



Qualitative Sociology Review

Volume IV, Issue 3 – December 2008

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Narratives in Illness: A Methodological Note

Abstract

As a result of the general growth in the interest in narratives different conceptions of what a story is and how to analyze has emerged. One especially interesting and methodologically relevant difference is between the conception of narratives as textual objects and narratives as part of a storytelling event. The paper discusses the theoretical differences between these two analytical approaches to narratives. An example from my own research on Alzheimer's patients telling stories illustrates the possibilities of using a performative and micro ethnographic approach to the study of storytelling in order to understand the functions of narratives – especially in relation to identity work. If stories not only are thought of as representations of events it becomes possible to view stories and story telling as social action: social states are both established, negotiated and changed through stories. This is especially important in the field of health and illness where diseases almost always are embedded in conversations and the telling of why and how symptoms were discovered or traumas received. For many patients and persons with especially communicative disabilities story telling is a challenge, but also an opportunity to actually master, maintain and often transform their identities.

Keywords

Narrative; Methodology; Identity; Performance; Ethnography; Video analysis

The number of books and articles with word "narrative" in its title or abstract has increased explosively during the last two decades. As a consequence a narrative research field has been established with the story, in all different guises and manifestations, as the focus (Kreiswirth 1994, 2000).

The interest in narrative has historical roots going back to researchers like Sigmund Freud, William Thomas and Florian Znaniecki, and Claude Lévi-Strauss who all early on observed the centrality of the narrative form. To Freud the case story constituted a centre in his writings. Thomas and Znaniecki systematically collected stories from Polish immigrants in the US in the twentieth century. To Lévi-Strauss the myth constituted the motor of culture, determining ways of thinking and understanding the world.

One explanation for this interest in stories may be linked with a changed conception of language and language use in the social sciences during the 1960's and 70's. To Freud and his contemporaries, language was conceived as being fully

transparent making social reality directly accessible through words and stories. Through the influence of modern philosophers like Ludwig Wittgenstein it became evident that social reality is created through the use of language. The linguistic turn” in the social sciences could be noted already in the early book by Berger and Luckmann (1966), and further conversation analytic works (Atkinson and Heritage 1984) and in the more recent work interested in narratives (Bruner 1990; Andrews et al. 2004).

Another reason for the interest in narratives is the character of much of the empirical material used in social scientific research consisting of text, talk and story telling – whether collected in surveys, interviews or in observations. The fact that storytelling is found in all of these practices has also generated an interest in looking in detail at the ways in which the story and the telling of stories can have consequences for the way in which empirical materials are analyzed and theorized (see for instance Mishler’s (1986) discussion about research interviews.)

As a result of the general growth in the interest in narratives there has also been a rise in interest in different conceptions of what counts as a story and how to analyze stories. This has led to different methodological conceptions and practices (for an overview see Riessman 2008). One especially interesting and methodologically relevant difference exists between the conception of narratives as textual objects and narratives as part of a storytelling event. In the former case the methodological focus is on the internal discursive structure of the narrative/object, while in the latter case it is the social organization and performance of the narrative that forms the analytic focus.

In the following I will start with a discussion of the theoretical differences between these two analytical approaches to narratives. I will then use an example from my own research in order to further discuss the methodological differences.

Narrative as Text and Performance

Many social sciences researchers have a tendency to favour a textual conception of narrative over a performative and situated one (Hydén and Brockmeier 2008). In the social sciences this often means that narratives produced in conversations are treated analytically as if they are an instance of a written, text based narrative. This means that the focus is on the discursive organization of the narrative in terms of coherence, plot and so on. It also implies that the meaning of the narrative is thought to be found inside the narrative. And, finally, that the narrative primarily is about something, it represents for instance events in the past.

Especially in interview studies the idea that narratives represent events that took place at some previous time, is quite salient. In this case, the narrative is not of interest as such, but only as a vehicle, a form for representing the past. Similarly, the narrative can be treated as a constructed expression or reflection of the interview person’s emotions, identities, “meanings” or ideas.

One problem with the textual approach to narrative is that narratives told in interviews or in some other kind of interaction are analyzed in relation to norms for textual production. That is, they are analyzed as if they are instances of, for example, written autobiographical texts. The norms for written stories are in many ways different from those of spoken language (Linell 2005). The textual narrative allows a more elaborate and formal style and use of imagery, and a refined chronology of events. These norms and forms are rarely used in the telling of oral, conversational narratives, where those aspects having to do with the necessity and importance of

engaging the audience through the whole story telling event and delivering a point are much more important (Bauman 1987).

Textual narratives are generally composed in order to be read and consumed by anonymous readers in quite different settings and points in time, something that to a certain degree makes written stories de-contextualized. Whereas oral narratives are heavily dependent on the specific social situation, audience, physical setting, gestures, prosody, etcetera, that is, aspects related to the performance of the narrative. In producing a text, at least some of these contextual resources have to be transformed into textual elements.

These textual norms are also present in the transformation of the empirical material, especially in the transcription of talk into text. If narratives told in interviews are transcribed without notation for hesitations, pauses, repair, listener support, para-linguistic features, non-verbal aspects and so on, all interactional features of the performance of the narrative are left out. Consequentially everything “outside” the narrative text is left out of the analysis, which makes it difficult to analyze the telling of stories as social action.

In many cases a focus on the narrative text can of course be a feasible strategy – especially if researchers primarily use narratives as a way of accessing representations of events in the past. But a focus on the narrative as text becomes problematic if researchers instead are interested in the functions of the narrative and the storytelling, that is what is accomplished through the telling of a story. In studies using, for instance, an ethnographic or micro-ethnographic approach it is often found that story telling occurs at certain moments in the social interaction, joining tellers and listeners in concerted action, sharing experiences or memories. Story telling can then be seen as part of a family’s or a group’s social life, establishing, re-establishing and negotiating, relations, membership and connections (Langellier and Peterson 2004).

The focus on story telling in various social contexts has led researchers to focus on both the performance of the story and its performative aspects. That is, both the way the story is told and performed in interaction jointly with the listeners, and what is done or accomplished through the telling of the story (Bauman and Briggs 1990, Langellier 2001; Peterson and Langellier 2006; Hydén and Brockmeier 2008).

To many researchers a performative approach also makes it possible to regard language not just as a vehicle used to communicate a story. Instead of a focus “on processes within the individual or on structure within the talk of a single speaker or narrator” it instead becomes important to regard “how language is organized as a public sign system” (Goodwin 2004: 154). As a consequence the focus is much more on how stories are told in interaction using several different communicative modalities (language, para-language, gestures, eye movements, bodily positions, material and social artifacts in the immediate context, etc). This makes it important to look at the ways tellers and listeners use all available communicative resources in the narrative situation (Goodwin 2004).

Methodological aspects

Working with narratives from a performance perspective raises a different set of methodological considerations as compared with a focus on the narrative's textual organization.

First of all, it is necessary to collect data that allows for an analysis not only of the narrative as such but also the wider social and cultural context of which it is a part. Generally this means using an ethnographic or micro-ethnographic approach (Streeck and Mehus 2000).

Second it is preferable to use video recording as material if possible. The reason is that video recording allows an analysis not only of the spoken word, but also body movements, gestures, use of gaze and so on (Goodwin 2004). That is, using video recordings allows for a multi-modal analysis.

Third, a descriptive and analytical focus on a wide variety of communicative resources makes it necessary to use transcription conventions that allows for this type of analysis (cf. Goodwin 1981).

Although a performative approach to narrative analysis is much more complex and in many ways more labour intensive than just analyzing the narrative as a text, it at the same time makes it possible to discover and see new aspects of human social interaction.

In the following example from my own research I illustrate the possibilities of using a performative and micro-ethnographic approach to the study of narratives in order to understand the functions of narratives – especially in relation to identity work.

Alzheimer's Disease as a Methodological Case

The example concerns patients with Alzheimer's disease (AD). The study of Alzheimer's disease has traditionally been dominated not only by the medical discourse, but also by a – at times at least – quite pessimistic and dark view on persons suffering from AD, even among sociologists (see Ballenger, 2006, for a historical review). Much of the research on Alzheimer's patients has been methodologically dominated by experimental and clinical approaches, even in studying the narrative competencies of persons with AD. Generally few researchers have designed studies in order to be able to analyze narratives told by persons with AD in everyday settings and around self-selected topics rather than ones suggested by a researcher.

Persons suffering from brain trauma or dementias like AD all have an issue with telling and using narratives due to their cognitive and linguistic impairments. To these persons, telling a story challenges their use of their actual cognitive and linguistic abilities together with all other communicative resources they can muster. Stories told by persons with AD can be severely fragmented, parts can be repeated over and over again, certain events can be left out, and other events that never occurred or involved the teller can be included etcetera.

Accepting that telling stories is one of the most important ways of establishing and negotiating identity, having problems telling a story can of course tend to challenge a person's identity. An important question then is whether persons with AD actually can tell stories about themselves as a way of establishing and negotiating their identity in the social interaction (Hydén 2008).

Those researchers interested in how persons with AD tell stories have primarily been interested in the discursive organization of autobiographical narratives, especially the temporal and referential aspects of narratives. That is, their research has been guided by the idea of narrative as a text and hence the patients' ability to reproduce the narrative text. As a consequence the focus has been mainly on the ability of the person with AD to remember or retrieve and present memories of certain events correctly, and to elaborate and connect them into a story. This approach tends to preclude other ways for persons with AD to use autobiographical narratives in order to sustain their identity.

One way to answer the question about the relation between storytelling and identity in AD is to find out if and how persons with AD use storytelling as a way of negotiating identity; and whether they use other communicative resources due to their linguistic and cognitive problems and limitations.

Methodologically this question challenges the established methods used in research on persons with AD and especially the research on the role of narratives. It becomes important to use methods and material that allows for a different type of analysis of narratives; namely an analysis that views stories as situated, part of an ongoing social interaction, and as a multi-modal activity.

In order to avoid the limitations in previous research an ethnographic study based on collecting naturalistic data was designed and conducted. During a period of five months video recording was taken place at an elder center in Sweden serving eight residents, seven of whom were diagnosed with some form of dementia, mostly of the Alzheimer type (for further details see Örvilv and Hydén 2006; Hydén and Örvilv 2009).

By serendipity we were able to identify one story, "The driver's license story", that was told several times by the same resident, Martha. She is about 80 years old and was diagnosed with AD about five years prior to her participation in the study. The story was told on different occasions, in various contexts and with shifting audiences, both in group activities lead by staff and in spontaneous conversations between residents.

"The driver's license story" is a story about how Martha as a young person decided to learn to drive and to get a driver's license, and then to buy her own car. Both her husband and father questioned her ability, both to learn to drive and to save up for a car by herself, but they were both proved wrong. In one sense it is a story that portrays Martha as not only challenging the values of her generation about what women could and ought to do, but also overcoming those values, going her own way, and making a statement about herself. The story is organized around a set of reportable events and the actual story is then adapted to the different contexts and audiences and, therefore, told in different ways.

It is a typical autobiographical story of the kind most of us tell as a way of presenting, establishing, negotiating or defending our identity in social interaction with other persons (Georgakopolou 2007; Linde 1993). Telling a story about what happened many years ago, is a way of making a connection between the "I" of then and the "I" of the present social situation. Through the storytelling the "I" of the past can cast a shadow over the present "I" and thus allow the listeners to see the teller in a new light, as a person having certain traits of the past "I" not noticed before (Bülow and Hydén 2003).

Having problems with telling stories due to Alzheimer's disease potentially jeopardizes Martha's identity and her identity-work. What is interesting with Martha's telling of the driver's license story is how she and her listeners deal with her difficulties, using ordinary linguistic structures and devices. As she has problems at

times finding words and above all with the higher order linguistic organization of narratives, she creatively makes use of other communicative resources such as gestures, eye movements, touch, and so on.

The Story and its Telling

The driver's license story is organized around several sub-themes like deciding to get a driver's license, learning to drive, buying a car and so on. These sub-themes form a part of a temporally progressing story with some events happening first, and then giving place for succeeding events. This progression constitutes a higher order temporal organization of the story.

When Martha tells her story this higher order temporal organization of the narrative is problematic and even missing. That is, the temporal relation between the sub-themes is broken up and the sub-themes are told without any internal temporal organization. Further, some sub-themes are told over and over without Martha noting it or being concerned about this repetition. Martha's rendering of the sub-themes of the story in contrast, are generally well organized, and told in a similar way and generally end with an evaluation of the events.

In all these instances, the interactional organization has a similar structure: the audience is drawn in together with Martha, the teller, in appreciating the point of the story, and those parts of the story that are related to its evaluation. Evaluations are very important in storytelling, as it is one of the most prominent means a teller can use in order to convey to the listeners why the story is being told. It is also a way to position the teller in relation to the events in the story. This can be done either through the teller commenting on what happened or by the teller having some of the characters in the story deliver a comment. In the latter case the teller often quotes some person allegedly commenting on the events that took place.

In the example below Martha tells her story to her co-patient Catherine while no staff member is present. Just before the start of the example Martha has been relating to Catherine that her husband did not believe she could save money to buy a VW car. This part of the story, organized around her husband's disbelief, ends with the evaluation we see in the following example. In the transcription non-verbal aspects are added, as they are quite important in understanding what is transpiring.

Example 1

- (1) **Martha:** ((*seeking eye contact*)) "oh ss sure I can" I said
- (2) ["one can"]
- (3) **Catherine:** [(xx xx)]
- (4) **Martha:** "one can do whatever one wants to" [I said]
((*turning the upper part of her body towards Catherine, leaning against her and maintaining eye contact during the whole utterance. At the same time she pats Catherine on the arm with a slow and dramatic gesture, timing the bodily contact so as to further underline the word "whatever"*))
- (5) **Catherine:** [yes]
- (6) that's true ((*nodding*))
- (7) **Martha:** yes
- (8) and then one does not give up until one is there
((*marking the beginning of the line with two downward strokes with her fist and the stressed word in the end of it with a short nod accompanied by eye contact*))

(9) **Catherine:** =no

(10) **Martha:** and one is about to do it

((*raising her loosely clenched hands so as to underline the stressed part maintaining eye contact during the whole utterance*))

(11) **Catherine:** =yes

In the example Martha delivers her evaluation of what happened when her husband questioned her ability to save money and buy a car. Martha does this by quoting herself at the time of the event, embedding her evaluation in the story (lines 1-2, 4): “one can do whatever one wants to’ I said”.

At the same time she actively engages her listener, Catherine, in the evaluation by seeking and maintaining eye contact, by turning the upper part of her body and leaning towards her, and by patting her arm while stressing one of the words (after line 4). Catherine responds to Martha’s words and bodily movements by a supportive “yes that true”, showing her agreement with Martha’s evaluation.

Martha also actively dramatizes what happens in the story by using reported speech, that is, she quotes what someone else said. In line 1 for instance she quotes her past self saying “oh sure I can” at the time of the events in the story. By quoting herself Martha not only reports what happened, but actually enacts the utterance as a way for creating a feeling of presence and drama.

Martha further underscores this evaluation by rewording the utterance, underlining some of the words as a narrator in the speech situation and using gestures to give further strength to what she is saying (lines 8, 10). Catherine supports Martha’s telling by affirming, thereby showing her support of the evaluative conclusion (lines 5-6, 9, 11).

It is apparent that this part of the story, the story evaluation, is not only linguistically and cognitively well organized. It is also enacted and also embodied in the gestures and in the qualities of Martha’s voice. Some words are stressed paralinguistically and/or enhanced with gestures, and in this part of the telling the eye contact stands out as more intense and prolonged in comparison to the non-evaluative parts of the telling that surround this sequence.

The evaluative section of the story thus basically tells something about Martha as a person, both in the past and in the present. The Martha of the past, the young person challenging her husband and family, casts her reflection on the present person, the teller, an elderly resident in a care unit. By telling the story and winning support from her listeners, Martha is able to make claims about her identity and present herself not only as a woman who used to be brave and daring, but also as (still) being the very same person – hence a person with the same moral qualities.

The identity work here is inherent in the performance of the story and in the storytelling event as organized by the teller and the listeners together – and in this interplay where points are jointly established and acknowledged, indeed mutually performed. This means that both the teller and the listeners use embodiment in their joint performance of the story. Maybe this is an aspect of the storytelling activity that becomes especially salient when the person has severe linguistic and cognitive problems, as may be the case in AD. Using the body and other non-verbal communicative resources is a way of dealing with the loss of verbal fluency and the ability to create complex narrative temporal structures.

Conclusions

In conclusion I would like to suggest four general theoretical and methodological points.

First, in methodological terms the design, type of material used and the way it is analyzed is closely connected to wider theoretical issues; in this case the conception of what a narrative is. Traditionally narratives are often thought of as texts and verbal representations of events – an idea going back to the literary studies of narratives, especially narratology (see for instance Rimmon Kenan 2002). This may be a feasible idea in some contexts, but it certainly introduces limitations in terms of the type of data one might collect and analyze.

I have tried to argue for viewing narratives as part of social action and interaction. Telling stories is *doing* something, and almost always, doing something together with someone else (the audience or listener or recipient to the story). In order to capture this wider idea of what a narrative is, it becomes important to use data gathering methods and ways of analyzing data that allows for a focus on *interaction and action*. This implies that studies of narration – both among persons with AD and all others – should strive to include not only both verbal and non-verbal aspects of talk in interaction, but also contextual aspects like the organization of the speech event and even institutional frames.

Second, I have tried to show that non-linguistic elements play a prominent part in story telling. Stories can be enacted, that is, *performed* which generally means that communicative resources like gestures, bodily contact, paralinguistic means, laughter, and not least the coordination of all these aspects in the speech event, are used. In other words, telling stories is a *multimodal event* – something that needs to be reflected in the methodological and analytic strategies used by social scientists in working with narrative analysis.

Third, this indicates that identity in relation to persons with AD, but certainly also more generally, may not primarily be a linguistic construct but very much *embodied*. That is, identity does not reside *outside* bodily movements and appearances, verbal utterances and stories, but *in* and as a *part* of all these actions. Identity can apparently be performed in many ways, of which the telling of stories is but one way and maybe not even the most important one.

Finally, I would like to suggest that the telling of narratives also has a *performative* aspect. Telling an autobiographical story is a way of changing – or at least an attempt to change – the identity of the teller. This is done by positioning the teller as a person who shares certain traits – moral or otherwise – with the character in the story. In this way the listeners have the possibility to relate not only to the teller but also the teller as a character in the story. In other words, through the story telling event the teller accomplishes a transformation of self: the old self merges with the teller-self.

If stories not only are thought of as representations of events it becomes possible to view stories and story telling as social action: social states are both established, negotiated and changed through stories. This is especially important in the field of health and illness where diseases almost always are embedded in conversations and the telling of why and how symptoms were discovered or traumas experienced. For many patients and persons with especially communicative disabilities story telling is a challenge, but also an opportunity to actually master, maintain and often transform their identities.

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Citation

- Hyden, Lars-Christer (2008) "Narratives in Illness: A Methodological Note." *Qualitative Sociology Review*, Vol. IV Issue 3. Retrived Month, Year (http://www.qualitativesociologyreview.org/ENG/archive_eng.php)