

Telling the Story of Stroke When It's Hard to Talk

Jacqueline J. Hinckley

Illness narratives may be told in various contexts and are reported to be associated with a variety of positive health outcomes, such as fewer doctors' office visits. The story of stroke onset can be highly varied among people without language impairments, seeming to reflect the way the individual is understanding and adapting to living with the consequences of stroke. Although individuals with aphasia due to stroke appear to have the linguistic capability to construct the typical forms included in a stroke narrative, it is unknown whether the range of narrative styles among individuals with aphasia parallels those produced by individuals without aphasia. Therefore, 20 consecutive stroke narratives drawn from the AphasiaBank database were subjected to content analysis through open coding to identify the major categories of the narratives. The narrative categories ranged from some that were highly detailed to others that were vague. Still others emphasized that stroke has a specific ending or beginning. Interestingly, only 20% of the stroke narratives produced by people with aphasia included the experience of speech symptoms at the time of onset. Researchers who study stroke narratives produced by people with or without aphasia should acknowledge the range of narratives that may reflect individual adaptation beyond other cognitive–linguistic abilities. Clinicians are encouraged to support the telling and retelling of the stroke story because it may contribute to the wellness of the individual. **Key words:** *aphasia, illness narratives, stroke*

IT seems natural to tell the story of one's illness or injury, and such a narrative is often shared in a number of different contexts. It is told to family members and friends as a way to garner social support, to doctors and health care providers as part of one's medical history, or to newly formed acquaintances to share potential common experiences. Illness stories also have the potential for influencing long-ranging health benefits, such as decreased self-reported physical symptoms or fewer doctors' visits (Pennebaker & Seagal, 1999). The telling

of illness narratives can also facilitate the reformulation of identity (McAdams, 1999).

When focusing on the long-range perspective of recovery and life with stroke, according to Faircloth, Boylstein, Rittman, and Gubrium (2005), clinicians and researchers often ignore the importance and disruption of the exact moment of stroke onset. Using interview data from 111 stroke survivors, patterns of description about the exact moment of stroke emerged. Many individuals described in detail the physical sensations that occurred at the exact moment of stroke. Others described the distancing between their mind or thoughts and the ability of their body to respond, objectifying the body as something separate from themselves, even during the minutes of stroke onset. Others minimized the bodily sensations, describing them as an "annoyance" that might soon pass. Faircloth et al. argued that by listening to how individuals characterize the onset of stroke, we gain a better understanding of how they will perceive their life from that point forward. Is it an attempt to regain an arm that, as the stroke evolved, seemed to

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become what one interviewee described as the flipper of a fish? Is recovery a process of understanding why the stroke and its consequences happened? Or is the stroke a relatively trivial event for some? Differences in the content and themes of the stroke narrative may help researchers and clinicians understand the role that the consequences of stroke play in the whole life of the individual.

To complicate matters, what happens when language impairment, such as aphasia, affects the individual's ability to tell the stroke narrative? Do individuals with aphasia relate similar themes within the story of their stroke onset as others without aphasia? The purpose of this article is to describe the content themes of the stroke-onset narrative of individuals with aphasia and to discuss those themes in relation to the existing literature on stroke narratives produced by those without aphasia.

ILLNESS NARRATIVES

Because the onset of illness or disability is often self-defining, narratives of illness frequently are vivid accounts that reflect an individual's grappling with issues within a specific cultural context. Illness narratives reveal one's culture's view of living with illness or disability, along with the individual's unique reaction to this set of circumstances. Because illness and disability are events that can befall anyone without warning, they are of interest to everyone (Hinckley, 2008).

An illness narrative is the story a person tells about becoming ill, first indications that something was wrong, what help was sought, how doctors and other health care professionals responded, and what treatment was recommended and pursued. An important part of an illness narrative is the individual's emotional reactions, intentions, motivations, and inner experiences during diagnosis and treatment. Illness narratives, like all narratives, are socially constructed. The context of the telling—to whom it is told, why, when, and where—contributes to the characteristics of the narrative. The illness narrative, thus, can-

not be divorced from the life story of the individual (Beck, 2005).

The illness narrative is a particular genre of story because it forms a bridge between the ideal life and real circumstances (Riessman, 1993; Skultans, 1998). These circumstances are founded within the cultural context, and illness narratives can inform clinicians and researchers about others' perceptions of health, illness, and coping within society.

Illness narratives are often described as their own form of healing, with reported psychological and psychosocial benefits. Telling the story of one's illness can reduce social isolation because telling the story is, of itself, a social constructivist process. Retelling (or rewriting) a traumatic experience yields more focus on personal emotional reactions, coping strategies, and meaning-making (e.g., Caplan, Haslett, & Burleson, 2005), and benefits can accrue from even a single telling of one's experience, combined with listening to other similar stories (Chelf, Deshler, Hillman, & Durazo-Arvizu, 2000).

STROKE NARRATIVES

Three general categories of illness narratives (Frank, 1995) can be observed across examples of stroke narratives. The first type, a *quest narrative*, which has been observed as the most frequently produced illness narrative form, is evident in the following example. In a book about her stroke, Perez (2001) reflected back on the years after her stroke. She wrote explicitly about how she interpreted her journey as a process that led her to a positive place:

My own journey to "stroke-land" was different from any journey I'd taken before, but it was worth all the effort because I learned to laugh at myself and to trust myself. Before the stroke, I wouldn't have been able to see a brain attack as an opportunity for growth, but it gave me the chance to delve deep inside myself and find that I was tougher than I thought possible. (p. 221)

The second type, a *chaos narrative*, although generally less frequently shared, is also represented in published accounts of

stroke. For example, Robert McCrum (1999), in *My Year Off*, wrote:

... I say that sometimes I feel like the pilot of an aeroplane who on looking over his shoulder in the cockpit sees his tailplane and the end of his fuselage suddenly blown away, but who finds, amazingly, that although his plane has gone into a “graveyard spin” somehow it has not crashed. Today, I feel like a pilot who is nursing his crippled craft to a safe landing somewhere unfamiliar, but close at hand. (p. 215)

The third type, a *restitution narrative*, typically depicts the story of illness or disability as a transitional state. Such is the case of Sir Frederick Andrewes’ account of his stroke, which was first published in the *St. Bartholomew’s Hospital Journal* in 1931 and later reprinted in the book *Injured Brains of Medical Minds* (Kapur, 1997). Andrewes wrote:

About three weeks from the first onset of my illness my temperature became normal and my physical recovery was now uninterrupted. The return of speech, which began in about a week from the onset of the aphasia, was really a process of thrilling interest, and left on my mind no shadow of doubt that it was one of the rehabilitation of the old cortical centres as a collateral circulation was established. How else could one explain the fact that I regained the power of counting the numerals up to 10 simultaneously in English, French, and German?

Despite the chaos and change described in these narrative examples, older adults who experience stroke do not always describe the stroke experience as much of a disruption in their life narratives as might be expected (Faircloth, Boylstein, Young, & Gubrium, 2004). Indeed, a range of reactions and perceptions about the experience of having a stroke and living with its consequences is paralleled by narrating and performing the stroke story, and much can be gained by examining how the stroke story is told. McKevitt (2000) addressed the range of how the stroke story is told with a few well-selected examples from a total of 40 interviews of stroke survivors.

Some interviewees relished the opportunity to recount the details of the stroke onset. Mrs. G., for example, was an interviewee who recounted the details of the stroke experience,

including health care experiences, the daily routine, and family stories. Mrs. M. also enthusiastically embraced the opportunity to tell about her stroke story, tearfully telling vivid details about the exact onset. Then, she went on to describe her rehabilitation course and the process of readjusting to poststroke life at home with her family and friends. She talked about spiritual views of the event and imagined the future.

I think the whole point is coming to terms with the way you are. I’m no longer the person who can walk for miles . . . I’ve got to take it quiet, take every day as it comes, that’s basically it. It’s a whole new way of life, really. (p. 84)

Mr. C., in contrast, provided the briefest answers to the interviewer’s prompts to talk about the circumstances surrounding the onset of stroke, his hospital stay, or his current life. He said: “You can’t do what you used to do anymore, like, you know. Finished . . . Nothing you can do about it, is there?” (p. 91).

Interestingly, Mrs. K. was interviewed in a similar fashion but had great difficulty with communication. Mrs. K.’s family identified her as deaf. Although the article does not report that Mrs. K. had aphasia, it is a likely possibility because the interviewer and Mrs. K. communicated via writing of single words or short phrases and gestures. “Despite, or perhaps because of, the frugality of the language available, the text of Mrs. K.’s interview is an evocative one, illustrating that fewer words can be as powerful as many” (McKevitt, 2000, pp. 89–90).

McKevitt (2000) suggested that the skilled, complete, detailed stroke narratives were produced by individuals surrounded by supportive family and friends and that these individuals had probably had the opportunity to tell and retell their story on many occasions. The participants who had limited ability to tell the stroke story “had less opportunity to articulate their own story to others and rehearse, piece together and reformulate a narrative of life after stroke” (p. 94).

Reluctance to share the stroke story may affect people’s ability to redefine themselves

and find purpose in life after stroke. Reluctance was not due to language impairment in these cases, but it could be a factor when aphasia is involved. The question addressed in this study asked how language impairment affects the telling of the stroke-onset story.

THE CHALLENGE OF APHASIA AND ILLNESS NARRATIVES

Literature and film depictions of illnesses such as dementia and stroke often show that the loss of cognitive-linguistic abilities disturbs the ability to narrate one's own story (Roy, 2005). But even in the face of the cognitive-linguistic impairments associated with dementia, narratives seem to continue to contribute to identity in meaningful ways (Hyden & Orulv, 2009).

Individuals with language impairments such as aphasia are at greater risk for social isolation, lower participation in activities, and reduced quality of life (Hilari, 2011). For them, barriers to the ability to tell the stroke narrative, and the contexts in which to share it, may affect social connections and perceptions of self and quality of life. People with aphasia may use a variety of means to embody or perform the stroke narrative (Hyden & Antelius, 2010). Research has shown that many people with aphasia demonstrate the ability to produce illness narratives while telling the stroke story that contains all of the basic narrative structures and to use both direct speech and reported speech while doing so (Ulatowska, Reyes, Santos, & Worle, 2011).

The story of how a stroke narrative evolved for a person with aphasia revealed how important it was to the individual's self-knowledge to tell and retell the stroke narrative (Bronken, Kirkevold, Martinsen, & Kvigne, 2012). The stroke narrative was coconstructed over several sessions during the first-year poststroke with a visiting nurse. This individual wanted to perform and communicate her experiences to enhance informational understanding and self-knowledge.

In the beginning, I wanted to talk about the stroke all the time The nurse helped me to give order to all of the thoughts and feelings that were swirling around all the time, which I didn't know where to put or what to do with. It helped me to find words and to put words to my thoughts and feelings. (p. 1310)

Do the stroke narratives of people with aphasia vary in similar ways to those without aphasia? In this article, a content thematic analysis was used to explore the themes conveyed within and between the words produced by individuals living with aphasia after stroke.

METHODS

Twenty samples of the stroke story, told by individuals with aphasia, were selected from the AphasiaBank database, a project in which interactions are stored and shared for the purpose of studying communication in aphasia (MacWhinney, Fromm, Forbes, & Holland, 2011). The AphasiaBank protocol was designed to elicit various types of discourse. One of the protocol questions is "Do you remember when you had your stroke? Please tell me about it." A starting point was selected randomly within the database, and 20 consecutive samples were analyzed from that point forward in the database.

The 20 participants all had given informed consent to have their samples included in the database for use by other researchers. Of the 20 samples, two had Aphasia Quotients from the Western Aphasia Battery that were above the cutoff for a diagnosis of aphasia; however, their stroke stories were still included in the analysis. The remaining 18 participants were aged 41–78 years, with a mean age of 59 years. The sample included 11 individuals with a diagnosis of fluent-type aphasia and 7 with a diagnosis of nonfluent-type aphasia.

The complete, transcribed response to the protocol item requesting the story of stroke onset was reviewed for each of the 20 samples, and the transcribed responses are shown in the Appendix. Content analysis (Elo & Kynas, 2008) was applied using open coding to

generate categories and link samples within and across categories. Initial codes were those that corresponded to narrative characteristics from previous work (Faircloth et al., 2005; McKeivitt, 2000). Verbatim, in vivo phrases were sorted and organized so that other new categories could also emerge.

RESULTS

Content analysis revealed four major categories among the 20 samples. Some of the stroke narratives were highly detailed, whereas others were vague and associated with an inability to recall the stroke onset, creating two of the categories. The two other generated categories were samples that described the stroke as a sudden ending or beginning and those that focused on speech loss as a primary symptom of the stroke onset (see Table 1).

Six of the 20 stroke stories were highly detailed. Here is the most detailed of these.

I was outside working in the garden . . . and it was hot, it was in the beginning of June, and it was three years ago when it was in the nineties, but I love to work in the garden . . . and all of a sudden I was getting not dizzy but you know I just wasn't feeling right, and I thought, "I think I better stop because it's getting too hot," so I cleaned up, I had a shower, and I went shopping, I was looking for curtains, and it was getting later because I always like to be home by 3:00 to watch my program,

Table 1. Characteristics of stroke stories told by people with aphasia

Narrative Characteristics	No. of Samples (N = 20)
Rich, detailed, thick descriptions	6
Vague, sparse, inability to recall stroke onset	6
Stroke is a sudden ending or beginning	4
Speech loss as a primary symptom of stroke	4

and on my way home I was passing another store which had curtains, and I thought "well let me check it out in there," and as I'm walking around all of a sudden you know it was like the flashing light going in and out you know, nothing hurt, but it was just getting weird, and I thought "what is happening?" [Appendix, 6]

Another one of these six highly detailed stroke narratives was less lengthy but still focused on the details of the experience.

Yeah um I was in my bedroom . . . my husband and I were going to sleep . . . and I wanted to get some medicine because my head was killing me . . . and then I couldn't speak after that . . . and then I went to the hospital. [Appendix, 9]

Six of the 20 samples related an inability to recall, or a loss of consciousness by emphasizing sleepiness. For example:

It was like the end of August. In fact it was Labor Day. When I was sick, I didn't, I was in intensive care . . . don't remember nothin' . . . I think I was sick I didn't even remember a lot of things. . . . [Appendix, 1]

Oh yes, one two three four five years ago . . . all of a sudden . . . I was sleeping . . . all of a sudden . . . I was in the hospital . . . all of a sudden boom . . . it was terrible. [Appendix, 2]

Three of the 18 samples emphasized the stroke as a sudden ending or beginning point.

Oh I have a stroke . . . and uh I can't do nothin' about it . . . [Appendix, 13]

I was gonna do something . . . I guess I was gonna do something with my computer . . . and I accidentally fall . . . went over the side . . . and I went down a flight of stairs . . . and I was that way I guess it was my brother or somebody found me . . . and that's when everything started. [Appendix, 14]

Four of the 20 samples described the stroke as a specific ending or beginning. Here are two examples:

. . . all of a sudden . . . [Appendix, 2]

. . . and that's when it all started. . . . [Appendix, 14]

Finally 4 of the 20 samples specifically mentioned their loss of speech as a primary

symptom at the onset of stroke. Here are two of those samples as examples:

um it's two years ago . . . when I had the stroke I couldn't say a word for a year and a half . . . then after that six months ago . . . I could talk slowly . . . now it's okay. [Appendix, 7]

um . . . hospital . . . and I'm going "I don't understand" . . . and [points to mouth] I don't know . . . [Appendix, 19]

DISCUSSION

The stroke stories of individuals with different types and severities of aphasia show that, even in the face of limited language abilities, differences in individual perceptions and different emphases on various aspects of the experience can emerge. Despite aphasia, some of these stroke narratives are detailed, similar to many of the stroke narratives produced by those without aphasia (Faircloth et al., 2005). Other characterizations of the stroke onset were similar to previously reported descriptions, such as describing the stroke as a sudden ending or beginning or describing the stroke in vague terms. Interestingly, only 20% of the narratives in this sample highlighted the speech symptoms associated with stroke onset, even though the samples were all drawn from people with aphasia.

How should we imagine how the loss of an ability to put into words an experience of potential life disruption? The experience can be, and is, performed in a variety of ways even with the language limitations. Others, perhaps, might have used few words to describe their experience even if the stroke had not diminished the use of those words. Others would perhaps want to use different words if only they could retrieve them. From the experiences of individuals who have had stroke

without aphasia, we learn about the variety of narratives. Similar types of narratives appear to exist among those with aphasia.

Telling and retelling the stroke narrative appears to be an important, perhaps crucial, part of the process that can return an individual from the disruption and chaos of a stroke and aphasia to a renegotiation of the self. Some work suggests that characteristics of how a life story is told may be associated with higher or lower levels of resilience (Randall, Baldwin, McKenzie-Mohr, McKim, & Furlong, 2015). For example, older community-dwelling individuals with higher scores on a measure of resilience tend to tell life stories that are richer in description, more complex, show more optimism and agency, characterize themselves and their actions in more positive ways, and tell more "redemption" sequences about learning or gaining something from life events. The current study found parallels between how people with aphasia told the stroke narrative and how those without aphasia tell the stroke narrative. It would be interesting to see whether the relationship between certain characteristics of the way the life story is told and the relationships to resilience would also be similar, despite the language limitations of aphasia.

Researchers who analyze stroke narratives must recognize that some of the variation between narratives reflects the personality, culture, and adaptation of the individual. The role of the speech-language pathologist is to listen to the stroke story, even when it has been told before, because it may represent individuals' work toward understanding what has happened and how they will approach the future. Communication supports and training to caregivers are tangible efforts that the clinician can offer that support the return to selfhood.

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APPENDIX

1. "It was like the end of August. In fact it was Labor Day. When I was sick, I didn't, I was in intensive care . . . don't remember nothin' . . . I think I was sick I didn't even remember a lot of things . . ." [58-year-old man, anomic, WAB 86]
 2. "Oh yes, one two three four five years ago . . . all of a sudden . . . I was sleeping . . . all of a sudden . . . I was in the hospital . . . all of a sudden boom . . . it was terrible." [69-year-old man, conduction, WAB 74.9]
 3. ". . . it was a Sunday night I think . . . and I don't remember anything at all . . . they found me laying on the floor . . . so I imagine I had been out from the night before . . . and I don't remember going to the hospital . . . and I woke up in the hospital . . ." [78.5-year-old woman, not aphasic by WAB]
 4. Interviewer: Can you tell me about your stroke? "No . . . because I was in and out of consciousness . . . the hospital told me . . . well um the hospital told me but I don't remember . . ." [75-year-old woman, transmotor, WAB 72]
 5. "I woke up through the night . . . and I didn't know what was wrong . . . and I woke up in the morning and I couldn't uh my clothes . . . I went downstairs . . . and I couldn't go anywhere . . . so I called my boss . . . and he was in surgery . . . and he called to the house . . . and he came to me . . . cause he just knew something was wrong" [68-year-old woman, conduction, WAB 65]
 6. "I was outside working in the garden . . . and it was hot, it was in the beginning of June, and it was three years ago when it was in the nineties, but I love to work in the garden . . . and all of a sudden I was getting not dizzy but you know I just wasn't feeling right, and I thought, "I think I better stop because it's getting too hot," so I cleaned up, I had a shower, and I went shopping,
- I was looking for curtains, and it was getting later because I always like to be home by 3:00 to watch my program, and on my way home I was passing another store which had curtains, and I thought "well let me check it out in there," and as I'm walking around all of a sudden you know it was like the flashing light going in and out you know, nothing hurt, but it was just getting weird, and I thought "what is happening?" [88-year-old woman, not aphasic by WAB]
7. "um it's two years ago . . . when I had the stroke I couldn't say a word for a year and a half . . . then after that six months ago . . . I could talk slowly . . . now it's okay" [56-year-old man, anomic, WAB 78]
 8. "sleeping . . . sleeping, tired, just tired man . . ." [44-year-old man, Broca, WAB 51]
 9. "yeah um I was in my bedroom . . . my husband and I were going to sleep . . . and I wanted to get some medicine because my head was killing me . . . and then I couldn't speak after that . . . and then I went to the hospital" [41-year-old woman, anomic, WAB 92]
 10. [after struggle] . . . "March 2005" . . . [52-year-old man, Broca, WAB 55]
 11. [71-year-old man, conduction, WAB 83]—detailed—dentist
 12. "we're going to dancing out in island . . . for dancing his birthday . . . so we're going . . . I saw them about seven that night . . . and I got up and I'm going "boy, something's really funny" . . . so I called to my friend . . . he says we're gonna leave you know . . . and I said . . . I have a problem . . ." [78-year-old man, anomic, WAB 73]
 13. "Oh I have a stroke . . . I get serious about my stroke . . . and uh I can't do nothin' about it . . ." [71-year-old man, transcortical motor, WAB 59]
 14. "I was gonna do something . . . I guess I was gonna do something with my computer . . . and I accidentally fall

- ... went over the side ... and I went down a flight of stairs ... and I was that way I guess it was my brother or somebody found me ... and that's when everything started." [65-year-old man, anomic, WAB 75]
15. "It was ... lemme see ... I don't remember anything ..." [66-year-old woman, transmotor, WAB 63]
16. "I woke up at one in the morning ... and I was on the floor ... and it took me about six or seven hours to get to the phone ..." [52-year-old man, anomic, WAB 90]
17. "one and a half days, nothin' ... and uh following one week ... slowly re-solving ..." [57-year-old man, anomic, WAB 70]
18. "uh no ... sleep sleep ... look around people people ... doctor nurse ... Bob husband ..." [61-year-old woman, conduction, WAB 72]
19. "um ... hospital ... and I'm going 'I don't understand' ... and [points to mouth] I don't know ..." [63-year-old man, transmotor, WAB 73]
20. "oh yeah ... [gesture drive] [gesture surprise] ... 'ugh' [points to hand, face] ... 'how do you do' ... 'sleeping ... sleep' ... 'done done.'" [70-year-old man, Broca, WAB 16]