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Signs of aphasia: Online identity and stigma management in post-stroke aphasia

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Abstract

This study aimed to investigate online strategies for re-negotiating identity, in terms of stigma management, developed by working-age Swedish Internet users with post-stroke aphasia, i.e., acquired language impairment caused by brain injury. Interviews were conducted with nine individuals (aged 26-61, three men and six women) with post-stroke aphasia. In addition, a total of 1,581 screenshots of online posts (e.g., photos, videos, text, emoticons) created by the same participants were collected. Drawing on social semiotics (specifically the three dimensions of online communication mentioned by Kress (2003), i.e., composition, content and context) and Goffman's theory of stigma (1963, specifically the concepts of stigma management and passing), qualitative thematic analysis was performed. Regarding composition, three themes emerged: Relying on others or technology, Beyond speaking and writing, and Controlling speed and timing. The participants rarely posted content about aphasia, but some of them used the Internet to raise awareness. Different online contexts had different meaning to the participants in terms of identity. Being open about the aphasia in one forum did not imply the same behaviour in another forum (e.g., dating sites). For the participants to pass (Goffman, 1963), should they want to, they needed to control all three dimensions. If the context or the composition revealed the stigma, controlling the content was not enough to pass. The multimodality of the Internet enabled the participants to manage their stigma in a variety of ways and to choose whether to be perceived as persons with aphasia or not.

Keywords: aphasia; identity; stigma; online communication; disability

Introduction

Human language is the mediating tool through which we express and construct our identities (Edwards, 2009; Van Leeuwen, 2009). We are, in many ways, the signs we make, i.e., our language. We negotiate the meaning of being who we are by constantly communicating with each other (Berger & Luckmann, 1966). We create and revise images of one another by interpreting verbal and non-verbal signs. In contemporary Western culture, "identity is always online" (Cover, 2015), meaning the negotiation of identity also takes place online. What happens, then, when someone's ability to communicate is reduced? What becomes of their identity – offline and online – when they become unable to use their words? These questions are crucial for people living with aphasia, since their language is severely impaired overnight, possibly evoking identity crisis (Shadden, 2005) and stigma (Goffman, 1963).

Therefore, we investigated online strategies for re-negotiating identity when living with aphasia. Our specific aim was to identify online strategies for stigma management developed by working-age Swedish Internet users with post-stroke aphasia, by scanning online data for stigma symbols and compare those to interview data.

The study is relevant to people living with aphasia, because of the potentially increased knowledge among clinicians, researchers and technology developers. Awareness is raised about the importance of including identity issues and online aspects within aphasia rehabilitation and the need of further research in this field. In addition, knowledge about disabilities like aphasia is required to create accessible and inclusive technology.

Disability and Online Identity

Research about the Internet as an emancipatory environment for people with disabilities is contradicting (Thoreau, 2006). On one hand, the Internet may be empowering because of its disembodying capacities. For instance, Buckley (1997) argued that teachers with physical disabilities may benefit from teaching in online settings compared to traditional classrooms, due to the potential disembodiment. On the other hand, when studying identity construction of people with disabilities, specifically on dating sites, Saltes (2013, p. 96) concluded that “despite the Internet’s capacity to facilitate disembodied anonymous interaction, the body and impairment play an important role in how disabled people construct their self-identity”.

Many studies of identity and disability assume intact linguistic function. For instance, Bowker and Tuffin (2002, 2003) , studied online identity construction by people with physical or sensitive impairments, concluding that they may construct “able-bodied” identities online. Those participants were literate, though, meaning we cannot entirely compare their situation to those living with language impairments.

Aphasia and Online Identity

Aphasia is a language disability caused by brain injury, most commonly stroke. Depending on cerebral location, severity of the stroke (Pedersen, Vinter, & Olsen, 2004) and time since onset, the linguistic consequences vary. Both written (Behrns, Ahlsén, & Wengelin, 2010) and spoken language may be affected.

Since language is central to identity construction, aphasia not only effects language but often evokes identity crisis (Shadden, 2005) and a need of “re-negotiation of self” (Hinckley, 2006). Corsten, Konradi, Schimpf, Hardering, and Keilmann (2014) stated that identity is “a key objective” when improving quality of life with aphasia. Blom Johansson (2012) argued that “if identity is a product of relationships, it follows that it may be harmed by having aphasia” (p. 20). One central question is whether to be perceived (by oneself or others) as a person with aphasia or not (Hinckley, 2006).

Despite the fact that the Internet forms an important part of Western literacy practices (Barton, 2007) and hence our identity construction, only a few studies combine aphasia, identity *and* online communication. Moss, Parr, Byng, and Petheram (2004) described that people with post-stroke aphasia felt ashamed of their online writing, because the text represented themselves. They implemented various strategies to improve their writing, including asking others to assist them. Fotiadou, Northcott, Chatzidaki, and Hilari (2014) studied online narratives in blogs written by people with aphasia and concluded that aphasia may have negative impact on the individual’s “sense of self” and on the “connection to a wider community”. These conclusions are consistent with the idea that aphasia may lead to social exclusion (Parr, 2007). Caute and Woolf (2016) described how a speech recognition software helped an individual with aphasia to regain “independent writing skills” leading to “reconnecting with important aspects of his pre-stroke identity” (p. 245). They (Caute et al., 2016) also argue that reading books helped “reconnect to pre-stroke identity”, but that reading paper books seemed to be more successful than reading on tablets.

Previous Research on Aphasia and the Internet

Previous research shows that language is crucial in identity construction, entailing a need of re-negotiation of identity when living with aphasia. A majority of the affected individuals (if living in Western countries like Sweden) were Internet users pre-onset. Nevertheless, research combining all three fields aphasia, identity and online communication is scarce. Instead, online technology is often studied as a rehabilitating tool. Several studies advocate the efficacy of computerised therapy, in terms of online vocabularies (Yasuda, Nemoto, Takenaka, Mitachi, & Kuwabara, 2007), word prediction or spelling software (Behrns, Hartelius, & Wengelin, 2009) or special designed software (Furnas & Edmonds, 2014). Sjöqvist Nätterlund (2010) studied 20 individuals with aphasia, within the setting of an "Aphasia House", concluding that they were eager to increase their Internet usage, but that they needed support and help in doing so.

Mortley, Wade, and Enderby (2004) studied online tele-rehabilitation, finding it to be successful because of increased independence of the individuals with aphasia. Almost a decade later, Hall, Boisvert, and Steele (2013) confirmed these findings in a systematic review, concluding that there are both benefits (e.g., improved attentiveness and reduced costs) and disadvantages (e.g., concerns regarding privacy and vulnerability due to technological malfunctions) and that more research is needed.

In addition to the rehabilitation approach, the Internet is sometimes studied as a source of information *about* aphasia. Kerr, Hilari, and Litosseliti (2010) investigated the information needs of stroke survivors, with and without aphasia. The requested information included "stroke causes and effects (particularly emotional issues), roles of local agencies, and returning to previous activities (driving, going out)" (p. 1170). Similarly, Ghidella, Murray, Smart, McKenna, and Worrall (2005) evaluated aphasia websites regarding quality and accessibility, concluding that accessible websites are not necessarily of high quality, or vice versa. Addressing issues of Internet accessibility may be a way of reducing the social exclusion following aphasia (Menger, Morris, & Salis, 2016).

Thus, further research combining all three fields aphasia, identity and online communication is needed. Fotiadou et al. (2014) advocated further research about how people with aphasia use social media, "both as a therapeutic outlet and also as a way for people with aphasia to feel connected to a wider community" (p. 1281). Brandenburg, Worrall, Rodriguez, and Copland (2013) argued that further research is needed about accessibility for people with aphasia, in particular regarding mobile technology. Shadden (2005) wants researchers and clinicians to better "understand this complex phenomenon called aphasia. Loss of identity is a critical clue in the understanding process" (p. 221). Within writing therapy for people with aphasia, there has been a dominant tradition of aiming to improve single-word writing (Thiel, Sage, & Conroy, 2015). Functional writing, especially in natural contexts, is much less studied. Considering the importance of the Internet as a literacy practice of the contemporary Western society (Barton, 2007), the study of functional writing in natural contexts should include online writing.

Theoretical and Analytical Framework

Two main theories constituted the theoretical and analytical framework of this study: Goffman's theory of stigma and social semiotics. While social semiotics is about sign-making in general, signs of particular interest were those revealing potentially discrediting information about a person, so called *stigma symbols* (Goffman, 1963). From the field of social semiotics, the three dimensions of communication described by Kress (2003), i.e., *composition*, *content* and *context*, were used to analyse the data. From Goffman's theory of stigma (1963), the concepts of *stigma management*, *stigma symbols* and *passing* were central to the analysis.

Identity and Goffman's theory of stigma

According to Goffman (1963) identity consists of three aspects: *ego identity* (your sense of self), *personal identity* (your biography and the documentation used to distinguish you from others) and *social identity* (the way you are perceived, by yourselves and by your partners, when interacting with others). In this article, the term 'identity' refers mainly to social identity, since that is where a *stigma* may emerge, as a discrepancy between an individual's *virtual* and *actual social identity*. The term 'virtual' is not to be understood as 'online' but rather as 'created by others'. The 'actual' identity is the way you see yourself regardless of context or interacting partner(s). Thus, a stigma emerges when there is a discrediting discrepancy between what others perceive about you (based on categorization) and how you see yourself. You then "[possess] a stigma, an undesired differentness from what we had anticipated" (p. 15).

A stigma varies over time and between contexts, and is to be seen as a "pervasive two-role social process in which every individual participates in both roles, at least in some connexions and in some phases of life." (Goffman, 1963, p. 163). A "language of relationships, not attributes" (ibid, p. 13) is needed when addressing the issue of stigma. On the other hand, Goffman (1963) also stated that some attributes are discrediting almost everywhere:

> "… there are important attributes that almost everywhere in our society are discrediting." (p. 14)

Within the contemporary Western society, aphasia might be such an attribute, due to the pervading literacy norms (Barton, 2007). Not being able to meet demands to communicate properly, as is the case when living with a language disability (such as aphasia or, as in the study of Thompson, Bacon, and Auburn (2015), dyslexia), may therefore be a stigma in almost any situation. Therefore, this study did not focus on whether aphasia is a stigma or not, but on stigma management (specifically in online settings).

Stigma symbols as sign making

Whether to be perceived as a person with aphasia or not is the result of managing the potentially discrediting *stigma symbols* (Goffman, 1963), which form part of the signs constantly made to represent meaning and (re-)negotiate identity (Berger & Luckmann, 1966). If you don't want others to notice your stigma you need to control the stigma symbols, i.e., you need to perform information control or *stigma management* by choosing whom to tell and when. Or, in Goffman's (1963) words:

> "To display or not to display; to tell or not to tell; to let on or not to let on; to lie or not to lie; and in each case, to whom, how, when, and where." (p. 57)

In the light of stigma symbols, *social semiotics* was a suitable perspective for this study, since it focuses on sign-making (semiosis) as a social phenomenon (Hodge & Kress, 1988). The signs are not merely words (Barton, 2007; Van Leeuwen, 2005) but also e.g., the media used to communicate or body posture. For people with aphasia, gestures form a crucial part of communicating (de Beer et al., 2016; Sekine & Rose, 2013) and should be recognised as valid signs.

Goffman (1963) differentiated types of stigma based on *visibility*, i.e., whether a stigma is visible to any interaction partner or not. Visibility is not to be confused with *know-about-ness* (Goffman, 1963). The fact that an interaction partner knows about your stigma is not the same as the stigma being visible. A non-visible stigma requires a more careful stigma management.

Should you want to *pass* (i.e., hide the stigma to the extent that others will categorize you as "normal"), concealing stigma symbols becomes important. The arguments as to whether attempting to pass is a preferable strategy, when living with aphasia, are contradicting. Hinckley (2006) argues that "successful living appears to require an adaptation of one's perception of self" (p. 25), implying that attempting to pass is not fruitful. Hamilton (2000), on the other hand, argues that people with post-stroke aphasia should be encouraged to maintain their pre-stroke identity. This is confirmed by the findings of Wallace et al. (2016) who found recovery to normality, including "to be seen as the same person as I was before" (p. 1371) to be an important therapy outcome for people with aphasia. To maintain the pre-stroke identity, attempting to pass then becomes a desirable strategy. Due to these contradicting implications, stigma management strategies are analysed without being assessed as positive or negative in this study.

Kress (2003) argued that online communication takes place in three dimensions: "that which is to be communicated" (here labelled *content*), "the modal realisation of the same" (here labelled *composition*) and "the site of appearance" (here labelled *context* below). He also argued that contexts have different *affordances*, which are to be considered when choosing how (composition) and where (context) to communicate. Affordances are "the range of possible activities" (Norman, 1999, p. 41) a person can perform upon an object. In relation to a certain online environment, our behaviour is limited to a possible set of actions. Affordances are not to be confused with conventions (Norman, 1999), since the former are properties of the artefact rather than socially accepted and anticipated behaviour. Thus, when studying stigma symbols online we need to consider the three dimensions and the affordances of the online contexts.

Method

A triangulation (Creswell, 2014) of methods, combining qualitative interviews and online observations was used to collect data. Nine working-age Swedish individuals with non-fluent aphasia following left-hemisphere strokes participated in the study (table 1).

Table 1. *Characteristics of the Participants.*

Name	Gender	Age at interview	Age at onset	Time from onset to interview
Einar	Male	54	53	13 months
Ellen	Female	29	24	~ 4.5 years
Frida	Female	41	33	~ 8 years
Johan	Male	53	51	17 months
Malin	Female	52	46	~ 6 years
Monica	Female	37	31	~ 5 years
Oskar	Male	61	54	~ 6.5 years
Rosa	Female	26	25	18 months
Sofia	Female	35	29	~ 6.5 years

Recruiting Participants

The participants were recruited by advertising in aphasia forums offline and online, with help from the Swedish Aphasia Association and speech and language therapists. Already recruited participants also suggested others. In this respect, the sample can be described as a combination of *convenience sample* (Creswell, 2014) and a so called “snowball” sample. All interested were invited to participate, if they met the inclusion criteria. They should be aged 25-65 and living with post-stroke left-side aphasia (medical records were consulted for confirmation); have Swedish as their mother tongue (since focus might have shifted from the aphasia to second language issues, had they another mother tongue); and be somewhat familiar with the Internet (so that online issues were not simply dismissed). Time since onset was set to be at least 6 months (according to praxis within Swedish aphasia research). The only pronounced exclusion criterion was any prior relation to the researchers.

Problem-Centred Interviews

Interviewing people with aphasia is challenging since their ability to communicate is limited. This makes *Problem-Centred Interviews* (PCI), developed by Witzel and Reiter (2012), a suitable choice when interviewing people with aphasia. The PCI is a qualitative discursive-dialogic method, combining inductive, deductive and abductive approaches. The interviewer engages in clarifying any misunderstanding by switching between questions generating storytelling and comprehension. While based on an interview guide, the PCI emphasizes the flexibility to meet the communicative capacity of the respondent, because “the respondent has the right to be understood” (Witzel & Reiter, 2012, p. 82). The goal is to reconstruct knowledge about a relevant *problem* (in this case the re-negotiation of identity when living with aphasia).

During 2015, nine PCI’s were conducted, ranging from 70 to 140 minutes (average length 100 minutes). Prior to the interviews, two pilots were conducted to ensure the relevance of the interview guide which eventually consisted of the following themes: stroke and aphasia, online behaviour pre- and post-stroke, multimodality, self-presentation, being the same person or not, stigma management and social aspects of living with aphasia. The interviews were recorded and later transcribed verbatim using NVivo. Immediately after each interview a postscript was created to summarize the experiences of the interviewer.

Online Observations

Methodologically inspired by *netnography* (Kozinets, 2015), online observations were conducted on online material produced by the participants. Unlike in original netnography where online cultures are studied in one single eligible forum, individuals were followed across forums. Thus, which sites to include was not determined in advance. Like the Swedish population in general (the Internet Foundation In Sweden, 2016) the participants turned out to mainly use Facebook, Instagram and blogs. For a few of them, relevant material was also found on specific webpages. Two of them (Ellen and Frida) previously had accounts on dating sites, but their profiles were no longer active. During the online observations, the researcher was connected to the participants as "friend" on Facebook and "follower" on Instagram. No interaction took place between the researcher and the participants within the included sites. One of the participants, Johan, was not actively participating in any observable online network. His online communication was limited to professional e-mails, and since his employer wouldn't permit access to his e-mails, no online data was collected. Nevertheless, Johan was included in the analysis since his interview provided relevant information.

Initially, more than 2,000 online posts (containing e.g., photos, videos, text and emoticons) were collected as screenshots and then sorted and scanned for duplicates. For most participants, all available post-stroke posts were collected and coded. But, regarding Frida and Rosa posts were excluded when saturation was considered reached, i.e., when (firstly) collecting and (secondly) coding more screenshots were considered redundant, or in terms of Fusch and Ness (2015, p. 1408) "when the ability to obtain additional new information has been attained and when further coding is no longer feasible". Frida was very active online, producing a great amount of posts. But since her topics were reoccurring, saturation was considered reached when no new topics occurred. Similarly, a website containing information about Rosa repeated the same kind of content, why coding more than the 11 included screenshots was considered redundant.

The total number of screenshots finally included in the analysis was 1,581 (table 2). The included posts were created post-stroke, but some of them contained information created pre-stroke but re-posted within the timespan of the study.

Table 2. *Overview of the Online Data: Number of Screenshots Included in the Analysis,*

Participant	**Facebook**	**Instagram**	**Blogposts**	**Items on webpages**	***Summary***
Einar	142	-	-	-	*142*
Ellen	187	1	-	-	*188*
Frida	575*	35*	1	11*	*622*
Johan	-	-	-	-	-
Malin	-	-	15	-	*15*
Monica	-	35	-	-	*35*
Oskar	127	5	-	-	*132*
Rosa	291	-	-	5*	*296*
Sofia	60	91	-	-	*151*
Summary	*1382*	*167*	*16*	*16*	*Total: 1,581*

**= saturated data*

The online data collection was conducted retrospectively from the date of the above-mentioned interviews, i.e., data created after each interview was excluded. This retrospective, or in Kozinets' (2015) words *archival*, approach is unobtrusive since data was created without any interference of the researcher.

Ethical Considerations and Approval

Ethical approval was granted by the Ethical Review Board in Lund, Sweden (Dnr 2015/109). Close attention was paid to the Helsinki Declaration (WMA, 1964) and to the ethical recommendations of the Association of Internet Researchers (Markham & Buchanan, 2012). Effort was made to ensure that the participants understood the conditions of participating. Written consent was collected from all nine participants, separately for interviews, online observations and access to medical records.

During the interviews, attention was drawn to clarifying any misunderstanding caused by the aphasia, and to any signs of the participant needing a break or wanting to end the interview. When collecting data online, the researcher used anonymous Facebook and Instagram accounts (Baker, 2013), to ensure the privacy of the participants. Some of the participants were members of online stroke or aphasia communities and out of respect for other members, no posts from these communities were included. As suggested by Kozinets (2015), any online alias was treated as personal names and thus de-identified. To prevent that online quotes could be used to identify the participants, all quotes in this article were translated from Swedish to English.

Analysis

Drawing on Kress' dimensions (2003) and Goffman's theory of stigma (1963), and using NVivo, qualitative analysis was performed based on these questions:

- Are signs of the aphasia (i.e., stigma symbols) or passing strategies visible in the online data?
- If so, are these stigma symbols or passing strategies visible within the composition, the content or the context of the communication?
- What do we know from the interviews about the participant's stigma management strategies, and how do these strategies interact with the findings from the online data?

In line with the PCI (Witzel & Reiter, 2012), the analysis was thematic but framed with predefined concepts from the literature, i.e., the dimensions (composition, content and context) and stigma management (in particular passing). Interview statements regarding stigma management and online communication were identified and coded accordingly. Stigma symbols, defined as follows, were sought in the online data of each participant respectively, across the three dimensions:

- Composition: linguistic anomalies not found within colloquial Swedish online communication (hence, overuse of blank spaces, misspellings of "de/dem/dom", conventional sound imitating writing, overuse of lower case letters and subject-less sentences were excluded)
- Content: explicitly mentioning aphasia or difficulties related to aphasia
- Context: participating in forums or groups related to aphasia

Then, analysis was conducted both *horizontally* and *vertically* (Witzel & Reiter, 2012) combining the two sets of data; first focusing on each participant (vertically) and then on each interview guide theme across the group (horizontally). As Witzel and Reiter (2012) point out, these analytical dimensions are constantly intertwined and dependent on each other, and this study was no different.

Notes were taken on the rationale of every analytical decision in a *reflexive journal* (Lincoln & Guba, 1985) which was then used to trace back decisions when needed. Performing a *negative case analysis* (Lincoln & Guba, 1985), the interviews were re-played to ensure no accounts contradictory to the results were found outside the coding.

Results

When reporting our findings, accounts are illustrated with authentic and de-identified quotations and screenshots. Quotes have been translated from Swedish to English, imitating the way each participant communicated (including repetitions and errors). In terms of transferability and validity, the ambition has been to provide *rich descriptions* (Creswell, 2014) of data.

Composition

Regarding *composition*, the participants were divided into those who attempted to pass, and those who did not. Oskar and Sofia made the least effort to pass, when posting on Facebook or Instagram. They seemed to have accepted their post-stroke ways of writing, and sometimes expressed pride over their aphasia and their improvements.

The rest of the participants mostly tried (and often managed) to pass regarding composition. Their strategies varied, but they shared the sense of wanting to post correctly written text and when that proved to be impossible, they preferred other modalities. When attempting to pass regarding composition, three main patterns emerged inductively from the data: *Relying on others or technology*, *Beyond speaking and writing*, and *Controlling speed and timing*.

Relying on others or technology. Some of the participants relied heavily on people surrounding them or on technology, when communicating online. For example, Johan had no Facebook account of his own, but since his wife was active in at least one Facebook group concerning stroke and aphasia, he still had access to the support of that group. When asked how he felt about his wife telling his story online, he said he was fine with it.

Einar only made a few Facebook posts himself, but was frequently mentioned and tagged by his partner. Since their privacy settings allowed her to tag him, the posts were visible to all his Facebook friends too. In his interview, Einar stated that he was comfortable with his partner handling most of the online activities for them both.

Rosa was, among other things, represented online by paintings she had created. Her mother posted pictures of her paintings on a Facebook page, and they were also available on a webpage. When someone made a comment on the site or the Facebook page, Rosa's mother was the one responding.

The online activity of Malin was limited to being represented in photos on a blog, where she also had made two posts. The texts in those posts were impeccable, though short, implying that she put great effort in writing them and that she had used word prediction software and had someone helping her. She complained about the word prediction tool (called Saida) not being available on her phone.

> Malin: But it is great that ehm have. But ehm I…I have help, on ehm, what? Sandra? No, what? it's called ehm…san/ they ehm, there is a help, on the computer, that corrects, what name? […] Sejd…Seja.
> Interviewer: It's called Saida, no? Saida?
> Malin: Yes! It very good!
> Interviewer: Yes, that's right, I know of it.
> Malin: Yes. It has, it has from her that ehm makes, that works ehm spe/apist. They say that.
> Interviewer: That's right. What do you use it for then? When you are writing on the computer?
> Malin: Yes, a little like that. But ehm I ehm…most is on the phone.

Rosa also pointed out the importance of well-functioning word prediction software, though she preferred the one installed on her phone.

The participants who were open about their difficulties relied on the understanding of others. For instance, Einar experienced support from his Facebook friends. They knew about his stroke and aphasia, and seemed to be happy that he was back online.

> Einar: They…they don't need that I a/a well express so much. They settle for what little I give. Whether it's just a like or… if I kind of write…whole comments or so, it really doesn't make that big…
> Interviewer: It is less important.
> Einar: Yes. Because at least they know that I can just "like" a little bit.

In the same way, Frida's Facebook friends knew about her aphasia, and were tolerant to her errors.

> Frida: Then there is the possibility that it's the wrong words…it's like they, they know I have problems.

Beyond speaking and writing. Through its multimodality, the Internet provided an alternative to speaking and writing. This was a relief to the participants, not least to Oskar who had great difficulties speaking. When asked about his feelings about communicating online (specifically on Facebook) he said it was easier because he didn't have to speak.

> Oskar: It…// Here [means offline]. ”Ssssspeak”.[talking exaggeratedly badly to show that it is difficult].
> No, here [means Facebook],'tis wonderful.

All the participants (except Johan, who had no accounts of his own) frequently posted photos of themselves or things they had experienced. For many of them, posting photos was a more effortless and thus preferred way of communicating than writing, although they occasionally combined the photos with a short written caption.

Emoticons were frequently used among the participants (most frequently by Frida, Ellen and Sofia). On Valentine's Day, Einar posted a set of hearts instead of writing something to his partner in words (Figure 1).

14 februari

Figure 1. Post by Einar on Facebook on Valentine's Day.

Also, the like-button was an easy way for the participants to interact with others, most clearly verbalized by Einar. When asked about progression he answered that he was unable to write immediately after the stroke. The like-button was then a way for him to interact without having to type.

> Einar: I've kind of noticed that I could, ehm…comment more. I, I…before I was all blank kind of. I cli/clicked on “like” and such. Now I have started to write a bit more, like ehm…well, all sorts, just small things like, but not too much.
> Interviewer: Okay. And before the stroke, what was it like then?
> Einar: Well, then I wrote all the time.

Another recurrent strategy was sharing texts, often embedded in pictures, as in the many “memes” shared by Ellen. She frequently shared memes containing quotes (screenshot 2), not least because she didn't have to write the message herself.

> Interviewer: How about writing?
> Ellen: Well, it's… okay. [tapping the table with her fingers] It's like… [laughter]
> Interviewer: Yes, that's right, only using your forefingers.
> Ellen: Well, but… I don't write badly that much. Well… in the beginning it was like all wrong, so… […]
> Interviewer: Do you post a lot of pictures?
> Ellen: […] Yes…and such. Like, I'm very into like, what I do a lot, like…quo/ what's it called? quotes and such, like…/pictures and stuff, like…they say a lot!
> Interviewer: Uhuh… And then you don't have to write by yourself?
> Ellen: No, exactly. A picture says…[laughter] Yes.

These strategies (i.e., posting photos or emoticons, “liking” and sharing) have in common that you use very few keystrokes to share visual or written information, no matter the length of the shared content.

One strategy used by Oskar, offline and online, was to name years to signal tense. Hence, he did not need verb forms to signal present, future or past tense. Online, he formulated sentences in the shape of mathematical formulas. Combining those two strategies resulted in posts like:

> Abby=Smalltown (and Daffy=Dead)
> (Boxer on 2016?2017? on Oskar…)

Knowing Oskar from the interview, we understand this post as "One of my dogs, Abby, now lives in Smalltown, and my other dog, Daffy, is dead. Maybe I will have a boxer again in the future, in 2016 or 2017."

Some of the participants (most obvious Rosa, but also Ellen and Frida) used colloquial language when writing online. Their writing was adapted to the accepted, and in many ways anticipated, ways of online writing, including overusing lower case letters, spelling words like they sound (e.g., Frida constantly writes "oxo" for the Swedish word "också", which is the way it is pronounced), and the typical Swedish error of inserting too many blank spaces separating words in the wrong places.

Controlling Speed and Timing. Several participants expressed not being able to communicate as fast as pre-stroke. Thus, they chose modalities in which they were in control over speed and timing, e.g., by choosing asynchronous tools over synchronous. Frida needed time before posting since she wanted her writing to be as good as possible.

> Frida: Well I have to, it takes me a bit more time, if I am to write something, then I have to think, before I put - just like poof! kinda - because I want it to be like correct.

In the same way, Einar didn't use the synchronous Facebook Messenger as much as pre-stroke since it was hard for him write.

> Einar: Yes, it is. It is very hard. Both reading and writing and all that stuff. […]
> Interviewer: Do you use Facebook a lot to write messages directly to people, in the chat window?
> Einar: No…not as much, bef/ as ehm before…
> Interviewer: Is it the same, that writing is a bit hard?
> Einar: Yes, I guess it is what's troubling me…So it's…

When writing e-mails, Johan's strategy was to let writing take its time. He considered himself almost recovered in terms of spoken language, but not when writing and especially considering the time needed to write. On the other hand, he appreciated that writing gave him time to think before posting.

> Johan: But…I CAN write. However, it just takes longer time. But I mean it works. And ehm…sometimes it is like it's better to write, because then I can write exactly how it is, then I can think and write out the whole…If I speak to people, simultaneous to other people, a lot of people, then I can't keep up.

All the participants were right-handed before the stroke, and most of them had motor control impairments on their right side, which meant they struggled with writing by hand. Typing on a keyboard was more effortless, which also meant reducing the time needed to write. Monica, Sofia and Ellen stated this explicitly.

Content

Regarding *content*, the participants chose between disclosing and revealing their aphasia, and their strategies varied across forums but also across individuals. For some of them, the content contained no signs of aphasia at all. For instance, Malin's blogposts did not include anything about her aphasia. Neither did the Instagram posts made by Monica. Instead, they were about everyday topics, like the weather or having nice meals. In terms of stigma, they passed as normal regarding the content of their posts.

Others mentioned the aphasia explicitly. Oskar posted short texts on Facebook about the activities during rehabilitation, including aphasia:

> Morning workout (8.30!!). Reading, Verbs and word order, computer, theatre, voice training (Speech Lang), singing, Aphasia, tell something and life before & after. See you…

Some of the participants used Facebook to raise stroke and aphasia awareness. In fact, Frida had her medical record published on a Facebook page intending to raise awareness. Alongside the medical record, she posted notes about her experiences, in which she mentioned her aphasia at several occasions.

> And I couldn't speak, could say two sentences-I want…but I couldn't, -Maybe want…I tried to formulate…But I couldn't…I wanted to go home.

Sometimes Frida tried to anticipate any critique towards her literacy skills. She openly told about her difficulties, and asked for people's understanding:

> I couldn't write but practice a lot at writing, so there is risk of me writing wrong, just so you know.

Ellen posted a lot of memes, occasionally containing implicit information about aphasia. When she shared a quote saying "Silence is the most powerful scream" (Figure 2), the interpretation got clear because we knew about her aphasia.

Figure 2. Post ("meme") shared by Rosa on Facebook.
Embedded caption: "Silence is the most powerful scream".

Context

The *context* in which the communication takes place also matters when it comes to stigma management. For instance, several of the participants were engaged in Facebook groups concerning stroke and aphasia. During the interviews, they expressed joy and gratitude over being part of these groups, not least because they didn't have to be ashamed of their difficulties. Depending on the purpose and target group of these communities, the mere belonging often indicated living with aphasia, which was also the case for entire social networking sites. The clearest example is that Malin made two blog posts on an aphasia blog, where she was also portrayed in pictures. She signed both posts with her full and authentic name, meaning that if her name was put into an online search engine, the information about her aphasia became obvious. Though her posts were correctly written and their content was not explicitly about aphasia, the mere fact that they were posted on this specific blog still revealed her stigma.

When Ellen was asked if she was active on LinkedIn, she answered that she wasn't because she thought it was only for working people, implying that she no longer identified herself as an employable person.

> Interviewer: So, LinkedIn. Are you on it?
> Ellen: No. I understood it is, like…it's mainly for people that work. No? I don't know…

On Facebook, Frida was completely open about her aphasia, but on dating sites she was more restrictive. Thus, she made a distinction between different social media networks regarding whether to reveal her difficulties or not.

> Interviewer: Did you tell [on the dating site] about your experience? That you have been afflicted by this?
> Frida: No, not in my profile, not like "hello, I had a stroke!" you know…
> Interviewer: No?
> Frida: No…people will think you are plain stupid. And then that…that you are in a wheelchair, and can't talk…then like…

Ellen had also been active on a dating site, but she had implemented another strategy than Frida, and synced her profile with her Facebook account causing her Facebook information to be visible on the dating site too.

Affordances varied across sites. For instance, on Instagram posting photos or short videos (and then writing comments) is the only afforded way to communicate (i.e., you cannot post anything without uploading a photo or a short video). This enabled Monica to pass completely since she acted like everyone else on Instagram, i.e., posting photos of her everyday life combined with a short comment like “ah, roses!” (Figure 3).

Figure 3. Post shared by Monica on Instagram.
Her own comment: ”Ah roses.... <3”

Another aspect of context was that the participants, to various degrees, were members of Facebook groups or followed pages related to stroke or aphasia. Thus, on their Facebook profiles, their Facebook friends could see that they were interested in these issues. While some of the groups or pages were subtler, others were more explicit. For example, Sofia was a member of the Facebook groups “Training with disability”, “Rehabilitation after stroke” and “Aphasia”, implying that she was living with post-stroke aphasia.

Discussion

Even with the relatively small number of participants, a large variety of strategies was found. For example, Oskar was completely open with not being good at writing, while Malin chose to use technology and support from others to only post correctly written text. A variety was also found regarding online forums. The clearest example was Frida posting her medical record on Facebook, but attempting to pass on the dating site.

Stigma Symbols across Three Dimensions

Stigma symbols were identified across all three dimensions (composition, content and context). Regarding *composition*, the strategies were clustered into three themes. The theme *Relying on others or technology* confirmed the findings of Moss et al. (2004) about people with aphasia taking help from others before publishing text online, and of Sjöqvist Nätterlund (2010) about people with aphasia wanting assistance to access the Internet. The theme *Beyond speaking and writing* raised questions about how the multimodality of the Internet may be related to the use of gestures described by e.g., de Beer et al. (2016). And finally, the theme *Controlling speed and timing* emphasised the importance of developing asynchronous communication tools to enhance accessibility and thus reduce social exclusion following aphasia (Menger et al., 2016).

The participants rarely posted *content* about aphasia, though a few of them (most explicitly Frida) used the Internet to raise aphasia awareness. Most of them did not explicitly mention aphasia (or the difficulties associated with it) at all. The fact that we, as researchers, knew beforehand that they were living with aphasia made it possible to interpret some posts as aphasia related, but to someone who didn’t know these posts would have been non-revealing. This was, for example, the case when Rosa posted a picture of her damaged brain or when Ellen posted the “Silence is the most powerful scream” quote. Thus, the distinction between know-aboutness and visibility (Goffman, 1963) becomes clear. We noticed signs of aphasia because we *knew* about it, not because they were in fact visible.

If the participants belonged to a certain *context*, their stigma was revealed by their mere presence in that forum (e.g., blog or Facebook group). Some of the participants made clear distinctions between forums. Being open about having aphasia on Facebook did not imply the same behaviour on a dating site, as told by Frida. Therefore, the Internet must be regarded as a set of many forums rather than one coherent forum, as is also indicated by e.g., the findings by Saltes (2013) describing the use of dating sites for people with disabilities.

Stigma management should be discussed in relation to in which of the dimensions the communication takes place, since they proved to be dependent of each other. Should a person with aphasia want to pass, stigma symbols need to be controlled within the dimensions in a specific order, namely context, composition and then content. The most obvious example was the online communication of Malin, whose composition was flawless and whose posts contained no information about aphasia, but who still could be identified as a person with aphasia because of the context of her communication. Hence, if the context and/or the composition contains stigma symbols, and therefore reveals the aphasia, the content becomes irrelevant.

Contextualised Stigma

Goffman (1963) argued that a stigma is not a static state but rather a continuum and a process. This was obvious in our findings, where the stigma of living with aphasia could be seen to vary over time and between contexts – between offline and online, but also between different online forums or sites. Stigma management should therefore be discussed in relation to conventions, norms and affordances. As Kress (2003) points out, the context and the composition of the communication are restricted by the affordances of the medium, but our findings showed that the affordances also created settings where the participants were more likely to pass, i.e., if their abilities lied within the afforded activities of the sites. The content, on the other hand was not restricted by affordances but rather by norms and conventions, confirming the assumptions made by Kress (2003).

Methodological Considerations and Limitations

As suggested within the PCI methodology (Witzel & Reiter, 2012), flexibility was needed during the interviews to meet the communicative capacity of the participants. The only identified drawback with this flexibility was that the interviewer sometimes helped the participant finding words. In this respect, those interviews could be argued to have a low validity. However, great effort was made to ensure consensus between interviewer and participant. The clearest example was Oscar, who had great difficulties finding words and repeatedly wanted help from the interviewer. Oskar did not give up until consensus was achieved, resulting in prolonged parts of the interview. Not helping him, and thus not meeting his communicative needs, would have been disrespectful and probably would have led to less meaningful data.

It is a known problem within disability research that the most vulnerable individuals are often left out, which unfortunately often means excluding those with severe language disabilities. The participants of this study volunteered after seeing our advertising. Presumably, this means the participants are not representative for the entire population living with aphasia. Some would never volunteer because of the severity of their aphasia.

In addition, in some cases the participants were recruited via speech and language therapists, the Swedish Aphasia Association or already recruited participants. This may well have influenced the results, because those “gate keepers” probably only recommended well-functioning individuals to participate. The stories told by the participants were in many ways “success stories” (although containing elements of frustration, grief and pain), and we presume that those stories are not representative for individuals less rehabilitated.

The triangulation of methods enhanced the validity of the study because it resulted in rich descriptions. Only observing the online communication would have left us wondering about the participants’ intentions and we would have missed important aspects such as the severity of the aphasia when speaking and writing by hand. In the same way, only relying on interviews would have denied us the opportunity to analyse the authentic online communication. It would have been risky, since there might have been differences between how the participants talked about their actions online, and how they actually acted.

Conclusion

The findings emphasise the importance of not assuming that everybody with aphasia prefers the same strategies, and that the Internet must be regarded as a set of many forums instead of one single forum.

The online multimodality enabled the participants to pass, should they want to, by choosing non-revealing ways to communicate. Whether to be perceived as a person with aphasia was in their own control, and we know from the interviews that this choice mostly was intentional. When attempting to pass, they needed to control the dimensions context, composition and content – in that particular order.

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