



Everyday Imaginaries, Narratives and Strokes An Ethnographic Exploration of Narratives Among Stroke Patients and their Spouses

By Michael Andersen

Abstract

That a stroke is a disruptive event in many people's lives is no secret. That it also represents challenges to the communal construction of narratives between couples is less explored, and is the subject matter of this paper. With a narrative theoretical approach to ethnographic fieldwork conducted among couples where one partner has had a stroke, this article explores how everyday imaginaries are challenged when narratives are reassessed following a stroke. The paper suggests that sometimes the communal narratives are taken over by the part not directly afflicted by the stroke. Thus, when the non-afflicted spouse is in control of the narratives, they may be utilized as a way to monitor both the relationship as well as the brain of the spouse afflicted by the stroke.

Keywords: Illness, Narratives, Relationships, Ethnography, Everyday Life.

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Introduction

“...if I hadn’t been here things would be really bad, because Mr. Nielsen has no initiative whatsoever...zip, absolutely nothing. It’s an okay life anyway; you know I wouldn’t be without it. You get used to it, but if you think about it, I’m 71 and I was 56 when it happened (Mr. Nielsen’s stroke), that’s a lot of years. We have been married for forty-two years. Fifteen of those years have been in this way. If you begin to think like that it hurts. After all, we weren’t supposed to be in this situation” (Mrs. Nielsen).

The children’s book “*Found in the Waterlily*”, written and illustrated by the Ukrainian artist Svetlana Dorosheva (2016), tells the tale of magical creatures that set out to describe the anatomy and behavior of these hitherto mythical human beings. What the magical creatures discover is that the human brain is an interesting construct, invented by humans to make it seem like we live in the same reality, although inside each brain is a unique world where the person really lives. Inspired by Kathleen Lennon’s use of the term *everyday imaginaries*, which signifies the constant construction of imaginary shared entities within everyday life, I will discuss what happens when someone has a neurological condition that causes one to lose the ability to share these imaginary constructs. To encapsulate how such imaginaries are shared, I approach them through the analytical lens of narrative ethnography (Ricoeur 1984). In line with anthropologists Cheryl Mattingly and Linda Garro, I argue that we share our imagined reality through, and in, our communal narratives (2000). It is by analyzing the ruptures in these narratives that we get a sense of how our “imagined being together” is constructed.¹ Based on fieldwork among stroke patients and their significant others in Denmark, this article discusses what happens when the brain is affected by a stroke, and the impact this has on the everyday imaginaries of people who have had a stroke, but also how this affects their spouses. Thus, the article analyses interviews with stroke sufferers and their spouses. On the basis of the analysis, it considers what happens when the everyday imaginaries are challenged, and how the narratives are transformed in the process.

Literature on the topic of stroke has grown exponentially in the past three decades, ranging from self-help books on preventing strokes (Spence 2006) and coping with strokes (Raymond 2009) to neuroscientific articles on the correlation between strokes and genetics (Hassan and Markus 2000). Strokes represent a major medical issue that may cause expressive and receptive aphasia, loss of vision, paralysis, cognitive impairment as well as death. Consequently, strokes have a presence in almost all areas of society. Class (McFadden et al. 2009), gender (Petrea et al. 2009), race (Gaines and Burke 1995) and sexuality (Valanis et al.

2000) are just some of the parameters that are taken into consideration when the susceptibility to stroke is assessed and when looking at the impact of stroke. So it makes sense not only from an individual perspective, but also from a societal standpoint, that strokes are widely researched. As statistics from the “American Heart Association” shows, although the rates in CVD (cardiovascular disease) have dropped in recent years, leading to fewer fatalities (Go et al. 2013), strokes are still a major cause of deaths and long-term disability. In an article from 2003, Jan A. Staessen et al. state that worldwide, stroke is second only to ischemic heart disease as a cause of death (Staessen et al. 2003). A great deal of emphasis has been put on prevention. Lifestyle changes in particular have been promoted as being important to lowering the risk of stroke (Kurth et al. 2006). Identifying a number of risks as disparate as tobacco use and the level of education (Galimanis et al. 2009), stroke has manifested itself outside the confines of the body. A large number of social scientific studies show that stroke may have a significant impact on people’s everyday lives. (McKevitt et al 2004). Among these studies, many deal with how strokes affect not only the individual but also the afflicted person’s social surroundings, including a potential spouse (Becker 1997; Pilkington 1999). This article places itself within the group of studies that explores how the shared narratives of couples are affected by a stroke (Manzo et. al 1995).

Everyday Imaginaries and Narratives

That we share and construct our lives communally is an old anthropological axiom. Whether this life is constructed through, for example, shared myths (Levi-Strauss 1955) or inherent socio-material interdependence (Tsing 2005, Latour 2013), the point that we are interwoven into each other’s lives is the basis of all social sciences. In phenomenological and existentialist terms our Being-in-the-world is characterized by being thrown into a world in which it becomes itself through this relation to the world (Heidegger 1962 [1927])—a world shared by numerous other beings. Hence, as Alfred Schutz (1967) argues, many of us share life-worlds. Following up on the phenomenological tradition, Kathleen Lennon proposes the use of the term *everyday imaginaries* in her book entitled *Imaginations and the Imaginary* (Lennon 2015). In this work, she explores how we embody and construct imaginaries through our bodily and social presence in the world. As our openness towards the world is defined by these imaginaries—they essentially allow us to see certain meanings emanate from the world, while not being fixed categories—we have a responsibility to register, and be aware of what these imaginaries do. As Lennon argues:

[...] imaginaries need to be countered by alternative (and multiple) imaginaries, which make both cognitive and affective sense to the different groups of people who share a social space. We have suggested that one of the tasks of writers, visual artists, musicians and, perhaps, political leaders is to offer us new imaginary structures. But this is also a task in which we all take some part, via our everyday *iteration* of everyday imaginaries” (Lennon 2015: 138).

The question is how to approach these *iterations* of everyday imaginaries. In this article I suggest that imaginaries can be approached through their manifestations as narratives. By looking at how everyday imaginaries are sustained and created through, and in, the shared narratives of couples that live together, I will argue that these imaginaries are disrupted when a partner has a stroke. Furthermore, I will argue that the stroke, as a disruptive event, imposes a reassessment of the narratives that sustained the everyday imaginaries.

There is one name that continuously appears when doing research on narrative theory; Paul Ricoeur. With Ricoeur’s reformulation of narrative theory, he brought hermeneutics back to the forefront of modern philosophy by arguing that a hermeneutical approach to linguistics or language allows for an understanding human subjectivity (Ricoeur 1966). With his threefold *mimesis*, which is a significant methodological feature in one of his most famous works, *Temps et récit* (1991 [1983]), Ricoeur analyses how humans create narratives to construct meaning, and how these narratives are intrinsically tied to temporality. According to Ricoeur, narratives go beyond a “normal” description of time as the experience of linear succession (i.e., one minute following another), and instead express a phenomenological time in which time itself is experienced through its threefold dimensions: past, present and future. Everyday life is comprised of narratives; these often have a strong suggestion of causality, which negates the meaningless succession of events. Thus, when telling a story about everyday life, one is choosing what to tell, how to tell it and how to connect one’s choices in order to create a cohesive narrative (Ricoeur 1984).

Ricoeur explains the versatile use of events in narrative configurations by pointing to the structure of the *mimesis* model that consists of *mimesis* 1 (*prefiguration*): the prefigured basis that underlies the logic of the narration’s plot (Ricoeur 2002) and *mimesis* 2 (*configuration*): a kind of narrative “emplotment” in which an imaginative order creates and sustains a plot (Kaplan 2003). All of the narration’s elements become feasible within the plot, and so it mediates between the story’s objects and subjects, configuring their place within the network of the plot. Further, there is *mimesis* 3 (*refiguration*): which takes the imaginative perspectives from *mimesis* 2 and integrates them into lived experience—making

them part of one's identity and self-understanding. In short, for something to be understood it must rely on the ways in which our being-in-the-world is presented to us in our everyday lives, as it relates to how we understand the world. This is possible because, as human beings, our experience of the world is always already ordered, or prefigured, in a certain way. In effect, the narratives that we create play on our expectations and experiences. As a cyclical and hermeneutical process, the mimesis never ends. This is basically due to the fact that new life circumstances constantly alter and change the narrative, something which continuously calls for new interpretations. On the basis of our altered circumstances and new experiences, new networks of interpretation between subjects and objects are realized, and become part of one's identity formation. Events from the past are then prefigured, configured and refigured to match the new circumstances (Ricoeur 1984).

According to Ricoeur, a narrative lives by cohesion and structure, and a narrative that does not consider the plot (or the contemporaneous state of affairs) lacks that structure. Yet impressions of events are not fixed once and for all, but are malleable and change over time. This means that a narration is constantly open to changes and may co-exist along with other, perhaps contradicting, narratives of a certain event. This is best understood if one considers how a certain person, who one knows, may be configured in various narrations as defined by a range of different adjectives; e.g., good, bad, ugly, etc. While any given narration presents a part of the person in reference to the plot, the person might be different in another narration. Of course, we all know that people are multifaceted, but in the narration there is little structural difference between people or objects, or even events, as they pertain to the plot of the narration. As will become apparent in this article, in my informants' narrations, particular events are almost always configured in a certain manner; namely, that the stroke is a seminal event—an event that is thoroughly reviewed and disseminated as something that has altered the informants' communal way of life, as well as the everyday imaginaries of the couples.

Numerous philosophers and social scientists have conducted research on the use of narratives in the ethnography on illness. One of these is Arthur Frank, who in his book, *The Wounded Storyteller* (1995), presents three types of narratives that he argues are often encountered when dealing with people who are suffering or recovering from a prolonged period of bad health. Frank's illness narratives should not be confused with Ricoeur's narrative theory because of the similarity in taxonomy. Frank does not present the process of creating narratives as much as he describes the results of the narratives. These results are typologized into "restitution", "quest" and "chaos" narratives. The restitution narrative follows the narrative often encountered when dealing with a minor illness, such as the flu—

namely, locating the virus, getting treatment, rest or medicine and finally getting better. The quest narrative is somewhat opposite to the “return” of the restitution narrative; it is the integration of the experience of the illness into a retrospective as well as prospective dimension. An illustrative example could be a stress-related illness, which causes one to reconsider the pace and direction of one’s life, potentially altering it. In essence, the quest narrative could be interpreted as an eye-opener; it offers a premonition about what might happen if one does not alter one’s course in life. Finally, the chaos narrative is the direct opposite of the restitution narrative. It is devoid of a route, a plot or even a meaningful beginning or end. It is essentially difficult to understand, as there is no predictability or attempt to create a common thread throughout the narrative. As sociologist Sarah Nettleton et al. argue in “Enigmatic Illness: Narratives of Patients who Live with Medically Unexplained Symptoms” (2004), chaos narratives are often found among patients who live with undiagnosed illnesses. Thus, the chaos narrative—far from having what Mattingly and Garro (2000: 18) would call the “power of the narrative”, namely, connotative language and shared imagery—is a narrative without control and without the time to create any kind of narrative stability.

Much of the ethnographic literature on disease and illness stresses that illness is often disruptive to narratives (Murphy 1987; Kleinman 1988; Becker 1993; Kaufman 1988; Bury 1982; Mattingly 2002), and as will be discussed in this article, it can also be disruptive to everyday imaginaries. As Gaylene Becker writes on the construction of post-stroke narratives in *Disrupted Lives* (1997), illness narratives all begin with the advent of a disruptive event that questions one’s temporal being in the world:

Illness challenges one’s knowledge of one’s body. People experience the time before their illness and its aftermath as two separate realities. This perception of a dual reality of the known world (the recent past) and the “bad dream” (the present) constitutes chaos (Becker 1997: 37).

Coupled with Frank’s reasoning, the chaotic narratives represent a change in the structure and function of the former narratives, and as Becker argues, new narratives gradually replace the old ones. But sometimes this replacement takes on the character of a reassessment of old narratives, and thus, as Kleinman (1988) argues, post-illness narratives change not only the constitution and production of current narratives, but also previous narratives.

In the following section, I will discuss the role of reassessment in the communal construction of post-stroke narratives among the informants. The interviews that will be presented were conducted between 2011 and 2014. They primarily dealt with the informants’ experiences of everyday life after a stroke. During the

interviews, the spouses of the afflicted were present, and, as John Manzo et al. argue, the involvement of the spouse in the communal narrative—particularly concerning the event of the stroke—was very significant (Manzo et. al 1995). Also of interest is the fact that all these interviews were conducted with couples that have been living together and shared an everyday life for more than 40 years. It could thus reasonably be argued that the narratives presented in the interviews have been assessed and reassessed numerous times at the point of interviewing. Similarly, it is interesting to note how all of the persons afflicted are men, and how gender could potentially be seen as playing a role in terms of the expectations of caregiving as well as caretaking in communal narratives.

The Narratives that are Being Reassessed

Mr. and Mrs. Olsen live in a small apartment in Amager, Copenhagen. They are both around the age of 80 and have been married for more than 50 years. When I meet them, it has been less than a year since Mr. Olsen had a stroke, followed by a week of hospitalization. Mr. Olsen seems nervous, and Mrs. Olsen explains to me that, ever since the stroke, he has had a hard time finding the right words. Mr. Olsen says very little during the interview, and when he does, he asks his wife if what he is saying is true. The following is an excerpt from the interview:

(MA) *What can you remember, Mr. Olsen, from when it happened?*

(Mr. Olsen) Not much other than we were having dinner here, weren't we?

(Mrs. Olsen) No, we hadn't started eating yet.

(Mr. Olsen) But we were about to, weren't we?

(Mrs. Olsen) Yes, we were about to, and you hadn't had your glass of red wine, like we usually have, and then I knew something was wrong (smiles). Otherwise, I can't really say what we experienced, and you can't remember it. You can remember lying in the recovery room. Do you remember that?

(Mr. Olsen) Yes, kind of—don't I?

(Mrs. Olsen) (...) But in everyday life, things are working out fine, except not exactly as I would like it.

(MA) *In what way?*

(Mrs. Olsen) It's when you (*looks at Mr. Olsen*) can't reme...I have more things to do because you don't do so much. And then the fact that you can't remember makes me very sad, but we can't change that.

(MA) *But what is it you can't remember, Mr. Olsen?*

(Mrs. Olsen) I just tried something. We saw one of the women we know, who used to clean at our shop (they used to own a dry-cleaning shop). She said that her father also had [a stroke] and that he can't remember phone numbers anymore. So I asked you (*looks at Mr. Olsen*), "What's my mobile telephone-number, and what's the number for the landline?" But you do remember those numbers...so how is it you feel that you can't remember?

(Mr. Olsen) That's difficult to say, I think.

In this example, it is interesting to note the construction of the narrative in combination with assumptions about the nature of a stroke. While Mrs. Olsen assumes that Mr. Olsen has a limited memory because of the stroke, he does actually remember the things that Mrs. Olsen questions a person who has had a stroke would remember (i.e., telephone numbers). What is particularly curious is how his minor speech deficiency is perceived as a sign of memory loss. In other words, Mr. Olsen is presented as being incapable of constructing his own narrative—and thus his own identity—due to the stroke, and instead his wife becomes the constructor. However, she seems to construct a narrative that is influenced by what she assumes a person afflicted by a stroke would be like, which her talk with the cleaning lady exemplifies. Similarly, when speaking about the actual evening of the stroke, Mrs. Olsen introduces assumptions about the cause of the stroke.

(Mrs. Olsen) It's a strange thing, but it was Friday the 11th of February, and our son was here, and we were about to have some lovely food – it was steak tartare—so we were going to have a glass of red wine along with that. So I arranged the plates, but you were very fidgety (*she looks at Mr. Olsen*), you were all over the place, and then suddenly you sat down in here (the living room), and then our son called me. Then Mr. Olsen sat like this (*portrays a lopsided position*), with your mouth and leg hanging down.

(Mr. Olsen) On my left side, wasn't it?

(Mrs. Olsen) Then he said, "It's a strange thing", you know he could speak: "It's like my jaw is dislocated."

(Mr. Olsen) But that was just on the other side, wasn't it?

(Mrs. Olsen) Yes, it was the opposite side, and that was to a certain extent also correct, because in May 2008 we went to Rigshospitalet (a large hospital in Denmark) and a constriction of arteries was identified, and it was apparently the one that had darted up into his brain... that's how it happened. But our son was rather quick and called for an ambulance, and then I said, "We have to go to Rigshospitalet", because that's what they said back then, but they don't do that—the paramedics—and then we were driven to Glostrup. But it's an ugly ordeal—a very ugly ordeal.

As outlined, the narratives surrounding a stroke tend to be communal. But what is of particular interest in the narrative above is the sudden shift in time. Mrs. Olsen begins by talking about how the evening of the stroke progressed, going through the events meticulously and chronologically. However, when the question arises about where the stroke was first physically detectable, Mrs. Olsen incorporates another point in time into her narrative. This occasion serves to provide an explanation for the event of the stroke—namely, Mr. Olsen's constriction of arteries and the identification of this problem some years earlier. In her narrative, Mrs. Olsen manages to connect a previous event with the event of the stroke, even though she claims that the constriction of Mr. Olsen's arteries was detected on the right side of his jaw, whereas she also claims that the stroke was physically detectable on the left side of his jaw. This fact is lost in the overall narration due to the explanation that Mrs. Olsen offers about the mythos of the stroke. In essence, the retrospective dimension of the narration becomes the overall figure to explain the event of the stroke—as a sort of premonition, the stroke was always inherently present in the constriction of the arteries. Mirroring the structure of ancient Greek tragedies, the subtle or invisible warnings suggested at the beginning of the plot only become fully apparent at the end. The narrative essentially shows how a past event foretold the plot of the narration; i.e., the end was always present at the beginning. To that extent, the narration also represents a failed incorporation of the warning, which alludes to the possibility that the future event of the stroke could have been avoided if one had incorporated this warning into everyday life.

The interview excerpts also show how different heterogeneous elements become tied together, even though their significance to the narration is slightly obscured. For instance, the steak tartare that the family was supposed to eat along with a glass of red wine is a piece of information that does not immediately seem to add anything to the overall story. But it could be analyzed in relation to the establishment of a former prefigured basis for the narration. Although steak tartare is not an item commonly found on Danish dinner plates, the information creates the sense of a specific dining situation and establishes a background through which the shock of the stroke is filtered.

All the same, the narrative does not correspond very neatly with the narrative typologies presented by Frank. While Mr. Olsen knows that he has changed, he doesn't seem to know how he has changed, and Mrs. Olsen constantly attempts to put her finger on this change, but cannot really identify where it actually is. Thus, Mr. Olsen's narrative is not one of "restitution" or "chaos", nor is it a "quest". Different pre-stroke and post-stroke "signs" are taken into consideration by the couple during their narration. However, the changes in their everyday practices are not presented as willful; rather, they are changes that have been forced upon them. But identifying these changes—i.e., placing them in a meaningful relation to their notion of a stroke—is difficult. Mr. and Mrs. Olsen struggle to gain meaning from their pre-conceptions of what a stroke is, the information they receive about strokes in general and Mr. Olsen's actual experience of a stroke. In essence, something has to be wrong with the brain of Mr. Olsen since he has had a stroke, and this must have caused a change in his identity—the question is what this change is.

The stroke occupies a specific space in their communal narration as something that changed the couple's particular way of being. Mr. Olsen's brain is not the same, and hence their relationship has changed. This becomes clear when Mr. and Mrs. Olsen each explain how they think their everyday lives changed after the stroke. One of the things Mrs. Olsen notes is how her husband is no longer able to take their usual walk around the neighborhood. As Mrs. Olsen attributes this to Mr. Olsen's stroke, I ask at the beginning of the interview when his inability to walk this distance had started; she answers that Mr. Olsen had not been able to manage it for over two years. As she realizes that this does not correspond with the timeframe of his stroke, she blames general ageing instead. This demonstrates how Mr. Olsen's categorization as a stroke victim initially serves to explain the change in their everyday lives, while general ageing is later given as the explanation. In this sense, it is important that the stroke is used as an explanation in the narrative; i.e., to assign meaning to a change. This is something one often encounters in interviews, where the stroke—being a seminal event—is used to explain changes, most of which are often for the worse.

There are, however, also several positive narratives about stroke survival; general stories about how the stroke changed a hectic career into a more reflective and balanced life and stories about how to regain one's old lifestyle. The story of a neurologist who had a stroke that provided her with new insights into understanding the brain in *My Stroke of Insight* (Taylor 2006) and a movie, *Flawless*,² about how a stroke may force one to overcome prejudice (Schumacher 1999), are just a few examples of stories that fit into the cult of positive thinking (Ehrenreich 2009). The stroke is depicted in the media as a tragic event that may be mitigated if one "just" listens to what the stroke (as an anamorphous being) "is trying to say"—e.g. to change your lifestyle, reconsider your relationship with your family, work, etc. Hence, the stroke is not only an event: in many cases, it also becomes a point of identification. Thus, being a stroke victim is also potentially an identity that may give meaning to everyday life and explain a variety of limitations. However, being identified with one's brain deficit represents a challenge to one's notion of subjectivity (Andersen 2015) and thus the narratives that support this subjectivity are similarly challenged.

The hesitant way that Mr. Olsen talks about what happened—i.e., answering my questions by posing questions to his wife—shows how doubtful he is about his own narrative and subjectivity. One could argue that this uncertainty is due to the relatively unique situation Mr. Olsen finds himself in, but one could also say that it is difficult for him to reclaim a narrative that has been taken over by his wife. A narrative that Mrs. Olsen continuously, and throughout the interview, expresses that she feels she has had to be in charge of ever since Mr. Olsen's stroke. Finally, we could add that Mr. Olsen might appreciate Mrs. Olsen's possession of the narrative, as it offers a kind of safety in terms of his unique identity; i.e. that there is someone who knows the narrative better than he does, thus confirming the existence of that particular narrative. Yet, this narrative is currently being reassessed due to the perception of how a stroke would impact the narrative, and hence the everyday imaginaries are challenged and unsettled. In that sense, the shared imaginaries have been dispersed due to the anticipation of a stroke's impact on the communal narratives. However, the fact that Mrs. Olsen possesses their communal narrative, also retroactively confirms the existence of everyday imaginaries that the couple could get back to. In many interviews with couples, who have been living together years after the event of the stroke, the new narratives have been told numerous times, and so, despite their ambiguity, are integrated into everyday life.

The Narratives that have been Reassessed

Mr. and Mrs. Nielsen are in their early seventies. Mr. Nielsen had a stroke 15 years ago and he and his wife have struggled with the repercussions of the stroke ever

since. Amongst these is a partial paralysis of the right side of Mr. Nielsen's body. When Mrs. Nielsen talks about Mr. Nielsen's stroke she produces a very powerful narrative. This may in part be due to the fact that they have "performed" the narrative a couple of times for nursing students, as Mrs. Nielsen is the chairman of a local stroke organization:

(Mrs. Nielsen) He couldn't even sit when he was struck—he was like a toddler. Then he had what I would call an idiotic expression, and I thought, "Wow", but that's gone—it went away. A lot of things went away. He was discharged at the end of November and went to a day hospital for around fourteen days into December, and then I was talking to [the staff at the hospital], asking if he could get into Montebello. "No, that's totally hopeless. It's very difficult getting down there". Then I asked, "Can you apply?", "Yes, if you have to be so difficult, then we will." After fourteen days, we could go. We went for three weeks, and, at that time, I could come as a helper, and when Mr. Nielsen left the hospital, he could walk with a cane and then someone had to walk beside him, and when we came to Montebello, they made him walk by himself with a cane, and he has done so ever since. It just goes to show that intensive training gives such a result half a year later. Just think what would have happened if it had been intensive from the beginning...you know that...there are numerous research studies that show that if you are given a hand and get a quick rehabilitation then...maybe you're not capable of running a marathon, and you will probably always have to walk with a cane...but a lot can happen, and you know that, but it's not prioritized, because it's old people. I can see that when we apply for money [for the stroke foundation]. If I can integrate something into the application about how it might help young people as well, then it helps. It's a strange society. It's slightly bitter because young people also get old. That's how the youth is—we would probably have thought the same. You forget that you get old one day.

As Mrs. Nielsen tells the story of her husband's stroke, the narrative becomes the story of a struggle to get help. She alludes to the fact that, if it had not been for her own persistent behavior, Mr. Nielsen would have had little to no help in regaining some of his physical abilities. Telling the story, Mrs. Nielsen uses the narrative to portray an overall ideological point—namely, that young people are indifferent to old people who experience illness—and this is reflected in how the healthcare system in general cares for elderly people. The way Mrs. Nielsen operates in time is particularly curious here; she argues that she, due to having

been young once, can understand the attitude and premises of this attitude. In this way, Mrs. Nielsen uses her former self as a universal character of “youth”, who—due to her experience and a new categorization in life—is able to see how elderly stroke patients are somehow forgotten and written off by the Danish healthcare system. Mr. Nielsen’s categorization as “old” within the narrative supports the general view that he is not eligible for further treatment in the form of training. Nevertheless, this categorization seems to contradict another categorization earlier in the interview, where Mrs. Nielsen describes Mr. Nielsen’s categorization in the healthcare system as “young”:

(MA) *How long were you admitted, Mr. Nielsen?*

(Mr. Nielsen) It’s a long story because I was moved from there and over to Bispebjerg Hospital, because Mrs. Nielsen knew that out there, they had some proper facilities...

(Mrs. Nielsen) *(interrupts)*...they had a real stroke department. Back then, there weren’t so many of them. Then a neurologist came by and said they would take him because he was so young. They wouldn’t have told me that today, now that I am the chairman of the local stroke foundation. If so I would have said: “What did you say?”

(MA) *That’s an interesting explanation.*

(Mrs. Nielsen) But that was the explanation—that he was young. I didn’t think he was young...he was 60, but yes, he was young. But then they said “yes” and a bed was just supposed to come, so we moved out there on the 19th of May. Otherwise, he just lay and withered away at Amager Hospital with a physiotherapist coming by once a week... maybe twice.

As alluded to in the interview excerpts, Mrs. Nielsen explains how she has experienced that Mr. Nielsen has received different kinds of treatment depending on whether the healthcare system categorized him as old or as young. This may seem contradictory, yet Mrs. Nielsen expresses that she has experienced that Mr. Nielsen has been categorized as “old” due to the nature of his disease, even though his chronological age indicated that he was not old compared to most stroke patients. He was 60 years old at the time of the stroke, which situated him in a kind of limbo, or as Mary Douglas frames it, *Betwixt and Between* (1966), as the two narratives illustrate. Navigating through a healthcare system that does not

seem to definitively place Mr. Nielsen within a certain category has confused Mrs. Nielsen, and has made it difficult for her to figure out what she thinks Mr. Nielsen is entitled to and not entitled to. This confusion of categories and their perceived relation to healthcare entitlement has continued ever since, and so when Mrs. Nielsen experiences that Mr. Nielsen is framed as “young” in this system, he is entitled to certain benefits; but the same applies to him being framed as “old”, as exemplified by the extent to which Mr. Nielsen will receive free training to regain certain physical abilities. This limbo, being neither one nor the other in the system, represents an overall narrative on the disruption of identity following a stroke. Mrs. and Mr. Nielsen were searching for an identity for Mr. Nielsen within a healthcare system in which Mr. Nielsen was no longer a healthy 60-year-old man, but a diseased and crippled man of the same age. Even so, this uncertainty of categorization and identity also has some advantages that the couple has been able to utilize, such as actualizing a certain categorization and identity in different situations to achieve advantages. So when the narrative highlights the multiple identities given to Mr. Nielsen, it is consistent in showing how the disruption had an effect not just on him, but also on the management of his identity and experienced categorization within the healthcare system.

There are numerous examples of contradictory statements in narratives such as the one above. Sometimes, the dates are mixed up while, at other times, an event previously interpreted one way may be given an alternative interpretation within another narrative. The event may thus be configured in multiple and often contradictory ways that make sense within the specific narrative. In that sense events in narratives may be reassessed and altered every time the narrative is told. Sometimes, an event in the narrative may signify one thing and, at another, it may signify something completely different. A certain event might be the plot of one narrative and a minor feature in another. In essence, although the event might be the same, it is configured differently depending on the narrative and the plot of the narrative.

In a third interview, with Mr. and Mrs. Jensen, we see another example of how narratives may be constructed communally in order to assess the relationship between the couples. Between 1990 and 1997, Mr. Jensen had a total of seven strokes—approximately one each year—with the last stroke being, as he expressed it, the one that “broke the camel’s back”. During a conversation about traveling, Mr. and Mrs. Jensen construct a very illuminating narrative about a journey to the North Pole:

(Mrs. Jensen) ...but you’ve felt like traveling before, and we’ve also been out traveling. We’ve been to the US twice, and we visited some friends at the Ministry of Foreign Affairs in Brussels, but when you had just been

discharged from the hospital, we went abroad, and Mr. Jensen walked a lot better than he does now, and tell us, Mr. Jensen, where we went...

(Mr. Jensen) First, we were at the North Pole.

(Mrs. Jensen) (explains about their friends at the North Pole) ...then Mr. Jensen became ill, but we did it, anyway – didn't we, Mr. Jensen?

(Mr. Jensen) Yes, and I don't regret it.

(Mrs. Jensen) (directed at Mr. Jensen): Tell him how we did it...how we got up there.

Mr. Jensen tells the story and, as in the excerpt above, his wife supports him whenever he misses a detail she finds important. What is so interesting about this is the seemingly rehearsed aspect of the narrative. They both know how to tell the story, and it becomes Mrs. Jensen's way to assess Mr. Jensen's mental state; i.e., as a way of asking: "Is Mr. Jensen still capable of telling the narrative that we both know?" Thus, the narrative—and the way the narrative is told as agreed to by both parties—is crucial for assessing both Mr. Jensen's health as well as his identity (e.g., does he have some degree of dementia, etc.). Hence, the narratives become a way to assess and reassess their relationship.

That Mr. Jensen has changed, and that Mrs. Jensen feels that she has had to be in charge of everything—including their narratives—is exemplified by a story in which she talks about her frustrations with Mr. Jensen developing kleptomania syndrome after his last stroke. This was subsequently the cause of social alienation. Mrs. Jensen sought the help of a neuropsychologist to explain to her what had become of the old Mr. Jensen, and how to make the new Mr. Jensen accommodate to a new version of their former life together. However, this life has not been without its bumps and hurdles, and Mr. Jensen is reliant on Mrs. Jensen's caregiving, as well as caretaking of their narratives.

Mr. Jensen makes it quite clear during the interview that he does not want to be in a persistent vegetative state and that, if he has another stroke, his wife has promised not to call an ambulance immediately—something that Mrs. Jensen knows will be extremely hard not to do. The multiple strokes—and the last one, in particular—have solidly placed him in a liminal state with limited control of his own narrative identity, which is confirmed continuously throughout the

interview when Mr. Jensen asks Mrs. Jensen if what he is saying is actually correct. Paradoxically, it is through placing his trust in the communal narrative that he confirms that he is more than his damaged brain.

Concluding Thoughts

When we share our lives, our everyday imaginations crisscross and become interwoven. We express these imaginations through sharing narratives and the longer we stay together the more conjoined they become. When a stroke occurs, these entangled narratives may become challenged, and sharing a life where communal stories are challenged, often creates the need to reassess one's life. In this article I have approached how such a reassessment following a stroke, may cause the person with whom one is sharing a communal narrative to become increasingly involved, as well as in charge of the construction of the communal narrative.

As seen in the examples, the communal narrative is not simply a negotiation between each of the couples. Mrs. Olsen is in charge of theirs due to her husband's uncertainty; Mr. Olsen continually seeks his wife's help to re-tell their set story. However, his wife reveals her own insecurity about the narrative when she realizes that the stroke cannot explain a change in their everyday lives (e.g., being unable to take their daily walk). Mr. and Mrs. Nielsen have been able to alter their narratives to fit with their everyday life, despite various discrepancies. To a certain degree Mrs. Nielsen has taken over the construction of the communal narrative, albeit not to the same extent as Mrs. Jensen. The latter knows, and to a certain degree owns, the couple's communal narrative and can correct Mr. Jensen if he makes a mistake when telling a story. Mr. and Mrs. Jensen seem to have constructed a story upon which they have both agreed; but Mrs. Jensen uses it to test Mr. Jensen's mental abilities, and the narrative thus gives meaning insofar as Mr. Jensen is able to tell it.

The fragility of shared everyday imaginaries is exemplified when a disruptive event such as a stroke occurs. The narratives through which these imaginaries are continuously affirmed become disordered, and the partner who was not directly afflicted by the stroke is put in charge of the narrative. However, this simultaneously reveals to the partner not afflicted, the inherent construction of the imaginary nature that sustains the couple's communal everyday life. Consequently, the brain of the partner who has had a stroke essentially represents the loss of shared everyday imaginaries.

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Notes

¹ The resemblance between the notion of "imagined being together" and Benedict Anderson's coining of the phrase "imagined communities" is intentional (Anderson 2006[1991]). However, the focus in this article is on the constructions of everyday imaginaries between couples, and does not go into the question of the construction of nationalism.

² *Flawless* (1999) Joel Schumacher, Hollywood: MGM.

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