

# The aphasic person's views of the encounter with other people: a grounded theory analysis

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## The aphasic person's views of the encounter with other people: a grounded theory analysis

Being affected by aphasia influences the total life experience. The aim of this study was to generate a theoretical model, from a nursing perspective, of what aphasic persons ( $n = 12$ ) experience in encounters with other people. Data were collected through interviews which adopted a biophysical, socio-cultural and psychological approach and then analysed using grounded theory method. Two main categories emerged, namely: 'interaction' and 'support'. Encountered experiences led to: 'a feeling of having ability'; 'a feeling of being an outsider'; and 'a feeling of dejection or uncertainty'. The feeling state was dependent on whether the interaction was 'obstructed' or 'secure' and on whether the support resulted in 'strengthened' or 'impaired' self-esteem. Therefore nurses need to give support that enhances patients' self-esteem and which results in them gaining a positive and realistic view of their aphasia, as well as involving those around them in this perspective. This then will give the possibility for the patient to turn the interaction process from an obstructed into a secure one.

**Keywords:** aphasia, grounded theory, interaction, nursing, self-esteem, support

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## Introduction

Aphasia is a language defect after brain injury in an individual who has had a normal linguistic function until the time of the injury (Reinvang 1978). The brain injuries can result from a stroke, trauma or tumour. The most common cause of aphasia is stroke (about 85%; Höök 1995). To lose one's language abilities means that the communication between human beings is obstructed. The life of an aphasic person and their next-of-kin is changed in many ways after injury. The condition of aphasia results in social and psychological strains which effect their relationships, and they will therefore need help in different ways (Houglan 1991). The focus of the treatment is to increase the linguistic

capacity and aid possible communication. The patients' total relationship situation must be engaged in this treatment regimen if the result is to be comprehensive (Borenstein 1988, Höök 1995). Brain injuries also give rise to other disabilities, and the new life predicament often leads to depression (Hafsteinsdóttir & Grypdonck 1997). Depressed aphasic persons experience reduced self-esteem which may change their self-concept. It is a task for nurses to co-ordinate the patient's treatment programme, recognize dysfunctional behaviours and implement interventions to help the aphasic person to a more positive self-concept (Tanner *et al.* 1989). Investigations of the aphasic person's life have mostly been carried out from a psychological or sociological perspective, with the work then used as a basis

in the nursing literature on aphasic persons (Keller *et al.* 1989, Tanner *et al.* 1989, Houglan 1991). Studies from a nursing perspective discuss the care of patients, mostly from the point of view of the psychological needs of the aphasic person and their relatives, but not the patients' own views of their lives (Bennett 1996, Christoffersen & Wells 1998). Some studies provide guidelines for the treatment of the psychological and behavioural problems following aphasia (Keller *et al.* 1989, Tanner *et al.* 1989, Houglan 1991).

Sarno & Gainotti (1998) state that aphasia is a catastrophe that brings with it changes to personal, familial and social life. Then the aphasia affects the total life experience of the afflicted persons. Nursing staff need to have knowledge of those experiences from both the time of injury and in the future to be able to give the help needed to achieve an effective rehabilitation. Therefore a holistic approach is necessary to gain knowledge. Sarvimäki & Stenbock-Hult (1993) propose that there are five dimensions to the way people realize and manifest themselves, namely: bio-physical, socio-cultural, emotional, intellectual and existential. Those dimensions are used to provide a holistic framework to this study, which aimed to generate a theoretical model from a nursing perspective of what aphasic persons experience in their encounters with other people.

## Literature review

Having an aphasia involves the physical, psychological, social and spiritual–existential dimensions, thus it involves all parts of the being. In addition, the brain injury often leads to other physical handicaps as well (Währborg 1991). From a psychological point of view, interaction with others can occur but, without verbal communication, accentuated feelings of loneliness and isolation may be present. Feelings of sadness, apathy and loneliness are fairly common in aphasic persons, and verbal communication can elicit negative emotions as it is hard to connect in a conversation. Due to depression, self-esteem may be reduced (Tanner *et al.* 1989). Depression is a very common attendant phenomena in aphasia. It can be caused by the brain injury *per se* or by the consciousness of being impaired not only linguistically but also physically (Währborg 1991, Gainotti 1997). Being unable to communicate effectively results in experiences of loss, which may show as a grieving process (Keller *et al.* 1989). Social life changes; for example, previous roles cannot be resumed and the possibilities for purposeful occupations may become limited. The language loss can result in withdrawal and isolation. Brain injury and aphasia can also produce new ways of reacting, which may result in life changes for those around the injured person (Währborg 1991, Gainotti 1997). The spiritual–

existential aspects of life are changed, as the 'self of the individual' is affected by the brain injury, resulting in great changes to life meanings (Währborg 1991, Holland & Beeson 1993). Personality changes can result from the brain damage, due to organic and biochemical changes, or from stress and social isolation, which alters the individuals' premorbid psychological defence mechanisms (Keller *et al.* 1989). Strategies used by the aphasic person for handling the threatened personality can be psychiatric, neuro-behavioural, psychosocial and intellectual (Währborg 1991). Language loss makes it hard to develop a new sense of self, as language is important in the establishment of the sense of who the person is (Brumfitt 1993). However, according to Christensen (1997), emotional, physical and social needs can also be expressed non-verbally. Further, it is not necessarily the case that aphasic persons experience themselves as just aphasic persons in the first place, but may see themselves as a person with an almost normal life, for whom communication can mean other avenues than verbal, such as art, literature and music (Christensen 1997).

## The grounded theory study

### Design and method

A qualitative descriptive design was chosen for this study, as it is acknowledged as a suitable way to study human experiences (Starrin *et al.* 1998). The method used was grounded theory as developed by Glaser & Strauss (1967) in the 1960s. This is an inductive method, making it possible to generate a theory or a model which speaks to the reality of a particular phenomena, as it is grounded in data generated through systematic constant comparison during collection and analysis. Grounded theory analysis consists of open, axial and selective coding. Such procedures aim to identify, develop and relate concepts (Strauss & Corbin 1990).

### Informants

The selection of informants was strategically made to gain as wide a variety of experiences as possible (Fridlund & Hildingh 2000). The informants in this study were seven men and five women, aged 28–92 years, living in a middle-sized town or surrounding small villages in the south of Sweden. They had suffered different kinds of brain injury as a result of trauma or stroke, and all of them were diagnosed as aphasic by speech therapists. The three types of aphasia were represented: impressive ( $n = 1$ ), expressive ( $n = 8$ ) and both expressive and impressive ( $n = 3$ ). Nine of the informants were recovered enough to be able to speak

for themselves; two needed support from relatives (their wife and husband); one had great difficulty in expressing herself.

### Interview

Data were collected through interviews carried out by the main author, a rehabilitation nurse with experience of caring for patients with brain injury and aphasia. The informants had been contacted by letter and telephone after the study had been ethically approved by the Local Ethics Committee for Human Research. The interviews were performed in the homes of the participants in all cases but one, which took place in a quiet room at a hospital. All interviews lasted about 1 hour. They were tape-recorded and subsequently transcribed verbatim by the main author. The interviews took the form of conversations guided by the five open-ended questions (Fig. 1). When the answers consisted sometimes of few words, the interviewer rephrased the questions in different ways to ensure that the person had the potential to answer fully. Data saturation was reached after nine interviews when no more substantial contribution to the model generated could be found.

### Data analysis

In line with the Scandinavian way of analysing grounded theory, the process of coding was continuously going on inductively and deductively through control of codes and categories found amongst the data (Hallberg 1998, Starrin *et al.* 1998). The relationship between data and theory was analysed when moving back and forth between those two levels. Open, axial and selective coding were used alternately to find relations among categories. The second author read the interviews and participated at all levels of the data analysis (Strauss & Corbin 1990).

In the open coding, substantive codes were identified and documented. For example, the substantive codes a 'feeling of despair' and a 'feeling of failure' were determined in the data and categorized as a 'feeling of dejection'. In the axial coding, connections between categories and

their subcategories were looked for, and the relations were tested according to the paradigm model (Strauss & Corbin 1990). For example, the relations between the categories 'impaired self-esteem' and a 'feeling of dejection' were shown in the following utterance:

You can't speak (causal condition)...it's terrible (phenomenon)...you try (action)...they can't understand (intervening condition)...there are misunderstandings...you feel stupid (consequence).

In the final step of the analysis, selective coding, the core categories 'interaction' and 'support' were selected and related to other categories as validated in the data. They could be related to other categories by means of the paradigm: The speech difficulties influenced the interaction, even if it was experienced as secure, as the support given impaired the self-esteem and resulted in a feeling of dejection.

## Findings

### Generating a theoretical model

Two core categories were found in the data, interaction and support. Interaction included communication, the ability to interpret what was happening and to give expression to experiences. The subcategories of interaction were security and obstruction. Security was present if those taking part in the conversation, whether known or unknown to the aphasic person, provided positive support. For example:

if there was something that I tried to say...they said nothing but waited and waited, so I tried and tried...but anyway, they expected that I would remember it. That was better.

Obstruction was experienced when there were many participants:

When there are many people, I mix it up, what one said and the other said...

or unknown people:

people I know well and friends and such, then talking, but difficult to phone and other unknown persons...worse speech,

**Figure 1**

Interview questions given to aphasic persons ( $n = 12$ ) in order to gain knowledge of how they experience the encounter with other people out of a holistic approach.

Do you have any physical reactions as a consequence of the aphasia and if so, which?

What does the aphasia imply for your social and cultural life?

What feelings does the aphasia give rise to?

How do you experience the information given by those around you?

How do you experience your life situation now and in the future?

or when the interaction was not so positive, for example:

Well, they talk with me and wait for an answer . . . when I cannot . . . some of them will not wait for me, so they fill in my reply, which makes me feel foolish.

Support was help given to enhance the possibility of the recipient leading as normal a life as possible. Support could be emotional, for example in the form of stimulation and encouragement, as well as material, such as wheelchairs, sticks and other aids. The quality of the support given influenced the self-esteem of the person receiving it.

The material support could enhance their independence and generate a 'feeling of having ability':

it's one of the best toys I've got [a bike with three wheels] . . . with this I can cycle . . . how much I want and go far away.

If material support was not sufficient, the experience could lead to feeling of discontentment and give rise to an awareness of limitation, which resulted in a 'feeling of being an outsider':

I want to go out to clubs and such, . . . go to the shop by yourself and, yes, there is so much I want to do that I cannot do now, like having a hobby and such things, you can't do any of those things.

Emotional support could encourage the informants in a way that meant their self-esteem was strengthened; for example:

my parents, they could wait, . . . 'what did you say' . . . 'no, no once again'. We could go on maybe seven, eight times, tried again and again, 'come on', mother said. Tried and tried . . . Then I managed . . . it took a lot of time, waiting and waiting and then . . . it was right!

The type of support could also lead the person to remain passive and then experience an impaired self-esteem:

[When talking about how the wife handles telephone calls] Yes . . . When, once, I wouldn't phone . . . I didn't think I could say what I wanted to.

Self-esteem and/or support had to balance the physical difficulties of having a staggering walk or slurred speech, if the person was to have any possibility of taking an active part in the interaction. If the self-esteem was strong enough, the informant made greater efforts to participate:

I had decided to make a speech . . . I practised a lot . . . so it was my turn . . . I could not speak, not a word, not a word and I had my head full of what to say, and it was impossible . . . in such situations it is enormous, enormous . . . of course I have to try once more . . . it's a pity to give up!

The informants had other physical difficulties other than aphasia. These could be counterbalanced by the material support. As Fig. 2 points out, if the interaction was perceived as secure, such support resulted in a strengthened

		INTERACTION	
		SECURITY	OBSTRUCTION
S U P P O R T	STRENGTHENED SELF-ESTEEM	A feeling of having ability	A feeling of being an outsider
	IMPAIRED SELF-ESTEEM	A feeling of dejection	A feeling of uncertainty

**Figure 2**  
The generating model of aphasic persons' views of their encounter with other people.

self-esteem, giving rise to a feeling of ability, while impaired self-esteem could give a 'feeling of dejection'. On the other hand, if the interaction was experienced as obstructed, strengthened self-esteem gave confidence enough to act in the situation despite the feeling of being an outsider. The obstructed interaction combined with impaired self-esteem led to a 'feeling of uncertainty'.

**A feeling of having ability**

A feeling of having ability was experienced when the interaction was secure and the support resulted in a strengthened self-esteem. This could be achieved when the participants were well known to the aphasic person:

when I try to phone here, to the children . . . I called my son, and he understood most, . . . he knows what I'm thinking, so we could talk . . . but when I have to talk with others . . . I just can't speak with anybody . . .

No, don't want to speak with them . . . I just talk with my daughter.

The people with aphasia supported each other by reading together and carrying out other exercises which strengthened their self-esteem. They felt safe and accepted in each other's company, which gave them a feeling of satisfaction, in turn increasing their ability:

We have . . . writing exercises, cross-word puzzles, reading, and, yes, many such things . . . above all, we have fun, maybe the most fun of all . . . it's good . . . we all look forward to it.

When the treatment was perceived as good and the support was given in a considerate way, this enhanced the person's self-esteem and resulted in a feeling of having the ability to communicate; for example:

Taxi-drivers and such people, some of them will talk and I can say some words and they understand... The young drivers, they want to know... they want to be engaged in such a way that they want to know what it's all about and that's fun, I think.

Strong social support could increase the informants' self-esteem to such an extent that it enabled them to act in a very open way:

at a big party... now I thought, I'll go up and sing... and tell, talk to them about me... tried to talk rather well... that was great.

### A feeling of being an outsider

When interaction was experienced as obstructed leaving the informants with a feeling of being an outsider, their residual self-esteem could result in sufficient strength to reduce that feeling:

I have been there, yes, at least 50 times now, so I know them, the girls working there and then the owners come and talk and so... yes that I think is fun, talking a lot... I have told them about the accident and such things and... they know who I am, that I have problems when speaking.

When the other person was not familiar, the support system which led to a strong self-esteem made it possible to take part in the interaction:

I know people, you see, who talk fast, I don't understand... Unknown people, I tell them.

[In a meeting] No. It's not difficult to listen, but it's difficult to ask... I don't avoid it, it's just to go on talking... it's just to give yourself time.

... when I hear two people talking. Then I have to cut it off... they must be silent and I have to ask permission to speak.

... in a shop and I would buy, say milk, where is it, then... [singing]... Hello, I would like to have some butter, milk, where can I find it?... to sing, then it's perfect... it's so easy to talk.

An obstructed interaction could create a fear of being seen as drunk, as the informants sometimes had an unsteady gate. Then it was important to inform others about their disability. For example:

strictly speaking, I should tell them directly that I... cannot speak so well... Often they look at me curiously.

### A feeling of dejection

When the support given resulted in a loss of self-esteem or if support was not forthcoming, the experience was one of

dejection, even when the interaction was characterized as secure:

I feel very small, so to speak... don't know how to explain it, but... When I can't get it out, what I want... I feel extremely unhappy.

[In response to impatient people]... they fill in, what I should have said maybe, but not said... and then comes the feeling of despair, sometimes very strongly.

Informants reported that they did not have sufficient energy to balance the physical or psychological difficulties caused by the aphasia and relied on others to perform many daily living activities for them:

I try to do as much as I can myself, but she has me, anyway, here at home... I think that's tiresome sometimes, to depend on someone.

... the problem is, that I cannot manage everything when I'm out meeting people if my wife isn't with me. I chatter and probably most of it is OK, but it can be wrong, but I don't know that.

The hospital staff were seen to have a great deal of understanding, but their support was not enough to strengthen the patients' self-esteem, and the feeling of dejection was present anyhow:

It's awful. You cannot speak and you want to say so much... you have lost it. It's awful... You hear other people talking all the time... but you cannot say anything yourself... and the other patients... can't understand... and this give rise to misunderstandings.

### A feeling of uncertainty

Uncertainty was the dominating experience when self-esteem was impaired and the interaction obstructed. For example:

You feel afraid to talk when you come out...  
... so you feel a bit stupid.

In the company of a number of people, the informants found it difficult to follow the conversation, and the interaction was experienced as inhibited. For instance, when they were together with others:

Yes, I lose the thread, that is, maybe I become nervous, because I want to say as much as possible and think, now, I may not forget it and so, yes, then it's gone all of it.

If support was perceived as deficient they had not the capacity to balance the disability:

Most people are understanding but there are some... they dissociate themselves 'cause they are a little afraid, I think...

... she couldn't understand and I couldn't say anything... she phoned and told other people... I was blown out and stupid and such things.

The anxiety about appearing stupid further degraded their sense of impaired self-esteem, which negatively influenced motivation to take part in the interaction:

I'm afraid to fail completely...I feel very foolish...don't know how to explain but...When I can't say what I want...I'm in despair.

Yes, those words I can't keep apart. No. That's why I don't dare to speak about it.

## Discussion

### Methodological aspects

A framework to promote reliability and validity which addressed applicability, concordance, security and accuracy was used in this study to ensure safety during data collection and analysis (Fridlund & Hildingh 2000). The demand for applicability was satisfied by a qualitative approach, as the purpose of such a method is to identify phenomena about which we have insufficient knowledge (Starrin *et al.* 1998). Employment of a grounded theory method was used to show the influence of aphasia on human beings and increase the understanding of such experiences. The strategic selection of the informants achieved a wide range of aphasic persons' experiences of their encounters with others. Use of interviews for data collection supported the aim of this study. They provided the aphasic person's point of view, which was not interpreted through any kind of research instrument but demonstrated how they could share their lived experiences with a nurse. The open-ended nature of the interviews was used to provide as much flexibility in the data collection as possible, and thus the interviews were used to obtain self-reported information from informants (Polit & Hungler 1983).

No general conclusions can be drawn from this study regarding aphasic persons' views on the encounter with other people, as the findings of qualitative studies cannot be generalized. However, the findings are useful in planning nursing care actions for aphasic persons (Dahlberg 1993). Concordance between the data collection and the findings was ensured by the use of the constant comparative method of analysis. That there existed a relationship between data collection and the phenomenon examined was confirmed by the methodologist, i.e. the second author. As the first author had previously been involved in the care of aphasic persons, there was a prior knowledge of their situation, which facilitated an understanding of the informants' answers. Accuracy in meaning interpretations was achieved through constantly switching between data, codes and categories during the process of analysis. A limitation of this study was that the aphasic persons' speech disabilities

made it difficult to conduct interviews. The fact that the interviewer had to ask questions in such a way that the answers could be given in single words meant it was not possible to get comprehensive answers. Often the questions had to be repeated in range of different ways to ensure that they were understood by the informant and that the interviewer had interpreted the answers correctly.

### Aspects of the findings

Interaction is the interplay between people when they are doing things together, such as talking and using their thought processes (Strauss & Corbin 1990). Language is of great importance in determining how interaction is experienced. Having an aphasia leads to emotional, motivational, behavioural and social change, and often the communication disability (the linguistic handicap) is accompanied by another physical disability (Währborg 1991). The informants had experienced avoidance by others due to their physical handicap, which led to interaction being experienced as obstructed. The linguistic disability and, hence, the experience of obstruction, had a negative effect on their interaction with people who were unknown to them. When interacting with unknown persons the aphasic persons experienced fear or uncertainty, which generated a feeling of being an outsider depending on their level of self-esteem. This supports the findings of Wenz & Herrmann (1990), who found that loss of speech was considered the most stressing symptom of aphasia by relatives and speech pathologists, while motor impairment was regarded as the most emotionally distressing symptom by a majority of aphasic persons. When in the company of many people, aphasic persons experience a feeling of being forgotten, due to difficulties in taking part in the conversation. Inability to remember words, both those uttered during conversation and those the person wanted to say, made them feel uncertain. To fail in conversations can result in impaired self-esteem as well as mistrust of one's ability to interact with others (Nilsson & Waldemarsson 1994). In such cases the quality of the support given was of great importance for the aphasic person's perceived self-esteem.

If the person had a feeling of being an outsider but had strength enough to overcome that feeling, the process could be moved towards a feeling of having ability. If the support provided did not positively influence the impaired self-esteem, the experience would generate a feeling of uncertainty, which could lead to dejection and even depression. These findings support Price's (1995) suggestions that poorly developed social support makes the need for additional psychological support a priority. It is obvious that the support received during the interaction is important for how the aphasic person experiences the situation. If the

support is good, the interaction will be perceived as secure as well as a means to strengthening their self-esteem. This can inspire a feeling of having ability even if the interaction at the beginning was obstructed and the aphasic person had a feeling of being an outsider. According to Christensen (1997), development of self-esteem should be supported, as the personality has its roots in self-esteem. The current study shows that aphasic persons need good support systems and secure interaction if they are to experience a feeling of having ability, irrespective of whether such ability is verbal or not. The right support can give the aphasic person a restored self-esteem and increase their motivation for rehabilitation (Gainotti 1997).

## Conclusion

This Swedish qualitative study generated a theoretical model via a nursing perspective on what aphasic persons experience in their encounters with other people. Interactions are influenced by the support received in the encounter, which can have the power to balance the disabilities, resultant from the reduced resources of those living with aphasia. Therefore the goal, a secure interaction with a feeling of having ability, can be attained. Nursing interventions need to provide support in such ways that the person's self-esteem is enhanced thus encouraging a positive and realistic view of themselves. Further, nursing interventions should also include efforts to increase knowledge about aphasia in the aphasic person's social surroundings. This increases the possibility with the wider community to turn the obstructed interaction into a secure interaction.

## Implications

Aphasia involves a changed life situation for both aphasic persons and the people around them. The strains of physical, socio-cultural and psychological effects make it necessary to co-ordinate treatment and to engage relatives and friends of the aphasia sufferer in this effort. Co-ordination is an important task for the nurses from the acute care in hospitals, during rehabilitation and when the aphasic person is transferred to community health care. An additional task for the nurse is to support the aphasic person in such a way as to enable them to handle an interaction, even when it is obstructed from the beginning. It should be possible to use the findings from the study for this purpose. In addition, other groups could benefit from the findings, for example people with spinal injuries, who will live many years after their lives have been changed due to their illness or accident. Knowledge about what aphasic people need and how to involve those around them is necessary to

improve the possibility of having a satisfying interaction. There is a need for nurses to provide information on how to handle new situations and the changes that are taking place on their personality. This information ought to be based on research and should be offered to carers, relatives and friends. It is essential that nurses have the nursing skills required to facilitate persons with aphasia to interact with others as effectively as possible.

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