

Experience of aphasia understood through patient narratives: focusing on the doubts about one's language and the coping behavior of patients

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Experience of aphasia understood through patient narratives – focusing on the doubts about one's language and the coping behavior of patients –

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Abstract

The purpose of this study was to clarify the experiences and coping behaviors of aphasic persons in their close relationships based on their own narratives. Semi-structured interviews were carried out with 16 aphasic persons. Analysis of data was carried out referring to methods from the ethnography of Spradley. Results revealed a process of experiences centering on a state of anxiety related to a «doubts about one's language». Participants who were aware of their language discomfort employed coping behaviors, while those who were relatively unaware had difficulty in developing coping behaviors. A number of categories of experience leading to the awareness were observed in this study, including [being unable to communicate with healthy individuals], [being ignored by others], and [realizing the existence of a language problem when pointed out by others]. The following variation of coping behaviors were observed: [the desire to recover as much language ability as possible], [covering the weakness in language ability with ingenuity], [obtaining cooperation by expressing that they have a language problem], [believing in the possibility of communicating with people in spite of aphasia], and [emphasizing the aspects of personality that have not changed with the onset of aphasia]. Participants whose coping behaviors were successful expressed appreciation as [appreciating support from others], and some participants whose coping behaviors were unsuccessful defiantly declared that [aphasia is my fate – that's the way it is]. The results suggest that it is crucial for nurses to listen to aphasic persons carefully, and to understand their experience empathetically – not only as a means of increasing their satisfaction at being listened to, but also to improve their language ability and support their coping behaviors.

Key words

aphasic persons, experience, coping behavior, narrative

Introduction

Aphasia is a communication disorder affecting a patient's production and comprehension of language caused by damage to the language center of the brain. Aphasia occurs in approximately 20% of patients suffering from cerebrovascular disease, with approximately 20,000 individuals developing aphasia each year in Japan¹⁾. Due to the unfortunate fact that a complete cure is difficult to achieve,

social reintegration rates and activity ratios are low^{2,3)}, leaving the majority of aphasic persons in a psychologically vulnerable condition⁴⁾. Therefore, the prompt organization of medical care and welfare service systems is required to enable aphasic persons to live independent lives in their own communities⁵⁾. Nursing care for individuals with aphasia generally focuses on support aimed at helping aphasic persons recover their ability to use

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language. However, in the chronic phase, during which aphasic persons have to live with disability, such support does not seem to be sufficient. In order to provide effective support, it is essential to understand the experiential setting that gives rise to these needs⁹. Moreover an understanding of the particular coping behaviors exhibited by patients in such settings can yield important information about the services they may require. It is assumed that the difficulty experiences associated with aphasia begin to exhibit themselves in their close relationships and gradually expand to relations in the larger community. Therefore, it is our hope that this study contributes to the examination of support for aphasic persons living in communities by focusing attention on their experiences in their close relationships.

As our experiences are usually expressed through language, it is generally believed to be difficult for other people to understand the experience of individuals with aphasic persons. Even when aphasic persons express their experiences, the credibility of the content is often questioned. Because of this, there is little previous research regarding the experience of aphasic persons^{7,8} – a situation that amounts to insufficient examination of the phenomenon. However, is it really prohibitively difficult to understand the experience of aphasic persons as related by themselves? Even though it is difficult to cure completely, aphasic persons can improve their language ability to the point that a certain degree of conversation becomes possible^{9,10}. This study was carried out in order to clarify the experiences of aphasic persons in their close relationships after leaving care through the narratives of themselves and to obtain suggestions for nursing care support.

Methods

This study employed a qualitative research design, referring to the ethnography of Spradley¹¹. Ethnography is a method of describing culture, i.e. the knowledge and sense of values through which people interpret their experiences and share social activities¹². According to Spradley, experience consists of facts which are expressed through language used by the individuals¹³. It has been reported that ethnography is useful as a method for deepening understanding of the experiences of aphasic persons^{14,15} and is an appropriate method for understanding behavior employed to coping behavior of illness¹⁶. The authors somewhat expanded this method in order to understand the process in which they developed the coping behavior, as well as to understand behaviors of aphasic persons based on the narratives of themselves.

1. Participants

In accordance with the purpose of this study, we set the following three conditions for the inclusion of participants: 1) individuals who had experienced moderate to mild aphasia for three or more years; 2) individuals deemed by the first author and a speech therapist (ST) to be capable of talking about their own experiences; and 3) individuals capable of expressing their experiences via writing where verbal expression is difficult. After a request for research cooperation was issued to the patient group, an explanation of the purpose of the research was given, both verbally and in writing. Informed consent was obtained from each participant who had indicated the intention to cooperate. Degree of severity and type of aphasia (Table 1) were determined by the first author and a ST using the Severity

Table 1. Demographics of participants

n=16

Gender	Male : 11	Female : 5
Age	58.3 ± 11.1 ¹⁾	(37~79years)
Length of years since onset	12.2 ± 6.4 ¹⁾	(3.6~24.5years)
Types of aphasia	Broca's aphasia : 7	Wernicke's aphasia : 7
	mixed aphasia : 1	residual state from global aphasia : 1
Severity of aphasia	mild : 7	moderate : 9
Job	jobholder : 5	jobless : 11

1) : mean ± standard deviation

Rating Scale of the Boston Diagnostic Aphasia Examination (BDAE)¹⁷⁾.

2. Data collection

The first author attempted to establish relationships with aphasic persons by participating in the patient group and having contact with participants visiting an outpatient speech therapy clinic prior to this study. Next, as a participant observer, the author observed participants’ interactions with their families, people at the patient group and STs, and observed their behavior during hobby activities and speech therapy. These contents were described in detail in field notes compiled after observation.

Semi-structured interviews were employed. The content of the interviews was recorded on tape after obtaining agreement from the participants. The number of interviews was between two and five per participant, and the average interview time was 48 minutes (Table 2). The interview procedure was as follows. The first author asked the participants, “Please tell me about your experience from the onset of aphasia until now.” The author asked additional questions based on the content of the participants’ narratives. If participants had difficulty in expressing their comments verbally, they were asked to express themselves in writing, thus providing a means to

proceed with the interview. In addition, previously collected information was shown to the participants during the second and subsequent interviews to determine whether the collected content was consistent with their actual experiences or not.

Furthermore, in order to gather information to complement the views and opinions of participants, the first author conducted interviews with families and the STs in charge. In order to gain a deeper understanding of participants’ situations, the author participated in an outpatient clinic for speech therapy and received guidance from the STs, thus advancing the study. Data, including numerous incidences of paraphasia, were shown to the STs in charge to ensure the reliability of interpretation and to verify the semantic content. Information for a record survey, containing such details as conditions of onset, type of aphasia, severity, and content of speech therapy, was obtained from speech therapy records. In addition, the author obtained more information from the diaries and picture diaries of participants.

3. Analysis

Analysis was carried out utilizing the analysis methods of Spradley¹⁸⁾ as a reference. First, the field notes and verbatim records created from interview data were read thoroughly. Then, words and sentences were extracted in the

Table 2. Outline of type and severity of aphasia and number of interviews

participants	types of aphasia	Aphasia Severity Rating Scale ¹⁾	time of interviews (min)					
			1st	2nd	3rd	4th	5th	
A	Broca's aphasia	mild	4	35	60	50	60	
B	Wernicke's aphasia	mild	4	60	65	80	70	
C	Wernicke's aphasia	mild	4	65	65	70		
D	Wernicke's aphasia	mild	5	45	45	30		
E	mixed aphasia	moderate	3	50	50			
F	Broca's aphasia	moderate	2	50	50	60	40	50
G	Broca's aphasia	mild	4	50	35	30		
H	Wernicke's aphasia	mild	4	65	60			
I	Broca's aphasia	mild	4	40	45			
J	Broca's aphasia	moderate	3	60	45			
K	Broca's aphasia	moderate	2	40	35			
L	Wernicke's aphasia	moderate	2	60	60			
M	residual state from global aphasia	moderate	2	40	35	20		
N	Wernicke's aphasia	moderate	3	45	50			
O	Wernicke's aphasia	moderate	3	25	30	30		
P	Broca's aphasia	moderate	2	30	30	30		

1) Aphasia Severity Rating Scale : 0~1, severe; 2~3, moderate; 4~5, mild

smallest units possible while still preserving meaning. These were encoded, and categories were extracted during a search for commonality in codes to increase the degree of abstraction. When extracting categories, characteristics, similarities and differences were compared by checking data and codes as needed to extract the associations between categories and to structuralize them. At the stage of extracting final categories, attention was focused on «doubts about one's language», which linked up with many experience categories of the participants and seemed crucial in understanding a variation of coping behaviors. The authors regarded it as the central category, and the entire record was restructured while clarifying the participants' storylines.

In order to assure reliability, the authors undertook verification based on the evaluation criteria for credibility proposed by Guba et al.¹⁹⁾. In other words, results of analyses were presented to participants at intervals, verbally or in writing, to confirm whether they matched participants' experiences or not. Furthermore, throughout the entire process, this study remained under the supervision of researchers involved in rehabilitation nursing science and qualitative research on psychology for the disabled. Research procedures and analyses were examined by the authors along with the supervisors in order to confirm the appropriateness of the analyses by checking verbatim records and modifying them as needed.

4. Ethical considerations

This study was approved by the Kanazawa University Medical Ethical Committee. Participants received an oral and written explanation of their freedom to withdraw from participation, the right to discontinue interviews, the protection of anonymity, and schedule for the announcement of results.

Results

In this section we will examine the «doubts about one's language», the point of participant narratives. We will then describe our results through a focus on coping behaviors. Participants were affected by a state of anxiety related to their

«doubts about one's language». Some individuals were able to overcome their anxiety to reach a state where they were aware of their language disorder and developed coping behaviors accordingly. Others, however, did not reach such a state of awareness and had difficulty developing coping behaviors. This state of awareness was related to experiences of **[being unable to communicate with healthy individuals]**, **[being ignored by others]**, and **[realizing the existence of a language problem when pointed out by others]** (Table 3). After having been affected by this «doubts about one's language» and acquiring an awareness of their language disorder, participants manifested such coping behaviors as **[the desire to recover as much language ability as possible]**, **[covering the weakness in language ability with ingenuity]**, **[obtaining cooperation by expressing that they have a language problem]**, **[believing in the possibility of communicating with people in spite of aphasia]** and **[emphasizing aspects of personality that have not changed with the onset of aphasia]** (Fig. 1). Coping behaviors in the figure are arranged indicating an increasing desire to change oneself as you move toward the left, and those indicating a desire to remain the way they are as you move toward the right. Participants whose coping behaviors were successful indicated an appreciation of family, friends and the patient group as **[appreciating support from others]**. Participants whose coping behaviors were unsuccessful sometimes defiantly declared that **[Aphasia is my fate – that's the way it is]**. We will now describe the details of categories using data from participant narratives. Central category is shown in 《 》, categories are shown in **[]**, sub-categories are shown in [], and direct subject quotes are shown in italics. We compensated for participants' paraphasia and words finding difficulty by paraphrasing their comments without interfering with the content.

1. **[The desire to recover as much language ability as possible]**

Many participants recognized that their language ability would probably not recover completely. However, they embraced a desire to

Table 3. Categories related to 《doubts about one’s language》 and associated coping behaviors

Categories	subcategories	
Being unable to communicate with healthy individuals	<ul style="list-style-type: none"> • I am the same as a baby • I worry about how people see me • I don't want to see anybody 	<ul style="list-style-type: none"> • I don't like talking • I cannot hide that I cannot talk smoothly
Being ignored by others	<ul style="list-style-type: none"> • When I ask again and again, people tend to ignore me • People don't give me work to do 	<ul style="list-style-type: none"> • I was fired • I cannot get married
Realizing the existence of a language problem when pointed out by others	<ul style="list-style-type: none"> • When I talk with people, I feel that they treat me as a fool • I guess even when I try to talk seriously, the other person gets the wrong idea 	<ul style="list-style-type: none"> • I don't think I talk so much, but I am often told to be quiet
The desire to recover as much language ability as possible	<ul style="list-style-type: none"> • I train with speech therapists • I consider daily life as an arena for training language ability • I enjoy conversations 	<ul style="list-style-type: none"> • I seek my own ways of improving my language ability • I make the chance to communicate with others
Covering the weakness in language ability with ingenuity	<ul style="list-style-type: none"> • I have conversations only with people who talk to me simply • I allow myself sufficient time to rest while considering the words • I use paper money to pay so I don't have to use coins 	<ul style="list-style-type: none"> • Understand by taking the time to repeat again and again • I speak slowly in short sentences • I write Japanese characters which make it easy for me to express my self
Obtaining cooperation by expressing that they have a language problem	<ul style="list-style-type: none"> • I tell people that I could hear, but couldn't talk • I always carry a memo pad and a pencil 	<ul style="list-style-type: none"> • I tell people that I could see letters, but couldn't understand them • I ask people again to talk gently and slowly
Believing in the possibility of communicating with people in spite of aphasia	<ul style="list-style-type: none"> • I think it is possible to convey feelings through facial expression • There are some places where I can enjoy communicating with others without using words 	<ul style="list-style-type: none"> • At the patient group I can say what I feel inside
Emphasizing aspects of personality that have not changed with the onset of aphasia	<ul style="list-style-type: none"> • I was never a good talker • I've always liked to talk 	<ul style="list-style-type: none"> • I forget words due to my age
Aphasia is my fate – that's the way it is	<ul style="list-style-type: none"> • I have no control over being ignored • It goes without saying that I cannot communicate with healthy individuals on an equal footing 	<ul style="list-style-type: none"> • I don't care about what I don't understand • I will try to enjoy myself even if I won't be able to improve my language ability
Appreciating support from others	<ul style="list-style-type: none"> • I could recover because of support from my family • I had the courage to go out because my friends asked me to do so 	<ul style="list-style-type: none"> • I take my frustration out on my family • Everyone at the patient group encourages one another

recover as much pre-onset language ability as possible and sustained themselves to make daily efforts to do so. These efforts included not just [I train with speech therapists], but [I seek my own ways of improving my language ability] without depending on specialists. For example, participants with jobs expressed the belief that participation in communication in their daily lives, including at their workplaces, would activate and lead to the recovery of their brain function, and considered

[I consider daily life as an arena for training language ability]. Moreover, participants who expressed the belief that aggressive communication with other people was the key to recovering their language ability made the effort to go out in order to [I make the chance to communicate with others], and this led to an expansion of their field of activities. “*I won't have the chance to talk if I am alone. If I try to talk with a friend, I'll regain the ability to talk. So, I go out to see my friends.*”

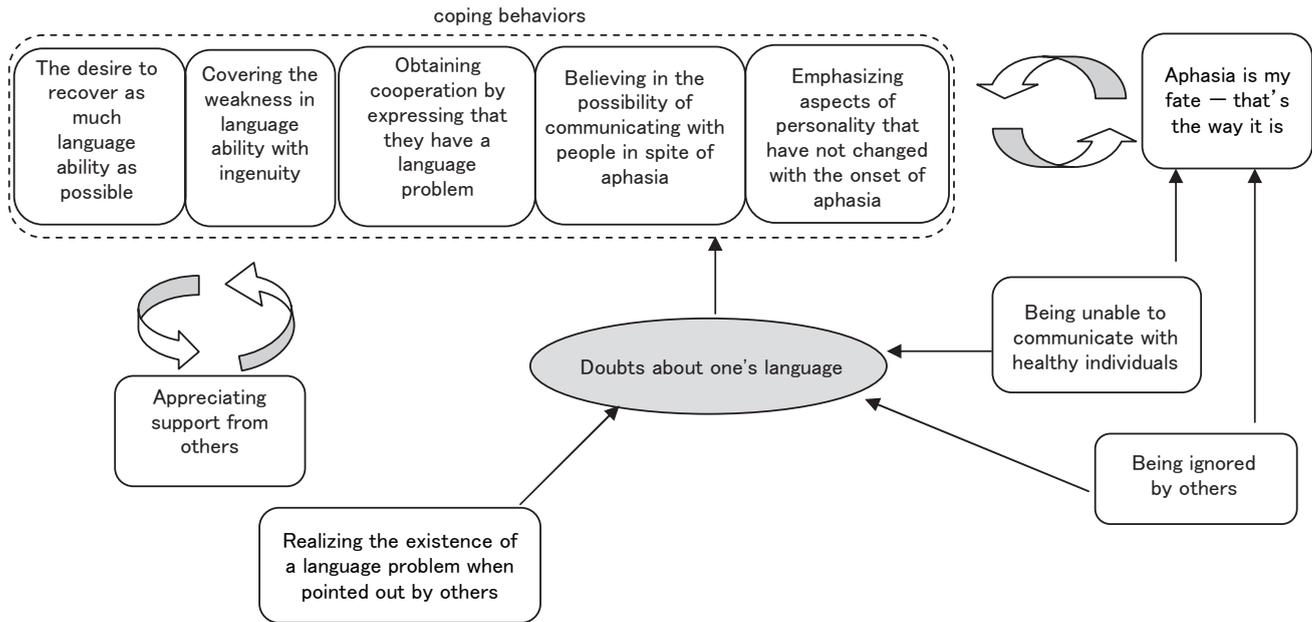


Figure1. Structure of «doubts about one's language» and get to coping behaviors

- Categories
- A central category
- ↻ Action between categories
- Action to the categories

Thus I am able to talk.” Furthermore, some participants mentioned [I enjoy conversations], and that the joy they felt in communicating with people through conversation served to support [the desire to recover as much language ability as possible].

2. [Covering the weakness in language ability with ingenuity]

This coping behavior is based on a participant recognizing their current condition and devising methods of communication that use their remaining abilities rather than focusing on changing the language disorder itself. Participants with Wernicke's aphasia focused on [I have conversations only with people who talked to me simply] because “*I slip through my ears what I heard*”. In other words, they chose people with whom they could easily have conversations by their own standard. Some participants attempted to [understand by taking the time to repeat again and again] because they found that they could understand what people say when sufficient time was secured, whereas it was difficult to understand semantic content in a short time. Many

participants reported feeling fatigue when required to think for extended periods of time. In order to avoid this, certain participants tried to [I allow myself sufficient time to rest while considering the words]. “*It is impossible for me to think about words for a long time. I think, let's say for 30 minutes, and then I take a rest. After thinking for a certain amount of time, I decide to stop and do more tomorrow.*” This strategy may take a lot of time, but it allows the individual to lose their fatigue and reattempt the task with a clear head. Furthermore, participants who reported not being able to communicate in long conversations attempted to express themselves to others by [I speak slowly in short sentences]. Many participants tried their best to understand, in their own way, the conditions or situations in which their language weakness manifests itself, and devised the technique of covering the weakness by utilizing their remaining language ability.

3. [Obtaining cooperation by expressing that they have a language problem]

This coping behavior is designed to announce the presence of aphasia an otherwise invisible

disorder, to gain the understanding of others in adjusting to the communication pace of the affected individual, and to facilitate communication by obtaining their cooperation. One participant with Broca's aphasia encouraged other people to adjust to the slow pace of the conversation by telling them that [I tell people that I could hear, but couldn't talk]. *"I told the people that I couldn't talk. If I hadn't told them, they would have thought that I could communicate as they could and would have spoken to me normally. So from the outset I told them I couldn't talk. That was the right thing to do."* As shown in this case, participants' communicating their difficulties to others is a means of showing, conversely, that there are other communication channels that can be used more easily. If others adjust the pace of their speech to that of the participants and allow them to utilize those means of communication that are relatively unaffected by the disorder, communication becomes easier. In fact, many participants reported that [I always carry a memo pad and pencil] using writing as a communication tool and expressing this to their conversation partner. They communicated in writing when there were words they found difficult to produce verbally, and when they could not understand what their partner had said, asking them to write the information down for them. Furthermore, participants who experienced difficulties with reading comprehension admitted that [I tell people that I could see letters, but couldn't understand them]. They could thereby gain the cooperation of their conversation partner and make more effective use of the written medium by using letters only for expressions.

4. [Believing in the possibility of communing with people in spite of aphasia]

Many participants maintained their relationships with others using this kind of coping behavior. Some participants met groups of friends or attended the patient group and went to other such places they needed to go, expressing the belief that [I think it is possible to convey feelings through facial expression] without using words. These individuals try to communicate their feelings

through their attitudes and actions. This tendency was particularly significant at meetings of the patient group, where a number of patients gather together. Here participants reported that [at the patient group I can say what I feel inside]. *"When I talk to others participating in the patient group, I can see from their facial expressions that they understand what I am saying. If people can understand the idea I want to communicate, then that is enough for me."* Conditions under which behaviors, actions, and facial expressions rather than words can be understood are limited to certain favorable partners, settings and locations. However, by actually choosing these limited conditions, they were able to reduce the value of words to a comparatively low level, while elevating the importance of "*feeling*" and "*spirit*" – constructs that are independent of language. Such cognitive measures serve to alleviate the negative feelings of those who cannot speak and act to promote psychological well-being.

5. [Emphasizing aspects of personality that have not changed with the onset of aphasia]

Some participants reported that *"my language ability did not change with the onset of this disorder,"* and emphasized continuity and consistency of self-perception. They insisted that problems of language ability are not disorders but aspects of individuality, and used cognitive strategies to exhibit their normalcy to themselves and others. One participant with Wernicke's aphasia could talk fluently and continuously. However, he reported that [I was never a good talker], and perceived no change compared to his pre-onset state. Meanwhile, some participants considered their disorders to be the result of aging, a physiological phenomenon that everybody experiences, and reported that [I forget words due to my age]. *"I just forgot the word. They don't come out so quickly. This is not because of aphasia but my age."* Furthermore, one participant with Wernicke's aphasia mentioned that people pointed out his talkativeness. However, he reported that this was not because of his disorder but rather his personality, and that [I've always liked to talk].

6. [Aphasia is my fate – that’s the way it is]

The five categories listed above expressed the coping behaviors for the anxiety caused by «doubts about one’s language». However, these behaviors are not always successful, and where they are not, many participants responded that [aphasia is my fate – that’s the way it is]. For example, participants with Wernicke’s aphasia sometimes repeatedly asked others what they had said because “*what they hear flows out of their head*”. Then, if ignored, they tended to think that [I have no control over being ignored]. “*What I hear flows right out of my head so that my children’s teacher gives up, ignores me, and talks only to my children. I cannot do anything about it. I just stay still and keep quiet.*” Furthermore, some participants indicated that when they become frustrated because they cannot say what they want to say, they try to normalize the situation by thinking that [it goes without saying that I cannot communicate with healthy individuals on an equal footing]. In this manner, some participants stopped fighting against the disorder, a problem they cannot do anything about, accepted the situation, and tried to take on a defiant attitude to create a feeling of stability. On the other hand, there were other participants with anxiety caused by «doubts about one’s language» who did not develop coping behaviors, responding that [Aphasia is my fate – that’s the way it is].

7. [Appreciating support from others]

The daily life of participants is supported by their family, friends and patient groups. It is when participants’ sense of well-being stabilized through coping behavior that they really recognized the support they received. As many participants reported that [I could recover because of support from my family], they truly recognized upon recovery that the presence of their families provided them with courage and led them in the recovery of their language ability and physical function. Family was not only recognized as support for the affected individual, but also as a model for others around them. Some participants tried new coping behaviors with their families, using those that succeeded when in the company

of other people outside their family. In addition, when coping behaviors did not succeed, some participants vented their stress by [I take my frustration out on my family]. They indicated an appreciation of their families, who accepted them as they were, and “*felt sorry about taking their frustration out on their families*”. However, this feeling did not always appear, and families sometimes failed to understand them sufficiently. “*I got irritated. When I got irritated, I always yelled at my wife, and we’d argue again. And, although I felt sorry about yelling at her, it was embarrassing for me to apologize*”.

Discussion

This study, based on the narratives of aphasic persons who were thought incapable of relating their experiences, clarified the processes that such persons go through to develop coping behaviors. Individual differences in experiences with aphasia and coping behaviors observed in this study will be discussed, and suggestion for practical nursing care will be considered in the following section.

1. Individuals differences in coping behaviors

Of the entire structure of processes shown in Fig. 1, the parts that will be experienced by any one individual with aphasia differ depending on the person. Differences are seen according to various factors, including age, gender, type of aphasia and family situation, with each factor appearing to vary in importance and influence. However, it was the type of aphasia that had the greatest impact on the results of this study.

Individuals with Broca’s aphasia, who came from a state of «doubts about one’s language» to developing coping behaviors, went through this process in a relatively straight manner. They face the fact that they cannot express a word at the precise moment they wish to, or come to realize and accept that they are disabled through the words and behavior of others. Through a repetition of this, they become aware of themselves as individuals with disorders, leading to «doubts about one’s language», a state of anxiety over “*whether or not I can express the words that are on my mind next time.*” As long as they remain in

this state, they are left stressed and uncomfortable by the uncertainty. In an attempt to overcome the problem, they start to consider coping behaviors. Lazarus et al.²⁰ describe coping behaviors as cognitive and active efforts to handle specific conditions that are evaluated as stressful. In other words, the clear recognition of the disorder as stress producing is a precondition for the development of coping behavior. Furthermore, there are some aphasic persons who had the attitude that [aphasia is my fate – that’s the way it is] while at the same time developing coping behaviors. They are believed to be attempting to reduce the anxiety caused by «doubts about one’s language» and live their lives comfortably by taking on the idea that they have no control over their disability and maintaining a delicate balance between their view of themselves as disabled individuals and their wish to preserve their identity. Treating their disorder as something they have no control over is seen a kind of strength that allows them to live their own life. In any case, many individuals with Broca’s aphasia seem to find the key to the next behavior while facing up to the «doubts about one’s language».

On the other hand, individuals with Wernicke’s aphasia are often determined to be relatively unaware of their disorder²¹. As a result, it is difficult for them to have «doubts about one’s language» and to develop coping behaviors, with the variation in such behaviors being necessarily small. However, this is a relative tendency, and many individuals with Wernicke’s aphasia, in fact, recognize that “*something is wrong*”, and do indeed experience «doubts about one’s language», though in a vague manner. They do not lack awareness of the disorder in terms of the language aspect. The response from one participant, that [I was never a good talker] does however seem to suggest a lack of awareness about the disorder. On the other hand, the same participant has reported clear irritation that although the sound seemed to have reached their ears, they could not understand the meaning of what was said “*what I heard slipped out and I could not catch the meaning*”. In other words, in terms of hearing, it is

possible for individuals with Wernicke’s aphasia to experience «doubts about one’s language». If such individuals develop an awareness of a problem in their hearing, it can be suggested that perhaps their nonverbal communication channels can play an important role. It is said that in face-to-face communication the verbal message accounts for 7%, while the nonverbal message accounts for 93%²². Others pay attention to the aphasic individual’s problems with language; however, this is also a part of nonverbal communication. It is assumed that discomfort with this attention causes the «doubts about one’s language» and becomes a reason to develop coping behavior.

2. Suggestion for practical nursing care

It has been considered difficult for aphasic persons to express their experiences; however, it seems that nurses also tend to overlook the experiences of these people. This study suggests that it is possible to understand the experience and needs of aphasic persons by carefully listening to them. Such people want to be listened to by others. In fact, they try to [I make the chance to communicate with others] every now and again part of their coping behavior. Some participants considered the interviews a chance to improve their language ability. According to Secret et al.²³, as the interviews proceeded, individuals with nonfluent aphasia began to speak more smoothly than before, and they appreciated researchers for listening to them carefully. Nurses need to listen to aphasic persons more carefully than before not only as a means of increasing their satisfaction at being listened to, but also to improve their language ability and support their coping behavior.

3. Limitations of this study and future issues

Many participants in this study belong to patient groups, which are organized with significant support from STs. However, this is not representative of the general aphasic population. There is a limit to how far the results of this study can be applied to all individuals with aphasia, including individuals with aphasia who have not participated in any community activities, due to the fact that such a population also includes individuals who have

recently developed this disorder and who have severe disability. It is necessary for us to continue research by classifying participants into smaller segments according to the length of time they have suffered from aphasia and the severity of their disorder.

Conclusions

1. After many aphasic persons developed anxiety through 《doubts about one's language》 they subsequently became aware of their language discomfort and attempted smooth communication through various coping behaviors.
2. Individuals with Broca's aphasia tend to easily develop coping behaviors for their disorder through the 《doubts about one's language》, which is believed to lead to an expansion in the variation in coping behavior.
3. Individuals with Wernicke's aphasia have limited experience of the 《doubts about one's language》 due to a limited awareness of their disorder, which is believed to limit variation in their coping behavior.

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当事者の語りにみる失語症という体験 — 自らの言葉への疑いとその対処行動に焦点を当てて —

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要 旨

本研究の目的は、失語症者の語りをもとに、退院後の身近な対人関係における彼らの体験を明らかにすることである。失語症者16名に半構成的面接を行い、Spradleyのエスノグラフィの手法を参考にしてデータを分析した。その結果、《自らの言葉への疑い》に揺れ動く不安な状態を中心とする一連の体験のプロセスが明らかになった。参加者の中には、この状態に向かい合って言葉の不自由さを認識し対処行動に至る者もいたが、この認識が比較的希薄で対処行動がとりにくい者もいた。その認識につながる体験のカテゴリーには、【健常者には言葉が通じない】【誰も相手にしてくれない】【周囲に指摘され言葉の問題に気付く】がある。また、対処行動には、【元の言葉に近付きたいと願う】【工夫して言葉の弱みをカバーする】【言葉の弱みを伝え協力を得る】【失語にも関わらず通じ合えると信じる】【病前と変わらない面を強調する】というバリエーションが見られた。対処行動が成功した場合には【周りの支えがありがたい】という感謝の語りが、成功しない場合には【失語になったことは仕方がない】と開き直す語りも見られた。看護者が一人ひとりの失語症者の語りを傾聴しその体験を共感的に理解することは、思いを話せたという満足感をその失語症者に与えるのみならず、言葉の上達への貢献など対処行動を支える点でも重要と考えられる。