Online and offline re-negotiation of self when living with post-stroke aphasia

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Background: Aphasia, i.e. language disorder caused by brain injury (most commonly stroke), affects some 10,000 people in Sweden every year, 30% of whom are between 18 and 65. Much has been said about neurological or medical aspects of aphasia, but experiences of people affected are much less studied.

When living with post-stroke aphasia, the stroke constitutes a boundary between separate phases of life, often evoking an identity crisis and a need of a re-negotiation of self. Considering that 90% of the Swedish working-age population are Internet users, this re-negotiation process will necessarily include online aspects. Nevertheless, research combining aphasia, identity and online communication is scarce. Thus, this study aimed to investigate how working-age Swedish Internet users with post-stroke aphasia re-negotiate their identity, offline and online.

Method: Qualitative interviews were conducted with nine individuals (three men and six women) living with post-stroke aphasia (all diagnosed R470). At the time of the interviews, they were between 26 and 61 years old. In addition, a total of 1,581 online posts (e.g. photos, videos, text, emoticons) created by the same participants were analysed.

Results: The analyses indicate that the participants, in their re-negotiation of self, frequently position themselves in relation to other disabilities, e.g. by stating “I am not stupid” or “At least, I can walk”. This positioning varied depending on which points in time (i.e. pre-stroke, acute phase, rehabilitation, post-stroke) were taken into account.

Conclusion: Whereas some of the participants struggled to maintain a representation of themselves similar to their pre-stroke identity, some proudly embraced aphasia as a new aspect of their identity. Furthermore, they seemed to have better opportunities to control the re-negotiation process in online settings than offline.