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Special Feature Article

Intervention for Improving Communicative Abilities in Patients with Dementia: Language Dysfunctions and Better Communication

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Abstract

Various cognitive functions, such as memory, language, and executive functions, gradually deteriorate over time in patients with dementia (PWD). Communication is regarded as the process by which information is shared between persons. The information sender conveys his or her intentions while the information receiver speculates these intentions by integrating verbal and nonverbal information based on the situation and context. Therefore, besides language, communication requires various cognitive functions. During the early stages of the disease, PWD do not experience severe language dysfunctions, but their communicative abilities begin to decline during this stage due to other cognitive dysfunctions.

This article aimed to review approaches for supporting augmentative and alternative communication (AAC) in PWD, depending on the severity of the disease. Also, it was reviewed on the characteristics of language and cognitive functions in dementia as well as relationships between language and cognitive functions during communication, in terms of implications for interventions aiming to improve communication in severe PWD.

In the late stages of dementia, as cognitive dysfunction worsens, assessing the effect of each cognitive function (including language) on communicative abilities becomes more difficult. Interventions based on these cognitive assessments are also challenging. In contrast, nonverbal communication or the desire for mutual communication is reported

to be relatively preserved in patients with severe dementia. This is important for establishing an effective intervention that would allow for interpersonal interactions.

Deterioration of communicative abilities in severe PWD also affects decision making. In such cases, family caregivers undertake proxy decision-making by speculating the PWDs' desire. However, this may burden the family. These problems occur due to the lack of information. PWDs in the late phase of the disease may find it difficult to communicate their feelings; thus, there is a lack of information for proxy decision-making.

AAC is basically the way to augment verbal language. There are a few reports on AAC for PWD in which a memory book, which records past experiences with pictures and explanatory sentences, served as an effective tool for communication, as it compensated for PWDs' memory decline. In this article, this form of AAC for PWD prove to be an effective tool for both communicating and obtaining basic information for proxy decision-making, as it helped family caregivers understand PWDs' view of life with the aid of a memory book, though further study is necessary to adapt in clinical settings. In the last stage of dementia when most PWD are unable to convey their wishes verbally, owing to which they cannot make decisions, it is speculated that AAC in the form of a memory book could help track events in PWDs' lives, which in turn would serve as basic information for proxy decision-making.

Keywords : dementia, communication, severe dementia, augmentative and alternative communication (AAC), decision-making

Introduction

Communication is not only verbal communication, but also includes information other than verbal communication. As dementia progresses, not only language function but also multiple cognitive functions decline. First, we will overlook the definition of communication and its characteristics, and discuss the relationship between the cognitive characteristics of dementia and the

features of communication disorders.

1. language and communication

Communication is the process of sharing information between people. For example, in conversational communication, information such as thoughts, intentions, ideas, and feelings are exchanged between a speaker and a listener, mainly using spoken language. Communication is a series of processes in which information is shared through such exchanges.

Human communication is complex. Words can be used to convey things that are not actually there (stimulus independence), words can be used to convey things that are happening in the past or in another space other than the present (transcendence), and words can be combined to express and convey an infinite number of things (infinity) 3).

In such communication, various types of information are exchanged. In particular, information communicated in spoken language includes "linguistic information" as information expressed by language symbols, such as the meaning of words, literal meaning, and sounds that express meaning; "paralinguistic information" as information that supplements and modifies linguistic information, such as voice inflection, loudness, and pauses; "non-verbal information" as information expressed by body movements and emotional states, such as gestures, nodding, facial expressions, eye contact, and posture.

This information exchanged in communication is combined with the situation and context in which communication takes place. The speaker expresses the intention behind the information, and the listener infers the speaker's intention from the information received.

2. spoken language communication

Communication in which verbal

information is exchanged mainly is called verbal communication, and communication in which non-verbal information is exchanged mainly is called non-verbal communication. Verbal communication is conducted using spoken or written language.

The spoken language communication process, such as conversation, is represented in Figure 1 called a speech chain 2). As shown in Figure 1, spoken language communication consists of a linguistic level, a physiological level, and an acoustic level.

The central nervous system, which controls the processing of language functions as a higher cognitive functions, is important in processing at the linguistic level. The central nervous system, which controls the processing of language functions as a higher cognitive function, is important for processing at the linguistic level. In order to receive the contents as speech sounds, the input of speech sounds from the outside world must be appropriately processed in the peripheral nervous system involved in auditory perception. In other words, as shown in the speech chain, communication, as typified by conversation using spoken language, requires body movements and auditory functions as a premise in addition to higher cognitive functions.

Furthermore, in communication such as conversation, we grasp for the

moment many elements that arise in the ongoing⁷). In other words, communication requires the integration of verbal and non-verbal information, as well as many factors such as situation and context, on the spot to make arrangements for the next exchange, requiring the simultaneous functioning of multiple cognitive functions such as attention, memory, and executive functions, in addition to the language function.

Therefore, communication deficits may be present from the earliest stages of dementia, when the disease is very mild and language impairment is not in the foreground. In addition, as dementia progresses, cognitive dysfunctions become more complex, which is different from the communication disorders caused by cerebrovascular disease, and interventions that do not take into account the characteristics of dementia are often unlikely to be effective.

In order to achieve effective communication interventions for dementia, it is important to understand the overall picture of dementia with progressive and complex cognitive dysfunctions and to select compensatory measures that can avoid communication stagnation. In other words, it is necessary to analyze the language function, including auditory and visual functions, that has been altered by dementia while considering

the communication process, and to understand higher brain functions other than language function, such as memory, attention, and working memory. The impact of these functions on the communication process should be borne in mind, and the means and methods that can compensate for them with the remaining functions should be considered.

I. Cognitive Characteristics of Dementia and Communication

The more severe the dementia, the more difficult it becomes to cope with communication skills. However, compensating for residual function and diminished capacity based on diversity of communication may help to devise communication. In order to devise more effective communication, it is important to start communication support before the time when communication difficulties become evident.

We will review the relationship between the causative disease of dementia and communication support, and the practical communication skills of dementia as perceived by family caregivers in their daily lives, and consider communication interventions to compensate for the decline in language function as a response to the communication skills of severe dementia.

1. Causal diseases of dementia and

communication support

In dementia, multiple cognitive functions such as memory, language, and executive functions are acquiredly impaired, and the condition persists chronically, resulting in a decline in the level of social life activities.

Since cognitive functions that begin to decline differ depending on the causative disease, it is important to respond to communication disorders according to each cognitive characteristic when it is possible to provide communication support according to the cognitive characteristics 6)7).

However, as dementia becomes more severe, many cognitive dysfunctions emerge, and it is often not easy to approach communication based on cognitive characteristics, including language function.

2. daily communication skills from the family caregiver's point of view: the decline in practical communication skills felt from the early stage of the disease

As mentioned above, communication requires memory and executive functions in addition to language functions, so even when language impairment is not in the foreground, dementia can be considered to present some kind of communication disorders. When language impairment is not in the foreground, it often gives the

impression that there is no superficial difficulty in communication. However, we conducted a questionnaire survey on communication among family caregivers of patients with dementia to investigate how family caregivers understand the communication abilities of dementia patients in their daily lives¹⁷⁾. The results showed that even in the early stages of the disease, when language function itself was relatively unaffected, family caregivers felt that the communication abilities of the patients with dementia were declining.

Even when language impairment is not in the foreground, family caregivers feel that communication is difficult in daily life, and it is important to intervene in communication from the early stage of the disease, before communication impairment is in the foreground. We believe that early intervention in communication in dementia can lead to the resolution of problems arising from communication in the early stages of the disease, and can also provide early indicators of communication strategies for the more severe stages of the disease.

3. Nonverbal communication skills in severe dementia

In the terminal stage of severe dementia, all cognitive functions, including language functions, are impaired, making communication through verbal communication

extremely difficult. In addition, many cognitive dysfunctions emerge, and approaches based on cognitive characteristics, including language function, become less easy, making it more important to respond based on the individual's pleasure or displeasure in daily communication. In other words, it becomes necessary for those around the patients to read the reactions to pleasure and displeasure expressed through nonverbal communication such as facial expressions and attitudes.

However, compared to the milder stage, nonverbal expressions are often more ambiguous. In addition, although the expression of reactions to pleasure and displeasure is said to remain, the expression of emotions becomes weaker (13)(14). In severe dementia, nonverbal communication is said to be relatively preserved, but it should be carefully observed, bearing in mind that expressions such as facial expressions and attitudes shown may become more subtle.

On the other hand, regarding the understanding of nonverbal information in nonverbal communication in severe dementia, it has been suggested that recognition of happy facial expressions is relatively perceived in facial expression recognition (5)(10).

4. motivation to communicate in patients with severe dementia

A study investigated the motivation

to communicate in patients with severe dementia using the still face paradigm(4). According to this report, when communicating in a situation in which the communicative partner does not make eye contact and does not respond in the interaction, the patients with severe dementia looked away from the communicative partner more frequently than in a communicative situation in which there was interconnectedness (4).

Furthermore, in communication situations that did not show such interrelatedness, the patients with severe dementia showed different responses than in normal communication situations based on interrelatedness, such as approaching the communication partner or, conversely, trying to leave the communication partner (4).

From these results, it can be inferred that patients with severe dementia are motivated to engage with others and to communicate in a way that brings about interrelatedness, even when their dementia is severe.

II. Dealing with Communication Skills of Patients with Severe Dementia

1. Communication Devices for Patients with Severe Dementia

Based on the communication characteristics described above, the table 1 summarizes the communication

interventions as a measure to deal with the communication ability of patients with severe dementia.

As a basic communication attitude, it is important to maintain the dignity of patients with dementia and to talk to the patients with an emphasis on mutual relationships. The patients should be positioned in a place where they can face each other head-on so that facial expressions and eye contact can be mutually confirmed. In addition, the patient's expressed words and attitudes should be accepted, and the intention expressed by patients with dementia should be interpreted not only based on verbal information but also in combination with non-verbal information such as facial expressions and attitudes.

Furthermore, it is important to emphasize the main points using words and phrases. The capacity to temporarily retain information in ongoing communication is reduced in dementia 15). The use of short sentences, avoiding the use of pronouns such as "this" and "that," and focusing on specifics and main points are encouraged to reduce the amount of guesswork by patients with dementia and to promote understanding of meaning. It is also useful to use visual materials such as diagrams and pictures to compensate for disappearing information. On the other hand, when

phonological processing remains even in relatively severe cases, we try to maintain the patient's motivation to communicate by giving him or her opportunities to express verbal information through reading aloud and recitation, so that he or she can feel the interactive interaction.

In addition, the communicator should be positioned in front of patients with dementia so that he or she can hear easily, taking into consideration auditory and visual sensation. The volume of the voice should be at a conversational level, neither too loud nor too quiet, and the communicator should speak while presenting a mouth shape. When presenting visual information, make sure that it is easily visible to the patient, including the position of the visual material, adequate lighting, and whether there is too much glare near a bright window, etc.

2. Decision-making support for patients with severe dementia

When dementia is severe, language and communication skills become unstable, and the ability to make decisions declines. Family caregivers must make decisions while presuming the person's intention in many situations, and this increases the burden on family caregivers. Although it is important for the family caregivers to understand the patients' life philosophy and wishes for life 12), it is

usually difficult to obtain such information during the severe period when the patient's communication ability is impaired. The lack of information about the patient's views on life and wishes for life, which is necessary for decision-making by proxy, cannot be confirmed through communication with him/her, which has been shown to be a barrier to decision-making by proxy 9).

To solve these problems, it is important to obtain the patients' basic ideas about life from the early stages of the disease, and the viewpoint of not only "what would you want me to do if something happened to you?" but also "how would you make decision for yourself if you were cognitively normal?" 12) Furthermore, it has been shown that it is useful to keep a written record of the person's life history, personality, etc. 12).

As a response to the communication skills of people with severe dementia who have difficulty making decisions, a memory book, one of the augmentative and alternative communication (AAC) methods, could be used in terms of keeping texts and records for decision-making by proxies 16).

AAC attempts to compensate for stumbling blocks in communication, and is often applied to cases such as speech impediment and motor speech disorders, especially those in which it is

difficult to express spoken language. There are methods of supplementation such as substituting gestures and facial expressions, and using tools such as notebooks with pictures and text, and devices that record messages. Non-verbal communication, as described above, can be broadly interpreted as a form of AAC.

Memory book is one of the AAC which uses tools for dementia. Memory books have been reported to be effective as an alternative and compensatory means of communication for dementia¹⁾. Memory books are used to look back on each period of life in chronological order and record them in a booklet along with photographs and descriptions of the time, and are considered an effective method of expanding communication while compensating for memory impairments.

If the memory book can be used as a tool to reaffirm the patients' way of thinking about life by communicating with the patients from the early stages of the disease, it can be used not only as a device for communication itself, but also as a tool for family members and others to make decisions on the patients' behalf when the communication disorder becomes more severe. If the memory book can be used as a tool for reaffirming the patients' perspectives on life by communicating through it from the early stages of the

disease, we assume that this is not only a device for communication itself, but also has elements that can be one of the factors in determining "what the patient would do if he/she were cognitively normal " by family members and others on behalf of the patient in periods of severe communication difficulties.

Decision-making by proxy involves complex factors such as the state of the patients and ethical issues, and there are many aspects that are not uniformly applied¹¹⁾. However, continuing communication based on the recorded content of the patients' life and thoughts about life from the earlier stage when communication is relatively possible will ensure that part of his/her wishes and thoughts will be passed on to the future. This can connect the patients, family members, and medical personnel, and can lead to better decision-making on behalf of the patients⁸⁾.

The usefulness of the memory book for decision-making by proxy needs to be verified in various situations and from multiple perspectives in dementia patients themselves. If the record of the patients' life and life-related information is not presented unilaterally by either the patients or the family caregivers, but through interactive communication via the record, the memory book will be highly useful as a decision-making aid for patients with severe dementia at the

end of their lives.

Conclusion

Based on the premise that language function and communication have multiple aspects, we reviewed the cognitive and communicative characteristics of dementia and discussed communication strategies and measures for communication in severe dementia.

When dementia is severe, cognitive dysfunctions are widespread, and communication through verbal communication becomes extremely difficult. On the other hand, if nonverbal communication is relatively preserved, it is useful ways of communication in patients with severe dementia. However, as the severity of dementia increases, expressions and responses through nonverbal communication may be more ambiguous and subtle than in earlier stages, and careful insight is required when taking advantage of nonverbal communication.

For decision-making by proxy, we considered the usefulness of introducing AAC, which complements communication in dementia, from the early stage of the disease in order to accumulate the patients' thoughts and feelings about his/her life as a record and to connect the patients, family caregivers, and medical personnels.

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References

- 1) Bourgeois, M.S., Dijkstra, K., Burgio, L., et al.: Memory aids as an augmentative and alternative communication strategy for nursing home residents with dementia. *Augmentative and Alternative Communication*, 17 (3); 196-210, 2001
- 2) Denes, P. B., Pinson, E.: *The Speech Chain: The Physics and Biology of Spoken Language* Second edition. Worth Publishers, New York, p.5, 1993
- 3) ウィルスン D., ウォートン T. (井門 亮, 岡田聡宏, 松崎由貴ほか訳) : 動物のコミュニケーションと人間のコミュニケーション. 最新語用論入門 12 章 (今井邦彦編). 大修館書店, 東京, p.7-21, 2009
- 4) Ellis, M. P., Astell, A. J.: The urge to communicate in severe dementia. *Brain Lang*, 91 (1); 51-52, 2004
- 5) Guaita, A., Malnati, M., Vaccaro, R., et al.: Impaired facial emotion recognition and preserved reactivity to facial expressions in people with severe dementia. *Arch Gerontol Geriatr*, 49 (Suppl 1); 135-146, 2009
- 6) 飯干紀代子: 今日から実践認知症の人とのコミュニケーション—感情と行動を理解するためのアプローチ—. 中央法規出版, 東京, p.64-71, 2011
- 7) 池田 学: 認知症者のコミュニケーション. *高次脳機能研究*, 35 (3); 292-296, 2015
- 8) Lamahewa, K., Mathew, R., Iliffe, S., et al.: A qualitative study exploring the difficulties influencing decision making at the end life for people with dementia. *Health Expect*, 21 (1); 118-127, 2018
- 9) Livingston, G., Leavey, G., Manela, M., et al.: Making decisions for people with dementia who lack capacity: qualitative study of family carers in UK. *BMJ*, 341; c4184, 2010
- 10) 牧 陽子: 社会生活障害としての認知症—アルツハイマー型認知症を中心に—. *認知神経科学*, 18 (3, 4); 146-153, 2016
- 11) 箕岡真子: 認知症の終末期ケアにおける倫理的視点. *日本認知症ケア学会誌*, 11 (2); 448-454, 2012
- 12) 荻野美恵子: 終末期における対応とは具体的にはどういったことなのか?. *神経内科 Clinical Questions & Pearls 認知症* (高尾昌樹編). 中外医学社, 東京, p.316-324, 2016
- 13) 植田 恵: 認知症の評価とリハビリテーション. *高次脳機能障害学第 3 版* (阿部晶子, 吉村貴子編, 標準言語聴覚障害学). 医学書院, 東京, p.228-251, 2021
- 14) 和田奈美子: 重度の人とのコミュニケーション法. *認知症の緩和ケア* (平原佐斗司, 桑田美代子編). 南山堂, 東京, p.121-130, 2019
- 15) 吉村貴子, 前島伸一郎, 大沢愛子ほか: 言語流暢性課題に現れた認知症のワーキングメモリの特徴—言語流暢性課題に

はワーキングメモリの中央実行系が関連する可能性がある— 高次脳機能研究, 36 (4); 484-491, 2016

16) 吉村貴子, 岩田まな, 齊藤章江ほか: 認知症高齢者に対する有効なコミュニケーション方法とその介入について—言語障害学の観点からのアプローチ— 京都学園大学健康医療学部紀要, 2; 1-11, 2017

17) Yoshimura, T., Osawa, A.: The

relationship between dementia severity and communicative ability from a family caregiver's perspective. Pacific Rim International Conference on Disability and Diversity Conference Proceedings. Center on Disability Studies, University of Hawaii at Mānoa, Honolulu, p.1-7, 2020

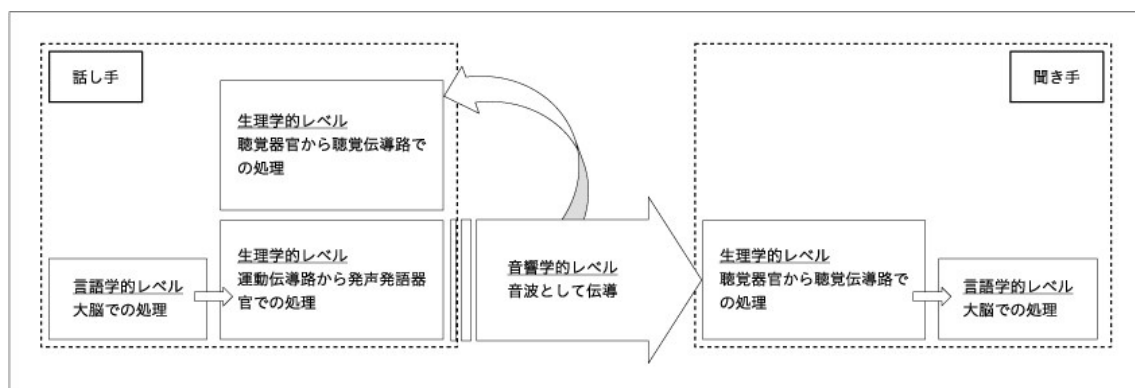


図 Speech chain (ことばの鎖) の模式図

話し手 (左側) と聞き手 (右側) が音声言語を用いて行うコミュニケーションでのやりとりは、言語学的レベル、生理学的レベル、音響学的レベルという複数の段階によって成立することを解説した図である。(文献 2 より改変して引用)

Figure 1 Schematic diagram of the speech chain

The figure illustrates that communication between a speaker (left side) and a listener (right side) using spoken language consists of multiple levels: linguistic, physiological, and acoustic. (Adapted from Reference 2)

表 重度認知症のコミュニケーション能力に対する意思疎通の工夫

方法	具体例
認知症患者本人の尊厳を保った相互関係性を重視した接し方	<ul style="list-style-type: none"> ・アイコンタクトをとる ・丁寧な言葉遣いをする
認知症患者本人が表出した反応の受け止め	<ul style="list-style-type: none"> ・アイコンタクトの有無や、軽い頷きなども丁寧に観察する ・認知症患者本人が表出した意図などを受容し、その受容について認知症患者本人にフィードバックし、コミュニケーションの双方向性を示す ・言語情報のみならず、表情や態度などの非言語情報と組み合わせて、表出された内容を解釈する
話しかけは、単語や句で要点を強調	<ul style="list-style-type: none"> ・要点は、図や絵などを併せて提示する ・音読や復唱など、比較的残存しやすい音韻処理などの言語様式を活用して、表出を実感する ・聴覚、視覚に配慮する（会話レベルの音量を基準に話す、見えやすいように、適度な照明下で話す）

Table1 Communication Interventions for Patients with Severe Dementia

Methods

Interaction that emphasizes interrelationships while maintaining the dignity of the patients with dementia

Accepting the intention expressed by patients with dementia

Emphasize the main points by using words and phrases when speaking to patients with dementia

Specific examples

Implementing eye contact

Use polite language

Carefully observe whether or not eye contact is made and whether or not a light nod is given.

Accepting the intention expressed by patients with dementia and providing feedback to him/her about the acceptance, thereby demonstrating interactive communication.

Interpret the expressed content by combining not only verbal information but also nonverbal information such as facial expressions and attitudes.

Emphasize the main points by using words and phrases when speaking to the Present the main points together with diagrams and pictures

Take advantage of linguistic styles such as phonological processing that are relatively easy to retain, for example reading aloud and recitation

Give consideration to auditory and visual perception (Speak at a conversational volume level. Speak under appropriate lighting for visibility.)