ORIGINAL ARTICLE

Aphasia – an existential loneliness: A study on the loss of the world of symbols

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Abstract

The aim of this study was to analyse the existential consequences of aphasia and the struggle to regain the ability to communicate. Data were collected by means of interviews, published books and diaries from four women and five men, who varied in type of aphasia and time since cerebral lesion. Data were interpreted in accordance with a lifeworld hermeneutic approach. The findings led to six interpretations, which serve as a base for a comprehensive understanding and which indicate that the intentional, non-verbal act when something is recognized as something is not affected by aphasia. Aphasia affects the world of symbols, which is necessary for interaction with others. It is connected, therefore, with feelings of alienation, inferiority and shame in social settings. Losing one's ability to recognize symbols thus makes it essential to cope with existential loneliness. The outcome, a sense of community or alienation, appears to depend on the quality of interpersonal relations. The results thus demonstrate that interaction and communication are important aspects of professional care giving.

Key words: Aphasia, intentionality, symbolization, care giving, lifeworld, hermeneutics, existential loneliness

Introduction

Aphasia is a malfunction in the use of language, which may occur in comprehension, expression, reading or writing. It is characterized by loss of or severely impaired linguistic capacity due to a brain lesion such as emboli, haemorrhagia, oedema, trauma or tumour. Aphasia can take different forms and vary in severity, but it often affects all verbal domains (Nance & Ochsner, 1981). Aphasia is also associated with acalculia, i.e. disturbance in arithmetic capacity (Basso, Caporali & Faglioni, 2005).

About one-third of patients with acute stroke also suffer from aphasia (Pedersen, Jorgensen, Nakayama, Raaschou & Olsen, 1995; Laska, Hellbom, Murray, Kahan & von Arbin, 2001). Laska et al. (2001) reported that mortality during an 18-month follow-up among aphasic patients with stroke was twice that of stroke patients without aphasia. After 18 months, 24% of the 119 aphasic patients in the study had recovered completely, 43% still suffered from significant aphasia, and 21% had died. Great improvements were seen, however, in many patients, irrespective of type and degree of aphasia.

If aphasia prevents a person from producing speech, i.e. expressive aphasia, there is an anterior brain lesion in Broca's area. While the individual concerned can understand language, the words are not properly formed and speech is slow and slurred. Posterior lesions in Wernicke’s area cause impressive aphasia, which is even more devastating, as it prevents a person from understanding language. Individuals thus affected can speak clearly, but the words do not always make sense. Ferro and Madureira (1997) found that expressive non-fluent aphasia was more common in young patients, suggesting an anterior lesion in Broca’s area, while posterior infarcts, in Wernicke’s area, were more frequent in elderly patients. Knepper, Biller, Tranel, Adams and Marsh (1989) found cardiac emboli in 40% of patients with posterior cerebral infarction.

The main treatment for aphasia, a condition that challenges the whole of the individual’s being (Nilsson, Jansson & Norberg, 1997), is speech and language therapy (Berthier, 2005). Depression,
However, is a common experience related to coping with post-stroke effects such as aphasia (Robinson, 2002) and has been found to have a negative impact on rehabilitation (Hafsteinsdottir & Gryponck, 1997). Depressed persons with aphasia suffer from reduced self-esteem, which may change their self-image (Tanner, Gerstenberger & Keller, 1989). Depression may further affect the motivation needed for improving functional independence, as failure to participate in the community due to impaired verbal ability often results in feelings of loneliness and isolation (Währborg, 1991). Many patients with aphasia have, however, been excluded from studies focusing on depression, in spite of their frustrating condition with its extensive existential consequences (Åström, Adolfsson & Asplund, 1993).

It seems fair to assume that increased knowledge about the existential consequences of aphasia, as a total life experience, is required in order to improve the provision of care for these patients. The present study is part of a major project about aphasia and its consequences. The aim has been to analyse and describe lived experiences of aphasia and the struggle to regain the ability to communicate.

**Study design**

The study design had a lifeworld hermeneutic approach. Life-world research emphasizes individuals as living wholes and focuses on the world as it is experienced prior to the formulation of any hypothesis to explain it (Dahlberg, Drew & Nyström, 2001). In this study, an interpretative analysis inspired by Gadamer (1997) and Ricoeur (1976) was used to understand the lifeworld of persons with experiences of aphasia.

In order to achieve the greatest possible degree of scientific openness during the interpretation process, in line with Gadamer’s request that “our need to become conscious of effective history is urgent because it is necessary for scientific consciousness” (Gadamer, 1997, p. 301), the starting point of this study was first to define and then to disregard the researcher’s pre-understanding. In order to approach the subject in a critical way, the interpretations also involved explanations of meanings in the data (Ricoeur, 1976). For this reason, theories were sometimes used as analytic tools. The tools employed in this study comprised philosophic aspects presented by Merleau-Ponty (1989) as well as ego-psychological aspects derived from Anna Freud (1966) and explanations in the realm of symbolic interactionism (Charon, 1989).

**Participants and data collection**

The study was conducted in Sweden, with Swedish speaking participants. They were purposefully selected from two branches of the Swedish National Fellowship for Aphasia, in order to obtain variation in age, gender, type of aphasia and time since cerebral lesion. Type of aphasia was reported by the participants and/or their spouses.

When gathering data it was considered necessary to communicate in a way that facilitated understanding. Some participants could speak adequately, while others still exhibited the symptoms of expressive and/or impressive aphasia. An important criterion, which limited the number of potential participants, was the need to communicate relatively well, orally and/or in writing. In this study, communication refers to both explicit and implicit meanings that are expressed and interpreted in social intercourse. Participants, representative of impressive aphasia had thus either recovered or learned how to carry on a conversation in spite of difficulties in understanding words. Four women and five men, aged 45–72 at the time of data collection, participated in the study.

The data mainly took the form of transcribed audiotaped interviews, which followed the principles of the lifeworld approach mentioned above. The participants were invited to reflect as openly and deeply as possible upon their experiences of aphasia, their struggle to regain the ability to communicate, professional care giving, consequences for family life and other interpersonal relations. Additional following questions were for instance, “could you elaborate this and could you give me an example”. When more information was required in order to establish the relevance of a tentative interpretation, some of the participants were contacted again for follow-up interviews. In the follow up interviews, the questions were more specific and aimed at obtaining information that could further illuminate the relevance of tentative interpretations (see validity criteria below). The follow-ups were not audiotaped but notes were made. Three participants supplemented their interviews with written material that further illuminated their statements, such as diaries or written advice from the participants to other persons with aphasia.

Two books that described experiences of aphasia (Tropp-Erblad, 2002/1882; Dahlin, 1997) were complemented by interviews in 2005. Some participants thus contributed to data on several occasions. Time between brain lesion and data collection varied from 1–23 years. All data were transformed into text. See Table I for distribution of participants and their contributions to the data.
Analysis

All data were read several times and the meanings were classified into three main categories that described experiences of:

- aphasia and the struggle to regain the ability to communicate
- professional care-giving
- consequences for family life and other interpersonal relations.

In the present study, the first category was analysed. However, it is fair to assume that this initial searching for meaning in the text was influenced by the researcher's pre-understanding. According to Gadamer (1997) pre-understanding often determines in advance what will appear as an object of investigation, “and we more or less forget half of what is really there – in fact we miss the whole truth of the phenomenon when we take its immediate appearance of the whole as truth” (Gadamer, 1997, p. 300).

In order to accomplish a critical reflection concerning pre-understanding the researcher's initial thoughts concerning the significance of language, communication and loss of language were identified, reflected upon and written down. Data from the first category were then compared and combined into themes and sub-themes (Table II). The procedure for identifying pre-understanding was concluded by comparing the themes and sub-themes with the written reflections.

Interpretations

All sub-themes in Table II were then used as pieces of a jigsaw puzzle that no longer belonged to the themes. They were compared and put together in a new way in order to understand further meanings in the data. Tentative interpretations emerged, each illuminating aspects of the complexity that characterized experiences of aphasia. The researcher's previously identified pre-understanding was restrained during this process and the relevance of the tentative interpretations was evaluated by using the following validity criteria:

1. The source of an interpretation should only be an actual piece of data. (Thus, theoretical support is merely a tool for explanation.)
2. There should be no other interpretations found that better (more meaningfully) explain the same data.
3. There must be no contradictions in the data concerning interpretations that are considered valid.
4. The level of abstraction is connected to the principle of moving from parts to the whole and vice versa, striving for consistency in the jigsaw puzzle of interpretations.

When more information was required in order to establish the relevance of a tentative interpretation, some of the participants were contacted again for follow-up interviews. As mentioned above and shown in Table I, several participants made more than one contribution to the data.

Finally, all interpretations that were deemed valid were compared with each other in order to arrive at a comprehensive understanding in line with the aim of the study. The consistency of the picture that emerged was further strengthened by ensuring that no data of general importance were omitted from the comprehensive understanding. (Analysis of the second and third categories is presented in other articles.)
Table II. Themes and sub-themes that describe experiences of aphasia and the struggle to regain the ability to communicate

| Themes               | Sub-themes                                | Example of statements                                                                 |
|----------------------|-------------------------------------------|---------------------------------------------------------------------------------------|
| The acute phase      | Shock and fear                            | No, this must not happen to me!                                                      |
|                      | Incomprehensible calmness                 | I was totally calm and analysed the situation.                                        |
|                      | Dizziness and confusion                   | My head felt as if it was filled with cotton wool.                                    |
|                      | No memories – was unconscious             | I was told afterwards what had happened.                                             |
| Cognitive consequences| Loss of ability to speak, read and/or write| I was totally mute.                                                                  |
|                      | Impaired arithmetic capacity              | I couldn’t count the coins.                                                          |
|                      | Impaired ability to estimate time         | I don’t know how many years I have been like this.                                   |
|                      | Impaired ability to use and understand gestures | I shook my head but meant yes.                                                       |
|                      | Impaired logic                            | I couldn’t place a pen in a box when asked to do so.                                 |
|                      | Finding a “meta-language” behind the verbal language | It’s not true that you can’t think without words.                                   |
|                      | To think of things as “wholes”            | Everything took the form of natural and immediate meanings.                          |
|                      | A trying and slow thought process         | It is hard and arduous to think and speak.                                           |
|                      | To have a rough understanding             | I just understand fragments and have to guess the rest.                              |
| Emotional consequences| Insecurity                                | I became frightened and insecure because I was unable to express what I meant.       |
|                      | Anger                                     | I became furious when I couldn’t find the word.                                      |
|                      | Humiliation                               | I was like a parcel labelled: useless sample.                                        |
|                      | Self-contempt                             | You are nothing if you cannot speak.                                                 |
|                      | Suspicion                                 | Comments like “your speech defect is minor” made me suspicious.                      |
| Existential consequences     | Being shut up in the body               | The soul is locked in an impenetrable prison.                                        |
|                      | To realize one’s impairment               | When the physician asked me to name the wall behind him, I understood that I was mute. It was horrible! |
|                      | Giving up efforts to understand           | There was a wall between me and everyone else.                                      |
|                      | Loneliness                                | When I looked at people it was as if they were wearing masks.                        |
| Strategies to handle life without access to adequate verbal communication | Humour and self-irony | Sometimes I made fun of myself. If friends fail to recognize me as the same person they are of no use to me. |
|                      | Not being afraid to make a fool of oneself | I work twice a week helping others with aphasia to regain language.                |
|                      | Commitment to other persons with aphasia  | I made every possible effort to take one thing at a time.                           |
|                      | Self discipline and rationality           | My world becomes smaller every time I find that I have been thinking in the wrong direction. |
|                      | Trying hard to understand by puzzling impressions together | I ask them to speak slowly.                                                        |
|                      | Taking initiatives                        | I practised words at the door of the hospital’s emergency department.                |
|                      | Finding out how to practice language      |                                                                                  |

**Ethics**

Principles from the Swedish Humanistic and Social Science Research Committee (HSFR 1999) were found to be a relevant guide for ethical considerations in this study. Hence, information about the study was provided orally and/or in writing, including the aim of the study, that participation was voluntary and the opportunity to withdraw at any time. The authors behind the published books (Tropp-Erblad, 2002/1882; Dahlin, 1997) gave their consent to be a part of this study. During the further data collection, the researcher made every possible effort to notice non-verbal signs of wishes to withdraw from the interviews. All participants were assured of confidentiality, and the analysis was conducted with the intention of maintaining the integrity of all persons who took part in the study.

**Findings**

Six interpretations are presented below that together explain the meanings identified in the sub themes (Table II). The comprehensive understanding about the loss of language and the struggle to regain it concludes the interpretative analysis.

*It is essential to repress feelings in order to act rationally during the acute phase*

Despite the fact that warning signs, such as TIA or thrombosis in veins, were common, all participants experienced their aphasia like a bolt from the blue. For some, all verbal communication suddenly ceased; while others could speak fluently but without making sense. Finding oneself in such a situation was generally perceived as a horrific experience,
although in retrospect it was only partly associated with feelings of shock and fear.

Only one participant was unconscious, while others were confused and unable to act rationally. One of them recalled that she just wanted to take a nap and lie down in the snow beside her car. For another, the first indication of a brain lesion was somewhat unusual; he bid on everything at an auction. Those who were less confused recognized that they must act in order to get help, and afterwards they were surprised by their ability to act rationally. One man, for example, was alone in his weekend house when it happened and knew immediately that he was unfit to drive. He understood that he had to walk quite a distance in order to contact his neighbour. His rationality seemed at least partly due to repressed feelings of panic.

Some concluded that the capacity to repress feelings of shock and fear was due to a biological process associated with their cerebral lesion, while others explained their calmness as a mix of biological and psychological processes.

Your body cannot accept that you cannot speak. You can’t understand it emotionally. (Is this, do you think, due to the cerebral lesion?) No, not just the lesion, it is also a psychological process.

Such statements indicate that the calm is experienced as a process of repressing feelings due to psychological defence mechanisms, such as isolation and rationalisation. The concept of isolation is used by ego psychologists (Freud, 1966; Blanck & Blanck, 1974) in order to describe mental processes where feelings are separated from thought. Isolation as a personal characteristic can indeed be problematic, but it is also an important resource in moments of threat and panic. Isolation of feelings seems in fact to make it possible to put them aside in order to act in a rational manner. The man who became aware of his aphasia while alone in his weekend house knew immediately that he must repress his feelings in order to get help and employed his isolation and rationalization skills as a conscious strategy (in contrast to the theory of unconscious psychological defence-mechanisms).

When I recognised that I could neither speak nor write I understood immediately that it was important to remain calm and take one thing at time, and I repeated that to myself every time I was almost seized by panic.

After arrival at the hospital, it was possible to stop repressing feelings. This supports the explanation that feelings are repressed only when it is necessary to act in a rational way. However, other participants stayed calm for a long time, even after their arrival at the hospital. One woman was unaffected by her severe communication disabilities for a period of two years. It was not until she started to speak again that she became frustrated and angry when she was unable to communicate.

It thus appears impossible to fully explain the calmness in the acute phase of aphasia. Nevertheless, it seems fair to conclude that it is important to be able to repress feelings in an acute situation when it is urgent to make decisions about how to get help.

Emotional life is intertwined with the struggle to regain language

Four participants in the study regained the power of speech within three months. The others still exhibited greater or lesser language impediments, both oral and written, at the time of data collection. They spoke slowly and now and then failed to find the right words. Some also experienced difficulty understanding non-verbal expressions of meaning, such as nodding for yes and shaking the head to indicate no. Others could neither count nor estimate time. One woman could not read or write, while others had difficulties writing. A few participants failed to understand some questions during the interview, mostly those with an abstract meaning. In such cases, being allowed to read the questions increased their ability to communicate.

As time passed and the ability to communicate improved, the participants successively became more and more frustrated and angry when failing to express their thoughts and/or understand what other people were saying.

Nowadays I am so angry about not being able to speak properly. It [the ability to speak] can be locked away when something else, such as a headache, is bothering me. It is so infernally hard and arduous to think and speak.

One woman recalled two mute years and described a sense of tranquillity that afterwards became totally inadequate for her. When she was unable to express herself, she had a feeling of being on the point of death, where nothing seemed to really matter. Another woman said that her head was emptied of all thoughts during the period of severe aphasia.

It was so odd, as if there was no activity in the brain. It must have been the stroke and the oedema in the brain.
After a period of successful speech training, this woman became anxious and frightened, as she felt pressurised by the idea that if one fails to regain the power of speech within five years one will remain mute forever. Other participants also reported that their calmness disappeared when they began to speak again, thus implying that the force driving them to speak increased in line with their anxiety. One participant, who had recovered from expressive aphasia, recalled having many words in her head but that they were just a chaotic mess. Initially she was calm, because she was able to understand and believed the physicians’ reassurances that she would recover. Feelings of anxiety, fear and anger, however, seemed to increase in line with her successful efforts to regain the use of language.

For one participant, the acute phase of aphasia coincided with the death of her son. She could not cry “properly”, her body just shook. Furthermore, she could not stand being close to others, not even her own family. When she regained her speech, she started to cry and work through the sorrow in her heart and was pleased to have her family by her side.

Is language a precondition for feelings and feelings a precondition for language? If so, it would be impossible to explain sadness, rage and anxiety among infants and animals. It seems more reasonable to assume that increased activity and capacity in the brain trigger feelings of despair, the struggle to regain the power of speech as well as the ability to communicate. Such experiences are probably best understood as an intertwined process of biological and existential conditions that enable the human being’s most significant ability: language. It appears important for the initial calmness to disappear in order to make room for a fighting spirit.

*It is not necessary to name the world in order to recognize its meaning*

Some psychologists (cf. Blanck & Blanck, 1974) emphasize verbal language as a precondition for thought, especially those thoughts that are necessary for formal operations (Piaget, 1955). In the present study, the participants with expressive aphasia were silent, even inside their head, but by no means devoid of thoughts. They claimed to have been able to grasp meaning without access to words. One of them described how “words ran out of my head” with amazement and confusion. He found that in spite of the total silence inside his head he could still think, albeit nonverbally.

It is not true that you cannot think without words. I just stood there and analyzed the situation. I was totally calm, incomprehensibly tranquil as a matter of fact, and I discovered another language, a nonverbal language, and it worked!

This participant talked about a “meta-language”, a nonverbal and silent language, which, according to him, may be hidden behind the verbal language and therefore not accessible to a person who can speak. He stated that this “meta-language” is complete in itself, and it consists of entireties, whole meanings. These meanings are experienced as absolute truth; you do not consider any other options or alternatives, as meaning already exists.

All participants, despite their different types of aphasia, claimed that they had been aware of everything around them in their waking life, despite the fact that they could not communicate anything about it to other people.

I can’t explain exactly how it was. I knew that I could think, and I did think, but I don’t recall any words.

One participant, who was unconscious from a stroke, found that she was mute when she regained consciousness. When she tried to shake her head for no and nod to indicate yes everything went wrong. Her head was empty; she had no access to any words with which to communicate. After a while, she recognized single words from time to time, but no coherent language. Nevertheless, she claimed that she understood everything that was going on around her. Another participant knew immediately that he must act in order to get help. He could neither speak nor write, but he could consider his options and ponder alternatives, in order to obtain assistance. A third individual, who had experience of impressive aphasia, claimed to have been able to understand concrete as well as abstract matters in spite of the chaotic language inside his head.

However, a few participants appeared not to understand all questions during the interview. One of them said that he had learned to maintain the initiative in a conversation in order to avoid situations that included interpretations of another person’s verbal messages. When given time during the interview he proved capable of adequately answering questions that were concrete and complemented by gestures and/or written words. He related that, after four years with impressive aphasia, he had learned how to have a rough understanding.

We may all have experience of word-less and holistic meanings in our dreams, and it seems reasonable to interpret the “meta-language” described by one participant and the immediate understanding described by most of the others, as an
unreflected dreamlike recognition that does not require words.

In common with some of the participants in this study, we are not always as upset as we might have reason to be during the surrealistic experience of dreaming. When we wake up, we can be overwhelmed by feelings, but cannot understand the feelings without reflection. Reflection requires access to words. Interpretation of dreams also presupposes language (Freud, 1968/1900). Similarly, some participants in this study reflected upon their initial dreamlike condition for the first time during the research interview.

Worrying about being considered stupid

Becoming fully aware of the consequences of aphasia appears to be both frightening and humiliating, despite regaining the ability to communicate, which increases over time. One man, who had regained all his communication skills at the time of data collection, recalled his awareness of the gravity of his condition when a physician talked to him with the purpose of gaining an overall picture of his brain lesion, without saying anything about rehabilitation.

It was a shock! The physician pointed to the wall and asked me what it was. The words were not there, I couldn’t name anything. Nothing was there!

Another participant, who immediately understood his disastrous situation, described in his diary feelings of rage, humiliation and despair, when after some time he realized that his communication impairment would remain, even when the physical consequences of the stroke had more or less abated.

To just sit there mute and stupid, with one’s head full of more or less brilliant comments, not being able to make use of them, it is trying, dreadfully trying, and it makes me very angry. I feel totally worthless, like a parcel labelled: “worthless sample”.

Several participants were in the habit of always using bank notes when they went shopping, in order to avoid the humiliation of failing to hand over the right coins to the salesperson. A communication impediment, or worse, total muteness, was thus experienced as a much more devastating individual catastrophe than any physical handicap. The participants described feelings of being shut up in their bodies. They lost their sense of dignity due to being unable to communicate adequately. Verbal language was experienced as a prerequisite for participating in society, and without language, they thought that they were considered stupid. The participants’ self-esteem and sense of dignity were thus threatened by their own interpretations of other people’s assessments of their capacity to think and talk properly.

When I lost my speech I lost my sense of security. As I had no words, I couldn’t give expression to nuances. When I could not speak I appeared to be a person who could not think with shades of meaning. It was impossible for me to change that, I simply had to put up with other people’s way of looking at me.

Existential loneliness creates feelings of alienation

Most participants also claimed that the health care system abandoned them, due to the fact that no professional caregiver supported them in their early efforts to regain the power of speech. Some of them started to practise words at night in the hospital, soon after the onset of their condition, in spite of recommendations to rest and take it easy. A librarian, as opposed to a care-provider, understood one man’s mute plea for something to read, after which he started to recall words. In another case, the patient’s 12 year-old grandson wrote words on flash cards, to be used for communicating care needs.

Absence of professional support in the participants’ struggle to regain speech caused feelings of loneliness. But even more devastating were the severe consequences for their private interpersonal relations.

If everything previously well-known appears as strange, and communication with those around you is cut off, then the soul is incarcerated in an impenetrable prison, it must be the loneliest soul in the world.

A previously unknown feeling of loneliness, which increases and extends to all domains of everyday life, can thus follow the single-handed struggle to regain the ability to communicate.

Feelings of being alone, imprisoned in the body, appear to create a distance to other people. Some of the participants no longer knew who they were, due to their inability to communicate adequately. Their identity seemed to vanish and they considered themselves as merely handicapped persons. Not knowing who you are and being unable to keep up your self-esteem make it easy to distrust the good intentions of others.
When B called he said that my speech was much better than last time he talked to me. But last time he said that I spoke just as well as before the stroke.

Existential loneliness seems to increase when other people ignore or make light of the communication impairments. In the most harrowing moments, there are feelings of alienation that include both internal life and the surrounding world. One woman, who used to enjoy her own company when thinking and talking to herself, found that she was not the same person inside when she suffered from impressive aphasia. It made her feel completely alone. In the following statement, she describes her feelings of alienation after being unsuccessful at an evening course in English.

The last bus was very crowded. I looked at the people. It was like a Brecht play, as if they were wearing masks. I could not see the faces behind the masks, and their eyes were like empty hollows. I got off the bus and started to walk home. When I arrived home my husband looked at me. He was also wearing a mask!

Strategies to handle communication problems help to create distance to the situation

Many statements could be interpreted as strategies to regain control over a life situation despite impaired ability to communicate. As previously described, the strategy aimed at regaining control could start with an immediate and single-handed fight to learn to speak again without help from professional caregivers, who were considered negligent in terms of their responsibility to assist patients in their struggle to regain the ability to speak.

For others, who continued to suffer from the effects of impressive aphasia, it remained difficult to interpret messages from other people. One strategy that could reduce the moments of humiliation was to control a conversation by choosing what to talk about. This increased the chances of guessing the meaning in a conversation. This strategy was, however, not always successful due to the risk of being excluded from the conversation if one guessed incorrectly. Under such circumstances, giving up could be the easiest way out. A more successful strategy was to ask other people to speak slowly, in order to increase the time available for understanding a verbal message. This may be a similar strategy to the one previously mentioned, i.e. avoiding paying with small change.

Other activities that could be interpreted as strategies to increase control, especially among those who had been successfully rehabilitated, were commitment to other persons with aphasia, either professionally or in non-profit making organizations. Yet another was not to be afraid to make a fool of one self. Friends who failed to recognize them as the same person as before were not considered real friends. Another way to control the situation was to keep up one’s self-esteem and dignity with the help of humour and self-irony. Using humour in such a way may serve as an internal triumph in a life situation that might otherwise be hard to manage.

Sometimes I made fun of myself just to make things easier. But I was deeply concerned and frightened.

A common denominator among the different strategies was that they created distance to one’s own problems and motivated the participants to undertake various measures. Well-being also appeared to increase through involvement in something other than problems, for example taking an interest in the resources available for rehabilitation and policies for prioritising health care problems.

Comprehensive understanding

When the participants in this study fell ill with aphasia, they were unconscious, confused, or wide-awake and recording what was happening. In spite of the occurrence of initial shock and fear, the following period of silence or unconnected, inadequate words in the head was as a dreamlike state characterized by a surrealistic sense of total calm in the eye of a storm. The external world was experienced as an unconditional entity that was possible to grasp without being able to talk and sometimes not even understand what others were saying.

The phenomenological theory of intentionality may help to understand such non-verbal, pre-reflective grasping of reality. By employing the concept of “intentionality”, Husserl had no doubt about the inherent power of what he called the “natural attitude”, i.e. “the everyday immersion in one’s existence and experience, in which we take for granted that the world is as we perceive it, and that others experience the world as we do” (Husserl, 1970; Dahlberg et al., 2001). In the act of intentionality we do not critically reflect, we are merely in the everyday world in which we live.

When the participants in this study were stricken with aphasia, they appeared to lose the ability to move from a natural attitude to a more reflective stance. The world around them was taken for
granted in the same way as the air they breathed. They obviously did not find it necessary to analyse their experiences, during the time when they had no access to words.

Is it possible to recognize reality intentionally without words? According to Merleau-Ponty (1989), one of Husserl’s followers, such a conclusion seems eminently reasonable. Words are not a precondition for thought. On the contrary, thought is a precondition for language.

It [the word] is not without meaning, since behind it there is a categorical operation, but this meaning is something which it does not have, does not possess, since it is thought which has a meaning, the word remaining an empty container. It is merely a phenomenon of articulation, of sound, or the consciousness of such phenomenon, but in any case language is but an external accompaniment of thought. (Merleau-Ponty, 1989, p. 177.)

A further aspect of intentionality is the ability to think in entitities, without words, immediately after being struck by aphasia. Most of the participants not only grasped and recognised their reality, but also were later surprised at their own calmness as well as their ability to cope with the acute situation. Even those with strong elements of impressive aphasia remembered and were able to describe the acute phase, despite the fact that they were confused when it occurred.

Hence, aphasia decreases neither perception nor the immediate ability to recognise something as something. It is rather the reverse; the act of intentionality appears to be a more powerful experience than ever before when the words a lost, and it was therefore interpreted as a “meta-language” by one participant in the study.

Instead, the devastating consequence of aphasia is its effect on interpersonal life, one’s ability to interact with others. Interaction presupposes symbols and signs that mean something due to convention within a specific cultural context (Charon, 1989). Words, money, signs and many non-verbal expressions of meaning are examples of symbols. In order to communicate we must make use of significant symbols that are accepted as carriers of meaning in our society. Communication also involves the ability to generate a certain meaning in the minds of others, as well as the capacity to understand what others want to say. The impaired capacity for symbolization was exemplified in this study by the participants’ difficulty in using coins, estimating time and understanding gestures and so on. Most devastating was of course the loss of those symbols that are important for language. It was not just the written or spoken word itself that appeared to be devoid of meaning but also complementary symbols associated with speech such as nodding for yes and shaking one’s head to indicate no, recognizing expressions of joy or sadness or whether a voice is raised in anger or happy excitement etc.

Due to the impaired capacity for symbolization, the most serious existential consequences of aphasia appear to be loneliness, feelings of humiliation, inferiority and alienation when efforts to exchange thoughts, feelings, attitudes and experiences with others turn out to be unsuccessful. The participants in this study suffered, or had suffered, from different types of aphasia of varying severity. For some, this condition more or less affected all domains of their ability to use and interpret symbols.

The emotional consequences of the loss of one’s world of symbols seemed to increase the existential consequences. This was most obvious in one participant who lost her son two weeks after a stroke and was unable to mourn for him until she regained her power of speech. She could not cry when she had no words, as if tears are also a part of our commonly shared system of symbols. She and several other participants described their difficulties in relating to others, not because they could not speak, but due to feelings of alienation. One of them even felt that the people she encountered were wearing masks. There was only one feeling that all participants experienced at an early stage, namely anger.

Over time with increased, but still inadequate, verbal communication, the initial sense of calm disappeared and feelings of self-contempt, suspicion and insecurity emerged. This stage of aphasia was like being in prison. The dreamlike state described above, was now over and the participants were fully aware of the consequences of losing access to those symbols that constitute connecting links in society. They began to struggle to regain speech and other skills that are connected with symbolization, because they now realized that this was the only way to reclaim their position in society. Their fight was associated with many threats to their self-esteem, but those who were successful were no longer shut-up in their bodies. Even if some communication impairments remained at the time of data collection, the participants with mainly expressive aphasia could leave their prison with an understanding of the importance of communication and interpersonal relations. The most significant sign of successful rehabilitation appears to be the capacity to be completely involved in something other than one’s own problems, such as work, caring for one’s family, commitment to others with aphasia or political involvement in prioritising rehabilitation for patients with aphasia and so on.
To sum up: the existential meaning of reversible aphasia is that communion, interaction, and interpersonal relations become more important than ever before. Strong elements of continuing aphasia is characterized by a life-and-death struggle to use and/or understand words. Individuals thus affected still, several years after their brain lesion, find themselves excluded when failing to express their thoughts and/or guess the meaning of a conversation. In their struggle for existence, they need much more time than they are given to talk and/or to puzzle their fragmented impressions together. During such circumstances, it is impossible to direct interest beyond oneself in order to be involved in something other than a struggle for language. The existential meaning of continuing severe aphasia is thus characterized by alienation and loneliness, leaving the individual to find a balance between a fight filled with agony and giving up in order to avoid further humiliation.

Discussion

The findings thus show that a person with continuing aphasia must cope with existential loneliness. The experience of community or alienation not only varies according to the type, severity and reversibility of the aphasia itself but also appears to be associated with interpersonal relations. The comprehensive understanding derived from this study emphasizes human language as a world of symbols. The proposed interpretations also imply there may be a difference between those thoughts that can be explained as unreflected and those that require words. To recognize something as something appears to be a nonverbal process and is, therefore, not affected by aphasia. It also seems possible to consider alternatives and make choices without access to language. The participants’ narratives, however, did differ in this area, which may be due to various influences from those elements of pre-understanding that are not triggered by words.

Exactly when words are necessary is a question that remains to be analysed. In a phenomenological study by Carlsson, Dahlberg, Lützeén & Nyström (2004), an “inner dialogue” is described as a process where caregivers in psychiatric settings handle their fear of violent patients by quietly and rapidly asking questions that they themselves answer by means of their own lived experience. The subjects in the above-mentioned study by Carlsson et al. (2004), reported how they sorted out the matter within themselves. They did not describe verbally expressed thoughts, but feelings. However, one participant in the present study with experiences of impressive aphasia described feelings of loneliness inside herself when she could not perform inner verbal dialogues.

Sooner or later aphasia leaves the individual with major limitations concerning the further development of thoughts. Putting words to one’s feelings is a well-known psychotherapeutic basis for awareness of one’s motives and choices (cf. Blanck & Blanck, 1974). According to Gadamer (1996), words are “food for thought”, and humankind would have been unable to construct cultural traditions without the miracle of language. A further important aspect of language was introduced during the 1930s by Mead (1934). According to Mead, human communication is a consequence of role taking. In order to communicate, the individual must be able to assume the role of the other and address someone in a language that he or she understands. In other words, we cannot begin to communicate without making assumptions about the internal operation of the mind of the other. Role taking thus carries with it enormous social and personal benefits. It allows genuine interaction, permits cooperation and compromise as well as making possible a depth of interpersonal relations that would otherwise be unattainable. It is also important for our capacity to use and understand symbols and signs in accordance with our cultural tradition.

Many health care theorists emphasize the power of interaction between caregiver and patient. According to Peplau (1991), a caregiver must understand his or her own behaviour in order to help patients to understand their individual health problems. Orlando’s (1961) definition of care giving is rooted in the interaction between a caregiver and a patient at a specific time and place. A sequence of interchange takes place until the patient’s need for help is understood. In the literature, however, speech-language therapy, as opposed to care giving as an interactive process, dominates the efforts to assist patients with aphasia. The effectiveness of conventional therapies has as yet, not been conclusively proven (Berthier, 2005). This has led to attempts to integrate knowledge from several domains in an effort to plan therapies that are more rational and introduce other therapeutic strategies. Cunningham (1998) suggests, for example, a counselling approach for patients with severe aphasia, in order to enable them to adapt to their situation. Another example can be found in a study by van der Gaag, Smith, Davis, Moss, Cornelius, Laing and Mowles (2005), who propose that therapeutic approaches should include family members in order to improve quality of life and communication for people with aphasia.

Apart from a few studies within health care science, reflections on interpersonal relations in the care of patients with aphasia appear to be quite rare. Coping with the most devastating consequences of aphasia is, however, related to caring. It seems
reasonable to assume that inferiority, self-contempt and suspicion can be more successfully reduced with positive communication, interaction and a sense of community than with therapeutic techniques. Hence, a caregiver’s capacity to assist in finding functioning symbols for communication is of vital importance for patients with continuing aphasia.

Conclusions and clinical implications

The extent of the brain lesion is probably important for the point in time at which a patient starts to struggle to escape from the prison constituted by aphasia. Persons with aphasia are indeed vulnerable, as their ability to enter into a dialogue on their own initiative is extremely limited. A dialogue with a caregiver can be a part of both treatment and care, as an extra help to nature, and can contribute to the ill persons’ well-being. In this process, it is important not to conceive of language as a form of adherence to fixed rules. The real miracle of language is to be found when patients discover the meaning in the words of someone else and are able express meaning themselves.

Frustration, anxiety and anger seem nevertheless to be aspects of this struggle, as they contribute to the disappearance of the illusory initial calmness, thus making room for a fighting spirit. Even patients with continuing aphasia appear to be helped by their frustration, as it serves as a driving force and motivates them to practice speech and written language. Understanding the lifeworld of patients makes adequate caring easier, and one clinical implication of this study is that patients with aphasia should be encouraged to express their frustration, once the acute phase of the brain lesion is over.

However, aphasia can leave the fighting spirit paralysed. Some patients require time, while others desperately seek a way out of their prison almost immediately. In all cases it is essential to prevent further isolation. Knowledge of the existential consequences and creative methods of communication appropriate to the various forms of aphasia can allow health care providers to intervene in order to reduce humiliation and feelings of alienation and loneliness, thus improving the functional ability of their patients.

It can also be concluded that persons who suffer, or have suffered, from aphasia have personal and individual experiences of both adequate and inadequate care. Questions aimed at eliciting such experiences were posed during the data collection and many of them remain to be analysed in the next part of this project.

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