

Let me tell you a story: A model of conversation for people with dementia

Deborah I. Fels

Ryerson University
350 Victoria St. Toronto, CANADA
dfels@ryerson.ca

Arlene J. Astell

University of St. Andrews
South St, St. Andrews, UK
aja3@st-andrews.ac.uk

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 paper we apply a conventional model of story telling 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.

Author Keywords

Storytelling, conversation support for people with dementia.

ACM Classification Keywords

K4.2. Social Issues: Assistive technologies for persons with disabilities

General Terms

Human Factors, Theory, Design.

INTRODUCTION

Storytelling is a common and everyday part of human existence. It is recognized in many fields of study (e.g., Folklore, Sociology, Communication Studies, Nursing research, and even human-computer interaction) as a major driver of human communication (Langellier, 1989; Gubrium & Holstein, 1989). Telling and sharing stories – reminiscing – is an essentially social activity that occurs across cultures. It emerges early in life and has an important role in making and maintaining relationships within and beyond families.

Within the storytelling field, personal narratives are those stories people tell about their own lives or lived experiences (Langellier, 1989; Orbuch, 1997). These narratives usually comprise everyday occurrences and events as lived by the individual and then organized, reconstructed, recounted and reviewed at some later date. Personal narratives proceed without restriction on topics and expectations of truthfulness (Gubrium 2003; Orbuch, 1997). Examination

of the narrative form of stories has identified four components relating to form and function (Langellier, 1989). 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 (Langellier, 1989).

We have applied this model of story telling to the narrative recollections provided by older people with a dementia diagnosis. Our contribution to this workshop is to share our findings of applying this formal model of storytelling to the recollections of older people with dementia. It is our hypothesis that older people with a dementia diagnosis retain their ability to tell stories. We propose that this presents a useful and failure-free opportunity for reminiscing as well as providing a conversation model for people with dementia and those who care for them.

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 (Brunnström, Gustafson, Passant, & Englund, 2009) and typically starts with people 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 make it difficult to form new ones.

Whilst people with dementia have difficulty recalling and discussing recent 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 (e.g., Astell et al, 2010ab; Basting, 2003; Bender et al, 1998; Brooker & Duce, 2000). For example, Astell and colleagues (2010a) identified three specific functions for people with dementia provided by engaging in reminiscing: *Social*, *Skills* and *Self*, where 'social' refers to the social benefits of engaging and sharing stories with other people, 'skills' alludes to the benefits for people with dementia of keeping using their social and cognitive skills and 'self' applies to the opportunity afforded to people with dementia to participate as equals in a social situation and feel positive about themselves.

Studies of storytelling with people with dementia have included one-to-one (e.g. Astell, et al., 2010b) and group

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settings (e.g. Lepp, Ringsberg, Holm, & Sellersjo, 2003). To facilitate storytelling Lepp et al. (2003) used a formalized storytelling and dramatic workshop process to involve people with dementia and caregivers together 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 model of the lifecycle, such as childhood, adulthood, marriage, etc (Lepp, et al., 2003). The dramatic workshops involved formal elements of performance in that 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 (Lepp, et al., 2003).

Group processes in storytelling were explored further in the TimeSlip project (Basting, 2003). This used a formal, structured process to support and enable a group of people with AD to produce one common story based on a series of prompts (e.g., newspaper articles/headlines, images, greeting cards, etc.) and questions asked by a facilitator (e.g. what should we name this character). In this study the stories that emerged tended to be non-linear and did not necessarily follow the traditional beginning, middle and end structure. This may be due to the group process or may reflect changes in the storytelling abilities of people with dementia.

In their comparison of personal and generic photographs as prompts for reminiscing, Astell et al (2010a) found that while older people with dementia produced fewer stories than their relatives about family photographs, they generated as many personal autobiographical stories in response to generic photographs as a matched group of older people. In their study, stories were loosely defined and analyzed as the total number of words and turns taken, providing an overview of storytelling (Astell, et al, 2010a). A further examination of story details may supply some additional insight into how and why stories can be a successful social activity for people with dementia.

PERSONAL NARRATIVE ANALYSIS

The data for generic photograph reminiscence sessions reported by Astell et al. (2010a) were part of a larger data set collected from 27 older people with a dementia diagnosis. For the present study we analyzed a new subset of reminiscences from the original 27 to examine story properties as outlined by Langellier (1986) and Labov and Waletzky (1967). To summarize the data collection process, twenty-seven people with a dementia diagnosis were asked to reminisce about their memories elicited by six different generic pictures. The topics represented in these images related either to culturally relevant annual events such as Christmas and Burns Night (celebrated in Scotland) or settings where people may have taken a vacation (e.g., the beach). Based on their scores on the Mini Mental State Examination (MMSE; Folstein, Folstein & McHugh, 1975)

the participants' level of dementia severity, based on a score out of 30, was classified as mild (20-24, n=4), moderate (12-19, n=17), or severe (less than 12, n=6). Five participants (3 with severe classification and 2 with moderate classification) did not tell any identifiable stories (either linear or non-linear). All of the remaining participants told at least one story however, not all photographs elicited stories. Of these remaining 22 participants, thirteen were selected (4 mild, 6 moderate, 3 severe) to balance the number of people in each category (six people in the moderate category were randomly selected).

All responses were transcribed from the audio recordings. One story from each of the 13 participants was selected for analysis using the storytelling model.

Components of personal narrative

The first of the four components of personal narrative Langellier (1989) identified is narrative as a "story-text".

1. Story text

First described by Labov and Waletzky (1967) as a result of work carried out with street youth, story text consists of five basic characteristics: progression, evolution, contextualisation, 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 timeline 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 (e.g., "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 timeline could be easily identified for each story in our data set from the use of such time-oriented words. For example,

[1] ME: *Does it remind you of any time of the year MF?*

[2] MF: Well, when I was in, in the school I remember₁, remembering so much er trying to capture, catch these things₂. And we had done, done it once₃, quite, quite often. But er, but er, not for many, no.

[3] ME: *Right.*

[4] MF: ...and then it just goes away among, among the fields₄

[5] ME: *Hard to catch?*

[6] MF: That's it, yeah, yeah. Uh-huh . That's it₅.

In this example: ME is the facilitator and MF is a person with whose level of dementia places her in the severe category. This excerpt is from a longer story produced in response to a photograph containing an image of an Easter rabbit. It has five story phrases as indicated by the subscripted numbers showing 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 timeline indicators providing a time context and flow to the story. The phrase “that’s it” indicates the end of the story.

Labov and Waletzky’s (1967) second characteristic of a story text evolves from and captures the experience, events and emotions associated with that event. Mills (1997) 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-song₁.

[2] ME: *Hmmm*

[3] BM: And cars coming down used to join in₂. And we had a great time₃. And then, we used to invite the girls that we had picked up in the dancing₄

[4] ME: *Hmmm*

[5] BM: To come and get a meal₅. And they came₆. And we gave them a good meal₇. And then er, we sat and blethered₈. About everything and a’thing₉. And there was a camp of lassies in the next tent to us₁₀. And you’ve never seen a mess of faces in all your life₁₁. They let the sun get at their face₁₂.

In this example, we learn that BM was involved in a sing-song and chatting (*blether*) with some girls 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 and Waletzky (1967) is that there can be non-sequential 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 (e.g., “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.

The fourth characteristic of personal story is that the story has a point to it, that is a climax or ending that is

meaningful (Labov & Waletzky, 1967). In our sample all of the stories analysed contained this characteristic. However, the study situation may have encouraged this as the storyteller would often ask their conversation partner, ME, if the story was sufficient to answer the initial question posed when shown the generic photographs “what memories came to mind when looking at the picture?” Other stories ended when ME asked whether the person was ready to look at another picture after a period of silence.

[1] ME: *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] ME: *You'd be getting into trouble*

[4] TH: 'Said well, that's right. 'Said well, we'll get the seven later (both laugh)

[5] ME: *Will we move on to the next picture?*

[6] TH: Yeah

This story example has a facilitated ending resulting from a period of silence after the line about finding the seven pennies later but there is an obvious climax, that the storyteller was not the culprit because he had his six 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 (Labov & Waletzky, 1967). There were examples of ‘self’ and ‘fact’ types of conversations in the data that were collected from the thirteen people selected, however, these recounts were not considered as “storied”. However, to illustrate this type of reporting we offer the following examples from one of the selected individuals (in response to an image of two children holding a wrapped Christmas present):

[1] ME: *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] ME: *Hmmm*
 [4] BD: And they've got a parcel between them.
 [5] ME: *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] ME: *(laughs)*
 [8] BD: That's what it conveys to me.

When prompted, this person 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 two people on a beach):

- [1] ME: *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] ME: *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] ME: *I've got something else here Barbara,*
 [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.

2. Social/cultural setting of narrative

After story text, the second component of personal narratives Langellier (1989) identified is the context and social/cultural setting in which the narrative occurs. The location in which the story takes place and current cultural norms influence what story is told and how it is told (Gubrium & Holstein, 1998). One person might tell the same set of events in two different ways when he is in two 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. The constraints and affordance of the setting (e.g. formal versus informal) provide external limits to storytelling.

The current data set were collected in a one-to-one setting where an individual with dementia looked at a series of photographs with a single conversation partner. As such it was not possible to examine whether these same individuals might relate the same story when in a different setting (e.g., group setting) or with a different partner.

However, the setting did enable the participants with dementia to tell their personal narratives. This may be due to the one-to-one setting, the input of a supportive conversation partner or the provision of prompts to stimulate reminiscing. In their analysis Astell et al. (2010a) demonstrated that generic images can elicit personal autobiographical stories from people with dementia suggesting that the provision of external objects may stimulate storytelling activity. The provision of different objects may offer more opportunity for influencing cultural diversity and/or norms.

3. Importance of the listener in personal narrative

A third, and we suggest critical, component of personal narratives is the audience or listener contributions (Langellier, 1989). The listener has an active role in the storytelling activity and influences the flow and outcome of the story. For example, listeners allow the storyteller to "have the floor", however, they may also provide other mediating effects such as continuance words such as "uh huh", "oh really", "that's interesting" in order to encourage the storyteller to continue. Listeners may also interrupt with their own contributions and stories thereby redirecting the original narrative.

Another role of the listener is to take part in the evaluative component, offering opinion, direction or a reaction to certain points made in the story. For example, interviewers may interrupt a storytelling session and ask the person to "make their point" or "answer the question". Audience reactions such as "what are you trying to say" or "what are you getting at" may divert a current story if the audience believes the story is dwelling too much on one point. In addition, a listener's attention level may also influence the story length and direction. If the storyteller has the full attention of her audience, the story may be different than if the audience is distracted with other activities (e.g., writing notes, or diverting gaze).

In the present data set, only one skilled facilitator/listener was present and the same listener collected all of the data used. In the examples 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.

Different conversation partners may have different expectations or cultural perspectives that would mediate the storytelling environment (e.g., 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 and how it is told. Further study using different people as conversation partners and in different

settings (individual versus group) may provide further insight into how a variety of conversation partners could draw out, or indeed impede, stories from the people with a dementia diagnosis.

4. Elements of performance, ownership and control

The fourth component of personal narratives relates to performance, ownership and control (Langellier, 1989). 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 Lepp et al (2003) using dramatic workshops, which appeared to offer a formal mechanism for the performance aspect of storytelling. Similarly, the groups processes used in the TimeSlip project (Basting, 2003) successfully supported the collective emergence and performance of a story. These findings suggest that group settings may encourage the performance aspect 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. In her study of the TimeSlip project involving structured storytelling with people with dementia, Basting (2003) 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. For example, in a story of a pet dying, the story may end positively with the lesson that was learned or how the storyteller successfully recovered from that event.

In the data set presented in the present paper, story endings were categorised 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 two positive, one negative and one neutral ending in the mild group, five positive and one negative in the moderate group, and one negative and two 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 Basting's (2003) findings. However, none of the stories told by people in the severe group had positive endings. Although there were few people in the severe category, it would seem that the need for a "positive" ending in this category was less important for these participants than for people in the other two categories.

Issues of ownership and control also form important components of the storytelling process and provide storytellers with a social anchor and responsibility. Ownership of the narrative is the storyteller's responsibility. However, the listener who attends to the story plays an important role in confirming ownership (Langellier, 1989). Ownership is thus a collaborative or negotiated 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 the evolution of 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 and workshop position

Participants in this study were empowered to tell stories by the social setting and the attention of the listener. They were prompted to reminisce using photographs often accompanied by a basic question about their memories of the event/topic depicted in the photograph, e.g. vacations. 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 a general model of personal narrative (Langellier, 1989). In keeping with this model there were no expectations or measures of accuracy or truthfulness, just that the listener was engaged. However, expectations of veracity may occur with other types of prompts 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). We suggest that our original hypothesis, that people with a dementia diagnosis retain their ability to produce a "tellable" story was supported and that storytelling as a viable and potentially successful method of reminiscing was supported.

We also contend that prompting with generic images can successfully stimulate personal stories by people with a dementia diagnosis. Our study was organized as a reminiscence session 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.

In this workshop, we will present our analysis of personal narratives structured by this general storytelling model that has existed for over forty years as a result of work carried out with street youth (Labov et al, 1967). We suggest that this model also fits the storytelling process undertaken by people with a dementia diagnosis. However, it is incumbent on audiences to participate appropriately as a conversation partner and enable the storyteller to control the story. We will encourage discussion on what appropriate listening may involve and how people (care givers, family members,

medical staff, etc.) can become good listeners for a storytelling session.

We will demonstrate that using appropriate prompts and allowing a person with a dementia diagnosis to customize their interpretation of those prompts assists in the storytelling and reminiscence processes and makes those processes interesting and engaging for everyone involved.

Finally, we will discuss opportunities for how computer-based interaction may be used appropriately to support the storytelling process as discussed. For instance, computer interaction systems can provide the prompts or assist in the listening process. Software can be designed to gather, produce and display sets of randomly selected but culturally appropriate images that can be acquired from the billions of online images or specialized sets can be collected from other media sources (as outlined by Astell et al., 2010b). Interactions can be designed to facilitate a conversation setting that allows the person with dementia to participate and/or control the situation (an example of a touch screen interface is presented by Astell et al., 2010b). Intelligent computers that use the qualities of speech to determine appropriate responses (Turing effect) could possibly behave as active listeners. As a result, we expect that our presentation will provide an engaging discussion.

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