Continuity Amid Chaos: Neurotrauma, Loss of Memory, and Sense of Self

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In serious illness or disability, individuals commonly say that their sense of self has dramatically changed. One might expect that the experience of a radically altered sense of self would be even more profound in individuals after neurotrauma because it is the brain itself that suddenly, and often literally, becomes “strange.” The aim of this study was to investigate how people left with autobiographical memory impairments—impairments that also affect the capacity to organize complex linguistic productions such as autobiographical narratives—experience themselves and, specifically, their sense of self. Seven adults who had primarily anterograde memory impairments for 1 year were interviewed. Regardless of the profound changes in their everyday functioning and lives, the stories the participants told evoke a surprising sense of a continuous self. Employing several narrative and discursive techniques, they emphasized sameness and an unbroken connection between their pre- and post-morbid lives. We believe that most individuals felt they did not have to recover their former sense of self because they subjectively seemed to have never lost it.

Keywords: neurotrauma; narrative; self; memory loss; brain injury

Serious illness and disability often culminate in a crisis, a crisis that presents a fundamental threat to one’s experience of self and identity. Talking about their experiences of such a crisis, people commonly say that their being in the world has changed dramatically. Interestingly, in trying to sort through and understand these changes, individuals almost always turn to narrative. Why narrative? To make a long answer short: Illness has meaning, and narrative is the language of meaning. Narrative discourse, as many studies have pointed out, offers a wide space to connect with others and reflect about oneself. We might call this a unique experiential space that proves to be particularly helpful—indeed, necessary—under such extreme circumstances.

Within the space of narrative we have access to manifold ways and stances to deal with existential challenges. Every culture is a narrative culture, and every narrative culture provides us with a broad repertoire of genres, plot models, and storylines—not to mention metaphors, symbols, and other figures of speech. This repertoire is not just about language but about accumulated human experiences, not least of which are experiences of crisis. All of us, sick and healthy, young and old, draw on this repertoire when we talk about our lives, loves, and lost hopes, and when we try to figure out why we feel uneasy, uncertain, and unhappy. We have grown into the storytelling universe of our language and our culture since early childhood and use its resources in the same familiar and spontaneous way as language in general.

In this view, then, narrative is the name for a special repertoire of instructions and norms of what is to be done and not to be done in life, and how individual experiences might be integrated into a generalized and culturally established canon (Brockmeier & Harré, 2001). And this might be exactly what brings seriously ill people to talk about themselves and narrate their experiences: trying to come to terms with a radically challenged sense of self.

In his exploration of narratives from individuals with chronic illness and disability, Frank (1995) observed that they organize their experience along three general

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plots, each associated with a different sense of self. In what Frank called “restitution stories,” tellers emphasize that their present illness will not interfere with their previous plans for the future and that their former selves will be restored at some future point. They insinuate, in other words, that they are not presently themselves but soon again will be. In “chaos narratives” there is only little discernable narrative order which, as Frank suggests, makes it difficult for the sick to reflect on their illness experience at all. Finally, there are “quest stories,” stories in which people claim that their illnesses or disabilities have produced new identities.

Although there have been many studies of such changes in people and the stories they tell about these changes, only a few studies have been carried out with patients affected by neurotrauma caused by a stroke, accident, anoxia, or infection of the brain. One reason for this is that psychological qualities such as awareness or emotionality have been traditionally regarded as causally linked to brain functioning. In this view, damage in a specific brain area might affect certain aspects of one’s self. Leduc, Herron, Greenberg, Eslinger, and Grattan (1999), for example, have stated that damage to the frontal lobes is causally linked to decreased self-awareness. Other researchers have argued that it is the number, not the location, of the lesions that is associated with decreased self-awareness (Sherer, Hart, Whyte, Nick, & Yablons, 2005). Although we certainly agree that it is important to investigate the role of the brain and its contribution to self-experience, there are, however, serious limitations to viewing “self” as a “dependent variable.” First of all, such a view tends to negate agency; that is, it denotes individuals’ active responses to their brain damage. It does not tell us how the persons themselves experience the symptoms of their changed brain and how, in turn, this influences their sense of self and how this again might influence their symptoms.

However, if it is in the first place through narrative, as we argue, that people actively try to give meaning to their being in the world, then individuals with neurotrauma are uniquely challenged. Why? Neurotrauma almost always affects the very cognitive and communicative abilities one needs to narrate. More specifically, it disorders or reduces one’s capacity to remember, to focus, and to organize complex plot structures. If, for example, memory capability is severely limited, obviously it is difficult to remember one’s personal past, never mind tell autobiographical stories. Individuals suffering from neurological lesions can be left without one of the most powerful tools in the toolbox of meaning-making: narrative discourse and narrative thought. Not only, then, is an individual suffering from a neurotrauma confronted with the existential crisis of illness and disability, but also with the crisis of narrative dysfunction. And as the idea of one’s self is so intimately intertwined with autobiographical narrative (Bruner, 2001; Eakin, 1999), it is likely that such a radical alteration of narrative competence would have profound consequences for a person’s experience of his or her self, in fact, for the entire process of identity construction. If identity construction is understood as the ongoing narrative, that is, the discursive localization of one’s self in time—terms such as continuity, coherence, integrity, reflexivity, and intentionality only reflect aspects of this process from different points of view—then serious restriction to one’s narrative abilities cannot but result in a serious challenge to one’s identity and sense of self.

There have been very few studies examining the self-experiences—narrative and bodily—of people abruptly left with cognitive reductions because of brain lesions. For guidance in these matters one might want to turn to the literature concerning individuals with dementias (e.g., Sabat, 2001) or intellectual developmental disabilities (e.g., Croft, 1999; Medved & Brockmeier, 2004). However, there are fundamental differences between sudden neurotrauma—the issue we are interested in here—and these other diseases or syndromes. People with dementias, for instance, experience a gradual cognitive decline over years, sometimes over decades, and people with developmental disabilities experience a relatively stable, albeit reduced or pathognomonic, level of cognitive functioning over the years.

In contrast, individuals with neurotrauma have to deal with a brain that has been abruptly transmogrified, a brain that all of a sudden has become “strange.” Their brains, as well as their minds, have suddenly acquired new “habits” that are hard to understand, not to mention deal with in everyday life. On top of this, these individuals have to deal with fundamental changes to their intellectual capacities and, most dramatically, their narrative sense-making. The research literature suggests that victims of neurotrauma have, in fact, profound difficulties adjusting to these alterations, which understandably might have a profound impact on their sense of self.

In examining narratives from people with traumatic brain injury—an injury typically resulting in diffuse cognitive impairments—Nochi (1998) found that such individuals, even years after their original injury, expressed what he called the sentiment of a “lost self.” More specifically, they indicated they had serious difficulties figuring out what they were or were not capable of, and they compared their present
status to their pre-injury status while mourning their “lost” past self. At the same time, most of Nochi’s participants felt uneasy being labeled as “brain-injured,” because they believed that this further negated their sense of self.

Whether a particular sense of self or an idea of one’s identity is uniformly experienced at different time points from the original injury or across populations with different cognitive limitations is unknown. The participants in Nochi’s (1998) study were on average 9 years post-injury, and it is not clear whether individuals closer to the time of brain damage would experience a similar sense of a lost self. If anything, one might expect this “lost self” experience to be even more profound because there has been less experience dealing with and adjusting to neuropsychological changes. It is also not known whether individuals with focal impairments—such as a memory deficit that influences autobiographical remembering—would have an experience similar to those with diffuse impairments. Again, if anything, one might expect the experience of a “loss of self” to be even more profound because, without autobiographical memories, the raw materials from the past on which personal narratives draw are missing.

So how does one tell stories about oneself when there are no autobiographical memories? In earlier research we found that people used specific linguistic techniques, in fact, “tricks,” to tell their stories under such emergency conditions (Medved, 2007; Medved & Brockmeier, 2008). Our microanalysis of such stories revealed that individuals with memory deficits employed three readily available linguistic strategies. One was a strategy of “memory importation” (transplanting a memory from the time before to after the neurotrauma); another was a kind of “memory appropriation” (taking another’s memory as one’s own); and a third one involved what might be called “memory compensation” (conversationally compensating for missing memories). These strategies appeared to provide helpful means to sustain personal narratives even in the absence of autobiographical memory. This is not to say that even in people who have serious difficulty remembering, or amnestics, there is no recollection— islands—of autobiographical memory at all (Medved & Hirst, 2006), but what we did not examine, however, was what sense of self would emerge in personal narratives (or self-narratives) when such strategies are used.

The aim of the present study is to investigate exactly this question: What sort of sense of self, if any, takes shape when the strategies of memory importation, memory appropriation, and memory compensation are used in autobiographical narratives by people who have had severe anterograde memory impairments for 1 year? But let us ask first: What is an anterograde memory impairment? It is a memory deficit that reduces the ability to form memories of events occurring after neurological harm, while at the same time memories occurring before are retained. In interviewing individuals with such an impairment, our focus was to understand how they experience themselves in such a precarious situation. More specifically, we wanted to find out whether these experiences involved a sense of self that could be compared to the ones expressed in Frank’s (1995) restitution, chaos, or quest narratives, whether they experienced a sense of Nochi’s (1998) “lost self,” or whether they experienced themselves in a different fashion altogether.

This question bears important ramifications, not least for the rehabilitation services offered to these individuals. Various authors have argued that the primary goal of both cognitive and emotional interventions in rehabilitation should be to enable the individual with brain damage to reaffirm a sense of self (e.g., Hill, 1999; Pollack, 1994). But as Prigatano (2000) has pointed out, the psychosocial rehabilitation of such people is often misguided and mismanaged because what is called the “self” is only poorly understood. There is a lack of knowledge about how the experience of oneself varies according to the type of cognitive deficit and at different points in development. Drawing on Prigatano, we believe that the “self” is often used as an opaque label whose ubiquitous (and substantializing) usage makes things more difficult. We believe that as clinical professionals we need a better understanding of how people make sense of themselves, especially under extreme circumstances, before “reaffirming” or “reconstructing” a putatively damaged “self” in people of whom the only thing we know is that they have a damaged brain.

**Method**

**Sample**

After receiving ethical approval certification by an institutional ethical review committee, neurological inpatients in a rehabilitation health care center were approached approximately 2 to 3 months after their neurological event (just prior to discharge) concerning their willingness to participate in a study exploring how people cope with brain injury over time. Eight of the nine patients whose cognitive deficits were primarily...
restricted to memory agreed to participate. If participants provided informed consent, their permission was secured to tell their primary caregiver (e.g., parent, partner) about their willingness to participate in a research study. In no cases did participants deny this permission nor did the family member object to the participant’s involvement. Because one of the patients was not available at the time of the 1-year interviews, the final sample consisted of three men and four women ranging in age from 27 to 76 years.

These seven participants had an anterograde memory impairment that was identified by a standardized neuropsychological assessment. Their brain lesion resulted in at least moderate memory impairment and their memory quotient (based on the Wechsler Memory Scale-III) was at minimum 20 points lower than their intelligence quotient (IQ, based on the Wechsler Adult Intelligence Scale-III). Although the participants could be considered amnestic, many of them were not “dense amnestics” (as often depicted in movies), because they retained some memory and learning capability. For this reason, we refer to them as individuals with memory impairments rather than with amnesia. None of the participants demonstrated any major indicators of retrograde amnesia. Other cognitive domains such as attention, executive functioning, intellectual ability, and speech and language ability were assessed as only mildly impaired or intact. The causes of the participants’ neurotraumata were various: traumatic brain injury, cerebral vascular accident, anoxia, or abscess.

In manifold ways, the impairments of the participants in this study, at least initially, appear unnoticeable to others because they do not have any physical restrictions and because their intellectual and language abilities remain relatively intact. Regardless of this “invisibility,” the participants have been profoundly affected by the neuropsychological consequences of their brain damage. At the 1-year post-neurotrauma mark, none of the participants had been able to return to work or school. If they were living independently at the time of the accident, they had to move back in with their family of origin.

In daily life, participants faced numerous difficulties, ranging from forgetting to shut off the stove when cooking to forgetting what their plans were for the day, repetitively asking the same question of others to continuously printing graduate school applications from the Internet. Even though the participants were fortunate enough to live with family members who provided support, many of them appeared rather isolated. Other than the occasional visit from the occupational therapist, almost all of them were left alone with very little to do during the weekdays. Most were housebound, whether because of (realistic) fears about leaving the house and getting lost or a lack of access to transportation and community activities.

All participants attended a day hospital rehabilitation treatment program for 1 to 2 months after their release from the inpatient program. Even though all of the working-age participants expressed a desire to return to work, they will probably not be able to work, or if they do, they will require less demanding positions. They were likely told that they might expect some neurological recovery in the first year that would continue in the second year to a lesser degree. Typically, individuals with such memory impairments do not receive a precise prognosis.

Data Collection

The primary source of data was transcripts based on interviews conducted 1 year after the neurotrauma. To protect participants’ anonymity and confidentiality, all identifying details and specifics of the narratives have been altered. We also draw on informal observations during several visits to the home environment of the patients and conversations with family members. In addition we accessed medical and neuropsychological reports. All interviews were conducted in the homes of the participants, in the absence of others; they were audiotaped and fully transcribed (see appendix for transcription conventions). The interviews ranged from 30 to 55 minutes in length. Each participant was interviewed twice, with the interviews separated by approximately 1 week. An interview schedule was used to elicit autobiographical narratives that primarily focused on events and experiences of the participants since their neurotrauma (e.g., How have you been coping? What have you been doing these days?).

We aimed to balance the need to include more interviewer prompting than might be usual when interviewing a person without neurological lesions during the interview (Paterson & Scott-Findlay, 2002) by using a conversational interview style (not “Tell me a memory from last week”). The idea was to give participants enough time to “inhabit a conversational space.” We were also mindful that responses of participants that seemed inadequate during interviewing could reflect, as Gregory (1998) pointed out, the patients’ unfamiliarity with their new neurological state after the brain injury.
Data Analysis

Each interview was separately analyzed following an ideographic approach. All seven interviews were analyzed, even though saturation of the data indicated fewer protocols would have been sufficient for the topic of this article. A comprehensive description of how the transcripts were analyzed to identify instances of memory importation, memory appropriation, and memory compensation is provided elsewhere (Medved, 2007).

The analysis included a detailed examination of how the narrative segments demonstrating the three linguistic techniques, with the aim of illuminating how people conceive of themselves, position themselves and others, and try to come to terms with the experience of their brain injury. We also studied the material from a discursive psychology point of view, in particular, identifying modes of linguistic coconstruction and strategies of positioning.

Moreover, all interviews were examined to find out how the selected interview segments related to statements elsewhere in the interview—not least to ascertain that our selection was significant in terms of content and speaker intention. This analytical procedure was carried out according to standard hermeneutic principles of modifications and reinterpretation of the segments and the whole interview. Finally, the results from each participant were compared with the results from all other participants. Results and interpretations were checked by members of our research team, who reviewed each step of the analysis, obtaining consensual validation.

Results

Our goal was to investigate how the participants experienced the symptoms of their changed brains, how this might have influenced their sense of self, and how this again impacted the experience of their symptoms. We now present the results according to the different “narrative memory techniques” people used. We will briefly describe each technique at the beginning of each subsection.

Memory Importation

In what we call memory importation, the autobiographical memory of a premorbid event is extended or transplanted so that it seems to have taken place postmorbidly. In other words, memories are shifted from the time before to the time after the neurotrauma. There were two ways to accomplish this importation. One involves changing the temporal framework of a general memory by altering temporal markers (such as verb tense) used to describe the remembered event; the other consists of inserting a memory into a narrative sequence in which it appears plausible but to which it originally did not belong.

We observed such memory importation in a woman who, in her narratives, appeared to view herself as someone struggling to balance family and career. She obviously was pleased with the results. Telling her story at a breathless pace, she emphasized how she had been responsible for most domestic activities during the past years of marriage:

We’ve been together 14 years and I’m the strong, organized one. I always used to do it all. B used to ask me about everything except for his work and what he does. I work at least 12 hours a day at least. I am responsible for < home, cleaning, laundry, everything, bills, groceries > (. . .) our daughter . . .

There is an interesting temporal jump in this little narrative, a sudden shift from the past (“I used to do”) to the present tense (“I work,” “I am responsible”), which allows this woman to turn her memories into a presently experienced reality, insinuating in this way that she has continued to be responsible for most of the household duties even in the difficult contemporary present. In effect, what she is saying is that her stroke has not really had much of an impact on her everyday life. Life in the domestic sphere, she claims, goes on pretty much as it always has, with her taking charge of chores.

In another example, a participant addressed a similar theme, except this time in the context of her professional life:

I question everything. I’m curious. I want to know how things work, how they are made, where they are from. Why I question everything (2) and since I’ve had my aneurysm, and realize my memory at times is really, really bad. (. . .) I question everyone. I tell my employees if you don’t understand, you MUST ask me.

Even as she acknowledges that her memory “at times is really, really bad,” she presents herself as someone who should be questioned, as someone who knows the answers, who is knowledgeable. With her statement “I tell my employees” (note that she does
not say I told or used to tell my employees) she brings a long-ago past—she has not been to work for a year—into the present. The tenor of her narrative is that she continues to be regarded by others as a figure of authority, as someone who is knowledgeable and competent despite her “bad” memory.

Another participant imports memories from his time as a university student. Again, by altering the verb tense he moves remembered events from the past into a present time frame:

Before my accident, I was in university and I pulled all-nighters. (．) A friend and I always did it together. We take turns keeping each other awake and making pots of coffee. (Laughs.) I pull all-nighters all the time.

In this way he creates the impression that even after his neurotrauma he continues to stay up the entire night to meet deadlines. Similarly, in other stories he insists he continues to be committed to his education, that he will do what it takes to succeed—including pulling all-nighters—presenting himself as someone who wants to be accepted to graduate school, and so forth.

In the next example of a memory importation, the participant does not rely on altering the verb tense but on shifting the general temporal location of a specific memory, moving it closer to the present:

Interviewer: How long had you been working there before your brain injury?
Participant: For about 2 years. I would like to move though. It’s not challenging enough. I got a call from another company. I spoke to the lady at HR [human resources]. We set up an interview.
I: You set up an interview?
P: YEAH, I know the job well.

Discontented with her work, this woman mentions a specific memory—speaking to someone about setting up an interview. In this short story, she expresses her perceptions at the time of the interview, namely, that her job is “not challenging enough,” even though she has been unable to work and, in fact, has not worked since her brain injury 1 year ago. The phone call she mentions happened before her brain injury. But in her story it appears in a present time frame. By importing it into her contemporary life she implies, willingly or not, that she retains the ability to perform her job and remains a desirable employee who is courted by other firms. Obviously, she sees herself not fundamentally changed, at least not in terms of her professional capacity, compared to herself when she had to leave her job 1 year ago. Her narrative does not speak of the challenge of her returning to work or her former life, but rather shifts to a challenge—applying for a new job—from her former life.

Memory Appropriation

The second linguistic technique we call memory appropriation. It involves taking someone’s memory, transforming it, retelling it in the first person, and in this way adding it to one’s own set of autobiographical stories. In short, it consists of presenting another person’s memory as one’s own.

This is demonstrated in the following excerpt from an interview with a bank employee. During the interview this woman appeared tentative and hesitant. Sometimes she lost track of what she was saying, particularly if she tried to remember something that might have happened since her stroke. In contrast to her typical hesitation, however, in this case she narrated the following story with confidence—a story about a visit she had with her neurosurgeon:

．．．My brother took me to Dr. D and then he saw me, he was so (. ) amazed at the recovery that I made. He said, “Do you remember me?” I said, “No.” And then he told me that he was my doctor and he did the operation. He told me I made an amazing recovery.

This story is a good example of a memory appropriation in that the participant actively transforms what she heard from others (in this case, her brother and sons confirm they had indeed told her this story many times), turning it into her own memory. This appropriated memory must be a seminal one as it makes five appearances in the interviews.

Notice that she does not say her neurosurgeon is amazed with her recovery so far, but that he “was amazed at the recovery [she] made.” What this phrasing suggests is that her recovery is complete. Although there might have been a time when she was in the process of recovering, at this point certainly this is no longer the case. This is quite consistent with the rest of the interview, during which she insists that she feels pretty much the same as she did before her brain injury and can do all the things she used to do.

Consider this example, a story about traveling to Kansas for a wedding:

P: As far as I can remember I took a plane on my own to get to Kansas. My sister picked me up at the airport. Then after flying and getting there, I missed
it because our car got STUCK in a puddle because of the dirt roads. My sister drove into a big ditch.

I: STUCK IN A DITCH (laughs). Did you push the car out?
P: Noo. I can’t remember who. (3) Maybe my sister?

Even here a memory appropriation takes place: in another part of the interview the participant explicitly states that she only remembers this event because it was repeatedly told to her. The memory she appropriates is a “positive” and confirming one, not a “negative” one that would, for example, assert change or loss in the aftermath of her stroke. Again, the message of this story seems clear: to emphasize that the teller can still carry out the activities she wants to, such as travel independently by plane. She suggests that her former self has only minimally changed.

A similar form of memory appropriation takes place in this story about a Christmas mess:

We went to my sister’s house for Christmas. There were 14 people. The dog jumped on the tree and it fell over smashing the ornaments. My nephew started crying. (.) We had to spend an hour cleaning up. The dog has never done that before. >We don’t know why.<

The teller places herself in the middle of a cozy Christmas scene, and in doing so she emphasizes her continued participation in “normal” family gatherings over the holidays. Although the content of this story is not as explicit as in the “amazing recovery story,” the self-confirming tone remains alike. The stories told are not ones of difficulties, changes, breaks, or losses, but of continuity and normalcy.

Memory Compensation

The third technique participants used to articulate their narratives we called memory compensation. It is different from the other two in that it does not involve the “manipulation” or “modification” of autobiographical memories. Rather, the focus here is on the search for memories, the attempt to compensate for their absence, to fill the gap. This might involve mental verbs such as “wonder” and “think,” and the expression of intentions such as “I’m trying to remember.” It is as if one wants to shift the attention from the result to the effort, from the recollected memory to the search for it.

As we also find such attempts to recollect, and to invite others to co-remember, in typical everyday conversations, this discursive device can easily work as a conversational “normalizer.” Using such a technique is a woman whose overall demeanor suggested detached puzzlement. During the interviews, she probed the multiple difficulties she was encountering: her constant fatigue and, in particular, her difficulty remembering:

P: I can’t remember anything. Why am I forgetting or am I not thinking things through? (.) Or was it really forgotten? I don’t know.

I: Mmm.

P: I should remember. Is that a symptom? I wonder what happened? You know, that’s what I don’t know. I don’t know if forgetting or asking things twice is a symptom of having an aneurysm or not? Is IT?

I: Depending on the part of the brain affected, it can be.
P: Is it?

I: Yes.
P: Well, there you are? Well, I think, why can’t I remember asking it? What happened to me?

I: What do you tell yourself?
P: Why am I forgetting things? I think I’m not trying hard enough to remember. I don’t know why. >I’m so tired< . . .

This woman puts strong emphasis on her role in figuring out as well as attempting to direct and define her story, which is indicated by her frequent use of mental verbs (“I think I’m not trying hard enough”). It is interesting that her insisting and persisting inquiries revolve around understanding the impact of her brain damage (What happened to me? Why am I forgetting? Why can’t I remember?). Yet it seems that this does not only serve to “normalize” the conversation, making it, for example, more interactive. In this discursive interplay she also positions herself as a continuously present “I,” and what’s more, an “I” that is very proactive—in the quoted sequence alone she uses the personal pronoun “I” 15 times. One might be inclined to think of the voice of an examining physician surveying her symptoms.

In a slightly different case of memory compensation, a participant speculates about what happened to his memory:

P: Why can’t I remember asking it, you know. Can’t think of anything else at the moment. Was it you that just took me into the kitchen? I don’t have a problem cooking.

I: No it wasn’t me.
P: I think, why can’t I think things through?

What is striking about these wonderings—which continue—is that this person is obviously very aware of his changed memory, and in fact, his entire mental
state. As in the previous example, he seems to be in a mode of continuous self-questioning. Left without concrete autobiographical memories of any dramatic changes in his life, it is not difficult to see how he might be led to a sense of continuity.

Discussion

What we see as the most surprising outcome of our research is that the participants, all people with severe memory impairments, appeared—despite the chaos in their lives—to have maintained a strong sense of sameness; in fact, of self-continuity. Even as they acknowledged their “really, really bad memory,” the gist of their stories unveiled a sense of self that seemed to have been largely undisturbed by their brain injury. Regardless of the obviously profound changes in their minds and lives, their narratives tell us about their persisting intentions and readiness to participate in everyday activities, whether these include managing household responsibilities, attending family weddings, or even pulling all-nighters.

A remarkable aspect of many stories was what they left unsaid: loss, limits, and adversity. It has often been pointed out that many illness narratives emphasize a break or gap between life before and life after sickness. The stories of our participants, however, are different—they evoke ongoing connections between pre- and post-morbid lives; they are narratives of unbroken senses of self.

All individuals in this study appear to draw on a self-experience that sustained the assault on their brain. This does not mean that their narratives were only ones of seamless continuity. There were elements of other stories, similar to those from people with chronic illnesses or disabilities, existing or emerging alongside the stories of self-continuity, sometimes (not surprisingly) contradicting each other. There was a suggestion of “chaos narratives” in that some of the stories appeared incoherent and lacked cohesion, and there were fragments of “restoration narratives,” although most individuals felt they had in some way already recovered their former sense of self, if they ever did feel the need to recover it at all.

Contrary to our expectations, the narratives from these individuals did not convey a sense of Nochi’s (1998) “lost self.” Given that the participants had only few or fuzzy autobiographical memories, and given that they only recently sustained their brain injury, one could have reasonably anticipated strong uncertainty, bewilderment, and disorientation ensuing from a loss of mooring in an autobiographical past. However, they told stories in which an amazing sense of continuity came to the fore.

To better understand this unbroken sense of self, we will look at it in three different ways, localizing matters in a neurocognitive, psychological, and linguistic context. Although we separate these different contexts for ease of presentation, they are closely intertwined.

The Neurocognitive Context

As with all language and all narrative, autobiographical narratives require neurocognitive resources. It is difficult to construct and alter stories about oneself and one’s postmorbid life if one is lacking memory ability, that is, without any autobiographical “raw materials” to fuel one’s personal narratives. As a consequence, as we saw, individuals draw on whatever is available—memories from their premorbid period of life, memories appropriated from others, and some remaining discursive skills to skirt the problem. Although participants might be aware of changes in their lives and selves, and what caused these changes, the experiences that reflect these changes are not remembered, and thus it becomes even more difficult to talk about them. It seems that all that has happened to them “after the catastrophe” must feel somehow distant, intangible, and odd. And even if they were able to construct, say, at least once, some narratives about what happened to them, it would be exceedingly difficult, if not impossible, to elaborate, thicken, or even simply repeat these stories because they would be unable to recall them.

The substantial loss of the capacity to remember apparently also led to a stark mismatch between individuals’ subjective self-experiences, on the one hand, and the catastrophes, the “real events,” on the other. Most patients, as we pointed out, felt that they did not have to recover their former sense of self because they subjectively seemed to have never lost it. Drastically speaking, they had forgotten the tragedies of which they were the protagonists. Indeed, many narratives attested to how, basically, they believed they were fine, ignoring—or as some might call it, denying—their clinical reality, namely, that they were drawing disability insurance and, most likely, unable to return to work or school and to carry out many daily life activities easily.

The Psychological Context

Another way to account for the surprising sense of continuity in our participants’ stories is to take a psychological point of view and think about the possible
impact of their needs and desires on them. Psychologically speaking, all narratives are intersubjective acts; they are moves in a discursive field, intertwined with motives, goals, and interests. Many storylines vary on the theme, “I think my lack of memory has not affected me a lot. But maybe it’s still going to,” as one individual put it. One can easily imagine what might drive tellers to stick to this theme. Emphasizing one’s self-continuity is not only comforting, it also allows participants to shield themselves from the possibly daunting and disheartening effect of becoming fully aware of how much their lives have changed and will continue to change. In fending off such threatening awareness, “continuity narratives” serve both stabilizing and reassuring functions.

Beyond comfort, there also might be a protective role of storylines that assert one’s continuous sameness. If someone is already struggling to cope with the immediate physical impact of a neurotrauma, then the shock of the full awareness and knowledge of the fundamental transformation brought about by a brain injury could lead to further negative psychological consequences. Such consequences could ultimately result in what neurologist Goldstein (1995) called a “catastrophic reaction.” A catastrophic reaction is a state of extreme confusion and disorientation mingled with anxiety, fear, and anger that has been observed in individuals after neurotrauma. Such patients experience their “new brain” and their inability to remember their own past as overwhelmingly distressing. Protecting against a catastrophic reaction, thus, might be a further important function of the narratives we have encountered.

The Linguistic Context

As mentioned earlier, language, and especially narrative, not only reflects and articulates the experience of brain damage, but also contributes to it. To understand this interplay, we must not, however, reduce language to its cognitive function. As far as the creation of a continuous sense of self in the absence of autobiographical memory is concerned, the social and communicative function of language might even be of greater importance. We should not forget one of the most salient qualities of narrative: that it fuses the neurocognitive, psychological, and evaluative functions with the communicative, that is, with social life.

As we have already discussed neurocognitive and psychological aspects, let us finish with a few words on the communicative and evaluative function of narrative. The communicative function of narrative is to connect the teller to the listener and the listener to the teller; it turns a narrative event into an interactive and social event. It is not difficult to recognize in the discursive and narrative behavior of our participants that they were particularly interested in this intersubjective and social function. For example, when one individual sets out to tell a slightly unusual story about a dog and a Christmas tree—a story obviously based on “memory appropriation”—she is not only moving her narrative along; perhaps more importantly, she is engaged in demonstrating that she can still be an active conversationalist and, what’s more, a teller of witty or, at least, unusual stories.

Piecing together stories about oneself almost always serves as a discursive facilitator, showing—in fact, performing—that the narrator is able to communicatively engage and keep up with this essential of social life. And it is true, listening to such autobiographical stories one can almost forget that they are told by people suffering from serious amnesia. It might not be too much of a stretch to assume that the tellers might have a similar experience in noticing that their stories “work,” which, as every storyteller can confirm, is ultimately more satisfying than bothering with the question of whether the details of a story might be factually true, or offer “only” what the psychoanalyst Schafer (1992) has called a “narrative truth.” We did not have any doubt that our participants liked sharing their stories with us. They appeared to enjoy the sociality of the narrative event, connecting intersubjectively, and in the process—as every social process is also an emotional process—presenting themselves as perfectly normal people with a perfectly normal sense of who they are and who they have been.

Finally, there is the evaluative function of narrative. Stories present a stance toward events and experiences of oneself and of others. They offer a perspective which often is linked to the way the teller positions himself or herself inside and outside the narrative. Many of the stories from our participants implied such an evaluative perspective, both on the narrated events and on themselves, but one that was taken from the premorbid past and used in an unchanged way in the present. Comparable to memory importation, one might call this a “positioning importation”: a stance or perspective from the past organizing an account about the teller’s present. Consider, for example, when one of the participants recounts how it came about that she set up a job interview. In this story, a picture emerges of herself as a woman ready and eager to take on more career challenges, a stance that was in fact typical of her in her life before her neurotrauma, but still underlies her
stories about herself in the present, as if her potential had not changed. Obviously her way of storytelling implies, for us and probably also for herself, a way of self-positioning and self-evaluation that strongly suggests a will to emphasize a continuity in her sense of self, a sameness that has not been affected by what has happened to her.

**Conclusions**

The experience of personal sameness (including the sense of continuity of oneself as an autobiographical subject), then, is the outcome of an interplay of factors within several contexts: neurocognitive, psychological, and linguistic. We are aware that the particular blending of factors from different dimensions that we observed and examined in our participants might not apply equally to all individuals with neurotrauma, or those who suffer from other types of cognitive impairment. This remains to be investigated.

We also believe that there is a need for further investigation into the specific developmental trajectories of narratives from people with memory impairment. One question, for example, is whether narratives that run counter to the continuity narrative gain more prominence over time. In other words, do individuals develop a sense of change, challenge, or even loss of self after they have lived their postmorbid lives for a longer period of time, and, furthermore, might this be related to psychological distress? In the present study we noticed participants did not express much observable distress. It would be worthwhile to examine whether changes in narrative style over time coincide with an increased level of distress. This would be consistent with the research literature on neurotrauma that suggests major psychological distress tends to have a developmental progression, increasing over time (e.g., Astrom, Adolfsson, & Asplund, 1993; Lezak & O’Brien, 1988; Prigatano & Summers, 1997; Robinson, Starr, & Price, 1987). This is of clinical importance as it might influence the rehabilitation interventions offered to these individuals.

One of the ten principles of neurorehabilitation put forward by Prigatano (1999) is that all individuals with neurotrauma should be given the option of receiving psychotherapy or counseling. But often, as Prigatano has observed, this service is not provided. If it is offered, many believe that one of the main objectives should be to enable an individual with brain damage to reaffirm or reconstruct a sense of self. However, the results of this study suggest that, at least for those with primarily memory impairments in the first year, this might be not what is needed in the first place. In fact, it might even be counterproductive for persons like our participants, who feel an unimpaired sense of personal sameness. It remains beyond the scope of this article to investigate if (and when) a sensitive challenge to this sense of continuity might be potentially beneficial. In contrast to people who say that their lives have changed dramatically because of illness or disability, our participants seem to claim that despite their brain injury, their being in the world has not really changed a lot; as if they did not have to concern themselves about recovering their selves because they feel they had never lost them.

**Appendix**

**Transcription Conventions**

<table>
<thead>
<tr>
<th>Symbol</th>
<th>Convention</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;&gt;</td>
<td>Speed up talk</td>
</tr>
<tr>
<td>&gt; &lt;</td>
<td>Slow down talk</td>
</tr>
<tr>
<td>(2)</td>
<td>Pause in seconds (here: 2 seconds)</td>
</tr>
<tr>
<td>( )</td>
<td>Micropause</td>
</tr>
<tr>
<td>( * )</td>
<td>Prolongation of preceding sound</td>
</tr>
<tr>
<td>Underlining</td>
<td>Emphasis</td>
</tr>
<tr>
<td>CAPITALS</td>
<td>Speech that is louder than the surrounding speech</td>
</tr>
<tr>
<td>Italics</td>
<td>Increase in pitch</td>
</tr>
<tr>
<td>[ ]</td>
<td>Transcriber’s comment</td>
</tr>
</tbody>
</table>

**References**


Medved, M. I. (2007). Remembering without a past: Individuals with anterograde memory impairments talk about their lives. Psychology, Health and Medicine, 12, 603-616.


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