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The journey of an aphasic in Japan
The impact of the Japanese language, the healthcare system,
and the support centers on the recovery of Japanese aphasics

Adonia Dhanjal

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UNIVERSITÉ DE LAUSANNE
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The journey of an aphasic in Japan;
The impact of the Japanese language, the healthcare system, and the support centers on the
recovery of Japanese aphasics

par

Adonia Dhanjal

sous la direction du Professeur Jürg Rainer Schwyter

Session d'Automne 2018

Abstract

This study explores the situation of aphasics in Japan and how their recovery process is affected by the complexity of the Japanese language, and the healthcare system. This is an important topic, as it is a matter of health. There is a gap in literature regarding aphasia and its context in Japan. In order to help fill the gap, this study is based on secondary research on key studies and qualitative fieldwork. The main findings are the observation of unique linguistic symptoms that need specific treatments. Second, the structural problems within the healthcare system may prevent aphasics from receiving optimal treatment. Time is vital for stroke patients. Third, there is hope from help of aphasic support centers, although their presence and reach to the public is limited. Therefore, this study is significant as it has the opportunity to draw attention to their involvement in making the life of aphasics better.

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List of abbreviations

ADL	Activity of daily living
ALS	Average length of stay
BTX	Botulinum toxin
CT	Computed tomography
DPC	Diagnostic procedure combination
JAPC	Japan Aphasia Peer Circles
LPH	Local public hospital
MHLW	Ministry of Health, Labour and Welfare
MIC	Ministry of Internal Affairs and Communications
MIT	Melodic Intonation Therapy
MRI	Magnetic resonance imaging
MTDDA	Minnesota Test of the Differential Diagnostic of Aphasia
NHI	National Health Insurance
NRCDD	National Rehabilitation Center for Persons with Disabilities
OECD	Organization for Economic Co-operation and Development
PET	Positron emission tomography
PRH	Private hospital
PWD	Person with disabilities
RTDDA	Roken Test of Differential Diagnostic of Aphasia
SALA	Sophia Analysis of Language in Aphasia
SCTAW	Standardized Comprehension Test of Abstract Words
SLTA	Standard Language Test of Aphasia
SOV	Subject-Object-Verb
ST	Speech-Language-Hearing Therapy/Therapist
t-PA	Intravenous tissue plasminogen activator
TLPA	Test of Lexical Processing in Aphasia
WHO	World Health Organization

1. Introduction

This study looks at the situation of aphasics in Japan and how their recovery process is affected by the complexity of the Japanese language, and the healthcare system. Such a topic is important as there is a gap in literature regarding aphasia and its context in Japan. It is a question of health and improving the life of aphasics. In order to do so, this study is based on secondary research on key studies and qualitative fieldwork. The main findings are the observation of unique linguistic symptoms that need specific treatments. Second, the structural problems within the healthcare system may prevent aphasics from receiving optimal treatment. Time is vital for stroke patients. Third, there is hope with help from aphasic support centers although their presence and reach to the public is limited. Therefore, this study is significant as it has the opportunity to bring attention on their involvement in making the life of aphasics better.

Stroke is one of the leading causes of death in the world. About 15 million individuals suffer a stroke every year and a third of them do not survive (World Stroke Organization). About half of the remaining suffers from the consequences for the rest of their lives. Those may be physical, such as paralysis, and the patient follows a physiotherapeutic treatment. However, language disorders can also appear and affect every level of communication. Aphasia occurs when there are damages in the language area of the brain, which is located in the left cerebral hemisphere. Broadly, there are in fact three types of aphasia: Broca, which is located in the frontal lobe and is the cause of language production disorder; Wernicke, which is located in the temporal lobe and is related to language comprehension; and global aphasia when both of these areas have been damaged (Obler & Gjerlow 1999). Not every stroke survivor suffers from aphasia. In fact, it concerns about 25% to 40% of that population. However, the most common cause of aphasia is stroke (National Aphasia Association, Aphasia FAQs).

In Japan, stroke is ranked as the fourth cause of death, following cancer, heart disease and pneumonia (Tsutsumi 2014:1; Ministry of Health, Labour and Welfare, Death rates (per 100'000 population) by cause of death and sex, by year). The exact number of strokes in the country is unclear, although there have been about 300'000 individuals officially reported, possibly up to 500'000 per year (Kotani 2008:110). There are various factors that can increase

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the probability of a stroke, such as smoking, alcohol, high blood pressure, obesity, and/or stress, for example. Long working hours that exceed 55 hours per week can increase the risk of having a stroke up to three times compared to working standard hours (Kivimäki et al. 2015:5). In Japan, annual average working hours are particularly high compared to other countries. In 2013, over 306 individuals suffered from cardiac or cerebrovascular diseases and 436 individuals were reported suffering from mental illness, as a consequence of overwork. In fact, *Karoshi* (meaning “death from overwork”) is a particularly serious issue in the country, as over 2323 employees committed suicide that same year, due to their working conditions (World Health Organization 2018:113). The work environment and the other previously mentioned factors increase the risk of stroke.

This research follows the journey of aphasics in Japan, through the following stages: the hospitalization, the rehabilitation, and the support centers. In addition, the relationship between the Japanese language and aphasia is discussed and provides insights on language therapy options. Indeed, it is necessary to introduce key elements from the linguistic context in order to better understand the language treatments for aphasics in Japan. Moreover, a chapter is focused on the overview of the Japanese healthcare system, as it directly impacts how hospitals and rehabilitation facilities are structured. This is a qualitative study, as it is a domain with limited research studies, and particularly regarding aphasia in Japan. Indeed, the source material is even more narrowed, especially in English. For this reason, I translated a selection of resources that I considered indispensable for a better understanding of the topic.

Although most of this paper is focused on studies, Chapter 5 (about support centers) is different. It introduces the Japan Aphasia Peer Circles (JAPC), and in particular the example of Ogikubo Center, which I had the opportunity to visit and meet Ms. Sonoda, the vice chief director of the association, and some aphasic members who kindly shared their story. This fieldwork has been very rich and provided many invaluable and precious insights, especially from the human side.

2. Overview on Japanese language, with a focus on written Japanese

A brain injury manifests itself in many ways, as all patient do not show the same symptoms. The severity of the injury, the length of the exposure before being hospitalized, or the areas in the brain that are affected may differ from patient to patient. These types of medical factors are necessary for the medical staff to determine the diagnosis. Thus, they can provide the best treatment to save the patient and limit the damage as much as possible. Doctors do their best to stop the injury from spreading to other brain zones and to stabilize the patient's conditions. These procedures are exhausting but they are not able to completely bring the person back to how he or she was prior to the accident. Again, symptoms vary a lot depending on the cases. Some suffer from paralysis (the severity can also differ), vision and/or perception issues, cognitive problems (such as memory loss, attention deficiency, etc.), and/or emotional disorders and so on (*Physical And Mental Effects of Stroke* n.d.). One of those is a language related disorder, called aphasia.

There are many types of aphasia, depending on the severity of impact on language production and comprehension. A lot of research has analyzed aphasia based on Indo-European patients and, therefore, Indo-European languages. However, there is a significant gap in literature regarding aphasia in Japan that needs to be addressed as there are particular aspects that are specific to the Japanese language. Examining them has the potential to provide a deeper understanding on aphasia and possibly explore different leads for language therapy.

This chapter explores the connection between the Japanese language and aphasia. Understanding the implications of this unique language guides the reader to have a better overview on how languages can be affected by aphasia. This is an indispensable topic to address before discussing support groups and centers, as the treatments options are directly connected to the linguistic specificities. Therefore, this chapter first presents an introduction to the Japanese language, presenting the three alphabets, Kanji, Katakana and Hiragana (Katakana and Hiragana are also referred together as Kana). Next, it is about orthographic impairment observed in aphasics, based on these characters. Then the link between orthography and

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phonology is examined, and highlights how semantics play an important role. From there, finally, semantic impairment is examined and discussed.

2.1 Japanese language; overview

Japanese is spoken by over 128 million individuals, including speakers from the Japanese archipelago and emigrant communities all over the world, mostly in Brazil, Peru and the United States of America (Shibatani & Kageyama 2015:vi). Due to its geographical context, Japanese speaking regions are isolated from the rest of the South-East Asian territories, reducing the influence of other languages. As Shibatani discusses, there are debates amongst researchers about the language roots, as there seems to be connections with other languages on mainland Asia (Shibatani n.d.).

Japanese belongs to the agglutinative type of languages, and is usually structured with associations of syllables. Those syllables are mostly composed of a consonant and a vowel; but a vowel or /n/, which is the only isolated consonant, can occur alone. Japanese grammar structure is classified as Subject-Object-Verb (SOV), although it is important to mention that the order in the Object-part is relatively free. It is indeed possible to construct the following example in two sentences (Makino & Tsutsui 1986:16):

Japanese version	スミスさん	は	日本	で	日本語	を	勉強している。
Phonetic conversion	Sumisu-san	wa	nihon	de	nihongo	o	benkyôshiteiru.
Word by word translation	Mr. Smith	(particle indicating the subject)	Japan	(particle indicating the location)	Japanese	(particle indicating the direct object)	Is studying
Translation	Mr. Smith is studying Japanese in Japan.						

2. Overview on Japanese language, with a focus on written Japanese

Japanese version	スミスさん	は	日本語	を	日本	で	勉強している。
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There are three different writing systems. First, there are Kanji pictograms, which are borrowed Chinese characters that give information about semantical contexts (they are represented by 日本 /nihon/, 日本語 /nihongo/ and 勉強 /benkyô/ in the previous example); Second, there are 46 Hiragana characters, which are function words that convey grammatical information (they are represented by は /wa/, を /o/ and で /de/ in the previous example); and third, there are 46 Katakana characters, which are symmetric to Hiragana but are used to express foreign words (for example, the representation of the name “Smith” is スミス /sumisu/ from the previous example) and mimetics (Shibatani & Kageyama 2015:xv-xvi). As Hiragana and Katakana characters mirror each other, they are also referred together as Kana characters.¹

There are no official records on how many Kanji characters exists. One of the most renowned Japanese dictionaries, *Dai Kan-Wa Jiten*, has listed over fifty thousand pictograms ("Dai Kanwa Jiten" 2018). However, a Japanese-speaking person does not need to know all of them. Children first learn Kana characters before any Kanji (Sasanuma 1974:142). When they graduate from elementary school, they know 881 characters that are listed by the Ministry of Education and considered as the basic requirement. In order to be as independent as possible concerning reading ability, an individual must know the 1'850 characters that are also numbered by the Ministry of Education (A Guide to Reading and Writing Japanese 1959:7). However, in order to be able to read and understand Japanese newspapers, it is required to know at least 3'000 Kanji characters. As the number of existing Kanji characters is very high, not all Japanese individuals have the same level of remembering and using them (it can also vary depending on their job, for example). Therefore, even highly educated people may sometimes have difficulties remembering certain characters, especially those which are not commonly used on

¹ See Appendix A: Hiragana and Katakana characters, on page 68.

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an everyday basis. They would then write the word using Kana characters, as they know the pronunciation of the word they want to use. It is important to mention that the opposite never happens: a Japanese person would never forget Kana characters and instead use Kanji to write them (Sasanuma 1974:143).

The logographic Kanji characters concern lexical morphemes, which can be nouns, roots of verbs or adjectives. One Kanji character represents usually one word, although most of Japanese words are formed with two or more Kanji characters (Sakuma et al. 1998:76). Moreover, one Kanji character has at least two pronunciations, which can be distinguished in two categories: the ON-yomi (i.e. readings taken from Chinese) and the KUN-yomi (native Japanese readings) (A Guide to Reading and Writing Japanese 1959:8). Usually, when a Kanji occurs in a set of combinations of other Kanji (or, very rarely, alone), it will be read according to its ON-yomi. If the character happens to be alone (or in a small set of combinations of Kanji), then the KUN-yomi will be chosen. Therefore, when confronted with a set of Kanji characters, the readings will usually be the same type: ON-yomi – ON-yomi or KUN-yomi – KUN-yomi (Sakuma et al. 1998:77).

Oral and written Japanese share a complex relationship, which will be discussed later on. The next section discusses how Japanese orthography meets with aphasia and what types of impairment can be distinguished.

2.2 Orthographic impairment

Written Japanese has both Kana and Kanji characters, which fulfill a specific role. Kanji represents lexical morphemes, whereas Kana characters are grammatical morphemes. This is a unique characteristic when compared to Indo-European languages, as it generates particular symptoms for Japanese aphasics (Sasanuma 1974:141). It seems that the level of impairment is disproportional between those two writings, which will be discussed in this section. Sasanuma (1974) has identified three types of impairment in written Japanese that can affect aphasics. They involve Kana impairment (type 1), Kanji impairment (type 2), or both (type 3). For this experiment, clinical observations of 400 Japanese aphasics were involved (Sasanuma 1974:144).

About a quarter of this aphasic population is concerned with the first type of impairment. As the author writes: “Selective impairment of Kana processing (Type 1) is predominantly

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found among patients with Broca's aphasia whose oral language is characterized by prominent errors of phoneme production with relatively well-preserved auditory comprehension" (ibid 1974:156-157). In short, this type of impairment is a usual symptom that manifests itself if the Broca-area is injured. In order to illustrate how Kana impairment works, the concerned individuals were asked to write common words in Kana and Kanji characters. The examiner showed them pictures and named out the targeted word (ibid 1974:145). The results are represented on the following image:

1.1. RELATIVE PERFORMANCES ON KANA VS. KANJI TASKS.

kanji	hiragana	katakana
子供	• このも	
• 毛皮		ク
着物	• き	
		• ポー
帽子	• こうち	
時計	• ときい	テレビ
封筒		セーター
太陽		
大根	• たくこう	• トッ
手袋		

• Error words.

Figure 1. *Performance of a Type 1 candidate on the task of writing commonly used words in Kanji, Hiragana and Katakana.*

As the author observed, 8 out of 10 words were correctly written in Kanji, versus 2 in Katakana and 0 in Hiragana. Although the difference between Kanji and Kana abilities are clearly differentiated, it is interesting to have a closer look at the contrast between Hiragana and Katakana. As previously explained, Katakana characters are mostly used to represent foreign words (or loan words), "therefore, the strength of graph-sound and graph-meaning associations for the former [katakana] may naturally be greater and thus more resistant to injury than the latter [hiragana]" (ibid 1974:145). Indeed, the relationship between the phonology and the

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semantics of a foreign word written in Katakana characters is particularly strong. They are unlikely to be affected like Hiragana characters that do not convey any semantic meaning.

The candidates were then tested on their ability to write sentences. Some fail to write any grammatical morphemes at all (as they're written in Hiragana). Sasanuma notices that it seems that their writing follows the same pattern as their speech. Indeed, when trying to speak, Japanese aphasics with Broca impairment tend to be able to say only lexical morphemes and have trouble with grammatical features. In short, what is written by a Japanese aphasic is also how they speak. Sasanuma then refers to two different levels of impairment: a phonological type and agrammatism (ibid 1974:147).

Regarding reading comprehension, there seems to be better results in general, although there is also a difference when a candidate is asked to read Kana or Kanji. One of the strategies most commonly used by patients is to look for Kanji characters (as they convey the lexical meaning) whilst effectively ignoring any Kana character. They would then try to guess the general meaning of the sentence, based only on the represented content words. "The patient is unable to use what Bever (1970) has called 'perceptual strategy' of assigning syntactic relations in the S-O-V order anymore, but has to have a fair comprehension of function words (represented in Kana) to be able to grasp the relationship of lexical items (represented in Kanji) and thus arrive at the semantic content of the sentence as a whole" (ibid 1974:148). The types of errors made, differ: Kana mistakes are connected to the phonological aspect, whereas the Kanji ones are related to their graphical aspects, as they are visually more complex than Kana characters. One of the most common phonological confusions is when an aphasic writes a Kana that shares a similar phonemic value with the targeted Kana. For example, if asked to write カメラ /kamera/ (meaning "camera"), it is not unusual to find them writing /kanera/, confusing /m/ with a similar phoneme such as /n/, or /karama/, mixing the order of the syllables. The details can be seen in the following image (ibid 1974:149):

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けいと・けいこ	ていこ	カメラ・カネラ	カラメ
ke i to	ke i ko	ka me ra	ka ra me
t + k	t + k	m + n	ka + me
(place)*	(phoneme)	(place)*	(syllable)
こども・とども	このも	テレビ・テベリ	デレピ
ko do mo	ko do mo	te re bi	de re pi
k + t/_d	d + n/_m	r + b	-voice + voice
(place)*	(nasal)*	(phoneme)	(voicing)*

*The unit involved in the substitution or metathesis in these cases is at the level of distinctive features.

Figure 2. Phonological errors of words made by Type 1 aphasics.

The second type of written impairment concerns Kanji and is called Gogi aphasia (語義失語 /gogishitsugo/), where Gogi means “word meaning” (or “semantic”). In this case, the injury is located in some part of the temporoparietal brain region, but it does not affect the Wernicke or the Broca areas and, therefore, is not connected to speech impairment. This is a rare symptom; therefore there are only very few cases. As Kanji convey lexical meaning, individuals suffering from this type of aphasia have difficulties with both writing and understanding what is written (ibid 1974:150).

The same exercises are done with individuals suffering from Gogi aphasia, where they have to write down common words that are spoken and shown on pictures by the examiner. The results are diametrically opposite when compared to Type 1 aphasics (ibid 1974:151):

kanji	hiragana	katakana
小供	こども	バス
靴物	けいこ	コップ
時計	きもの	カメラ
不当	ゆびわ	ホール
	ほうし	ベット
	とけえ	テレビ
	ふうとう	セーター
	たいそう	カーテン
	だいこん	トラシク
	てぶくろ	ネクタイ

● Error Words

Figure 3. Performance of a Type 2 candidate on the task of writing commonly used words in Kanji, Hiragana and Katakana.

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As can be observed, although the individual is able to write correctly all the phonological characters (in Hiragana and Katakana), he struggles a lot with Kanji and, therefore, semantic comprehension. As Sasanuma explains, “the Kanji characters are being used as if they were phonetic symbols with complete disregard for their semantic contents” (ibid 1974:151). Therefore, they are often misspelt or confused with other Kanji characters that share the same phonetic pronunciation. For example, on the 4th Kanji word written (不当 /futô/, meaning “injustice”), the targeted word was 封筒 (/fûtô/, meaning “an envelope”). The characters 不 and 封 share a similar pronunciation, respectively /fu/ and /fû/, whereas 当 and 筒 share the same pronunciation /tô/. Another example illustrated in the text is 着物 (the targeted word, meaning “kimono”) and 汽物 (what was written by a Gogi aphasic, meaning “air thing“). Both are pronounced the same way /kimono/, but are visually totally different characters and therefore, their meaning is unrelated (ibid 1974:152).

When it comes to their reading abilities, individuals suffering from Gogi aphasia show relatively good results when confronted with Kanji, Hiragana or Katakana words. However, it is significant that they express very poor comprehension of those same words. To be more precise concerning Kanji characters, the same people struggle a lot with the ON-yomi and KUN-yomi options. Indeed, choosing one or the other is intrinsically related to the word itself and therefore, its semantic content and context. This impairment seems to be a consequence of comprehension issues (ibid 1974:153).

Finally, Sasanuma presents an overview of nonselective impairment of both Kana and Kanji. In case of global aphasia, where reading and writing are extremely difficult for the individual, both Kanji and Kana characters share a similar level of impairment. Sasanuma also discusses alexic patients, who have difficulties with reading and understanding written or printed words. Even if they might be able to write, they face problems when trying to read and understand what they wrote. As with global aphasia, there are no particular differences regarding Kana and Kanji characters in terms of impairment (ibid 1974:154-156). This study provided valuable insights regarding how and which type of aphasia affects Japanese individuals and their relationship with the writing system. Because it is proven that Kana and Kanji characters can independently suffer from impairment, which results in particular symptoms that are connected to the Japanese language. As a result, it is important to understand that there needs to be two different approaches regarding therapy in order to recover as much

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as possible. The following treatment approach is based on research documentation, whereas language therapies, explained in Chapter 5, are based on information received from Ogikubo Center.

Regarding Kana recovery therapies, Sasanuma presents two programs that were developed by Kashiwagi and Kashiwagi (1978). She explains beforehand that most patients she encountered struggled more with Kana than Kanji characters and “thus, a number of programs focused on a variety of Kana processing deficits have been developed to meet the needs of these patients” (Sasanuma 1989:23). For that reason, she only mentions these types of therapy and not Kanji focused programs. The first program focuses on the writing aspect and the second one on the reading aspect of Kana characters. In the case of writing therapy, the patient is asked to say out loud a targeted word after hearing the first syllable of said word. In this example, they are asked to say /kaki/ (meaning “persimmon” in English) after hearing /ka/. Then, they write down the word in Kanji (in this case, 柿 /kaki/), before writing the first syllable in Kana, which is か /ka/ in this example. Step by step, the patient will be using the Kanji steps less, and progressively write the syllable in Kana characters. Once they are able to do so, they are asked to write the same syllable but facing a different target word, or even small sentences (ibid 1989:24-25).

The second program shares a similar structure. The patient is asked to write the targeted Kanji characters once the written representation of said character in Kana has been shown. Again, in this example they are asked to write 柿 /kaki/, after seeing か /ka/. They then read out loud the word written in Kanji. Once this step has successfully been completed, the patient tries to separate the syllables of the word and say them out loud separately. Again, the patient will gradually stop using the Kana step and directly gets to the Kanji character. The last steps are the same as the writing program (the phasing out and expansion processes) (ibid 1989:25).

With the help of these two programs, the meaning content of a Kanji helps the patient to make the correct connection to its Kana representation. Sasanuma made a qualitative study of three patients and used the above approaches. Two had Broca aphasia and the third one suffered from amnesic aphasia. All three of them improved their Kana abilities, therefore Sasanuma concludes these programs are effective and relevant (ibid 1989:26).

The following section takes a closer look on the link between orthography and phonology, and discusses how semantics play an important role.

2.3 Orthography and phonology

In Japanese, orthography is a complex connection between written and spoken words. In Kana characters (including Hiragana and Katakana), there is a direct link between the print and the sound. Every character is referred to a syllable, except for the /n/ character represented as ん for its Hiragana form and ン for its Katakana form. Therefore, there is no visible connection between Kana orthography and semantics. In that case, the meaning of written words can be accessed through phonology, but not entirely so. The authors Sakuma et al. (1998:75) argue that the semantics of written words can also be triggered with orthography.

They illustrate their point based on Van Orden's (1987) experiments, which show that meaning is accessed through phonology: "A visually presented word activates its phonological representation which, in turn, activates a candidate set of lexical entries (meanings). The orthographic representation of the most active lexical entry (meaning) is then retrieved and compared with the orthographic representation of the stimulus target" (ibid 1998:76). In other words, it seems that phonology is what brings an orthographic word to its meaning. Once lexical entries are gathered, the target will be determined after a spelling check. However, this process does not completely apply to the Japanese language, as a Kanji unit represents a word or a morpheme. This is in contrast to a Kana unit, which represents a phonological unit. Therefore, the connection between orthography and phonology is different from any Indo-European language, and it makes Japanese a unique example (ibid).

Although studies performed in a clinical context proposed that the meaning of a Kanji word can be directly obtained through its orthography representation, other studies, focused on the phonological context, have not reached the same observations and conclusions. As Sakuma et al. explain, there is "no clear evidence either for determining whether the phonology of Kanji words could be activated directly by orthography without semantic mediation or for determining whether phonology could contribute to the meaning activation of Kanji words." (ibid 1998: 77).

Sakuma et al. performed three experiments involving Japanese native speakers who were tested on orthographic words with homophones and nonhomophones (ibid 1998: 78). They observed that the meaning of written words in Japanese is activated by both, orthography and phonology, but not by only one or the other (ibid 1998: 80). They present two hypothesis

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on how the meaning of the word is reached and what kind of process is involved. In the first one, the meaning is first triggered through phonology. Orthography takes the role of verification (which took slightly longer in the experiment when the subjects were tested on orthographically similar foils than the orthographically dissimilar foils) in order to sort out between all of the phonological candidates. In the second hypothesis, the meaning is first reached through orthography. Phonology intervenes as the next step in the process of reaching the meaning (ibid 1998: 81). In other words, there is clear evidence that both orthography and phonology play an indispensable role in how to reach the meaning of a word in Japanese. But, the order of which comes first is not yet determined. The next section will explain what happens when the semantic context is affected.

2.4 Semantic impairment

As previously discussed, some aphasics face difficulties when confronted with Kana characters, and none with Kanji characters. It seems that aphasics rely on phonology and semantics in order to be able to process and understand these characters. However, some individuals faced the exact opposite and struggled with the Chinese ideograms, implying that their semantical process was affected.

The authors Hashimoto et al. (2017) explore the idea that aphasics use the nonsemantic lexical route in order to read Kanji characters. In order to do so, they based their study on the Dual-Route Cascaded (DRC) Model when reading aloud. The original model of the purpose of reading is to provide an explanation on how highly competent readers perform certain basic reading tasks (*DRC* n.d.). To do so, the model presents two avenues from a print character to the act of saying it out aloud: the lexical and the nonlexical procedure (Coltheart 2005:12-13).

Hashimoto K. et al. (2017) tried to apply this model to Japanese language and made a few modifications to make it fit as accurately as possible (Hashimoto K. et al. 2017:272):

2. Overview on Japanese language, with a focus on written Japanese

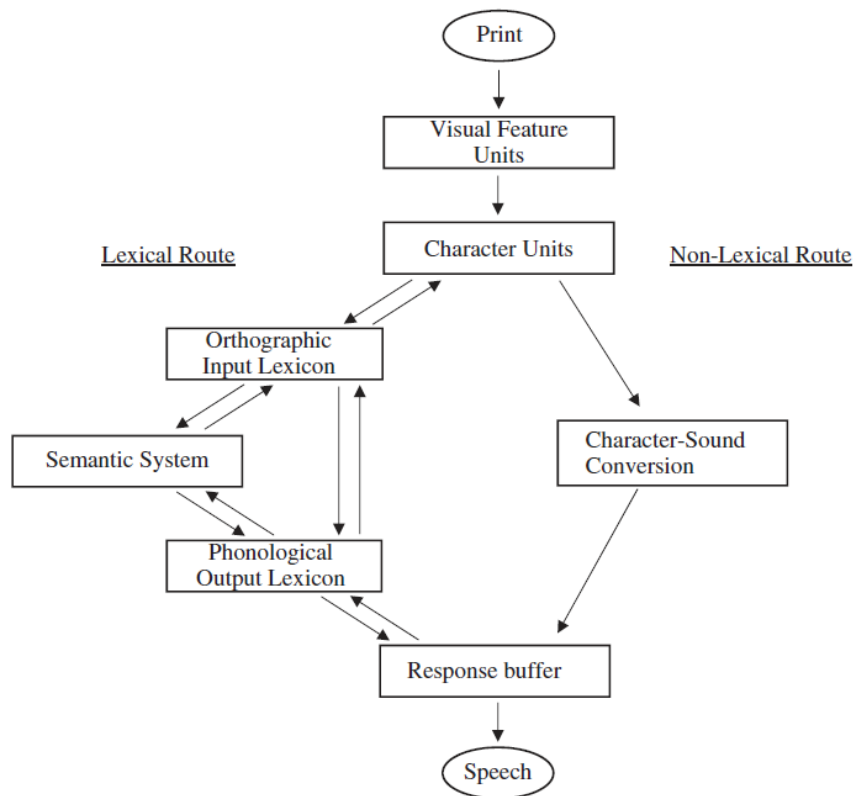


Figure 4. *DRC model adapted to Japanese by Hashimoto K. et al (2017:272).*

In this model, there are two ways to reach an oral response from reading aloud a word: either by taking the semantic lexical route, or the nonsemantic lexical route. The latter seems to be a frequent option for people suffering from brain damage such as aphasia (ibid 2017:270).

The study follows the case of a 66-year old woman who suffers from aphasia. She has problems with reading comprehension and reading nonwords aloud (ibid 2017:271), which suggest that her semantic system is impaired (ibid 2017:270). After a series of language tests, such as the SLTA, SALA and SCTAW² (see next chapter for more details on speech diagnosis tests), to evaluate the patient's reading and oral comprehension as well as reading and oral expression, the authors encountered an interesting observation. (ibid 2017:271-272). It is important to remember, as previously established, Kanji and Kana characters are two different set of characters in Japanese and need to be considered individually for further understanding of how to provide the best treatment options.

² The Standard Language Test of Aphasia (SLTA), the Sophia Analysis of Language in Aphasia (SALA), the Standardized Comprehension Test of Abstract Words (SCTAW).

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As a Kanji character can have up to three different pronunciations, a distinction is made between *consistent reading* (one Kanji equals one pronunciation only) and *inconsistent reading* (one Kanji equals two or three different readings). As Hashimoto et al. illustrate, the character 医 possesses one pronunciation only, which is /i/. However, a character like 都 has two ON readings, which are /to/ and /tsu/, and also has one KUN reading, which is /miyako/ (ibid 2017:271).

Those *inconsistent readings* can be divided into two structures: Kanji characters with a *typical reading* and those with an *atypical reading*. A Kanji character can be found in a variety of two-Kanji compound words: it can be located in the first or the second position. A typical reading of Kanji is expected to have the same pronunciation if it is located at the same position, no matter the word. For example, if we return back to the 医 character and have a look at two-Kanji compound words starting with this character, we observe that in 医療 (/iryô/, meaning “medical care”), 医学 (/igaku/, meaning “medical science”) or 医者 (/isha/, meaning “doctor”) among many other words, the 医 character has the same pronunciation (/i/) (ibid 2017:272).

However, as previously examined, the character 都 does not have a unique pronunciation option. It has an inconsistent *atypical reading* in the following word 都合 (/tsugô/, meaning “circumstance”), because the pronunciation /tsu/ is atypical, as most other words containing this character are pronounced /to/, such as 都市 (/toshi/, meaning “town, city”) (ibid 2017:272).

Referring back to the interesting observation they made, Hashimoto et al. carried out an examination. During the tests, the patient was confronted with typical and atypical sets of two-Kanji compound words. It was observed that the patient made many mistakes when being faced with inconsistent *atypical reading* words, both in production and comprehension. With these results, Hashimoto et al. argued that she was taking the nonsemantic lexical route in order to pronounce a written word. Indeed, by taking this option, the patient was not aware that she was not confronted with the typical pronunciation, because it is specific to a particular word, depending on its semantic (meaning). This observation led them to believe that “inconsistent-atypical words must therefore be read aloud by utilizing the lexical route” (ibid 2017:272).

These findings explain why the patient had barely any problems when confronted with Kana characters. Because each character represents one phonological unit, they do not require any semantic processing (as they do not have any meaning). Therefore, the patient was able to

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easily choose the correct pronunciation and score correctly on the reading tests, even though she still faced her global comprehension issue. She was able to read Kana characters without problems but failed to understand the meaning of what she was saying aloud (ibid 2017:274).

This study is highly significant as it showed the two different options a Japanese person has when reading aloud a word or a character, and how aphasics appear to struggle with the semantic process. It also provided some insights into understanding why they make mistakes in reading certain Kanji words or Kana characters, and how their global comprehension is affected by their condition.

Overall, this chapter provides insights into how Japanese language influences various symptoms that stand out when compared to Indo-European languages. Orthography, phonology and semantics all play essential roles and the impairment of one or all of them results in different level of aphasia, which then requires appropriate treatment. The next chapter explores the medical context and process that a Japanese aphasic faces.

3. The medical process for an aphasic in Japan

Aphasia most commonly occurs after a stroke; during the acute phase brain injuries must be treated first. For example, in the case of a hemorrhagic stroke, doctors will focus on stopping the bleeding. If they face an ischemic stroke, they will try to remove the clot that blocks the blood stream to the brain (Schwyter J. Lecture II). Once this procedure is done, the medical staff will be able to concentrate on the consequences of the stroke, which among many others can be aphasia, and provide personalized therapy. In theory, this process seems rather well structured and straight to the point. However, there are a few factors that need to be taken in account which are mandatory in the case of a stroke incident in Japan.

This chapter provides insights into the medical process of a Japanese aphasic in their home country, covering the following stages. The first step is the emergency process, which includes what type of protocols are used in case of a stroke, how to determine the severity of the attack on the patient, and to which medical facility the ambulance must bring the patient. Once the individual is brought in, the medical care staff treat the brain injury as the acute phase is a critical step for the patient's life. When the patient's condition is stable, the patient is then sent to a rehabilitation facility. The healing process starts and encompasses physical therapies, language therapies and any other assistance to help the patient regain independence. In any case, this procedure takes a lot of time and energy that varies depending on the severity of the symptoms. As soon as individuals are capable of taking care of themselves alone, they return home, where they continue their rehabilitation program. The following sections cover the emergency, the hospital, and the rehabilitation processes in order to provide an insightful overview of the medical context.

3.1 Emergency process and general overview on the medical and rehabilitation procedures

In case of an accident, Japanese people call the emergency telephone number 119, which will put them directly in contact with the fire and emergency medical services. The individual then explains whether there is a fire or if they need an ambulance. They do not need to pay for the

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transportation to the hospital as all expenses are covered by taxes (World Health Organization 2018:125). However, they are responsible for any medical fees, depending on their insurance coverage. The emergency staff drive the patient to the nearest and most appropriate hospital after they have identified and categorized the symptoms and health condition, as well as the context of the accident and the option list of the nearby medical facilities (*Calling for Help* n.d.).

In order to determine these key elements, emergency and medical staff refer to the Fire Service Act, which was established by the Fire and Disaster Management Agency of Japan in 1948 and was last updated in 2008 (*Fire Service Act* 2008). In this amendment, prefectural governments are asked to develop and present a list of medical institutions based on specific criteria that depend on the severity and condition of the patient (Aruga 2011:5). The following explains how these lists and criteria are made, by taking the example of the Tokyo Metropolitan Area.

In 2009, 162 hospitals in the Tokyo area were registered as being prepared to deal with acute strokes, including 104 that were also equipped for intravenous Tissue Plasminogen Activator (t-PA) medical therapy (ibid 2011:6). This procedure is used mostly during ischemic strokes, as the goal is to dissolve blood clots that block the blood circulation to the brain of the patient. However, this treatment is not without risks, as it can cause bleeding and further injuries to brain and body. Not every patient is qualified to receive t-PA as it also depends on the time of the onset, additional medical conditions and the type of stroke (The Stroke Collaborative 2008).

The hospitals follow the criteria that were established in order to categorize the type of patient, depending on the time of the onset. Therefore, Group A includes individuals who must attend a medical institution that is ready for t-PA and those in Group B can attend a facility that is not necessarily prepared for t-PA. The procedure is illustrated as shown below. In short, a protocol was established in order to determine which hospital should receive which acute stroke patient.

3. The medical process for an aphasic in Japan

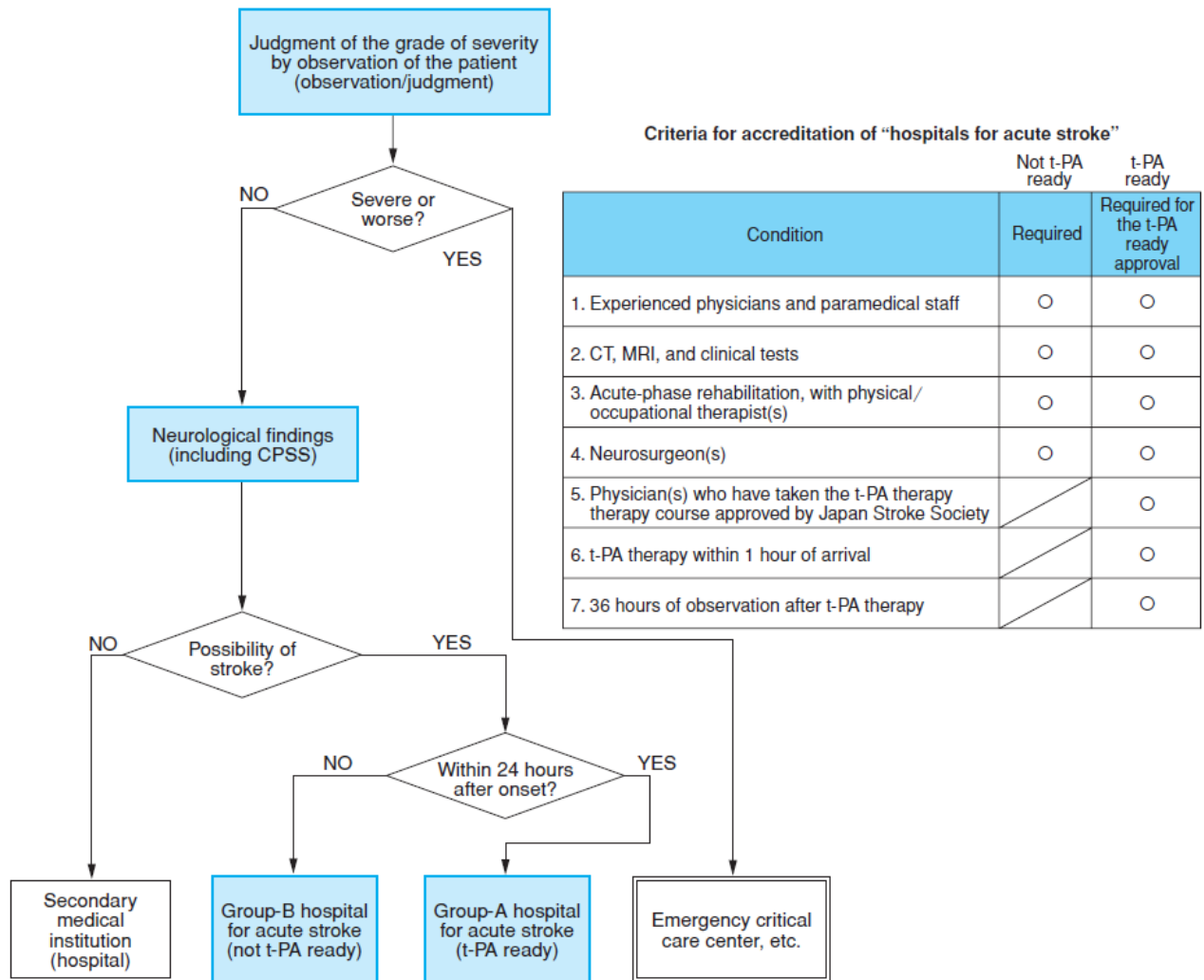


Figure 5. Protocol for selection of a receiving hospital for an acute stroke patient, by Aruga. (2011:6).

The diagram follows every step emergency staff go through whenever they are dispatched to where the accident took place. They first take note of the condition of the patient and evaluate if the situation can get potentially worse. In that case, they directly transfer patients to an emergency critical care center or any other facility that can take care of them. If not, they try to determine if the person suffers from a stroke or not. If they do not find any symptoms, they bring them to a general hospital. However, if they do diagnose a stroke, they need to know how much time has passed since the attack in order to determine if it happened in the last 24 hours or not. Once they know, they send the patient to a Group A or B hospital, depending if they need a facility that is t-PA ready or not.

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On the diagram, the right box is the list of criteria to determine whether or not a medical facility is fit to receive patients from Group A (who need t-PA medical therapy) or Group B. This form is filled out by the hospital and then sent to the Tokyo Metropolitan Government.

Aruga (2011) introduces three key elements that are problematic with this protocol and the emergency medical liaison system in general, which are worth mentioning. First, as previously mentioned, there are 104 hospitals that are registered as t-PA ready. According to the author, about 30'000 people annually suffer a stroke in the Tokyo area, which would represent about 0.8 of a patient per day for each of the facilities. This highlights the fact that there are not enough medical institutions prepared for these cases. Second, the geographical distribution of these hospitals is unequal. As Aruga writes: "For example, the northern portion of North Tama Medical District is rich in rehabilitation hospitals but has insufficient medical resources for acute care despite its large population" (Aruga 2011:8). Third, the transfer to the rehabilitation centers is not well coordinated. Indeed, once a patient's life is out of danger, they are usually sent to any facility that will look after their rehabilitation. However, it seems that patients tends to stay in the acute care facilities, which then are forced to limit incoming patients because of lack of space. These different aspects need to be taken in account when trying to build the most efficient emergency medical liaison for acute and recovery stroke care.

Once a patient is brought to the appropriate hospital, the stroke rehabilitation process begins. The following diagram³ offers an overview of the situation in Japan:

³ Please refer to the full translated article in Appendix B, page 69.

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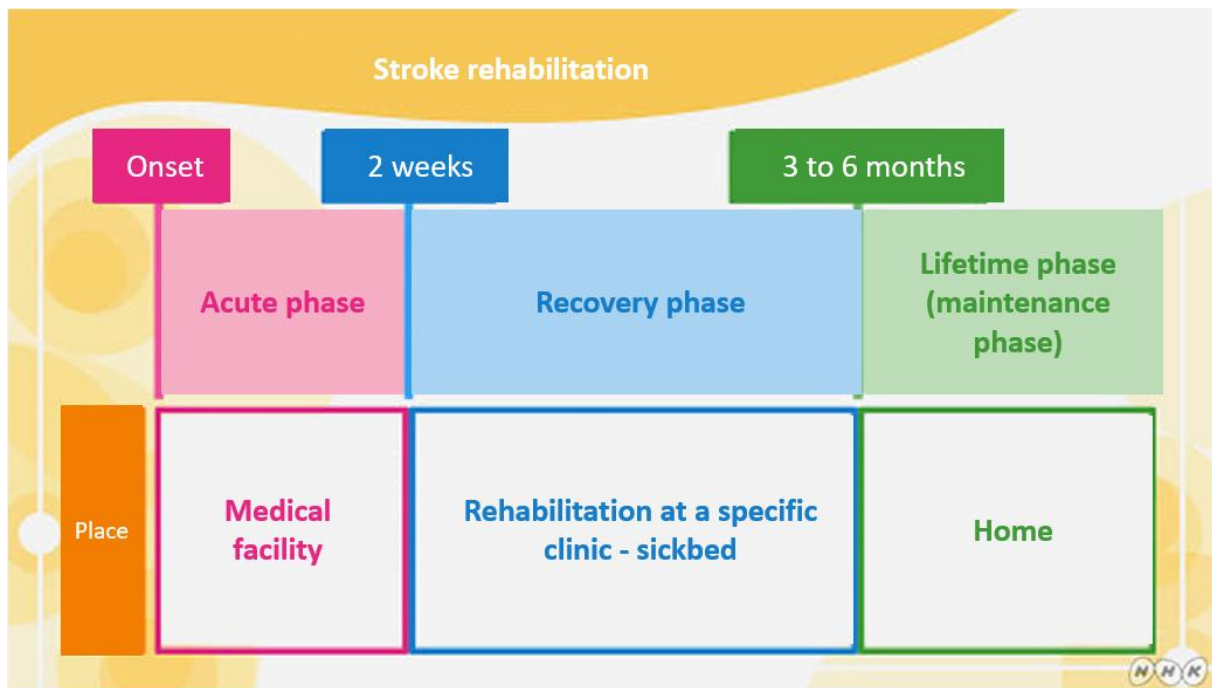


Figure 6. *Stroke rehabilitation overview in Japan. (Yamada 2016).*

As the article comes from Japan's national public broadcasting organization website, the illustrations and explanations were made for all audiences and are, therefore, accessible for all. The process is divided into three phases (as discussed and confirmed by informant, Mrs Sonoda et al.). First comes the acute phase, which takes place from the moment the onset and last for up to two weeks. The patient is treated and placed under observation in the hospital for that period of time. As soon as the doctors are able to save the person and maintain his or her health condition, the recovery phase starts. This usually lasts three to six months. The individual is transferred to a medical facility that is specialized in stroke rehabilitation. The patient is still in a sickbed but is encouraged to perform physical and speech recovery therapies. Finally, once they are able to look after themselves, they are sent back to their homes, where they will follow rehabilitation on their own. The home environment can be adapted to the patients' condition, such as adding handrails in the bathroom or in the entrance hall, and adding extra steps if the individual has difficulties walking (see images in Appendix B, page 69).

The following example is extracted from the World Health Organization 2018 Report on Japan's health system. It describes the journey of a stroke patient, covering all three mentioned steps.

A 55-year-old male taxi driver, residing in Tokyo, felt a sudden severe headache when he got up early in the morning on 30 December 2017. He told

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his wife that his headache was a “thunderclap headache,” which was his “worst headache ever.” Several symptoms appeared immediately after the headache, including nausea, vomiting, confusion and irritability. His wife called 119, and an ambulance car arrived at his home 7 minutes after the call. He was transported by the ambulance car to the nearest secondary-care hospital located 10 km away from his home. On arrival at the hospital, he showed decreased consciousness and alertness. The first-aid physician quickly did physical examinations, and he found a stiff neck and focal neurological deficit. The doctor strongly suspected a subarachnoid haemorrhage and made a prompt decision to transfer the patient to a tertiary-care hospital with a Stroke Care Unit.

The patient was then transferred by the same ambulance car to the tertiary-care hospital located 20 km away from the secondary-care hospital. Soon after he arrived at the hospital, a head CT scan followed by cerebral angiography was performed, which showed a ruptured intracranial aneurysm. Open craniotomy and clipping of the aneurysm were performed by a neurosurgical specialist on the day of admission. Postoperative intensive care included medication for controlling the blood pressure, calcium-channel blockers to prevent arterial spasms and phenytoin to prevent seizures. After two weeks of intensive care, his condition became stable and he was moved from the Stroke Care Unit to a general ward. He continued rehabilitation for his postoperative mild neurological deficits, and was discharged to home on 10 March 2015. The fees for surgery and hospitalization were mostly paid from the universal health insurance fund with cap payment for high medical expenditure, except for his OOP [i.e. out-of-pocket] payment amount of approximately US\$ 1400. Now he is happy to receive a rehabilitation programme from long-term health insurance, and wishes to go back to work in the near future (World Health Organization 2018:128-129).

As this is an actual case, it provides the reader with a concrete idea of how the emergency system works in Japan. Here, the person received an appropriate diagnosis and was sent accordingly to a medical facility that could take care of him. From the day he suffered the attack until the day he was allowed to go home, about three months had passed by, which correlates with the previous diagram (Fig. 6). The next two sections discuss in more detail how the hospital

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and rehabilitation process is structured. The insurance and medical expenses topics are covered in the next chapter.

3.2 Hospitalization process

The acute phase is the most critical for the patient's life as doctors have to stop the hemorrhage or deal with blood clots. Every second matters for the best recovery and to limit the damage as much as possible. Unfortunately, not everyone survives this step⁴ as it depends on various factors, such as the time passed between the onset and the hospitalization or medical complications during the surgery, amongst others. The following diagram summarizes the various steps of rehabilitation during the acute phase:

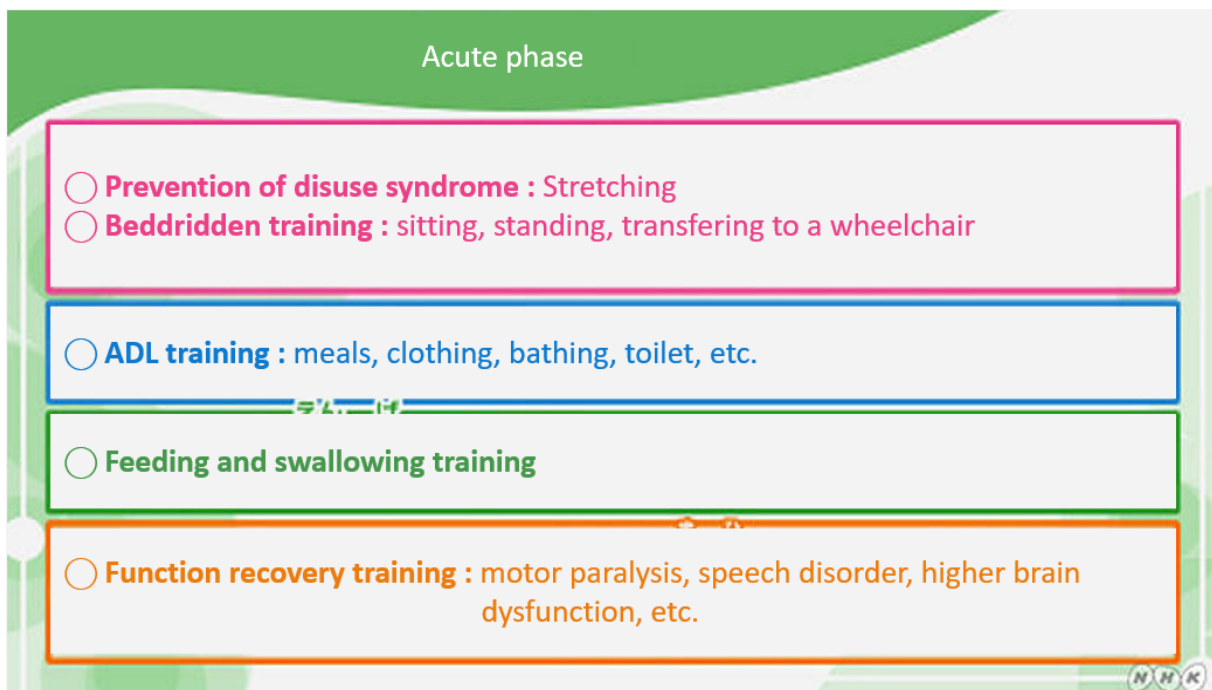


Figure 7. *Acute phase rehabilitation (Yamada 2016).*

Rehabilitation during the acute phase is usually expected to take place within the first 48 hours after the onset (Yamada 2016). During this process and depending on the damage, new symptoms can arise such as physical impairments which may include hemiplegia (on the right or left side of the body). Moreover, being bedridden can cause disuse syndromes, which

⁴ Stroke is the third highest cause of death in Japan, after heart disease and pneumonia (World Health Rankings 2017)

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means that a patient's muscles, joints or hypotension for example can be affected and ultimately weaken the individual (Abo & Kakuda 2012:241). The longer the patient is bedridden, the greater are the chances that they develop atrophy and other severe consequences. Therefore, physical exercises are given during this rehabilitation step, such as stretching, sitting and standing, and moving from the bed to the wheelchair in order to stimulate the muscles and the body as much as possible (Yamada 2016). This can be seen on the first part of figure 7 above, in the pink box.

The purpose of stroke rehabilitation in general is to make sure the patient can sustain themselves individually. Therefore, they follow a therapy for activities of daily living (ADL). They are trained to eat, to get dressed, to bathe and to go to the toilet by themselves (ibid). Moreover, as about 70% of stroke survivors face difficulties with swallowing, oral care and indirect swallowing training (including cheek and tongue exercises) take place as soon as possible so that it does not provoke any health complications for the patient (Abo & Kakuda 2012:242).

The last element of the diagram concerns specific therapy for those who have difficulties with their motor functions (such as struggling to move their hands, for instance). This also includes higher brain dysfunction therapy or speech disorder (which will be discussed in detail later on). The acute phase is a critical step for the brain as symptoms such as paralysis can partly recover due to the improvement of the blood flow in the brain. The rehabilitation therapy stimulates the brain and the physical faculties start to improve (Yamada 2016). Although not explicitly covered in the study by Yamada, it is important to mention the role of brain plasticity during this process, as explained in the next paragraph.

Scientists used to think that once the brain reaches its maturation stage, the neuronal connections became static and were not affected by changes, such as age for example. This idea was then rejected when it was discovered that the brain has a self-organization system that is capable of adapting itself. When the human body is damaged, the immune system acts and tries to repair itself the best it can. This is the same when the brain is affected by a stroke and reacts to it; brain plasticity is a key element in controlling and diminishing the damage caused. The brain is indeed capable of adapting itself to internal and external injuries by acting on a micro level, in the nervous and cell system, and on a macro level, in the behavioral system (Papathanasiou & Whurr 2000:31).

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In essence, brain plasticity allows neural connections to replace the damaged ones, even if their original function was initially different. In order for this natural faculty to work the best way possible, neurons must be stimulated so that they can find new connections. Therefore, the patient must practice tirelessly, and can expect a long delay before seeing any significant changes (ibid 2000:31). Kesselring (2016) wrote an interesting article that compares the human brain to an orchestra, highlighting the necessity of all these various actors to come together, as they all need to work as one. Each one of them must give their best in order to have the perfect musical composition, which is what happens in the case of a stroke. The patient must repeat those physical movements that they struggle with as many times as necessary in order to regain their pre-stroke faculties. This correlates with the NHK article that discusses an example of maintaining exercise of the paralyzed part of the body and also suggests that neuronal connections will get stimulated and help the body recover from the damage (Yamada 2016).

In sum, once a stroke patient is brought to the hospital, they follow the process that was described in this section. A qualitative study was undertaken in partnership with the University of Tokyo on the professional approaches to stroke therapy in Japan, with a focus on the relationship between doctors and patients (Slingsby 2005). The research was conducted at a national hospital that is specialized in neurological disorders, including stroke, in the Kanagawa prefecture. Slingsby compiled data from non-participatory observation on the interaction between professionals with the patients and their families, non-structured interviews that were informative regarding these three key actors' motives and intentions, and semi-structured interviews that were specifically addressed to the professionals to try to understand how they define rehabilitation and the main factors that would affect it.

The results show valuable findings: the medical professionals that were interviewed believe that a patient's own motivation is very important for rehabilitation and is mainly influenced by the relationship built between a patient and their doctor. The study points out that the fiduciary relationship is indeed greatly valued by the professionals as part of the patient's recovery. Therefore, doctors act the best way possible in order to build a strong fiduciary relationship, which strengthens the trust of the injured individual in their doctors and affects their motivation for rehabilitation (Slingsby 2005:220-221).

The author discusses the fact that Japanese people seem to value family-centered decision making when trying to find the best medical option for them: "When a patient was close with his or her family, professionals had the patient's family decide for or with the patient" (ibid 2005:224). This raises a question about ethics for the medical staff. Indeed, between this

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type of model and the individual autonomy, it is necessary to know which approach to use. Despite this issue, the author highlights the patient's motivation as a key factor for their recovery and that it should be at the center of the approach taken by any medical professional (ibid).

The next part addresses the stage after the patient's life has been saved and stabilized, and focusses mainly on regaining lost abilities due to stroke damage.

3.3 Rehabilitation process

Referring back to the diagram at the beginning of the chapter (Figure 6), the next step after the acute phase involves a focus on the consequences of the stroke. During the aftermath, patients are relocated to a medical facility that is specialized in rehabilitation.

Back in the 1920s rehabilitation medicine used to refer only to providing help for disabled children. In 1963, the Japanese Association of Rehabilitation Medicine (a national medical society) was inaugurated, and this enabled valuable opportunities for the domain to develop (Izumi & Saitoh 2014:1044). Indeed, the following year, a speech language specialist from New York University's Medical Center visited the Kageyu Rehabilitation Hospital in the Nagano prefecture. This meeting was one of the main factors that contributed to the establishment of the first clinic that offered specifically rehabilitation for aphasic patients, in 1965⁵. By 1988, over 500 similar rehabilitation clinics had been opened in the country (Sasanuma 1989:13).

There are usually three steps that structure the procedure in these clinics. The first one is obtaining information regarding the language disorder of the patient. This is established by doing a series of specialist diagnostic tests. This will determine the best treatment program for them to follow. Then, based on the analysis of the data which the medical staff has gathered, hypotheses are built up. Finally, these hypotheses are tested through therapeutic intervention.

In order to be able to make the best diagnostic evaluation, language assignments are given to the aphasic patients. One of the most common tests is the Roken Test of Differential Diagnostic of Aphasia (RTDDA), which is a revised version of the Minnesota Test of the Differential Diagnostic of Aphasia (MTDDA) (Fukusako et al. 1990:178). It is used to

⁵ At the time, there were three speech and language medical professionals and Sasanuma was the supervisor of the team.

3. The medical process for an aphasic in Japan

determine the type and severity of aphasia in a patient. It takes about two to three hours to complete, but most of the patients stagger it in short sessions, as it requires a lot of concentration and energy. They are tested on their auditory comprehension, oral comprehension, reading, writing, and arithmetic functions. Within those five sections, there are in total 48 subtests. Many of those are Kana and Kanji related tests. The results of this test helps the medical staff to establish a prognosis for the recovery of language and speech skills, and to define realistic treatment goals and tasks (Sasanuma 1989:19).

Once aphasics do the test, they are given other specific assignments in order to obtain as much information as possible for the diagnosis. Some do the Token Test, which focusses on oral comprehension abilities. There is also the Syntax Test of Aphasia, which evaluates reading and oral comprehension. For example, the patient is tested on various syntactic structures that are written down and is asked whether she or he understands the meaning. Concerning the oral comprehension tasks, the patient listens to a sentence produced by the examiner and has to choose which image (out of four) represents what was said. Patients are also asked to verbally describe those images before making the choice. The study also explores the Kana/Kanji Reading Test, which concerns reading comprehension and oral reading of Kana and Kanji characters (ibid 1989:20).

Once the diagnosis is fully completed, the patient follows a specific language therapy program that addresses their needs. No matter the therapy, all will do a test before and after their therapy so that the professionals can evaluate their progress. Reevaluations and updates of the treatment occur about every three months (ibid 1989:27). The language therapies are given every week, comprising two to six sessions, as last for about two months. Their improvement is calculated depending on the results the patient scores at the RTDDA (for example) after the therapy and is compared with the results pre-treatment (ibid 1989:28). According to a research led in 1984 by Fukusako and Monoi on 303 post stroke aphasic patients, about 46% showed improvement with this strategy (ibid 1989:29).

There are other language assignments, such as the Standard Language Test of Aphasia (SLTA). It includes auditory comprehension, reading comprehension, oral naming, repetition, reading aloud and spelling tasks. There is also the Test of Lexical Processing in Aphasia (TLPA), the Standardized Comprehension Test of Abstract Words (SCTAW) and the Sophia Analysis of Language in Aphasia (SALA) (Hashimoto et al. 2017:271).

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Not all aphasics go to a specialized clinic like the one in the Kageyu Rehabilitation Hospital. For example, in the Hospital of Tokyo University (The University of Tokyo Hospital n.d.), which is one of the oldest and most prestigious universities in the country, the Department of Rehabilitation Medicine provides medical care to patients whose condition affects their daily lives. Stroke survivors are sent to this specialized unit and get help from physiotherapists, speech therapists, clinical psychologists, occupational therapists, acupuncturists and others, in order to be sure to cover all potential consequences of the stroke.

Apart from aphasia, some patients suffer from spasticity, which is a muscle and coordination disorder. The communication between the brain and the muscles of the body is damaged, which results in cramps or spasms. One of the treatments that is performed in the Tokyo University Hospital uses botulinum toxin (BTX) injections. In this treatment, neurotoxic protein act on the muscles, decreasing muscle tone and thereby helping coordination by increasing the range of motion (Ozcakir & Sivrioglu 2007).

There are also two types of physical treatments worth discussing that were not explicitly mentioned on the Department of Rehabilitation Medicine webpage. One is the electric stimulation therapy, which involves using electricity to stimulate the nerves in order to help the body to move its muscles and regain motion (see image in Appendix B, page 69). The second therapy requires robotic technology that is designed specifically to support the movement of the muscles (see image in Appendix B, page 69) (Yamada 2016).

Another example of a medical facility specialized in rehabilitation is the National Rehabilitation Center for Persons with Disabilities (NRCDD), founded in 1979, in Saitama. This provide personalized medical care and welfare services to those who suffer from physical, visual, language, hearing, and developmental disorders. Their goal is to maintain and recover the patient's global living functions and to ensure they will be able to go back home and back to work. To do so, the center offers medical rehabilitation as well as social rehabilitation in order to help their return to their work environment and society in general. As they explain in their introduction document:

Our mission is to promote independence and social participation of PWDs (person with disabilities) through our services. As a core institution for rehabilitation for PWDs, the NRCDD also takes a leading role in the research and development of rehabilitation techniques and assistive products, and the cultivation of specialists in rehabilitation (National Rehabilitation Center for Persons with Disabilities n.d.).

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They also take action, in collaboration with local governments and associations, regarding disaster prevention by writing guide books and education programs designed for PWDs as well as for the public. They have published documents concerning autistic individuals and how to help them in case of earthquakes, for example; guide books that inform about support for PWDs in evacuation shelters, in their family circle or at home, etc. (Kitamura n.d.).

The Department of Speech-Language-Hearing Therapy is responsible for stroke survivors who suffer from aphasia. In fact, it is the first department that was established back in 1971. The team provides help for those who struggle with speaking and writing, as well as reading and hearing comprehension. As an exercise, patients are asked to do what the professional tells them. For example, they see a number of various objects and are asked to touch a particular one. Another one is to match a picture with the correct word (in Kanji and Kana characters) (National Rehabilitation Center for Persons with Disabilities n.d.).

NRCD also offers the possibility to professionally train rehabilitation therapists. In their college, various programs are available, such as the Speech-Language-Hearing Therapy (ST) course, the Sign Language Interpretation course, the Inclusive Physical Education course, etc. All of them are done in collaboration with the Research Institute, the Rehabilitation Services Bureau and the Hospital, which gives valuable insights to the graduates. The ST training program lasts for two years, and enrolls 30 students every year. They must pass the National License Examination for Speech-Language-Hearing Therapists⁶ and get the approval of the Ministry of Health, Labour and Welfare (MHLW) in order to become a Speech-Language-Hearing Therapist. As of February 2017, there were about 16'000 registered (i.e. with national licensure) speech language hearing therapists in Japan (Japanese Association of Speech-Language-Hearing Therapists n.d.).

Moreover, the NRCD College offers training programs for professionals in the field of rehabilitation who seek to improve their knowledge and skills. They have access to the latest innovative technologies and expertise. In addition, seminars are often organized throughout the year, gathering in total over 2000 participants, including speech therapists, physicians, nurses, etc. (National Rehabilitation Center for Persons with Disabilities n.d.).

Sasanuma also mentions the structure of the NRCD's ST training program at the time she wrote her article in 1989. Most of the speech therapists followed a one-year training course in speech and language pathology. There were some disparities among the students, as some

⁶ This test takes place once a year, generally in February.

3. The medical process for an aphasic in Japan

attended only six weeks of courses versus very few who had more than two years of professional training. Therefore, the quality of the therapies and the diagnostics varied a lot depending on the speech therapist's experience and on their availability, since not every clinic had a speech therapist in their team (Sasanuma 1989:17). The way the course structure evolved is a step forward and speech therapists nowadays are more prepared and organized to deal with aphasics than before.

Rehabilitation is a mandatory step for aphasics in their progress to return to their home and to their work environment. However, medical facilities and support centers face challenges with the MHLW, and the healthcare system does not facilitate the processes for aphasics' rehabilitation. This includes the types of insurance coverage, as well as the medical payment system. These rather political and technical issues are discussed in the next chapter.

4. The Japanese healthcare system

The previous chapter portrayed the medical journey of a stroke and aphasic patient in Japan, focusing on treatment and recovery aspects. This process is rather theoretical, as many variables can interfere whether it is during the emergency step, the hospitalization or the rehabilitation. Another important parameter to take into account is the healthcare system itself. Indeed, laws are constantly challenged and reforms take place. Moreover, there are different types of insurances, as well as payment systems, which affect the whole population of the country. The first part of this chapter does not specifically concern aphasics. It highlights key elements that can affect any patient during their hospitalization process.

This chapter complements the previous one by first exploring how the Japanese healthcare system works, by presenting medical insurance schemes and the types of hospitals. Then, the payment structure is discussed, focusing on the diagnosis procedure combination (DPC) system, what it implies and what are the issues encountered. The next section concerns various types of specific problems that are found within the current healthcare system, such as the length of stay in a hospital, the number of patients and medical staff, as well as funding issues. These issues can influence the hospitalization process of any patient, as it directly concerns the quality of care. Then, in order to answer these concerns, possible solutions are discussed in the fourth part. In the last section of this chapter, the focus comes back to aphasic patients and how support centers try to take action to get better support from the MHLW.

4.1 The healthcare system; the essentials

The Ministry of Health, Labour and Welfare (MHLW) acts as the main lead organization in the healthcare system and operates on national, prefectural and municipal levels. This ministry controls and defines mainly healthcare, work and social protection regulations. It was formed in 2001, after an administrative government reform plan led to the merger of the Ministry of Health and Welfare and the Ministry of Labour (World Health Organization 2018:23).

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Nowadays, every resident of Japan has to enroll in a health insurance program. However, it was not always the case. The Japanese healthcare system was initiated with the Health Insurance Act in 1922. At that time, the government and the industrial sectors decided to take action to provide health insurance to the working class (now referred to as the Employees' Health Insurance) as a way to prevent them from developing a strong interest in growing socialist movements (ibid 2018:7). It covered part of the population leaving the self-employed (including those working in the agriculture domain) and un-employed category of citizens excluded. Therefore, the Community Health Insurance (which would later become the National Health Insurance (NHI)) was created to encompass this particular community. However, both insurances needed to be voluntarily chosen by the citizens, which implied that many were not enrolled in an insurance program (ibid 2018:24-25).

The Second World War had severe consequences for the country, and particularly for the healthcare system. 1961 marks the year of the inauguration of the universal health insurance system for Japan, which allowed all citizens to have access to health services (ibid 2018:8). This insurance covers the acute phase, restorative rehabilitation, and chronic phase rehabilitation⁷.

Since then, all residents of Japan must contact their municipal government or ward office in order to be insured. The two main types of health insurance are the Employees' Health Insurance and the NHI. As previously mentioned, the first concerns employed workers as well as their dependents and the second addresses the self-employed and the unemployed part of the population (ibid 2018:24). Besides, in-patient rehabilitation at acute care centers and access to restorative medical facilities are both covered by the NHI. This includes services of physiotherapists, as well as occupational and speech therapists (ibid 2018:135). Based on data from 2015, 58.69% of the Japanese population were covered by the Employees' Health Insurance, and 28.31% by the NHI. The remaining 12.42% concerned all those enrolled in the late-stage medical care system that was created in 2008 for citizens that were above 75 years old (ibid 2018:56).

There are four types of medical facility in Japan: hospitals, clinics, health centers providing public health services, and pharmacies. The first act as the main providers of medical services in the country (Zhang & Oyama 2016:22). Depending on their ownership, hospitals

⁷ As a matter of fact, cerebrovascular diseases, amongst others (cardiovascular diseases for example), are covered and costs reimbursed under this program (ibid 2018:134).

4. The Japanese healthcare system

are divided into three categories: Local Public Hospitals (LPH), which are operated by municipalities and prefectures; Other Public Hospitals (OPH), which included national public hospitals, as well as social insurance organization-owned hospitals; and private hospitals (PRH), which are operated by medical corporations, individuals and others. The latter encompasses a larger number of facilities, beds, and medical staff compared to the first two (ibid 2016:23). Indeed, PRH represented 81.1% of all hospitals in Japan as of 2016 (World Health Organization 2018:72). As the WHO report explains, "under the current fee schedule set by the MHLW, large-size public hospitals mainly for acute and tertiary care are in a state of financial crisis and are largely subsidized by the Central Government and local governments, while most small, private clinics and hospitals for non-acute care are well-financed" (ibid 2018:74)⁸.

4.2 The payment system

Whenever Japanese residents require a medical service or product, they pay a specific percentage for every item or visit at a medical facility. In general, the insurance covers 70 to 90% of the cost, and the patient is asked to pay the remainder. As of March 2017, children up to 6 years in age pay 20% of the fee, 7 until 69 years of age individuals pay 30%, 70 to 75 years in age pay 20%, and those older than 75 years pay 10% (ibid 2018:24). This implies that the insurance coverage increases with age of patients.

From 1961 until early 2000, the payment system was a Fee-for-Fee (FFS) structure. Basically, the MHLW attributed for each medical service or product a certain number of points. The providers would then calculate how many points they gathered from any service or item they offered and they would then be reimbursed accordingly (Japan Health Policy Now n.d.).

The diagnosis procedure combination (DPC) system was introduced in 2002 by the MHLW, in order to address healthcare cost issues, the length of stay in hospitals and the growing age of the Japanese population (World Health Organization 2018:122). Moreover, low birth rates and the medical care progress caused financial issues for medical budgets. Therefore, it became a high priority back in 1997 to revise the medical system (Ishii 2012:279). Within the medical database, much valuable information is gathered for all in-patients discharged, such as administrative data, detailed diagnoses, and procedure related data. The hospital is asked to enter in the database the time and dates of all procedures, examinations, and medical device

⁸ The funding issue is discussed further, in section 4.3.

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utilizations (World Health Organization 2018:122). Reimbursements are calculated based on a flat-rate per-diem fee depending on the diagnostic group. In short, the DPC type of payment depends on the per-diem basis as well as the type of diagnosis (Ishii 2012:279). Since it has been integrated in the medical healthcare system, the length of hospital stays has significantly decreased from an average of 21.2 days in 2002 to 16.7 days in 2007. Moreover, “the transparency and accountability of participating acute-care hospitals are improving”, as the system database has been revamped (World Health Organization 2018:187).

The DPC classification system has been built up by medical professionals in each speciality. Therefore, the categories have a disproportionate range of cases, some have only a few cases and others have cases that vary widely in terms of cost. Some of these fees ended up not being part of the DPC payment system and were therefore transferred into a fee-for-service (Anderson & Ikegami 2011:2). In order to calculate the DPC fee, the focus is on the hospital length of stay, as seen on the following diagram:

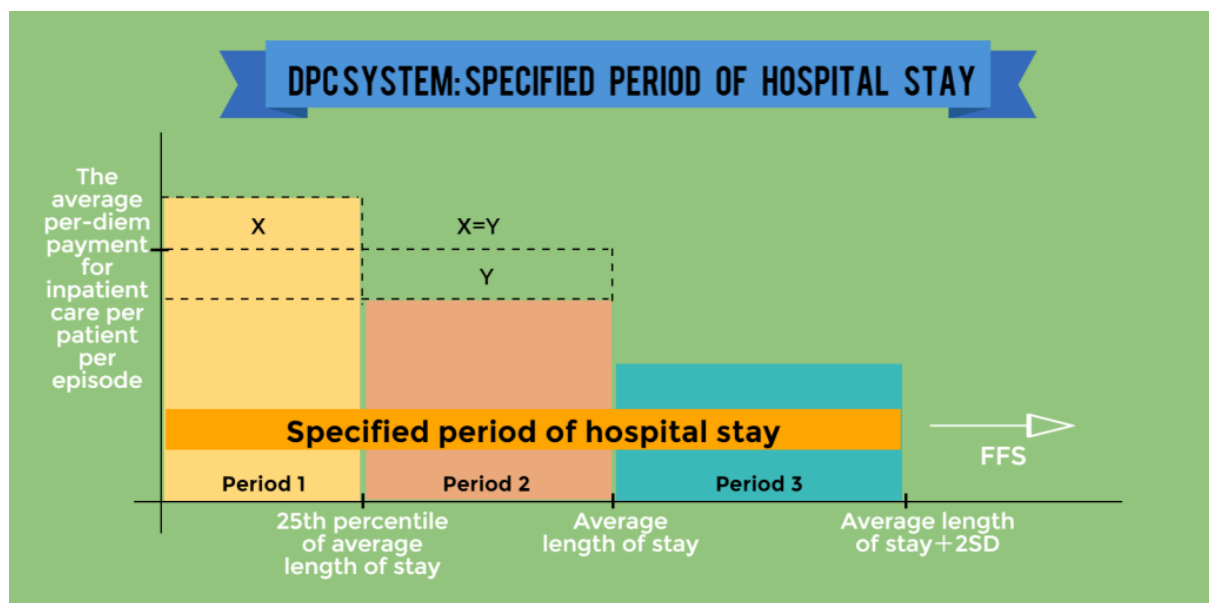


Figure 8. DPC System: Specified period of hospital stay (Japan Health Policy Now n.d.).

The first period depends on the length of time that is equal to 25% of the average length of stay (ALS). Period 2 covers the time from the 25% of the ALS until the full ALS. The third period covers two standard deviations of the mean ALS. If the length of stay exceeds the two standard deviations, then the system switches back to a fee-for-fee system (Japan Health Policy Now n.d.).

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The DPC system experienced a progressive introduction at the beginning, so only a selected number of hospitals actually used it. As of 2011, there were about 2700 DPC groups that categorized patients. However, only 1900 were actually used for payment purposes. This is explained by the classification system that was previously mentioned, as the remaining 800 hospitals did not have sufficient cases or had too many variables to build a strong database (Anderson & Ikegami 2011:4).

Another issue comes from reducing the length of hospital stays. Although it maintains financial stability, it might also prevent some patients from having necessary tests, medical procedures, etc., which could impact their well-being and recovery rates. In sum, the DPC system avoids having unnecessary treatments of expenses but some patients cannot receive the required minimal care for their specific condition (Ishii 2012:291).

4.3 General issues within the healthcare system

Japan's healthcare system faces many challenges in addition to the medical payment structure. Amongst them, there is an imbalance arising from low birth rates and the constant growth of the ageing population (World Health Organization 2018:xv). Indeed, the number of Japanese individuals over 65 years old is rising, while the percentage of Japan's working population decreases steadily. This situation directly interferes with the healthcare system, as over 50% of medical care fees are spent on this part of the population, and only 8% are dedicated to children who are under the age of 14 years. This disparity in the system is likely to become a significant issue by 2025, when the proportion of Japan's elderly population is expected to reach a peak (ibid 2018:191).

The length of stay in hospital beds is usually longer than the average in the developed world; it can be up to two to three times longer in Japan no matter the demographics or the type of diseases (Henke et al. 2009:61). In fact, in 2015, the average was reported at 16.5 days in acute care, which is high compared to the OECD rate of 6.8 days. However, the length of stay in Japanese hospital beds has been affected by the fee schedule revision that aims at reducing chronic care beds. In addition, Japan faces an increase of the elderly population, which creates more welfare homes. Therefore the long term care insurance fees are divided between these different medical facilities, which reduces the share for the hospital beds (World Health Organization 2018:77).

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Another main issue is the absence of a central control unit for the hospitals (most of them are private) (Henke et al. 2009:55). Therefore, "no central authority has jurisdiction over hospital openings, expansions, and closings (...) no central agency oversees the purchase of very expensive medical equipment" (ibid 2009:57). This explains how Japan has three to four times more CT, MRI, and PET scanners than any other developed country⁹. Moreover, there is a similar issue with the allocation of medical resources, as there is not any central control unit for the matter. Therefore, there is a lack of strategic planning for providers, which prevents them from responding efficiently to supply and demand (ibid).

When it comes to medical staff numbers, there are a few key features that stand out. First, the number of physicians is very low with a ratio of 2.35 doctors per 1000 patients. This number can be explained by the fact that access to medical facilities is included in the health care system and, therefore, people are more likely to use these types of services. However, this might become an issue for those with severe condition as medical staff can be overwhelmed with a large number of patients (World Health Organization 2018:190). Second, physicians work long hours and overtime, and they are not always compensated. As the WHO report states, "according to a 2006 survey of 3'388 medical doctors by the Ministry of Health, Labour, and Welfare, Japanese physicians worked 66.4 (+/- 18.0) hours/week, with the maximum reported at 152.5 hours, and physicians younger than 30 years old worked an average of 77.3 hours/week." (Suzuki et al. 2008:93). Third, doctors' medical licenses are valid for life and there are no regular check-ups to ensure that the specialists' expertise is still compliant. Fourth, physicians' salaries, as well as the funding for medical treatments and equipment have been repeatedly cut, in order to respond to budget issues. This directly affects the quality of health care as there is "no way to reward best practices or to discourage inefficient or poor-quality care" (Henke et al. 2009:57). Fifth, as doctors are too overworked with the large number of patients, they lack time to investigate new treatments or to participate in clinic trials. This leads to a significant delay in the development of new therapies which could be more efficient (and/or less expensive) than the ones that are currently used (ibid 2009:61). Overall, all of these observations affect the quality of health care for the patients and their rehabilitation.

As discussed, the number of doctors in Japan is highly disproportionate compared to the number of patients. The latter can be explained by the fact there is an open gate to any medical provider at any time for anyone. Patients do not need to be in a medical emergency situation to

⁹ This disparity is also the reason why most of this expensive medical equipment is underused.

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be able to receive a medical consultation and nor do they need full insurance coverage (ibid 2009:55). Therefore, easy accessibility to medical facilities implies many incoming patients. The small teams of doctors are quickly overwhelmed and the healthcare resources are more limited (World Health Organization 2018:91). In fact, Japanese people consult medical specialists 14 times a year, which is three times the number in other developed countries (Henke et al. 2009:58).

These low numbers contrast with another general issue: overutilization in the healthcare system. Indeed, for example, as reimbursement rates are low due to budget limitations, doctors and hospitals need to compensate. They do so by providing more services, which is allowed via the fee-for-fee system, as it does not affect the amount of care supply. As a result, there are about three times more consultations in Japan than in other developed countries (ibid 2009:59). Moreover, as previously mentioned, there is a disparity between the large number of hospitals and beds and the low number of medical specialists. This might be explained by the lack of control of doctors entering postgraduate training programs, as well as the allocation of specialists among regions in Japan. In addition, doctors' salaries in hospitals are lower than those who work in private clinics. Therefore, many specialists are more inclined to work in these medical facilities, which leaves the hospitals short of physicians, especially in emergency rooms (ibid 2009:60).

On the financial side, the healthcare system fees are rising and the cost of the NHI is likely to double by 2020, compared to the numbers in 2005 (ibid 2009:55). This is caused by four main reasons. First, medical technology is advancing and new medical treatments, products, etc. need more funding. Second, there is a growing wealth within the country, which implies that medical fees do not stop people from consulting a specialist. Third, the aging population, as previously discussed, changes priorities within the healthcare system. Fourth, treatment patterns for specific patients are shifting depending on their disease (ibid 2009:56).

Overall, these various issues may prevent patients from getting proper treatments and rehabilitation. What is mainly at stake is the sustainability of health care financing, the inequity within the population, and the unstoppable ageing population (World Health Organization 2018:192). The fact that any patient can consult any medical provider at any time without any full insurance coverage is problematic as is a lack of a main control unit for hospitals. It prevents having supervision of the quality of healthcare, as information is lacking concerning funding, supply and demand (Henke et al. 2009:55).

4.4 Actions

This short section covers a few key actions that were taken and have affected the healthcare system. In 2006, the Health Reform Act was revised to help reduce the numbers of long-term care beds. As a result, between 2005 and 2011, the numbers of local public hospitals decreased from 1060 facilities to 968, and the number of beds from 251'000 to 233'000 (Zhang & Oyama 2016:28). Regarding the ageing population, the long-term care insurance system established in 2000 and the Integrated Community Care System of 2006 focus also on the long-term care strategy. Moreover, it acts at the community level and encompasses prevention, medical services, etc. (World Health Organization 2018:191).

By the end of 2007, a Planning Guideline for Reforming Local Public Hospitals was published by the Ministry of Internal Affairs and Communications (MIC). Amongst its content, there are two key elements that stand out. First, local public hospitals and beds were reorganized in order to secure health care services in rural areas. Second, there was a management reorganization and the number of beds were cut (Zhang & Oyama 2016:28). Later, in 2010, the Comprehensive Reform of Social Security and Tax was introduced and focuses, amongst other topics, on the support of children and employment for the young generation (World Health Organization 2018:191). This reform was a result of Japan's demographic changes: it is a "joint reform for the social security system and taxation system that should improve fiscal sustainability for the Japanese social security system" (ibid 2018:xvi).

As for some other possible solutions to these issues, the authors Henke et al. (2009) highlight the following options. First, medical services should be limited in order to make sure the ones that are necessary are being taken care of. Second, the length of stay in hospitals should be reduced. Third, doctors should receive higher payment and compensation levels. Fourth, there needs to be a control unit of hospitals, especially on the supply and demand concerning medical treatments. There also needs to be a control unit for training programs for physicians (2009:62).

4.5 The medical system and aphasia

Once an aphasic patient leaves the rehabilitation center and returns home, they can, for example, contact and join the Japan Aphasia Peer Circles (JAPC). The following chapter describes their work and their engagement into promoting awareness of the public and support for their members. This section deals with their engagement and relationship with the healthcare system.

Ms. Sonoda, the head of the JAPC, explains that the situation with the MHLW is complex and frustrating. While the center was founded in 1983, it was never officially recognized up until the mid-2000s. Even after they had been recognized and thus received legitimization, they still remained unknown to most hospitals and medical specialists throughout the country. The information about their existence was not transmitted by the MHLW to medical institutions. Therefore, many doctors did not tell their patients about these centers because they were not aware of them (Ms. Sonoda et al., personal communication).

One of the activities organized by the JAPC is an annual nation-wide convention. The 2018 edition took place on the 17th November, in Fukui Prefecture¹⁰. These events welcome about 500 individuals, including STs, doctors, medical students, aphasics and their relatives, people from the area where the convention takes place, as well as one representative from the MHLW (ibid). Various activities are held during that day, including healthcare professionals, aphasics, and others involved with aphasia giving lectures. There are also activities where the participants are encouraged to sing and do exercises, for example (Elman & Endo 2009:1). There are live performances by local entertainers, but also by aphasics. These shows have two primary goals: for aphasics to enjoy themselves and to practice their speech, and to get the attention of the representative from the MHLW (Ms. Sonoda et al., personal communication). Aphasics also sing popular songs and hold symposiums, where they discuss what they did during the year and what is planned for the following year in terms of activities.

There is also a principal item on their agenda regarding their developmental targets. For example, one of the topics was the creation of SOS cards for aphasics and the need for help to finance it. The JAPC forwards the requests to the MHLW. However, JAPC may only submit

¹⁰ Please refer to the flyer in Appendix C, page 73.

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one request at a time to the MHLW representative. As there is usually only one representative per conference, only one topic can be addressed. In short, they need to talk to as many officials as there are requests. One issue that came up was that this process usually takes at least two years before any action is taken with the representatives at the MHLW changing every year. Therefore, the demand has to be followed up every year with the new person in charge. Ms. Sonoda explains that if there are, for example, five subjects that are on the planning to be discussed, the JAPC has to meet five different officials at five different times.

The 2007 changes of laws within the healthcare system have affected rehabilitation patients. The budget for rehabilitation was adversely affected and decreased. Doctors' salaries were reduced and many hospitals decided not to offer rehabilitation programs for this reason. However, about 440'000 signatures were gathered by citizens and sent to the government to protest against this new law. The protest worked and the law changed back to what it was beforehand. However, some hospitals had already let go of the staff and used the space for other structures. Therefore, the transition took some time (Ms. Sonoda et al., personal communication).

These examples express the complex relationship between support centers such as the JAPC and the MHLW. Indeed, the first struggles to reach the attention of the latter and is often slowed down due to administrative matters.

This chapter provides an overview of how the Japanese healthcare system can prevent patients from getting good quality treatment and care. Although the approach was general, it highlighted the various barriers that any medical patient can encounter in the system, whether they suffer from aphasia or not. These general systemic and structural issues are even more significant because of the highly time-based factors affecting stroke survivors. Building on these insights, the next chapter covers what happens to aphasics once their rehabilitation process is over, and specifically the role of the JAPC.

5. Support centers and Peer Circles for aphasics in Japan

Recovering from aphasia is a long and tedious process. It involves intensive training to regain the abilities that were affected by the stroke, or at least as much as possible. Some aphasics can afford to have a personal speech therapist and reach good results within months or years, depending on the severity of the condition. However, this only applies to a small part of the aphasia population, as it requires financial resources and time. Another option is to join a local community where aphasics can meet others with the same condition, as well as STs and other medical professionals who volunteer to help.

In Japan, support centers and Peer Circles for aphasics were founded by the JAPC since 1983, an incorporated non-profit organization. It is managed by an internal congress and an administrative board. As of 2017, there were 20 commissioners, two executives and 25 councilors that were the main actors on defining the action policy (Japan Aphasia Peer Circles 2017). As discussed in the last chapter, the JAPC communicates to the Ministry of Health, Labour and Welfare (MHLW) issues they need support on, although the administration process is long and complex.

I went to Tokyo in February 2018 and visited one of the centers in the suburban area of Ogikubo, in the West part of Tokyo. In fact, Ogikubo Center is the headquarters of the JAPC. I met Ms. Sonoda, the director of the center, and she provided valuable information mainly about how the center is structured, who were the members and what types of activities were proposed to them. This chapter brings insights mostly based on the meeting with Ms. Sonoda, as well as the café event that took place on premises near their office building. This is an in depth qualitative study, as Ogikubo Center captures all essential elements regarding the types of support and activities.

Ms. Sonoda appeared in a report from a local television channel called Tokyo MX News back in 2009¹¹. The short program informed the audience about aphasia and those living with the disease. Ms. Sonoda's husband suffers from aphasia and is seen trying to describe a recent

¹¹ Please refer to the video in Appendix I, page 78.

5. Support centers and Peer Circles for aphasics in Japan

dinner to his wife and the journalist (Tokyo MX News 2009: 00:46). Although he is able to write, his speech is affected and he has issues reading aloud. He was working in a car-company for years until he suffered from a cerebral embolism back in 2003 (ibid 2009: 2:19). Ms. Sonoda explains how this situation affected both of them (ibid 2009: 2:35). During the meeting in Ogikubo, she added that her husband spent a few years in Amsterdam for work and that he used to speak English. Since the accident, she observed that he regained English better than Japanese, but he developed another symptom called emotional incontinence¹². Since then, she has become very involved with the JAPC and provided support for other aphasics and their relatives.

5.1 Ogikubo Center, structure and members

Ogikubo Center is located in a 1.5 room apartment of a residential neighborhood, a few minutes away on foot from Ogikubo station. It is small and narrow, but it has the advantage of being close to the center of Tokyo, which grants easy access for the members. Many documents and resources are available in the room, such as copies of studies from the JAPC and other contributors, as well as books, posters and flyers of various activities proposed by the association. There is a large table in the middle of the room, with some chairs. This is where aphasics can come and are welcomed to sit with Ms. Sonoda, the vice chief director of JAPC, or other members from the association, and receive advice and useful information.

On the 15th February 2018, I met Ms. Sonoda and Mr. Hashima, the vice president of the JAPC of Chiba Prefecture. Many topics were discussed, such as how the JAPC is structured, activities, speech therapy, the annual convention, job interview support, etc. As they were very interested on the situation of aphasia and aphasics in Switzerland, we introduced an overview and thus we were able to compare and discuss the healthcare system in Japan. The following information comes directly from what they presented during the meeting.

Ogikubo Center has about 50 members. Most of them are aphasics, but there are also medical experts, aphasics' relatives and STs. In fact, there are over 100 STs throughout Japan that are registered as members. They are volunteers and serve as valuable support for aphasics. In total, there are about 2000 members in the country, which is surprisingly low compared to the high number of aphasics that is estimated between 300'000 and 500'000 individuals in Japan (Kotani 2008:110). According to Ms. Sonoda, this can be partly explained by the lack of

¹² Ms. Sonoda did not elaborate further on the matter, for personal reasons.

5. Support centers and Peer Circles for aphasics in Japan

time aphasics may have. However, the main reason is that most of them do not know about the existence of support centers, including doctors. Indeed, although the JAPC has been officially recognized by the government, they still remain unknown to most hospitals and medical specialists throughout the country.

In addition to holding the yearly convention (which was introduced in chapter 4.5), the JAPC organizes various activities for aphasics, such as consultations about language, training meetings, symposiums and lectures. They also do research on aphasia and publish their studies (all in Japanese) for the community. For example, they conducted a survey amongst aphasics about which tools or devices they use or have difficulties with, such as using mobile phones, computers, riding a bicycle, traveling, attending a meeting, etc. They also performed similar types of surveys concerning employment, and what aphasics go through during their daily lives. In addition to the first survey, questions regarding their relationship with their relatives were asked.

The JAPC is mostly financed by donations and membership fees. The latter varies depending on the center. Concerning Ogikubo Center, members pay 500 Yen (i.e. about 4.50 CHF) per year and companies pay 20'000 Yen (i.e. about 175 CHF) per year. Events are not included in the price, as they are optional. There are about 10 sponsors including hospitals and companies that also hire aphasics for small jobs (which is discussed in section 5.5).

5.2 Activities and Tomonokai

The JAPC manages support centers (such as the Ogikubo center), as well as Peer Circles that are called *Tomonokai*, which means "friends meeting". Their primary goal is socialization, and they do so by bringing aphasics together and organizing activities in a fun and friendly atmosphere. There are hundreds of circles across the country and they are all supervised by the sector in which they are located. There are in total 11 sectors, as seen of the following image:

5. Support centers and Peer Circles for aphasics in Japan

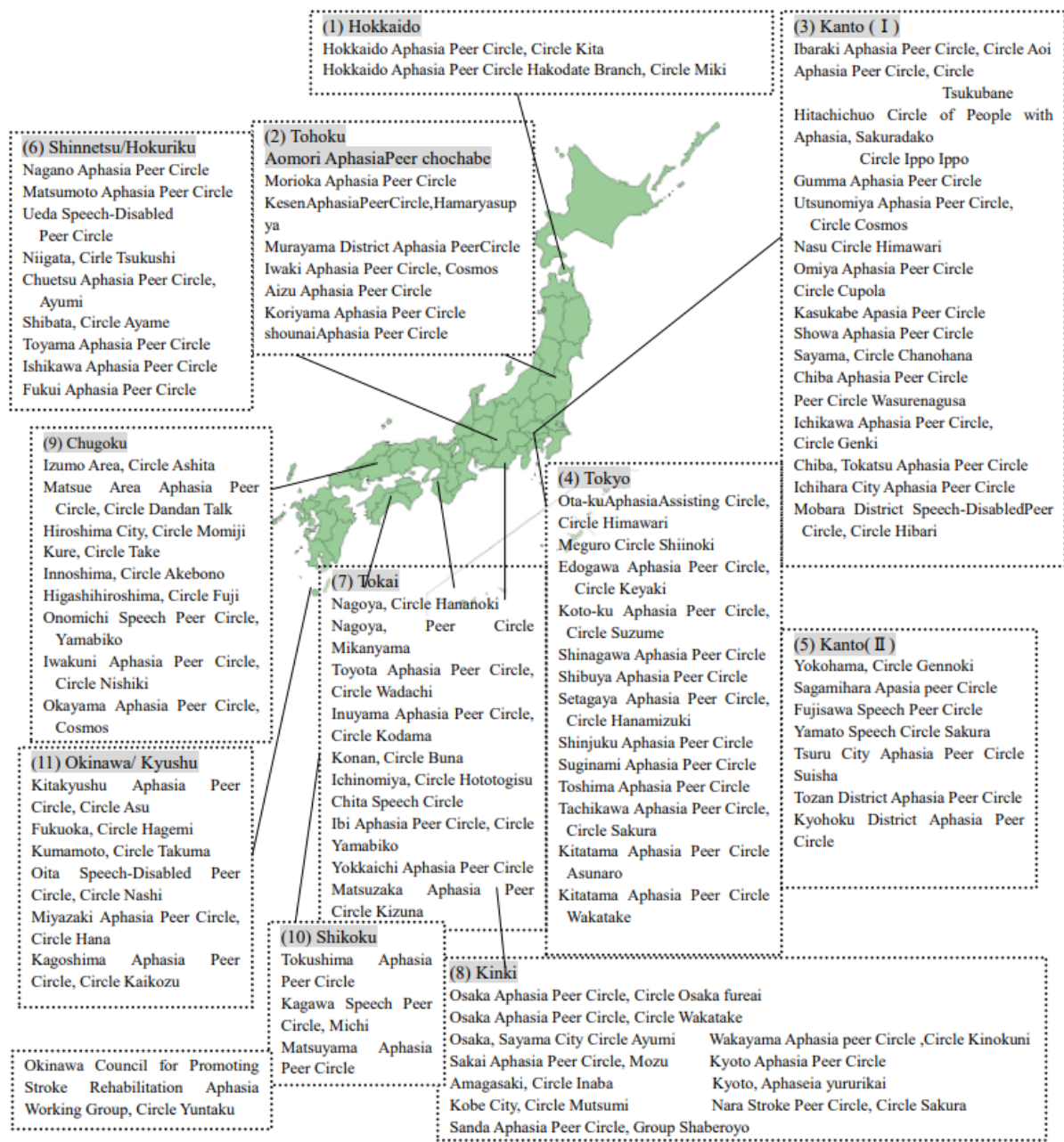


Figure 9. Distribution of Peer Circles in Japan (Japan Aphasia Peer Circles 2017).

As seen on the map, there is a large presence of *Tomonokai* in the Tokyo Metropolitan area, as well the Osaka and Kyoto regions. A circle can also depend on the age group. One associate from the JAPC team explained that her son had a bike accident when he was 25 years old and has been suffering from aphasia since then. His right side of the body was paralyzed and he had both speech and reading troubles, which prevented him from finding a professional activity. Although he received financial support from the insurance company, he would get

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confused with reading numbers. He joined a Peer Circle that included people his age and has been able to socialize and make friends with the other members.

Membership fees depend on each sector, but they can start from 1'000 Yen up to 5'000 Yen per member per year. Usually, activities are organized by each circle once a month and can include barbecues, café meetings, Christmas Party, or *Ohanami*, which means "looking at flowers", a typical Japanese activity where friends and relatives gather and witness cherry blossoms. Aphasics, ST students and STs are welcome to join and participate. Family and relatives usually meet among themselves and are encouraged to share their experience, while aphasics enjoy their activities.

In the Tokyo MX News report, the journalist attends one of the meetings organized by the Peer Circle in Shinjuku, one of the city wards in Tokyo (Tokyo MX News 2009: 4:14). Aphasics from the neighborhood meet and are spread into small groups (three to four people) called "conversation partner" that are coordinated by a member from the center. As described by the report, the general atmosphere in the room is very positive and cheerful (ibid 2009: 5:13). Aphasics are encouraged to talk to others and the mediator of the group provides support when needed.

Similarly, Ogikubo Center organizes every two months a "free talk" activity, where aphasics, their relatives, STs and anyone interested in aphasia or in the JAPC are welcome to join. One of those meetings was scheduled for the 18th February 2018 from 13:30 to 15:30 in premises near the office building. About 35 people were gathered, including husbands and wives, brothers and sisters, ST, ST students, nurses, etc. The entrance fee was 500 Yen per person and everyone was greeted with coffee and tea, as well as some Japanese snacks. There were five tables in the room and everyone took place around them. The meeting was animated by a ST who also happened to be a kindergarten teacher and was structured in two parts: there were two interactive group exercises and then discussions within smaller groups.

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Figure 10. *Free talk meeting organized by Ogikubo Center, table setting (Author's personal collection).*

First, everyone was asked to introduce themselves to the group. Many interesting stories were told from aphasics but also by STs and relatives. One explained that he would join these meetings every year since his stroke accident, when he fainted at work. During the first year, he had trouble remembering names and faces but he has improved since then and was pleased to say that he could recognize some of the participants in the room. There were also three sisters that attended the meeting to learn more about aphasia, because their father had suffered a stroke back in December 2017. One suffered from aphasia as well as paralysis. After some intensive training, he managed to get better physically and was happy to be able to serve everyone coffee and tea during the meeting. The animator also explained that her husband suffered from aphasia and that the stroke affected his memory. His hobby was related to railways and trains, and he used to know all the timetables, lines, trains and connections of all of Tokyo. Since the accident, he takes a look at maps and timetables to remember what he once knew prior to the stroke. Another one explained that he had problems with time. Although he would remember what he did, he would forget when something happened. These are only a few examples, but they highlight how everyone's story is different and unique. The atmosphere was very friendly and all participants felt comfortable sharing their experience with others.

The first activity was called バナナ語 ("banana-go", which means "banana language"). Everyone in the room were asked to repeat the word "banana" and clapping their hands depending on the intonation that the animator chose. If the intonation was high, they clapped

5. Support centers and Peer Circles for aphasics in Japan

their hands over their head. If it was low, then they clapped their hands lower than the head. The ST said that those who could not use both hands could clap one hand to their chest, so that all participants were involved in the exercise.

After a few successful attempts, another game took place that involved singing a very popular Japanese song called たき火 ("Takibi", meaning "bonfire"). There was a large poster with the lyrics written in hiragana characters, so that every syllable of the song stood out. With the help of a stick, the animator guided the singing by pointing at each character as the song went by, from left to right, top to bottom.



Figure 11. *Takibi* song poster with every syllable (characters) in a different color. (Author's personal collection).

Everyone sang a few times before the animator took a few bells out of her bag and distributed them to a few people in the room. They had different colors that matched the ones on the poster. Each time the animator pointed to a character on the poster, the one who was holding the bell with the corresponding color had to ring it. In short, the person with the light blue bell was the first one to do it, followed by the dark blue, then back to the light blue, and so on, as seen on the picture above. If done correctly and on the right timing, the bells played out the song, as each one of them has a different tune¹³. Once the song was over, each participant gave their bell to their neighbor and it was their turn to perform. In the end, everyone had been able to participate at least once at the exercise.

¹³ Please refer to the video in Appendix I, page 78.

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After this last group activity, the animator proposed to change seats and meet other participants, in order to encourage discussion. We sat down with a ST who had 35 years of experience in her domain. She suffered a stroke back in 2009 and suffered from aphasia. She followed intense training and was now able to give seminars about aphasia in the University of Kobe. She also wrote a book for the wider public that introduced what aphasia was.

We also met an aphasic who joined the Center in September 2017, after a recommendation from that same ST. He joined the meeting in the presence of his mother for support. He explained that he had been overworked and had been under a lot of pressure when the stroke occurred. His right arm was completely paralyzed back then and he has been training ever since the recovery process. Prior to the stroke, he was able to carry weights up to 85 kilograms, but now even after long training hours, he was able to bear a maximum of 60 kilograms. His speech was low, compared to his comprehension ability which remained the same. He used to work in Singapore and had an excellent level of English. He explained that he could not speak English anymore but was able to understand most of it. He did not follow a multilingual therapy.

Overall, the “free talk” meeting took place in a cheerful and welcoming atmosphere, where everyone had the possibility to share their story and experience and meet new people. As Ms. Sonoda explained the first time we met, the activities organized by Ogikubo Center mainly focus on socialization and enjoyment, and we indeed felt it that way.

5.3 Documentation

During the initial encounter with Ms. Sonoda, she provided us with valuable documentation, such as four research papers written and published by JAPC members, the latest edition of the newspaper the JAPC published and distributed to members, the SOS card that every aphasic has in their purse in case they have an accident, the aphasic booklet that complements the card, as well as a few button pins that informs others about aphasia. In this section, these items are introduced and reviewed. This shows that the JAPC members are not only active on supporting aphasics with language therapy and activities, they also do research on this condition in order to create public awareness, as well as improving the existing treatments.

As briefly introduced in section 5.1, the JAPC contributes to research on aphasia and writes studies. All of them are written in Japanese. However, here are a few key insights to be

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taken into account. All four of them that were given to me were based on surveys that were conducted among aphasics. They were mostly members from centers and circles. One of the studies is titled “Research on the everyday life struggles for aphasics” and 486 individuals participated in the surveys, which is high compared to most studies on aphasia. For example, they were asked about their use of mobile phone, and their ability to communicate their home address:

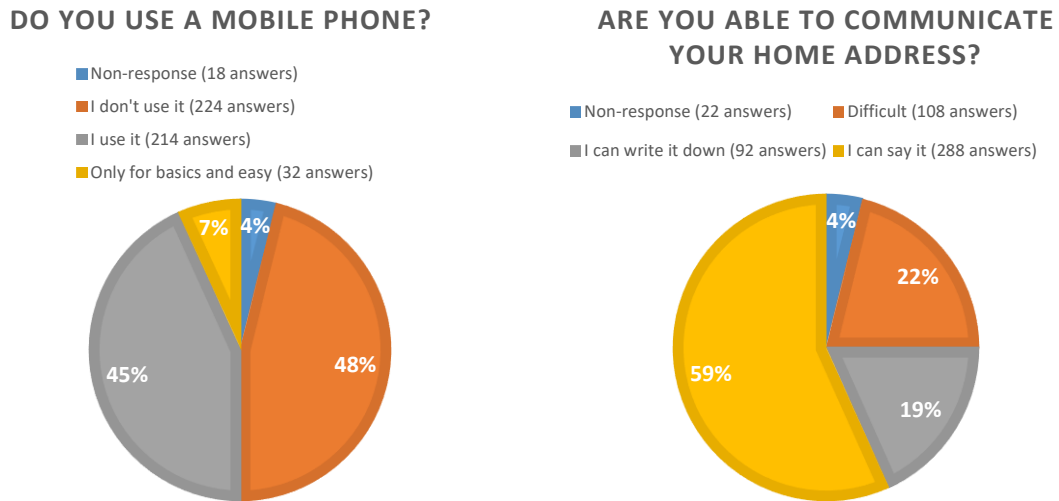


Figure 12. Two surveys from one JAPC study conducted on 486 aphasics (translated).

Both of these questions are interesting as they show a certain disparity between the answers, particularly for the first one. As the symptoms and their severity level depend on each individual, it is extremely complex to generalize or identify a “typical” aphasic. Other different surveys from the same report show similar observations, as shown below:

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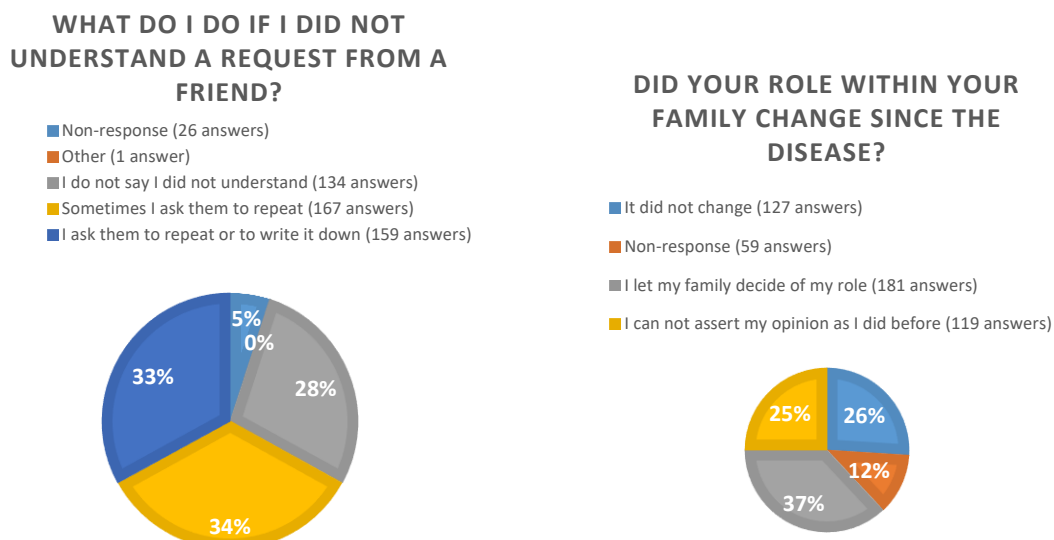


Figure 13. Two surveys from one JAPC study conducted on 486 aphasics (translated).

These types of questions focused on the relationship with relatives and friends thus extending other lines of research as they do not only focus on tools and the communication of basic requests. These two surveys show the struggle some face when trying to interact with close ones and how their relationship is affected. By leading such research, the JAPC's goal is to create awareness and inform the public about what an aphasic's daily life looks like and how to understand them better.

The JAPC also writes and publishes its own newspaper five times a year. About 2'000 copies are printed and distributed to all members. They do not charge extra for this, as the fee is included in the membership. I received the January 2018 edition which was the latest edition at the time of the interview¹⁴. This edition has 16 pages and starts with an editorial message on the front page. The latest events and meetings are listed shortly summarized, followed by the planning for the month. There are also a few word games, detailed information about an organized holiday in Canada for one week in September 2018 for aphasics, a short essay about aphasia awareness, as well as information on the next "free talk" activity which happened to be the one on the 18th February 2018 in Ogikubo.

Ms. Sonoda provided also an aphasia identification card for the wallet, as well as a communication book specifically made for aphasics. Both of these items were produced and designed by the JAPC and distributed to the members.

¹⁴ Please refer to Appendix G for a copy of the front page of the edition, page 76.

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The ID card comes in a small plastic pocket that also includes a how-to guide and stickers for the communication booklet that serve as bookmarks. It is the same size as a credit card and can easily fit in a wallet, as shown on the explanation file here below:

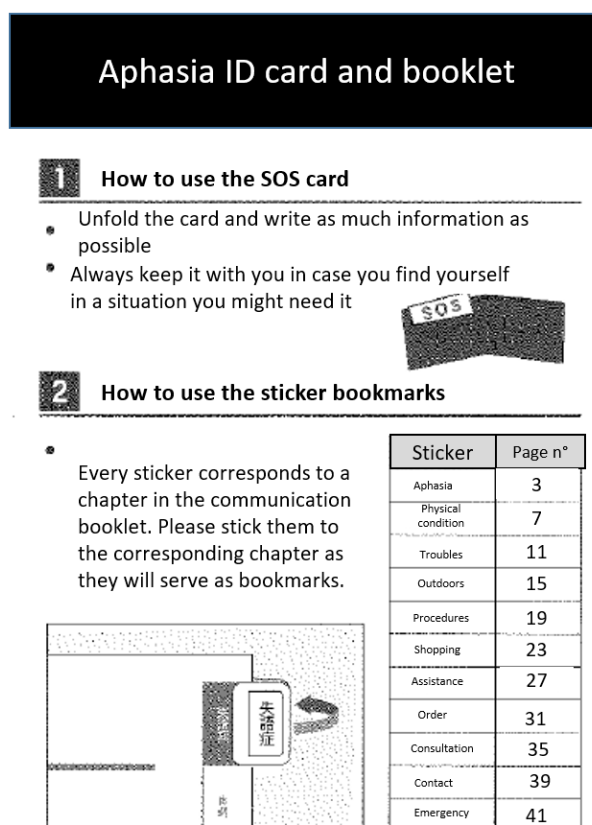


Figure 14. *Aphasia ID card and booklet how-to guide (translated).*

The aphasia ID card (or SOS card) needs to be filled in as much as possible. The card includes information such as the full name, address, phone number, blood type, name and contact information of the hospital or doctor in charge, any allergies, two contact persons, and any other relevant information¹⁵.

The stickers are used as bookmarks for the communication booklet¹⁶. There is a sticker for each chapter (total 11), which can be seen on the bottom-right side of the image above. The booklet provides various pictograms depending on the situation or the theme. Aphasics are recommended to keep it with them wherever they go, in case they have trouble communicating.

¹⁵ Please refer to Appendix E for a copy of the aphasia ID card, page 75.

¹⁶ Please refer to Appendix F for a copy of the stickers, page 75, and Appendix G the front page of the booklet, page 76 .

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In that case, they can easily open the booklet to the corresponding chapter and point out the drawing that best describes their needs. For example, the second chapter focuses on a few physical conditions that the person may need to convey to someone:

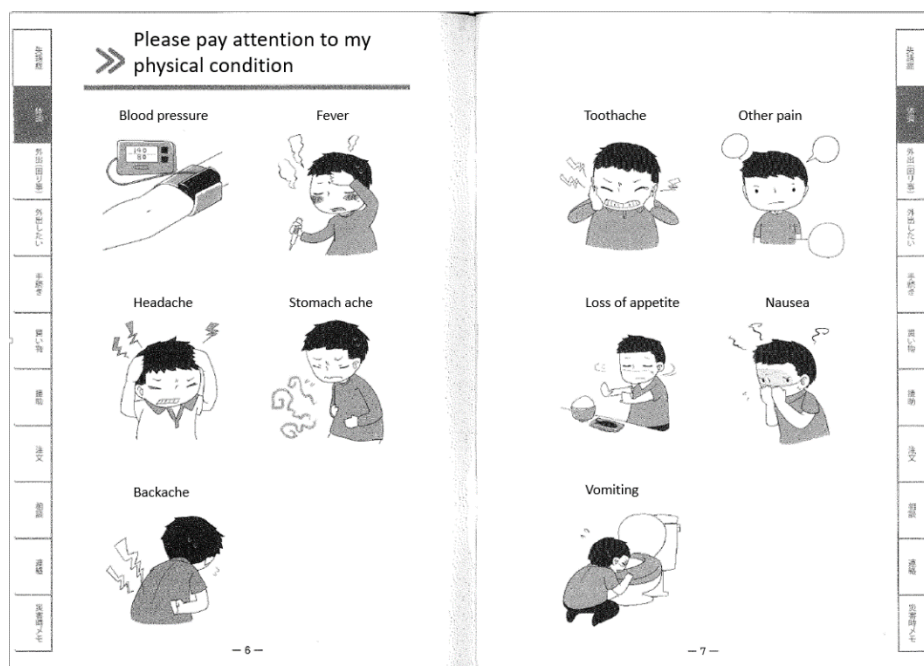


Figure 15. Example of the content within the communication booklet (translated).

The drawings are simple but highly intuitive, which enables a proper comprehension and a successful communication. There are many other situations that are covered in the booklet, such as asking for directions, names of useful places (i.e. home, the office, the bank, the hospital, the school, etc.), grocery and bank information, food, and many other essential daily life topics of conversation.

Ms. Sonoda also gave me a set of pins that one can stick on their clothes or bags that inform others of the aphasia condition with the phrase "I am aphasic" written on them¹⁷. These goodies are also produced by the JAPC.

5.4 Speech therapy exercises

Ogikubo Center is not limited to organizing activities and doing research, they also provide support and speech therapy to their members. Ms. Sonoda explained that they offered daily

¹⁷ Please refer to Appendix H section for a picture of the pins, page 77.

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sessions. There is group training three hours per day that includes 15 minutes per exercise, so that aphasics can join the session that suits them best and does not take all of their time. She also mentioned multilingual therapy and mentioned some Korean aphasics living in Japan who were able to find a ST to help them recover Korean and Japanese.

As briefly introduced in part 5.2, we sat down with a ST during the "free talk" event and asked her about what type of speech therapies were proposed in Japan for aphasics. It seemed that the Melodic Intonation Therapy (MIT) was the most common.

In short, the MIT was developed in the 1970s after the observation that some aphasics were able to sing words even though they were not able to speak them. Therefore, it seemed that the musical elements of speech, which were melody and rhythm, had an impact on the recovery process of aphasics (Norton et al. 2009:1). The exercises included taping out the rhythm of a word's syllable with the hand while singing or repeating the said word. The two activities that were performed during the "free talk" meeting (i.e. the "banana language" and the "Takibi" song) followed the same concept.

The ST also mentioned other exercises that were proposed to aphasics, such as naming a picture and repeating the word as many times as possible. They are also asked to write it down when they are able to do so. In case they cannot say the word out loud, they describe the object in the picture. For example, they talk about its shape, utility, color, and so on, until they are able to name it. Usually, every aphasic meets with their ST every 3 months to check their improvement. If their situation has not changed, they together search for another strategy or therapy that suits them better.

The change of law in 2007 (that was discussed in chapter 4.5) was brought up again during the conversation. Prior to 2007, group therapies were very common and held in hospitals. As explained, many hospitals cut their staff and rooms that were dedicated to patients suffering from aphasia, thereby reducing the number of group therapies due to budget pressures. The ST explained that nowadays therapies are mostly held between a ST and a patient. She believed that the group therapies were very effective because patients could socialize with others, and they could compare their level and their progress with each other. Moreover, she said that STs could provide psychological and/or emotional support if needed.

She also confirmed what had been discussed in chapter 2 by explaining that most aphasics have less problems with Kanji characters because the meaning is attached to them,

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compared to Hiragana and Katakana characters that only convey phonetic information and no semantics.

5.5 Finding a job as an aphasic in Japan

One of the final steps in the journey of an aphasic in Japan may be returning to their workplace. A few studies have discussed the matter and this section briefly highlights the key elements involved. Sasanuma (1989) writes that based on four survey that were led in the 1980s, only 12.4 to 16.2% of aphasic patients that received treatment were able to return to a professional activity (Sasanuma 1989:29). Indeed, aphasia and attention dysfunction have a significant impact on the return rate, especially within 18 months after the stroke onset (Tanaka et al. 2014:450).

Sasanuma pointed out that the three most important factors that influence the return to work for an aphasic are the age of the patient, the severity of aphasia, and the time spent in language therapy (Sasanuma 1989:30). Saeki et al. (1993:1184) also added that the patient's weakness, apraxia and occupation status may play an important part, but other studies have shown different possible factors.

Another piece of research led by Fukusako et al. (1990) introduces specific variables regarding the possibility to return to a professional activity, as shown in the figure below:

Table 5 Social adjustment in 303 aphasic patients

	Presence or absence of job* at the onset of aphasia			total
	paid job	no job	unknown	
return to the previous job	29 (15.7%)**	0	-	cases 29 (10.1%)
transferred to another section or changing the job	23 (12.4%)	0	-	23 (8.0%)
transferred to nonresidential sheltered workshop	2 (1.1%)	0	-	2 (0.7%)
return to home or institution for the aged	111 (60.0%)	95 (93.1%)	-	206 (71.8%)
transferred to hospital or rehabilitation setting	15 (8.1%)	4 (3.9%)	-	19 (6.6%)
dead	5 (2.7%)	3 (2.9%)	-	8 (2.8%)
unknown	7	0	9	16
total	192	102	9	303

*: Excluding house work.

** : The ratio of the patients in each group was calculated excluding the unknown cases.

Figure 16. *Social adjustment in 303 aphasic patients* (Fukusako et al. 1990:207).

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Out of 185 aphasics who had paid jobs before the stroke (excluding the 7 unknown cases), 52 (28.1%) returned to a professional activity, including 29 (15.7%) to the same job, and 23 (12.4%) to a new occupation. The remaining 128 (71.9%) mostly returned home or to institutions for the elderly (Fukusako et al. 1990:182-183). The authors agree with Sasanuma when they discuss age as being one of the main factors that influences whether an aphasic can return to a professional activity or not. They published a graph that illustrates the phenomenon:

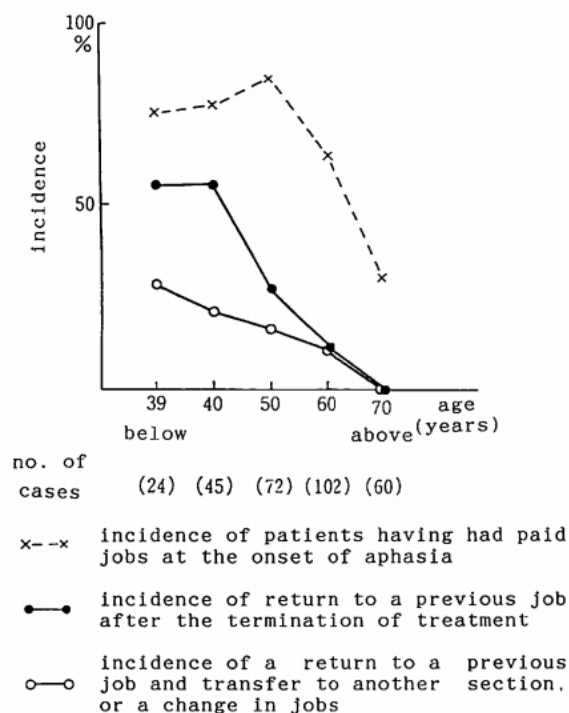


Figure 17. *The relationship between vocational adjustment and age in 180 aphasic patients having had paid jobs at the onset of aphasia (ibid 1990:201).*

As observed, individuals under 50 years old who already had a career prior to the disease had an over 50% chance of returning back to their professional activity. However, the ratio decreased drastically after 50 years old, reducing the opportunities of finding a job.

Overall, it is very difficult to establish a clear and precise pattern as there are many variables to take into account. These studies show that it is not impossible for an aphasic to return to a professional activity. In fact, for their recovery process (both physical and psychological) it is recommended to go to work as it favors socialization and language practice in an environment other than the hospital or home.

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Ogikubo Center provides help with aphasics who wish to apply for a job. They are asked to write down what they can and cannot do on a sheet of paper, which they will then give to the interviewer. A member from the Center accompanies them to the interview so they can provide extra information on the person's condition (Ms. Sonoda et al., personal communication).

There are also selected companies that have special tasks and jobs for aphasics only, in exchange for a small salary. Ms. Sonoda mentioned a wine factory in the Prefecture of Toshigo that hires aphasics to do simple tasks such as sticking labels on bottles, for example. The company also provides housing as the factory is isolated in the mountain area and offers wine during JAPC events. There is a bakery near Ogikubo station that provides small jobs for aphasics. Ms. Sonoda explained that the tasks, salary and possible benefits entirely depends on the company and may vary a lot. Usually, the Center tries to find a job that fits the physical and mental capacities of the individual.

A computer company called Yuzuriha also hires aphasics for producing teaching materials such as flash cards. These items are then used for JAPC activities or during speech therapy sessions (Tokyo MX News 2009: 3:08-3:24).

The support provided by the JAPC centers and members mostly concerns aphasics who cannot return to their previous workplace and are deeply affected by their condition. However, even though their abilities are limited because of the severity of the stroke consequences, there are companies that offer them opportunities to return to a working environment with others who share the same difficulties.

This chapter provided significant information on support centers for aphasics in Japan, through a first-hand and personal viewpoint. These insights offer a perspective of real-world implications and applications of different approaches. This field research was an opportunity to meet aphasics and to be able to understand their condition from their own words. In addition, it highlights the strong involvement of Ogikubo Center, as well as the positive and hopeful environment in which all their activities and meetings take place.

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Strokes affect hundreds of thousands of Japanese people per year and leaves them with life-long consequences. Among those is a complex language disorder called aphasia that damages and changes the way stroke survivors communicate with others.

This qualitative study explores the situation of aphasics in Japan, and in particularly the recovery process that depends on unique linguistics factors, as well as structural issues in the healthcare system. However, there is hope for them, thanks to the involvement of support centers. Based on key studies and fieldwork, this research contributes to the literature, as there is a gap regarding aphasia and its context in Japan on a linguistic and political level.

In order to better understand the situation in Japan, it was important to start by introducing the Japanese language and the different manifestations of aphasia in Chapter 2. Japanese writing is completely different compared to any Indo-European language; thus there are different types of impairments that are unique to the Japanese language. This means that language therapies and treatments have to be consistent with a range of symptoms. This chapter illustrates that there is an intrinsic connection between written characters that hold meaning (i.e. Kanji characters, that were borrowed from Chinese characters) and characters that only served as phonetic information (i.e. Hiragana and Katakana characters). From there, a few language therapy examples that answered these particular needs were discussed.

Once this fundamental information regarding the Japanese language has been introduced, Chapter 3 focused on the first steps of the journey for aphasics, and in particularly the medical process which encompassed the emergency, the hospital and the rehabilitation procedures. Issues regarding the protocol and the emergency medical liaison system in general were identified. Indeed, there was a lack of medical institutions prepared for stroke patients and they were not geographically well distributed. Moreover, the transfer to rehabilitation centers was not coordinated efficiently. Patients tended to stay in acute medical institutions and would therefore occupy the space that was needed for incoming emergency patients.

The way the medical process is structured in Japan brings up many questions regarding how the healthcare system is organized. This topic was then discussed in the following chapter

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4 which gave an overview on the key elements that structured it. Section 4.3 in particular pointed out socio-economic issues, such as the aging population and the working condition of medical employees (including doctors, nurses, etc.). There is a clear disparity between how the Ministry of Health, Labour and Welfare (MHLW) communicated with the hospitals and how the hospitals communicated with each other. This chapter highlighted that these issues within the healthcare system affect every potential patient, including stroke survivors and aphasics. However, due to the severity of the condition and the significance of speed of treatment, it is particularly critical that stroke survivors and aphasics get medical treatment and support as soon as possible. The last section returned to aphasics, and The Japan Aphasia Peer Circle (JAPC) was introduced through their annual conference and their complex relationship with the MHLW.

This led to a direct transition to the last chapter that focused on the support centers and in particularly the Ogikubo Center. Interviews with Ms. Sonoda and her colleagues provided valuable information on how the JAPC is structured and how it helps its members by organizing various activities, doing research and publishing their studies, crafting and distributing the Aphasia ID card, and the communication booklet. This particular chapter was different from the others due to the empirical fieldwork approach. The valuable testimonies from individuals within the aphasic community or who were actively involved with them offered the opportunity to understand real world implications of this unique condition.

Although strokes are a very serious topic, research studies regarding aphasia are limited. This makes it a difficult task for medical professionals to find new therapies that could be more efficient than the existing ones. Moreover, it is difficult to find documentation about aphasia in Japan, especially written in English. Although some information was translated because it was deemed necessary, the main goal of this paper was not a translation but a research essay.

Regarding the JAPC, although they have valuable research papers and a strong will to help aphasics, their reach is very limited due to the lack of communication with the MHLW and other medical institutions. Indeed, although there are up to 500'000 cases of strokes per year in Japan, there are only about 2000 JAPC members throughout the country.

It would be interesting to conduct further research to investigate other support centers in Japan, particularly those in less populated areas in order to compare the types of activities and help proposed. It would also be relevant to have a professional translator to focus on the research papers the JAPC published. Even though a few surveys were translated here, there are other surveys that could be useful for researchers on aphasia. As this community is rather small,

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it is important to rely on cooperation between researchers. Lastly, further research should include the potential use of new technologies for speech therapy. For example, the Department of Neurology in the National Cerebral and Cardiovascular Center in Japan is developing a new rehabilitation strategy for stroke survivors involving virtual reality technology (National Cerebral and Cardiovascular Center n.d.).

Aphasia is a journey that accompanies individuals for the rest of their life. Although there are various obstacles that they might come across, there are committed people, such as support centers members, voluntary speech therapists and so on, that aphasics can meet along the way.

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YAMADA S. 2016, [*The three steps of a stroke rehabilitation: acute phase, recovery phase and lifetime phase*], NHK, accessed 3.12 2018. (In Japanese¹⁸)

< https://www.nhk.or.jp/kenko/atc_133.html >

World Health Rankings 2017, *Health Profile: Japan*, accessed 3.12 2018.

< <http://www.worldlifeexpectancy.com/country-health-profile/japan> >

World Stroke Organization, Facts and Figures about Stroke, accessed XX 2018.

< <https://www.world-stroke.org/component/content/article/16-forpatients/84-facts-and-figures-about-stroke> >

In addition, reference is made to notes taken by the author during the two meetings at the Ogikubo Center, and material and documentation of the Ogikubo Center.

¹⁸ Please refer to the full self-translated article in Appendix B, page 68.

Appendix A: Hiragana and Katakana characters

From source: <http://www.fanpop.com/clubs/learning-japanese/images/33795018/title/hiragana-katakana-photo> (Accessed 3.12.2018)

Hiragana

あ a	い i	う u	え e	お o
か ka	き ki	く ku	け ke	こ ko
さ sa	し shi	す su	せ se	そ so
た ta	ち chi	つ tsu	て te	と to
な na	に ni	ぬ nu	ね ne	の no
は ha	ひ hi	ふ fu	へ he	ほ ho
ま ma	み mi	む mu	め me	も mo
や ya		ゆ yu		よ yo
ら ra	り ri	る ru	れ re	ろ ro
わ wa				を wo
ん n				

Katakana

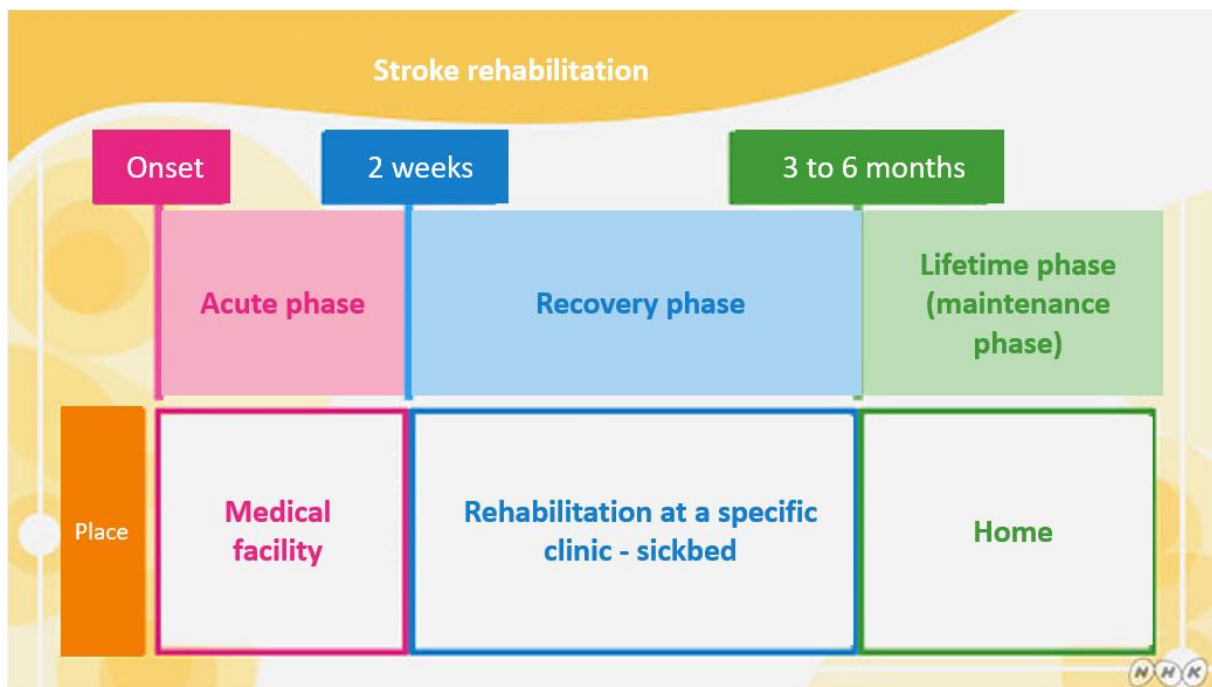
ア a	イ i	ウ u	エ e	オ o
カ ka	キ ki	ク ku	ケ ke	コ ko
サ sa	シ shi	ス su	セ se	ソ so
タ ta	チ chi	ツ tsu	テ te	ト to
ナ na	ニ ni	ヌ nu	ネ ne	ノ no
ハ ha	ヒ hi	フ fu	ヘ he	ホ ho
マ ma	ミ mi	ム mu	メ me	モ mo
ヤ ya		ユ yu		ヨ yo
ラ ra	リ ri	ル ru	レ re	ロ ro
ワ wa				ヲ wo
ン n				

Hiragana characters are mainly used for grammatical information, whereas Katakana characters are used to express foreign words and mimetics.

Appendix B: Translation of a Japanese article to English

From source: https://www.nhk.or.jp/kenko/atc_133.html (Accessed 3.12.2018)

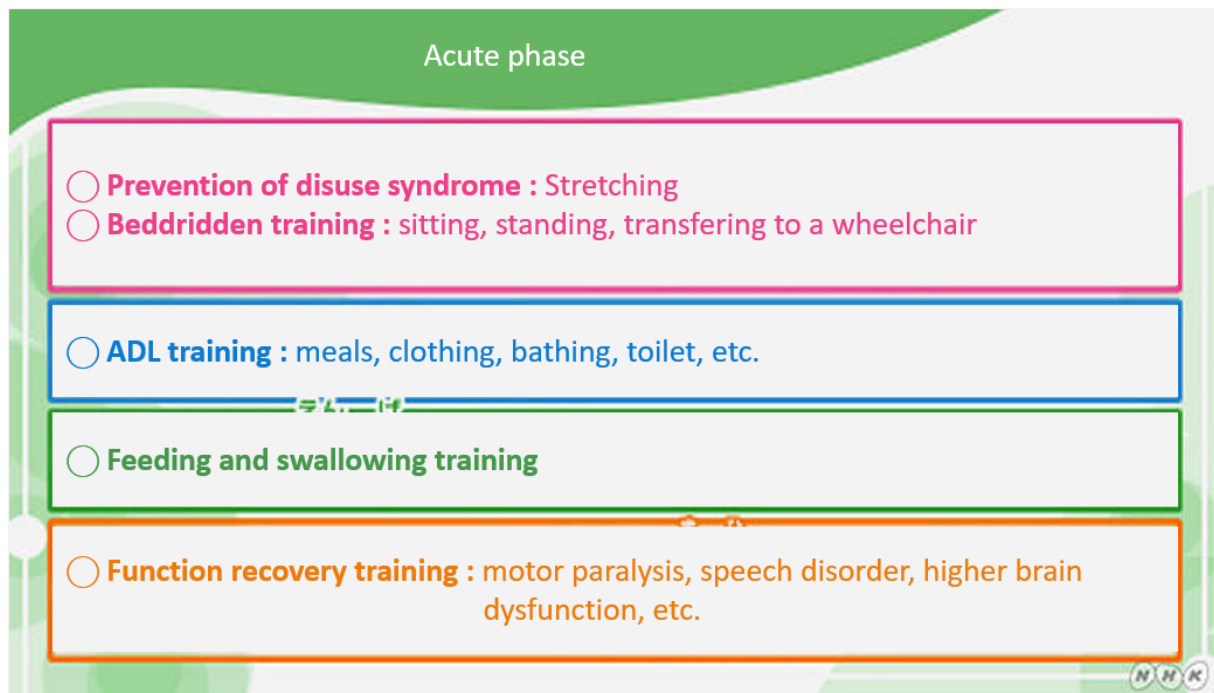
The three steps of stroke rehabilitation: acute phase, recovery phase and lifetime phase



In the past, it was common to hear that excessively moving a stroke patient would worsen the symptoms. However, in the last fifteen years treatment guidelines have been revised and rehabilitation right after the onset is now recommended. By doing so, symptoms can be reduced and complications such as pneumonia can be prevented. Moreover, it reduces the life-threatening risk.

The rehabilitation process after a stroke is divided into 3 steps. First, the acute phase which concerns the time period between the accident and two weeks thereafter. The 3 to 6 months that follow are the recovery period. The last step is called a “maintenance period” (although today it is called “lifetime period”), when rehabilitation will take place at home.

Rehabilitation in the acute phase



The rehabilitation during the acute phase is expected to start during the first 48 hours after stroke onset and its aim is to prevent the decline of physical functions. The longer the bedridden phase, the worse the condition of muscles (atrophy), joints or even bones may become. Physical and cognitive strength may decline. Such conditions are called disuse syndrome.

To prevent this syndrome, physical exercises are performed, such as stretching, sitting, standing and transferring from the bed to a wheelchair. Moreover, ADL (activities of daily living) training is also performed, such as eating, changing clothes, bathing and going to the bathroom. In addition, if the person has difficulties swallowing drinks or food, there is training to help him/her.

Function recovery training concerns patients who suffer from “motor paralysis” (who have difficulties to move their hands, for example), who suffer from "speech disorder" (difficulties to speak, to think of words or to concentrate), and those who suffer from "higher brain dysfunction", etc. For each one of those symptoms, there is treatment.

During the acute phase, the brain blood flow improves and the swelling of the brain decreases, contributing to the paralysis recovery to a certain extent. By following a more appropriate rehabilitation, the brain will start to learn again. For example, even if the left side

of the brain is damaged and the right side of the body is paralyzed, by maintaining treatment on the right arm, the neurons will start functioning again in the other area of the brain.

Rehabilitation in the recovery phase

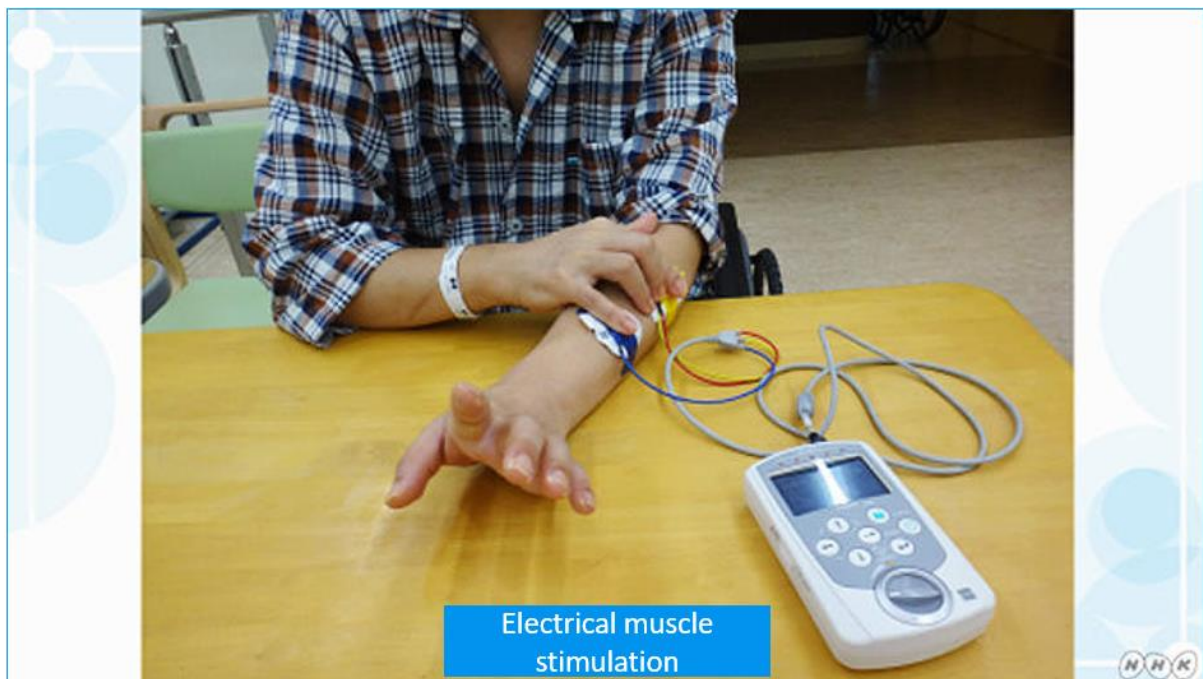
In addition to training exercises mentioned earlier, there are new treatment methods, which are introduced below.

Botulism therapy

To relieve muscle tensions, botulism therapy (injecting botulinum toxin) may be performed. It is used when limbs are subjected to excessive tension.

Magnetic / electric stimulation therapy

By using electric currents, nerves are stimulated and proceed to move muscles and regain motion. Recently, a new experimental method has been conducted, using magnetism and electricity to the brain, provoking stimulation and moving the muscles of the paralyzed arm.

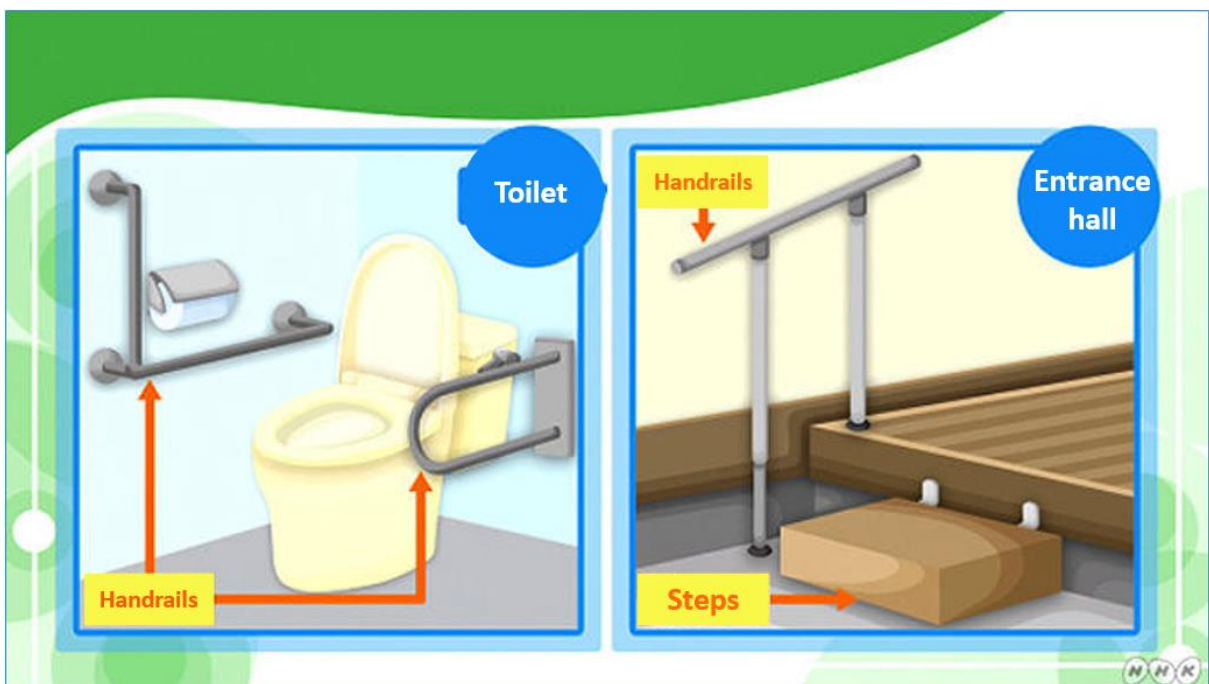


Robot rehabilitation

Robotic technology is being used to support the movement of muscles in the legs for example, helping the person to walk and improve balance by supporting the weight of the body.



Rehabilitation in the lifetime phase



As this part of rehabilitation is done at the patient's home, it is necessary to adapt the environment.

One of the important things to do in home rehabilitation is to remove steps, in order to avoid falls and to allow independent living. Therefore, handrails, stools and/or ramps are installed.

Appendix C: JAPC National Conference, 2018 Edition flyer

しつごしょうせんこくたいかい
失語症 全国大会 イン おおいた

きょう げんき えがお
今日も元気が、笑顔はあるか

～失語症のある人もない人も
心豊かに暮らせる街をつくろう～

音の泉ホール
Iichiko Otani

平成30年 **11月17日 (土)** 9:30～16:00

会場 iichiko総合文化センター 音の泉ホール

みんな
きちよくね(来てね)!!

主催：失語症全国大会インおおいた実行委員会
共催：NPO法人日本失語症協議会
NPO法人失語症デイ振興会
NPO法人ゆずりはコミュニケーションズ
大分県言語障がい友の会「なし会」
(公社) 大分県言語聴覚士協会
事務局：コミュニケーション・ディサービス言の葉
〒870-1176 大分県大分市富士見が丘東2丁目23-13
TEL：097-509-1320

大会マスコット
ねこやう
猫蔵

Appendix D: The front page of the JAPC Newspaper, January 2018 edition

SSKS 1995年8月10日第3種郵便物認可（毎週水曜発行）2018年1月28日 SSKS 増刊通巻 7276号 ISSN2424-094X

SSKS JAPCニュース

2018年 1月発行 第37号(新年号)

特定非営利活動法人日本失語症協議会機関誌
『言葉の海』 新聞版

編集人 特定非営利活動法人
日本失語症協議会
(旧全国失語症友の会連合会)

〒187-0051
東京都杉並区萩原 5-14-5-405
Tel 03-5335-9756 fax 03-5335-9757
1冊 400円

発行人 特定非営利活動法人
障害者定額刊行物協会
〒157-0072
東京都世田谷区祖師谷 3-1-17
Tel 03-6277-9611 fax 03-6277-9555
印刷 パンソンエディンブリック

巻 頭 言



大阪府言語聴覚士会
会長 藤井達也

読者の皆様、こんにちは。

先日、シーズ・ニーズマッチング交流会 2017 大阪会場において、園田事務局長とお会いし、機関紙の原稿依頼をいただきました。このような機会を与えていただき感謝申し上げます。今回は障がい者の就労による自立と、その支援についてお話をさせてもらえればと思います。

障がい者の就労による自立という点では法律が改定され、障がい者の法定雇用率は平成30年度から民間企業では2%から2.2%に引き上げられることになりました。他にもここ数年で障がい者の就労に関する法整備は進んできましたが、社会における受け入れ態勢の整備はまだ途上といえるでしょう。

まずは、障がい者を受け入れる企業や社会が、障がいというものを理解する必要があります。例えば、失語症という障がいでも「聞き取りはできるが、自分からうまく話すことはできない」「話すことはできるが、内容が伴わない」など様々な状態があります。受け入れる側の企業や社会は、どのような障がいを持っています、それを踏まえて①「円滑にコミュニケーションをとる方法」を考え、その方法を②「共有する」必要があります。就労による自立の

援助として、高齢・障害・求職者雇用支援機構が行っている職場適応援助者（ジョブコーチ）の活用も有効でしょうし、このような機関により多くのリハビリテーション職の配置が必要と考えます。また、リハビリテーション職が社会や企業との橋渡しの役割を担うことも可能であると考えます。

繰り返しになりますが、障がい者の自立とその支援のためには、まず支援する側が障害について正しい知識を持ち、円滑なコミュニケーションの方法を形成することで、その障がい者と良好な関係を築き、その「人」を受け入れること。ここが第一歩になるのではないのでしょうか。

**新年あけましておめでとうございます。
本年もよろしくお願いいたします。**

事務所に多くの年賀状を頂戴いたしましたこと、深く御礼申し上げます。数年前より経費節減対策としまして、協議会としての年賀ご挨拶状を新年号の紙面でのご挨拶とさせていただきます。どうぞご容赦ください。

特定非営利活動法人日本失語症協議会

理事長： 八島三男（木）

事務局ボランティア：

園田尚美（月～金）、進藤美也子（月）、
藤原みどり（火）、三池信一（水・金）、
志村孝子（木）、木村高子（随時）
山口滋（ホームページ担当）

Appendix E: The Aphasia ID Card

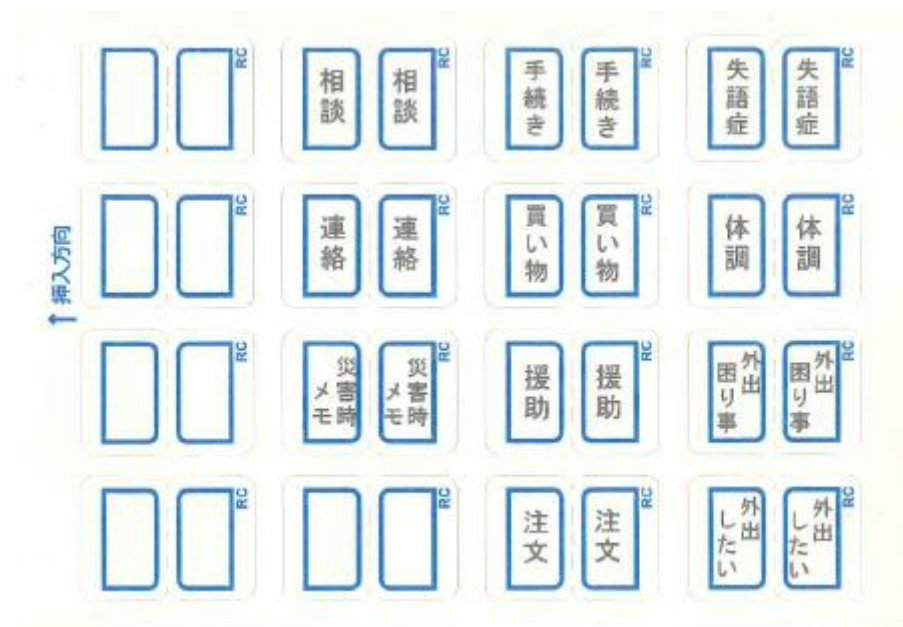
Cover:

緊急連絡先 (1) (関係)	緊急連絡先 (2) (関係)	<p>失語症の SOS カード — 当事者の自尊心を尊重し —</p> <p>伝達方法は下記のようにお願いします</p> <p>① ゆっくり、はっきり、短く話す ② はい・いいえで答えられる質問にする ③ 要点を漢字単語で簡単に書く ④ 絵・地図・実物を示す ⑤ 本人の言葉をゆっくり待つ</p>	<p>SOS</p> <p>今、困っています ご支援お願いします 私は失語症です</p>
<p>(発行) NPO法人日本失語症協議会 〒167-0051 東京都杉並区荻窪 5-14-5-405 TEL: 03-5335-9756 FAX: 03-5335-9757 メール: office@japic.info</p>			

Inside:

<p>フリガナ 氏 名</p> <p>住 所</p> <p>生年月日 大・昭・平 年 月 日</p> <p>電 話</p>	<p>血液型</p> <p>Rh + / -</p>	<p>かかりつけ医療機関</p> <p>病 院 名</p> <p>電 話 番 号</p> <p>診 察 科 名</p> <p>診 察 券 番 号</p> <p>療養中の病名 高血圧・糖尿病・心筋梗塞・喘息・不整脈 その他 ()</p>	<p>常用薬</p> <p>アレルギー 無・有 (のアレルギー)</p> <p>その他 (伝えたいこと)</p>
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Appendix F: The bookmark stickers



Appendix G: The Aphasia Communication Booklet
front page



Appendix H: The Aphasia pins (by the JAPC)



Appendix I: Videos

- 1) Report broadcasted by Tokyo MX News in 2009, self-subtitled



- 2) The *Takibi* performance using bells, personal footage



Both videos can be viewed on the CD that is attached at the end of this document. For any inquiries regarding a digital version of these two videos, please send an email at adonia.dhanjal@hotmail.com.