethered. About everything and a'thing. And there was a camp of lassies in the next tent to us. And you've never seen a mess of faces in all your life. They let the sun get at their face.

In this example, we learn that BM was involved in a sing-song and chatting (blether) with some girls that he and his friends had met at a dance and invited to the campsite to share some food. He also describes the girls (lassies) in the next tent getting their faces sunburnt—"you've never seen a mess of faces in all your life." As a listener of this story, one can imagine the campsite full of young men and women enjoying their summer holidays.

The third characteristic of the story text according to Labov et al[4] is that there can be nonsequential utterances that serve to explain or contextualize the main temporal components. These are considered evaluative elements that allow the narrator to provide interpretation or social context or (eg, "this was the way I saw it"). All stories from our data contain evaluative elements, most often containing words such as "it was good/ great," "it was awful," or "we didn't expect too much." These evaluative statements were inserted throughout the story text of all analyzed stories indicating that the storytellers had formed an opinion of themselves or their story and provided it with a greater context.

Other story elements that could also provide context would be body language, facial expressions, and gestures that might accompany the linguistic elements. The present analysis was confined to written transcripts but there is evidence that people with dementia retain the nonverbal elements of communication, even after speech has ceased[21] and that these are important

in building and maintaining relationships with caregivers.[17] However, further examination of the specific role of nonverbal behavior in storytelling is warranted.

The fourth characteristic of a personal story is that the story has a point to it, that is a climax or ending that is meaningful.[4] In our sample, all the stories analyzed contained this characteristic. This may have been encouraged by the interviewer asking participants "what memories came to mind when you look at this picture?" as they would often ask if the story was sufficient to answer the question. Other stories ended when the interviewer asked whether the person was ready to look at another picture after a period of silence.

1. I: Maybe it's more nowadays. Maybe it's more a more recent thing. Do you have any more memories of Christmas?
2. TH: Well just hanging up your stocking at night and your mum saying have you put them right now? Do you know where it is? Yeah, you got up in the morning and you were always up sneaking during the night (both laugh). You used to get up during the morning and go through and she said to him take your stocking and you went down to get it. You opened it to see what was in it. There used to be pennies, fruit, what have you. "Said, how many pennies have you got?" Say, oh six. How many have you got? I've only got five. So somebody must have seven (both laugh). I said well it's not me—there's my six.
3. I: You'd be getting into trouble
4. TH: "Said well, that's right." Said well, we'll get the seven later (both laugh)
5. I: Will we move on to the next picture?
6. TH: Yeah

This example has a facilitated ending resulting from a period of silence after the line about finding the 7 pennies later but there is an obvious climax that the storyteller was not the culprit because he had his 6 expected pennies and some unknown person had an additional one.

The final characteristic of story text is that the narrative focuses on presentation of the self rather than reporting facts or offering new ideas.[4] There were examples of "fact" types of conversations in the data that were collected from the 13 participants. For example, the following description (in response to an image of 2 children holding a wrapped Christmas present):

1. I: What memories come to mind when you look at that picture?
2. BD: Oh I see what it is. It's two wee boys. No a wee boy and a wee girl.
3. I: Hmmm
4. BD: And they've got a parcel between them.
5. I: Hmmm
6. BD: And, er, I think I think the wee girl is trying to get the parcel out the wee boy's hand.

7. I: (laughs)
8. BD: That's what it conveys to me.

In these examples, the participant, BD, is simply describing what is happening in the photograph and who is involved. However, when looking at a different photograph, the same individual (used in our formal analysis), provided with a similar prompt, provides this personal autobiographical response (in response to a photograph of 2 people on a beach):

1. I: Here's a picture of people on holiday. What are your memories of holidays?
2. BD: Oh my, we didn't get many holidays. Ehm you had to be content where we were. And my father was killed in the First World War.
3. I: Hmmm
4. BD: So that'll be an indication of er, how life was. My mother never, oh eh she did, she got married again. And er, things were never the same after that—was never the same. We all ended up biding [living] with grandma. That was worse (laughs). That was worse.
5. I: I've got something else here …
6. BD: Uh-huh

Here, the personal recollection is prompted by the photograph but is not about the depicted event. Specifically, the respondent reflects on how she did not have many holidays when she was younger and relates this to the death of her father and her mother's subsequent remarriage. The listener gains a sense of unhappiness and unpleasantness in the storyteller's early life.

Social/Cultural Setting of Narrative

After story text, the second component of personal narratives identified by Langellier[1] is the context and social/cultural setting in which the narrative, that is, the storytelling occurs. The location in which the story takes place and current cultural norms influence what story is told and how it is told.[2,22] One person might tell the same set of events in 2 different ways in 2 different locations. For example, a narrator may tell the story of a specific set of events differently when in a group setting versus a one-on-one setting or with family members as opposed to care staff or other residents in a care home. The current data set was collected in a one-to-one setting and so it was not possible to examine whether these same individuals might relate the same story when in a different setting (eg, group setting) or with a different partner.

However, the setting did enable the participants with dementia to tell their personal narratives. This may have been down to the one-to-one, or the input of a supportive conversation partner (the role of the listener is explored further below), or the provision of prompts to stimulate reminiscing. Storytelling activity may be stimulated by provision of external objects, such as generic photographs.[12] Providing a range

of objects may offer more opportunity for reflecting and responding to cultural diversity and/or norms.

Langellier[1] proposed that the constraints and affordance of the setting (eg, formal vs informal) provide external limits to storytelling. The current study used a formal one-to-one setting and as indicated above, the use of questions may have facilitated participants to produce endings for their stories

Importance of the Listener in Personal Narrative

> something that two people do together rather than separately—a duet rather than alternating solos.[23(p566)]

A third, and we suggest critical, component of personal narratives is the audience or listener contributions.[1] The listener has an active role in the storytelling activity and influences the flow and outcome of the story, that is, they collaborate with the storyteller.[24] The reactions and responses of the listener can support or undermine the storyteller. For example, supportive listeners allow the storyteller to "have the floor" and provide other mediating effects including continuance words such as "uh huh," "oh really," and "that's interesting" in order to encourage the storyteller to continue.

Listeners also take part in the evaluative component, offering opinion, direction or a reaction to certain points made in the story. How they deliver this will also influence the storytellers' behavior. For example the level of attention paid by listeners may influence the story length and direction.[25] If the storyteller has the full attention of her audience, the story may be different than if the audience is distracted with other activities (eg, writing notes or diverting gaze).

In the present data set, only 1 skilled facilitator/listener was present and the same listener collected all the data used. In the excerpts provided above, there is considerable evidence of the conversation partner playing the role of active listener. Utterances such as "hmmm" and 'Uh-hu" plus laughter were prevalent from the facilitator. At no time did the facilitator offer her own anecdotes or stories but she often opened the session with a question about what were the person's memories of the event illustrated in the picture and closed with a question about moving on to the next picture.

For people with dementia the role of the conversation partner is critical, "Letting [people] tell their story without judging them emphasizes that their opinions are valued, that they themselves are valued."[26(p341)] Different conversation partners may have different expectations or cultural perspectives that would mediate the storytelling environment (eg, an older storyteller and a child or a younger or unfamiliar care worker). Gender, age, cultural background, position in the communication or organizational structure, and literacy level may all influence what story is told, how it is told, and how it is interpreted by a listener.[22,27] Further study using different people as conversation partners and in different settings (individual vs group) may provide further insight into how

a variety of conversation partners could draw out, or indeed impede, stories from people with dementia and practical recommendations about positive and negative listener behavior for care settings.

Elements of Performance, Ownership, and Control

The fourth component of personal narratives relates to performance, ownership, and control.[1,4] Storytelling activities imply some level of performance on the part of the storyteller, often in response to the constraints and expectations or conditions of the audience. This was apparent in the study by[28] using dramatic workshops with people with dementia, which appeared to offer a formal mechanism for the performance aspect of storytelling. Similarly, the TimeSlips project[13] uses processes to support the collective emergence and performance of an imagined story by people with dementia participating in the group.[29] These findings suggest that group settings may encourage the performance element of storytelling.

One important aspect of performance is the notion of what constitutes a "good" or "tellable" story and the onus is on the storyteller to consider the audience's notion of a good story. "How a story is told for and received by particular audiences will often depend on the cultural context of the narrative event."[30(p11)] In her study of the TimeSlips project involving structured storytelling with people with dementia, Basting[13] reported that there is a strong desire by storytellers and listeners for a "happy ending" even though the story itself has a sad or tragic element to it. Grimm and Booth[31] also consider the importance of the ending, whether it is happy or catastrophic.

In the present data set, story endings were categorized as positive, negative, or neutral. A neutral story ending contained words such as "that's it" or "I am finished"; a positive ending would contain words such as "it was good" or "good times" often accompanied by laughter; and negative story endings contained words such as "I hate … " or end the story with on a sad or unpleasant note. In the 13 stories analyzed, there were 2 positive, 1 negative, and 1 neutral ending in the mild group, 5 positive and 1 negative in the moderate group, and 1 negative and 2 neutral from the severe group. It appears that there were slightly more positive endings (7 of 13 endings) than either neutral or negative in this data set, similar to the findings in ref 13. However, none of the stories told by people in the severe group had positive endings, which may suggest that the need for a "positive" ending becomes less important with dementia progression.

Issues of ownership and control also form important components of the storytelling process and provide storytellers with a social anchor and responsibility.[32] Ownership of the narrative is the storyteller's responsibility. However, the listener who attends to the story plays an important role in confirming ownership.[1] Ownership is thus part of the collaborative storytelling process. A person with dementia may experience the loss of control and ownership of many elements of their personal lives,

which storytelling opportunities may allow them to take back. People can own and control their personal narrative as long as they can fulfill the responsibility of producing a "tellable" story where "tellable" is determined by the interactive negotiation with their audience.

Discussion

> While dementia changes many things, everyone wants someone to listen to them, without being judged or feeling tested.[26(p341)]

Participants in this study were empowered to tell stories by the social setting and the attention of the listener. They were prompted to recall their memories of events or topics depicted in 6 photographs. All the 13 stories examined demonstrated the conventional form with respect to the 4 elements outlined in ref 1. That is, the 13 stories (1) comprised clear story text in the Labovian model, (2) reflected the context and sociocultural setting in which they were told, (3) recognized the listener contribution, and (4) provided an element of performance and ownership for people with dementia.

It was apparent that when a participant was inspired to recount a personal memory as a result of the setting and prompts, they took control of their narrative and produced a "tellable" story as defined by the general model of personal narrative.[1] In keeping with this model, there were no expectations or measures of accuracy or truthfulness, just that the listener was engaged. However, when other types of prompts are used to encourage people with dementia to tell stories, such as personal artifacts including family photographs or physical objects where there is an inherent notion of accuracy (the entity belongs to the individual and therefore she must know what it represents in her life). This places different demands on a person with dementia as there is an expectation that they will tell the "right" story.[12]

This study used generic photographs to stimulate the recalling and recounting of personal stories by people with a dementia diagnosis. The study was organized as an interview and the participants were informed of its purpose; it was not an unstructured situation where personal narratives emerged without intervention. However, looking at the photographs and reminiscing was free form where there was no expectation of right or wrong answers and no imposed order. There were many instances where the photographs did not elicit any stories. It was also unpredictable which images would result in stories and what the themes of those stories would be. Story themes were not necessarily the same as the viewed picture but were merely sparked by something of interest in it.

This point is important when considering the potential of storytelling as model for conversation between people with a dementia diagnosis and formal or informal caregivers. Recently Astell et al. (2010) argued that where a prompt is used to stimulate storytelling, if the story embarked upon does not relate directly to the prompt, for instance, a person looking at a picture of a Christmas turkey tells a story about spending a summer working on a farm, the person should not be stopped or discouraged from continuing with the story. Sharing our personal experiences is a key element in building relationships and one of the main ways we seek and make connections with other people. There is no reason why this should be any different when people have dementia. Indeed, the importance of this aspect cannot be overemphasized as one of the most important aspects of engaging in reminiscing with people with dementia reported by caregivers is finding out new things about the people they care for.[17]

Conclusion

The application of a normative model of storytelling to the personal narratives of people with a dementia diagnosis suggests that they retain the 4 basic components, even when dementia severity is quite advanced. Proceeding from this finding, family and formal caregivers can be encouraged to engage people with dementia in conversations where they are prompted to recall and recount personal narratives, perhaps with the aid of prompts, such as generic photographs. This should not be confined to the activities program as a specialized dementia activity, to be carried out only at specified times. People with dementia seem to engage in the same storytelling processes that they likely did before they had dementia. However, successful storytelling also requires listeners as well as tellers. It is incumbent on listeners in dementia care settings, who are often staff or family members, to be engaged listeners and understand the important role they have in the storytelling process. In this way, tellers and listeners using conventional, everyday conversational practices can engage in enjoyable shared interactions.

Authors' Note

This work was presented in a workshop at ACM CHI2011, Vancouver. The presentation was entitled "Let me tell you a story: A model of storytelling for people with dementia." The manuscript to the American Journal for has a stronger focus on the listener elements of the research.

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