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Title Page

Movement changes due to hemiplegia in stroke survivors: A hermeneutic phenomenological study

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Keywords

Stroke, Movement, Hemiplegia

Abstract

Purpose: Meanings of movement for stroke survivors could give therapists significant insights, especially during maintenance phase. The purpose of this study was to examine how post-stroke users of a long-term elderly care facility had experienced changes in movement resulting from hemiplegia.

Method: The participants of this study were 18 stroke survivors using a long-term elderly care facility. Based on phenomenology, between two and three interviews were conducted with each participant about their experiences with hemiplegia. Data analysis consisted of the following phases: 'data immersion', 'data transformation', and 'thematic analysis'. The study was approved by the ethics committee of the authors' institution.

Results: Participants experienced seven themes resulting from hemiplegia, perceiving themselves differently from the way they did before the stroke. The themes were as follows: 'inescapable dependence', 'sense of incompetence', 'lack of autonomy', 'symbol of deviation from normal', 'licence for *amae*', 'security of self-worth', and 'proof of effort'.

Conclusions: The first four themes attempt to express participants' pain and difficulty in living with their present body; the last three attempt to express methods for coping with the present body in the company of others. Results will assist therapists to understand the significant needs of their clients in the maintenance phase.

Implication for rehabilitation

- Hemiplegia is paralysis of half of the body; it represents one kind of physical disability caused by stroke.

- Re-interpretation of how patients had experienced the changes of their movements after they had hemiplegia is helpful for the therapists to understand the significant needs for their clients.
- It may be especially relevant for therapists working with stroke survivors in the maintenance phase, whose functional recovery of physical movements is not expected to occur to a greater extent.

Introduction

According to WHO,[1] annually, 15 million people worldwide suffer a stroke. Of these, 5 million die and another 5 million are left permanently disabled. Rehabilitation is arguably one of the most important phases of recovery for many stroke survivors.[2]

In Japan, where the current study was conducted, a long-term elderly care facility is one of the public facilities based on long-term care insurance (LTCI) to support stroke survivors' living after they have finished rehabilitations at hospitals. The Japanese Government initiated mandatory public LTCI in 2000, to help older people to lead lives that are more independent and to relieve the burdens of family carers.[3] LTCI system has made long-term care an explicit and universal entitlement for every Japanese older people based strictly on physical and mental status.[4-6] A long-term care health facility provides day services, which include outpatient day long-term care; outpatient rehabilitation; short-stay or long-stay services, which include long-term care of daily life; and rehabilitation for residents.[7]

Many stroke survivors are left with mental and physical disabilities.[8] One representative of physical disabilities due to a stroke is paralysis of one half of the body, hemiplegia. It is one of the main roles of rehabilitation therapists to approach physical movement functions, for instance, exercises, balance, transfers, and ambulation.[9]

In several studies about experiences of post-stroke people, it is reported that they experienced changes in their psychosocial and spiritual dimensions. For example, post-stroke older people reported a need for psychosocial, social and spiritual as well as physical rehabilitation.[10,11] Simeone et al. [12] reported that patients within three months after leaving a rehabilitation hospital had experienced the following five themes: deeply changed

life, vivid memory of the acute phase of the stroke, slowed lives, relief after recovering from stroke, being a burden for family members. Horne et al. [13] reported about confidences of post-stroke patients that the following six themes had become the significant indicators: loss of identity, fear, social confidence, role confidence, mastering skill, and attitudes and beliefs.

No studies have ever tried to focus on changes of physical movement due to hemiplegia, and to explore them from clients' viewpoints. The phenomenon of movement is often dealt with as a physical phenomenon that focuses on whether a body functions well as an object. On the other hand, this study is an attempt to reconsider movements from a phenomenological viewpoint. Meanings of movement beyond the physical dimension could give therapists important clues when searching how they could contribute to clients, especially those in the maintenance phase such as users of a long-term elderly care facility, because it is hard for clients to anticipate functional recovery of their physical movements. A therapist could conduct a therapy in which the therapist deeply understands the significances of a client's life and existence. Given this, the purpose of this study was to examine how post-stroke users of a long-term elderly care facility had experienced changes in movement resulting from hemiplegia.

Method

This study is an exploratory research to reveal the significances of what participants had experienced; therefore, the data of this study was collected using in-depth interviews. This study is based on phenomenology, the optimal method for determining the meaning of human experience.[14,15] Phenomenology focuses on the meaning of a phenomenon itself and qualitative experience with the goal of elucidating existential human

life. In this study, we used the hermeneutic phenomenological method of Cohen et al. [15]

Hermeneutic phenomenology is a method of researching how people understand the world in which they live and how they determine the significance of their experiences. The method places importance on the researcher's interpretation of the meaning of participants' experiences.

This research was carried out in Japanese, and translated into English for writing this paper.

Participants

Purposive sampling with a two-tier system was used in this study. Participants were included if they met the following criteria: they experienced hemiplegia after suffering a stroke, used the same particular long-term care health facility, were able to communicate verbally and had established a trusting relationship with the interviewer so that they could be expected to answer honestly.

Patients who met these conditions and agreed to participate in this research were approached to be interviewed as the first step of the two-tier system. One patient declined to take part. Participants who could both think introspectively and verbally describe their experience with hemiplegia were interviewed a second time as the second step of the two-tier system. One person did not participate in the second interview because of difficulties with verbal expression.

In this study, the researchers analysed the interview data and provisionally described its construction each time an interview was conducted with a participant. However, as the researchers reached the 10th participant, they concluded the interviews were no longer

generating new information. Nevertheless, the researchers carried on with the interviews until they reached the 18th participant, at which point they decided to conclude the data-collection process. Because of this, a total of 18 participants were interviewed for this study. Characteristics of participants are shown in table 1. Pseudonyms and basic information of each participant are shown in table 2.

Insert table1 and table2 about here

The long-term elderly care facility in which the interviews were conducted is attached to a suburban acute care hospital with an admission capacity of 100 beds and an outpatient capacity of 45 people. A part-time occupational therapist at this institution conducted all the interviews in plain clothes rather than in staff uniform to maintain a casual, friendly atmosphere.

Data collection

Data was collected over a period of eight months, from May to December 2009. Two or three interviews were conducted for each participant about their experiences with hemiplegia. Interviews lasted from 30 min to 2 h. The interviews were carried out in Japanese. Interview locations were selected on the basis of where participants felt most comfortable, ranging from private rooms to the institution lounge or the participant's home. The first author conducted all interviews of 18 participants.

The following questions were prepared for the interview: 'What was it like for you to have half of your body paralysed?' and 'Can you please tell me what has happened to you since half of your body was paralysed?' When participants had difficulty answering, the interviewer prompted them to recall the time when they had the stroke and to talk about the

most impressive incidents that had happened since the stroke. These questions were based on a phenomenological concept which says that the things people notice or discover around them are most important to them and revealing. The interviewer was instructed not to be inflexible regarding the guide questions, but to let the participants decide the course of the interviews as much as possible. Interviews were audio-taped and transcribed verbatim. The interviewer asked participants about their life history in order to know the contexts where they had lived.

The first author performed participant observation during the period of collecting data, and made field-notes; these were used as reference for interpreting the interview data.

Data analysis

Data analysis consisted of three phases, as defined by hermeneutic phenomenological research.[15] The first phase was ‘immersion in the data’. In this phase, the researchers simply read through the data several times.

In the second phase, ‘data transformation’, the researchers reorganised the data to group together material on the same topic. Movement was the main focus of the analysis.

The third phase was ‘thematic analysis’. In this phase, at first, the meanings of changing movements for each participant were analysed. The researchers provisionally interpreted meanings of participants’ experiences at the first interview, and then, the interviewer told the provisional interpretations to the participant at the second and/or third interviews; he/she added some explanations about those interpretations. The researchers compared parts of narratives from participants, and collected the episodes whose meanings looked similar to each other. These episodes were thoroughly analysed. The researchers

attempted to identify common themes between participants' narratives' parts and they discussed their interpretations. When they did not reach an agreement, those groups of episodes were undone; the researchers then resumed their comparisons of participants' narratives. These procedures were undertaken until common understanding and agreement was reached between the researchers.

The researchers recorded the provisional interpretations discerned at all phases, and whenever those interpretations were updated, the new interpretations were repeatedly described.

Ensuring trustworthiness

In this study, several measures were taken to ensure the trustworthiness of the researchers.[16,17] 'Critical reflections' and bracketing were performed. Phenomenological literature defines bracketing as the identification of preconceptions, assumptions and prejudices. Prior to data analysis, the researchers wrote down and discussed their ideas about hemiplegia. This work made them more sensitive to their own prejudices and assumptions. Writing descriptions in field notebooks allowed another kind of critical reflection.

'Opening their interpretations to inquiry also ensured researcher trustworthiness'. In this study, participants checked whether researchers' initial interpretations were accurate at the second and later interviews. In addition, two co-workers who were familiar with qualitative study methods examined the data. One final measure was to ask the opinion of each participant's occupational therapist regarding the findings, after consent had been obtained to share the original interview record with the occupational therapist.

For instance, Osamu told that he became able to get up and stand up from the

bedridden status, and that he felt strong emotion when he became able to move using a wheelchair by himself. The interviewer asked him the following interpretation at the second interview: 'Was it a feeling as if, in a restricted situation, things you can freely do were increasing?' He said, 'actually, I didn't become free.' He began to tell his feeling about his freedom, and the researchers understood that he was, after all, feeling he was becoming increasingly restricted. These narratives of him led to the extraction of the themes of 'sense of incompetence' and 'lack of autonomy'.

Ethical considerations

Objectives, methodology, risks and benefits of this research were explained to all participants. Verbal and written consent was obtained from all participants.

The study was approved by the ethics committee of the Faculty of Health Sciences, Hokkaido University (approved number 09-02-2).

Results

Participants experienced changes resulting from hemiplegia, perceiving themselves differently from the way they did before the stroke. Living in a body impaired by hemiplegia was different from living in an able body before the stroke, so that, participants experienced 'inescapable dependence', a 'sense of incompetence' and 'lack of autonomy'. Changes in their appearance of movements had become a 'symbol of deviation from normal'; 'normal' describes the situation to which they had belonged, and their status before the stroke.

On the other hand, some participants accepted the deviation and used it as 'licence

for amae', which is psychological reliance, a tendency to count on other people's kindness. For participants, physical movements became a new indicator to compare themselves with others, and they enhanced 'security of self-worth' through those comparisons. In addition, exercising with a changed motor function became a means to indicate 'proof of effort'. Each theme is explained in detail below.

Inescapable dependence

Participants always felt haunted by their dependence on others due to hemiplegia. Before the stroke, interdependence among participants and their families and other people around them was approved by all. However, after the stroke, this balance was disturbed, and occasions of dependence of the participants on other people increased. Most participants talked frequently about their experiences of dependence. They related their experiences of dependence in various situations, such as in hospitals, institutions and their homes.

When it was necessary for a participant to be assisted with his/her activities of daily living (ADL) and/or instrumental activities of daily living (IADL), the participant would have to depend on someone, and could not avoid doing so. If a participant had been a housewife and had taken on the responsibility of most of the housework before the stroke, it was a serious problem if she was no longer able to do the housework now. Mayu, who was a housewife, became dependent on her husband for changing clothes, using the toilet, and doing housework. She said, 'my husband takes on all housework he had never done before, including cooking. Though he hadn't done housework at all, he has to do it because I had a stroke, so, he has to do it.' She was seriously feeling that she had lost her role and place at home after she became unable to do the housework. She was feeling increasingly sorry for

him and embarrassed at herself.

On the other hand, if a participant with hemiplegia led his/her life in society, it required him/her to have a different inescapable dependence from someone of daily life. It was difficult for Sumire to go to the bank since she used a wheelchair. Therefore, she would leave her money with the office of the facility, which she regularly went to as an outpatient. When she deposited and withdrew the money from that office, she had to sign her name on the document. However, writing was a very difficult problem for her paralysed dominant hand. She said, 'I practised writing my address and name. But, my writing didn't look like characters.' Every economic activity of hers at the facility was interfered by the following unconcerned question: 'what will you buy?' asked by her family and the staff. The dependence in the transiting and writing caused her to inevitably depend on and to be interfered, and consequently, it led her life to become limited in a community where adults are financially independent.

In the case of Kenji, he talked about the dependence of minor things in his daily life. Because they were trifles, that type of dependence occurred frequently, and he felt pain. He said, 'whenever I do something, for instance, when I'd like to pick up something, I can't do that, so, I have to ask someone. Why do I ask it every time? I thought that it would be better that I died if I must live such a life.' He started having to concern about every activity that had been previously easy, which he had never been aware of before his stroke. When he realised he was not able to do something because of his motor function, he had no choice except for asking someone. Because a trifle became a difficult problem whose accomplishment by his own efforts was impossible, he felt he became an incompetent individual, and he faced heartbreak. Because the difficult problems which he could not solve without depending on the others filled up his every day, he became impoverished, and this

situation prevented him from thinking about any desire or hope he may have had.

Since the participants had their physical abilities decreased by the hemiplegia, they could not help depending on others to do the following activities: the activities which secured their roles and places in their home; the activities required in order to live in society as an adult; and the activities, no matter how trivial, which needed to be repeatedly performed in daily life. The everyday filled up with inescapable dependences made it difficult for participants to be willing to do something and it caused them to perceive themselves as incompetent, and a burden for their families and society.

Sense of incompetence

Though all participants had their physical abilities decreased by the hemiplegia, they still had many things they were able to do by themselves. Nevertheless, most of them often used this phrase, 'I became unable to do anything', and they talked as if they were not able to do anything. The focus of this theme was the following: to have lost the part of the physical function made the participants fall in the sense that they seemed to lose everything about their life. Objective incompetence was unimportant when the participants expressed a sense of incompetence.

Tami took pride in leading others, working by using others, and taking care about other people deemed inferior. Therefore, the current life was so painful for her because she could not but receive care from others. She said, 'the world has been overturned for me...It is the same even if I'm living or dead because I can't do anything.' The present life in which she was not helpful for any others meant the same for her, in the sense that she was not able to do anything. Through consuming time without being able to find the significance to live for, and

spending days to receive the care from others, she lost her identity and the will to live; as a result of that, she experienced the feeling as if she was incompetent.

In the case of Ryosuke, he had the sense of incompetence since he lost life's meaningful activities after having hemiplegia. Because he needed severe assistance in many scenes of his daily life, he spent time in a bed almost all day. Nevertheless, he did not talk about the dependence of his ADL, and it was his greatest concern that he became unable to go angling after having hemiplegia. He repeatedly talked about angling as the following: 'I can't do anything. And, I don't have the pleasure. I can't go to the sea. I can't do fishing...definitely, fishing is most important.' Fishing was the only pleasure to colour his life after retirement, and what had made his life worth living. A life without this significant activity because of hemiplegia was a wretched life without his individuality, and it caused his sense of incompetence.

As with Kenji's account, described above, when a participant noticed that he/she became unable to perform trivial activities which he/she had performed as usual, the participant had the sense of incompetence. Tadashi expressed this feeling as the following: 'After all, the most pitiful thing is, it's miserable that I have been able to do nothing. I can't drive a nail now, such a simple thing. So, I'm shameful, indeed. How can I say? Should I say that I am angry at myself?' He had been a craftsman to set the teeth of a saw, and also a carpenter before the stroke. To drive a nail was the symbol of the trifling which he had been extremely easily able to do. He was ashamed, embarrassed, and irritated with himself for not being able to do such a simple thing; so, he too developed a sense of incompetence.

It was tragic that the participants lost their significant activity, and became unable to do a simple thing due to hemiplegia; they lost the need for being there, and the significance of living. As a result, it caused the feeling that they seemed to lose all of their life, and it

made them experience the sense of incompetence.

Lack of autonomy

Loss of motor skills due to hemiplegia resulted in experiences in which participants were forced to give up their freedom and change various aspects of daily life to suit their caregivers' needs and schedules. This theme was deeply connected with the experience of 'inescapable dependence'; however, the focuses of each theme were different. The participants experienced the lack of their autonomies when they needed the help to do it, and in addition, when they could not perform the choice and action in line with their norms in spite of having the clear wills that they wanted to do something their way.

Natsu, who needed assistances to do her bed and transfer activities and her locomotion, was forced to wear a diaper in accordance with the hospital's policy. To obey the instructions of the nurse, she would defecate in her sickroom where other patients and she had been waiting for the supper. Furthermore, she complained that she was kept waiting for the exchange of her diaper for 30 minutes after that. She said, 'I'm vexed, and vexed. And, I'm pitiful, too. I can't do anything'. She had to use a diaper, she had to evacuate just before the supper, she had to evacuate in the room with the other patients, and she had to wait for the staff for the exchange of her diaper. The staff were out of keeping with her intention and norm. It was downgrading that she was forced to do the actions that were unsuitable for her norm; as a result, she was deprived of her sense of autonomy; she felt a serious pain and anger against that experience of 'lack of autonomy'.

Because Kenji was not able to ambulate, it was a really unpleasant experience for him that he was left unattended in the corridors by the staff. He explained, 'To be left alone

was most dreadful though I can't move by myself.' Even though the staff thought it had been a few minutes, because he could not manoeuvre his wheelchair without help, the perceived time when he was waiting for the staff was substantially long for him. In the deserted corner of the corridor, he solely wished the staff would come back. In addition, he was able to start communication only when others talked to him, or when they moved close enough to him so that he could initiate conversation. He was afraid that he might be a forgotten existence by the staff, and he suffered through the realisation that he was not able to defeat that fear. Because the staff did not notice or consider his will that he did not want them to leave him alone, he felt he had lost his autonomy.

Tami intended to attend the wedding ceremony of her disciple with pleasure. Actually, only her family took part in the ceremony, and she was forced to enter the facility for a short term. Her family thought it was too troublesome to travel a long distance with her, who used a wheelchair. When the interview of the present study was carried out, she was staying at the facility. She repeatedly grieved over her situation as the following: 'I can't use my arm and leg at all, so, I can't control things the way I'd like to do them', and 'everything does not accord with my mind. This makes me sad, indeed.' There were many opportunities to experience this theme as a participant with clear will. She thought that it was natural to participate in the wedding ceremony, however, it would have been necessary to depend on other if she had attended it. Because she could not gain the assistance of her family, her hope did not come true, and she felt the loss of her autonomy. She grieved over it, and she was overwhelmed by the feeling of incompetence.

The common feature of the participants who experienced this theme, 'lack of autonomy', is that all participants had clear wills and norms. Therefore, it was easy to produce the experience of this theme just in the scenes where the participants engaged in their

meaningful activities. Even if the participants displayed their wills or norms, they often could not avoid depending on people in order to accomplish the activities with their hemiplegia.

The participants felt easily that their autonomies were ignored depending on the relationship between them and the caregiver, and the caregiver's attitude. The experience of this theme made the participants feel strong pain, sorrow, fear, vexation, and shamefulness.

Symbol of deviation from normal

Changes in appearance and movements were easily observable for the participants and the people around them. These changes were not a mere difference; they symbolised deviation for participants. Those who used the day-care service often mentioned this experience because they frequently came into contact with non-disabled people. 'Normal' for these participants meant not only people who did not have disabilities but also their pre-stroke selves. It had a big influence on the social life, for instance, going out and mingling with others, if the participants had a sense of deviation from the normal about themselves with disabilities.

The difference in the outward aspect of their manner of walking made the participants feel deviation, most easily and frequently. Osamu really disliked the outward aspect of his manner of walking with an orthosis and a cane. He said, 'I want to become able to walk ordinarily. I don't want a cane. I don't want an orthosis. I just hope that I want to become able to walk like a usual person. I just hope so.' In addition, he recognised, '(his neighbouring people) watch me as if I were an animal at the zoo'. He thought that he was watched and observed by his neighbourhood because the outward aspect of his manner of walking deviated from others. Wherever he went to his town, he felt that he was meddled in

everything by the surrounding people, and he felt confined. Because of his deviated figure, he thought he might have become an alien entity in his society. He was often made irritated by the feeling of impatience and fear that he might have been removed by the society.

Yuki talked about the deviation from the culture in which she lived. Because her paralysed left hand was not able to grip tableware at meals, when the amount of food in a plate became small, she had to bring her face close to the plate on the table, and gulp it down. This behaviour is called 'eating like a dog', and it is a bad table manner in Japan. She said, 'now it's me the one who eats like a dog. Though I don't want to do so, I do so. I feel other people watch me, so, after all, I can't go for eating out. When young grandchildren come to my home, though, I say, "you must not eat like a dog", I think that if I do it by myself I am troubled.' She had a sense of shame at others seeing her deviated eating activity, therefore, she hesitated about eating out and eating with her grandchildren. The deviation from her custom made her social life limited. It was an act of humiliation to her the fact that she was able to perform the activity only with the deviated form due to hemiplegia compared with others who behaved in conformity to their custom. The imminent behaviour of others greatly influenced a sense of the deviation of the participants.

The episodes of Mayu and Yayoi were contrastive. At first, in Mayu's case, she suffered from a stroke, and her husband sold their single house immediately and bought a flat. Because he felt pity for her to be seen by neighbouring people after she had hemiplegia, he opted for the move. She said, 'my husband is sweet', and she was thankful to her husband. Nevertheless, through her husband's act, she came to more strongly recognise that her body was a symbol of deviation. Yayoi had the feeling of strong deviation like Mayu at the beginning after she suffered a stroke. However, when the staff of the hospital where she had stayed told her 'Yayoi, you may think you're strange, but you aren't. You're a normal human

being', she was greatly surprised at the words, and she was moved deeply. She said 'the member of staff treated me kindly, no, he treated me normally rather than kindly.' The fact that the others who were close to her treated her 'ordinarily' kept her feeling of deviation away.

The neighbouring reactions after a participant had hemiplegia greatly controlled whether the participant experienced this theme. In addition, the participants acquired hemiplegia, and they are 'the former able-bodied'. That is why, they strongly had the image of their 'normal' self, and they easily compared those figures and their present selves and they perceived the difference between them. The experience of this theme, 'symbol of deviation from normal', made a participant produce the discriminatory feeling for his/her figure, and they were abashed because of it.

Licence for *amae*

Matsudaira et al. described '*amae*' as indulgent dependence on others [18]. Doi explained that '*amae*' is the noun form of the verb '*amaeru*', which means to depend upon and presume another's benevolence [19]. This theme was deeply related to the theme of 'Inescapable dependence' and the theme of 'Symbol of deviation from normal'. Dependence and deviation did not necessarily have negative meanings for participants. Some participants recognised their own deviation and used it positively, accepting dependence and adopting an attitude of *amae*. They expected and received help, especially from family members. Moreover, some participants did not depend on, but instead they expected the kindness of others, and wanted the others to consider them because they are 'the disabled'. It was one case of *amae*. In other words, deviation from normal gave them a licence to depend on others.

Yuki managed toilet-and-dressing-related activities by herself at the facility. However, she often depended on her husband at home since she required efforts for performing them by herself, which made her tired. She said, 'I think that I have to do these tasks by myself if possible, and I'm trying to go to the toilet by myself. But I think I can do it if I try, you know, everyone sometimes wants to behave like a baby, don't they?' Since before her disease, Yuki and her husband had had the relation by which 'amae', i.e. indulgent dependence [18], is permitted mutually, and this relationship was continued after her disease. It was natural for her to sometimes depend on her husband, and he also permitted that behaviour of her.

Though Kyoko had a slight right hemiparesis, she took most of the housework upon herself. Preparations of the meal were also her role. It was a tough task to cook meat with her paralysed hand though it was possible. However, she pretended that she was not able to do it, and she asked her son to cook meat. She said, 'I entrust all the cooking of meat to my son. I pretend that I can't cut and mix meat though I can do it if I try.' She said about herself, 'I sometimes cheat', and she laughed.

However, because her hemiplegia was mild, people occasionally did not notice that she had a disability. For instance, a visitor would sometimes leave before Kyoko arrived at the entrance hall because the speed of her walking became slow. Even some friends did not notice or understand her disability. She felt it irritating the fact that she was occasionally not able to receive considerations from others since her impairment was mild, as was her physical deviation.

Yayoi also talked about her impatience about not fully receiving the consideration from the others because her paralysis was relatively mild. She said, 'I was neither one thing nor the other. I want to have a stronger body if I can walk, and I think even if it became more

difficult for me to walk, it would still be better than now.’ She expressed slight irritation and dissatisfaction, and she added ‘I’d like to say even “I am sick” for the time being’.

In this theme, the participants talked about the strategy of how they affirmatively used their hemiplegia and the changes of their movements due to their hemiplegia. The participants who talked about the experiences of this theme thought that they wanted to do what they were able to do by themselves, and at the same time, they thought it would be permitted that they sometimes took advantage of the others’ kindness and depended on them. After the participants took pride in their efforts, they sometimes relied on the others who would tolerate the participants’ reliance on them, for instance, their family, when they did what they were actually able to do by themselves. In addition, it was also an ‘amae’ that a participant expected another person’s kindness by turning around the deviation of his/her appearance, and affirmatively using it. If the deviation of a participant was clear, he/she was easily able to gain the ‘licence for amae’. Conversely, if a participant had a slight paralysis, and it was not easily noticed, he/she talked about the impatience resulting from the fact that he/she could not take advantage of the ‘licence for amae’ well.

Security of self-worth

When participants were in the environments of hospitals and facilities, there were a great many people with similar diseases and/or disabilities being provided care in those institutions. These patients were comrades and rivals for the participants in undergoing their rehabilitations. Participants compared themselves to people with similar physical functions. When comparing, they often overlooked the damaged part of the brain and the difference of the damage degree.

When a patient displayed a higher motor function, he/she was considered a person who had tried rehabilitation hard. On the contrary, a patient with a lower motor function was often considered as a dull person. Participants viewed their own conditions more positively when they could see their advantages over people with more serious disabilities. Moreover, when participants observed people with slightly better motor skills, they felt that they too could improve. Through these comparisons, the participants were trying to secure their own value of their current selves with hemiplegia.

Aoi told the following about the comparison her with others in the environment of an institution: 'Here, I can compare myself with everybody and everybody with everybody. If there are 100 people, I can compare the 100 people... If I do rehabilitation just with my therapist, I wouldn't see such people who have severe disabilities, and I might lose my motivation to do my best.' Users do rehabilitation and/or live in a long-term facility, and they can see a great many other users with disabilities. It meant that there were many and various targets for comparison. When Aoi saw the other patient with a lower motor function than her, she thought she should be better than this person, and she let herself be encouraged. Because the indicator of the recovery for Aoi was walking ability, this was the main indicator for her to compare herself with other patients. She had the experience that she worked at hospitals as a helper, and she had considered a patient who used a wheelchair lacked the motivation to do rehabilitation. When she saw another patient who was able to walk, she felt regretful that she was presently using a wheelchair, and at the same time, she repeatedly worked hard to exercise working because she expected that she should be able to walk. She said, 'I have guts', and she encouraged herself.

Another example was Tomoka's episode. She recognised the improvement of her motor function ability as the result of her effort. She had strongly believed her doctor's

advice that if she worked hard at rehabilitation, her hand might come to move a little. She strove to move and use her paralysed left hand as much as possible, and finally, she became able to grasp a weekly magazine with her left hand. She told the following: 'I got to be able to grasp a weekly magazine though Yuki couldn't hold it in her hand. I grasped it, and I went to show it to my doctor. He said "What a surprise. You became able to do such thing, didn't you?" At that time, I thought I had done my best.' Tomoka and Yuki were always together from acute setting to the present facility. Both of them were women with left hemiplegia; they became personal and close friends, and also, they became rivals in their rehabilitation. It was more important for Tomoka that she became able to do what Yuki could not do than that she became able to grasp a weekly magazine. She encouraged herself by having a sense of superiority toward Yuki. It was a rare and valuable opportunity when she positively recognised, after having hemiplegia, that she had worked hard at physical training, and she got the results that were better than her rivals'.

The participants had a sense of superiority over persons who had lower motor function, and they let themselves feel relieved that they were all right by trying to think that they were different from those other patients who had lower motor function. They thought that they did not want to be those patients, and this recognition led to the motivation to work hard at physical training. On the other hand, when they saw other patients who had little higher motor functions, they had hope that they should be able to make it happen if they did their best. To sum up, for the patients who expressed the theme of 'security of self-worth', the comparison with other patients was the act to encourage themselves regardless of the others' conditions, and it produced few valuable opportunities when they positively recognised themselves with hemiplegia.

Proof of effort

After having hemiplegia, motor function was a special indicator for participants at comparing themselves with others; moreover, a motor function's condition was sometimes connected with his/her personality. This theme expressed that participants proved their effort for others and themselves by exercising in order to keep or improve their motor functions. Exercising in this theme meant rehabilitation for the participants. The people whom participants wanted to prove his/her effort to through exercising were their families, therapists, and themselves.

Osamu was in his early 60s, and the youngest participant. He lost his job due to stroke. He had become independent about his ADL and IADL, and he began a part-time work three times a week. However, he still had to financially depend on his family to pay the fee for using the facility, and most of his cost of living. He said the following: 'I have to achieve results if I use day-care of the facility, like, for instance, being told, "you became able to walk with a stick". If I can't get a result, I would be sorry for my family. Though I have my family working for their money, I think there is no value in this (if I can't get a result). I do not want to betray my family, that's why, I was thinking about what I was able to do by myself, and thought that only what I could do was practising to walk'. Osamu became very apologetic to his family and shamefulness to himself. He lost his role of the financial and mental pillar among his family after having hemiplegia. However, he found his current role in showing the proof of effort to his family through working hard at rehabilitation and improving his function to walk.

A participant recognised exercising as a ground to let him/her believe recovery and maintenance of him/her motor function firmly. Naoki thought exercising was a ground to

believe in the improvement of his paralysis. He had kept a diary to undergo language rehabilitation, and to practise handwriting using his paralysed right hand. There were some pages written about motor function training in the diary. In the page titled 'the method of walking training', it was written the following: 'although the speed of my walking isn't increasing now, after I walk carefully for one month, I should obtain a result by all means.' His everyday was filled with a great deal of exercising, and he said, 'I'm busy'. Through filling his every day with plenty of exercising, and repeating his effort, he let himself believe that his motor function must be restored.

Kyoko and Tami were undergoing exercising, as recognising it was a ground to believe in the maintenance of their motor functions. The contents and quantity of exercising for a day were fixed, and when they finished it, they felt their actual effort, and they believed in improving or keeping their motor functions.

When participants considered that their families and/or therapists expected them to improve their motor functions, the participants underwent exercising as a proof of their effort. In addition, when participants felt sorry for his family, they considered exercising as their new duty; they showed the proof of their effort to their family through exercising like practising to walk. Participants' roles among their families were often changed due to hemiplegia. As it was stated in the theme of 'Inescapable dependence', the participants often came to have to economically and/or physically depend on their families. The participants often believed what they currently should do was to exercise for rehabilitation. They also sometimes underwent exercising to show themselves the proof of their effort in order to believe in recovering and keeping their motor functions.

Discussion

The purpose of this study was to investigate, from the viewpoint of patients, 'how they experience changes in movement resulting from hemiplegia, in the maintenance phase after a stroke. The significance of the experience of stroke survivors has been studied previously.[20-26]. However, the unique point of this study is its focus on significant experiences related to changes in movement caused by hemiplegia. These changes are important to therapists who perform rehabilitation for patients after a stroke. Participants described their experiences in terms of their lives before and after the stroke. As detailed in the data transformation phase of our analysis, these differences were divided into seven themes.

Comparing participants with their pre-stroke selves and/or others

Wyller et al. [20] interviewed six elderly people three years after they had experienced stroke to investigate how it had influenced their quality of life (QOL). They found that decrease in QOL due to physical change varied from one individual to another. When patients compared their lives before the stroke with their current situations, they reported that their QOL had decreased. On the other hand, when they compared themselves with their condition just after the stroke, with what might happen if they suffered a more serious stroke or with patients who had had more serious strokes, they reported that their QOL had been maintained. For these patients, QOL did not decrease despite their physical disabilities. Participants in this study chose their bodies and/or lives before the stroke as the point of comparison. They described seven differences between their present and pre-stroke selves.

When participants compared their present themselves with themselves before the stroke and/or others without a disability, the participants experienced 'symbol of deviation from normal'. On the other hand, when participants compared themselves with people who also have disabilities, the participants experienced 'security of self-worth'. When participants observed other patients with a little lower physical function than theirs, they had a sense of superiority. When they observed other patients with a little higher physical function than theirs, they expected they may become like those patients. In short, through comparing themselves with other patients, the participants tried to secure the worth of their present selves with hemiplegia. In the world of the participants, a physical function turned into an important indicator to evaluate a person. To compare physical functions may lead participants to emphasise 'symbol of deviation from normal'; on the other hand, it may become a strategy to secure the participants' self-worth.

However, the participant might easily lose their self-worth because of their hemiplegia. In addition, because they have only few ways to cope with situation described above, they might have to find their self-worth by comparing their motor functions with other patients'. At least one year or more had passed after the participants suffered from their stroke; therefore, it was hard to anticipate the substantial recovery of their physical functions in the future. In the short term, the strategy of securing the self-worth according to a status of motor function, could give a motivation for rehabilitation to a survivor, and the satisfaction of the survivor could also become higher. On the other hand, in the long term, this strategy might promote the idea that a survivor would persist in training of his/her motor function. It would become hard for the survivor to pay attention to his/her daily life; the survivor might easily lose the aim to undergo rehabilitation.

Changes in movement and new self-worth

New indicator of comparing self-worth: motor functions

McKevitt et al. [27] explains in the review article that effects on stroke survivors are described as 'losses' in previous qualitative studies, as in loss of activity, abilities, personal character, self, and independence;[21-23,28] emotional and social loss;[29,30] loss or change of identity.[31-33].

This study focused on changes in movement. Loss or restriction of motor functions caused participants to experience 'inescapable dependence', 'sense of incompetence', 'lack of autonomy', and 'symbol of deviation from normal'. However, participants also talked about a new indicator of a self-worth created by changes of their movements in the following themes: 'licence for *amae*', 'security of self-worth', and 'proof of effort'.

Kvigne et al. [34] interviewed 25 females stroke survivors about their bodies after their stroke, and the following three themes were reported: The Unpredictable Body, The Demanding Body, and The Extended Body. Because a body with hemiplegia is demanding for a survivor, the changes of the body may be easily observed and noticed. Therefore, the status of the participants' physical movements might have become a new indicator to measure mutations of themselves, and differences from others. According to the authors, the statuses of the participants' movements, in some cases, were used as an indicator to measure worth of themselves and/or other people as a human being.

The new indicator leads to 'proof of effort'

Because motor function became their new indicator for evaluating other people, participants felt the need of showing ‘proof of effort’, i.e. exercising and training, for three main reasons: to recover or maintain physical function, to fulfil new roles, and to meet the expectations of those around them.

As for the first reason, Maclean et al. [35] interviewed 22 stroke patients. All participants thought that rehabilitation was important for their recovery. According to the research of Pound et al. [36], stroke survivors thought that exercising was one strategy in the struggle against physical disability. Participants in this study also reported using exercise and training to prove not only to themselves, but also to the people around them that they are indeed striving to recover and/or maintain physical function. However, because 1–11 years had passed since their strokes (table 1 and 2), most participants had difficulty in improving their physical function. Therefore, many focussed on maintaining their condition rather than recovery.

As for the second reason, the stroke survivors interviewed for this study felt that they had new roles to play in life. The Japanese LTCI act declares that people who need care are obligated to try to improve and maintain their abilities.[7] However, most patients exercise and train for recovery voluntarily in order to minimize the negative effects of stroke. The participants might exercise and train in order to eliminate ‘inescapable dependence’, ‘sense of incompetence’, ‘lack of autonomy’, and ‘symbol of deviation from normal’. Stroke survivors might think that their roles are to exercise and train, which are the strictest meaning of rehabilitation.

As for the third reason, participants in this study wanted to meet the expectations of the people around them. Japan has a strong culture of collectivism, and most people try to be considerate of their actions for the sake of the people who are important to them.[37] Actions

praised and admired by their families and caregivers are more likely to be recognized as part of their new role.

The new indicator leads to ‘licence for *amae*’

The status of a motor function became the new indicator to evaluate a human being, which led to the theme of ‘licence for *amae*’. Participants realised that their motor function was impaired, and they recognised they were inferior people; at that time, they expected kindness from their families and others. It might be said that they took advantage of their restricted motor functions. This behaviour is called *amae* in Japanese, and is an intrinsic feature of Japanese culture.[38]. People who use *amae* to obtain a favour realise that others will be accepting of their behaviour; by doing so, they are displaying what can be described as an egoistic way of behaving.[39].

Although participants continued to strive for improvement, they might have expected sympathy from close people, such as family members, by demonstrating *amae* through their restricted motor functions as a licence. The theme of ‘licence for *amae*’ is a strategy, by utilizing their paralysed bodies, to wipe out painful experiences such as ‘inescapable dependence’, ‘sense of incompetence’, and ‘lack of autonomy’; it shows their strong-mindedness.

Doi said, ‘there is no single word in English equivalent to *amaeru*, though this does not mean that the psychology of *amae* is totally alien to the people of English-speaking countries’.[40]

Although *amae* may be interpreted as a psychological dependence on others, the experience of ‘licence for *amae*’ was a different theme from ‘inescapable dependence’.

Experiences of ‘inescapable dependence’ made participants feel indebted to, and very sorry for those close to them, and wonder how they could repay the favour. Not only the person who is depended on, but also the person who depends on them could have an unendurable burden. On the other hand, *amae* is a behaviour that is permitted by both who primarily benefits from *amae*, and the other or others who is/are involved in this behaviour. Participants might have felt that their present selves with hemiplegia had been approved, and felt relieved through having their *amae* permitted.

However, the partners upon whom the participants were able to use their ‘licences for *amae*’ were limited; in most case, those were only family members having a good relationship with the participants. In a facility, patients are usually requested to do by themselves what they can do by themselves; therefore, *amae* is hard to be permitted.

Implications

According to the seven themes in this study, as therapists generally have attached importance to the concept of independence, it could be an important indicator also for clients. When clients suffer from the feelings such as losing their autonomy and/or their competences, it is remarkably important for them to behave based on their norms, and to have an opportunity to gain the feeling that they are competent. When clients suffer from their deviation from normal, how they deal with their feeling of deviation about their appearances while moving becomes an important matter.

The following four themes are painful for a client: ‘inescapable dependence’, ‘sense of incompetence’, ‘lack of autonomy’, and ‘symbol of deviation from normal’. Therapists who do a therapy to support a client can use the following strategies to deal with

those suffering: 'security of self-worth', 'proof of effort' which strengthens 'security of self-worth', and 'licence for *amae*' which shows the client's mental strength.

If clients and their therapists aim to maintain or improve their motor functions in order to promote 'security of self-worth' and/or 'proof of effort', it may give the clients the motivations for the rehabilitations in the short term; however, in the long term, it might also encourage them to focus solely on their physical functional trainings because it is hard to anticipate the recovery of the physical functions for the clients in their maintenance periods. In addition, it might cause the clients to experience difficulties in paying attention to their daily life, and lose sight of the goal of their rehabilitations. It should not be denied at all the fact that the participants experienced 'security of self-worth' and 'proof of effort'. However, it is important that therapists support the processes where their clients find things to do regardless of the status of their motor functions; through exploring those things, they can reconfirm and show their self-worth to others.

As for 'licence for *amae*', if clients have important people who permit the clients' *amae*, it will become a strengthening factor to make the clients view their present lives and selves in a positive light. However, if the clients attempt to rely on their therapist and/or the other staff of their facility, it might spoil not only the clients' independences, but also their autonomies, and make them feel as if they are incompetent. If clients are suffering from 'inescapable dependence' and/or 'sense of incompetence' and/or 'lack of autonomy', and they do not have a close person who permits their *amae* (such as family members), it could be a beneficial strategy that therapists permit their clients' *amae* in the short term. In that case, the therapists should sufficiently pay attention not to make their clients feel as if they were incompetent. Because therapists are concerned with their clients in the limitative period, therapists should consider shifting the role permitting the clients' *amae* to others who are

suitable to the clients' use of 'licence for *amae*' such as their families; therapists should consider shifting the strategy dealing with the clients' painful experiences to the other sustainable ones.

The findings of this study could help therapists to understand the significant needs of their clients in their maintenance periods, and to explore the strategies to respond to those needs.

Significance and limitations

One to eleven years had passed since the participants in this study had experienced stroke; thus, they were all in the maintenance phase after stroke. Because they all used the long-term elderly care facility, the findings in this study reflect only the experiences of people who have access to rehabilitation and long-term care. Two of the 18 participants were in their early 60s, whereas the others were older than 65. Therefore, these findings need to be understood as the experiences of elderly people.

The interviewer was a staff member at the long-term elderly care facility used by the participants. Thus, the interviewer had an advantage in the process of building a trusting relationship. On the other hand, participants might have considered how their future relationship with the interviewer might be affected when answering the study questions. This point is a limitation of this study.

This study revealed the existential significance of changes in movement after a stroke from the viewpoint of the participants. This has seldom been the focus of previous research. Changes in movement caused by hemiplegia are important to the work of occupational therapists and physiotherapists. Therefore, these findings should be of help for

therapists who would like to understand the experiences of their hemiplegic patients. This understanding may facilitate the building of a trusting relationship between therapists and their patients and encourage therapists to consider the non-physical needs of their patients in their rehabilitation programs.

Conclusion

The purpose of this paper is to examine how maintenance phase stroke patients experience changes in movement resulting from hemiplegia. This research is based on a hermeneutic phenomenological method. Participants noted the following seven differences from their pre-stroke selves: 'inescapable dependence', 'sense of incompetence', 'lack of autonomy', 'symbol of deviation from normal', 'licence for *amae*', 'security of self-worth', and 'proof of effort'. The first four themes attempt to express participants' pain and difficulty in living with their present body, and the last three attempt to express methods for coping with the present body in the company of others.

When therapists explore how they could contribute to clients in the maintenance phase, these findings may prove very helpful for the therapists to understand the significant needs for their clients, whose functional recovery of physical movements is not expected to a greater extent. As a result, it will promote therapists to design a more meaningful therapy considering the world where their clients are living.

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Declaration of Interest statement

The authors report no declarations of interest.

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Annex

Table1. Characteristics of participants (n=18)

Sex	
Male	8
Female	10
Hemiplegia	
Right	7
Left	11
Range of age	61-88
Length from stroke to the first interview	1 year 2 months - 11 years 8 months
Using service of the facility	
* Long-term care	4
**Daycare	12
Daycare and ***Short-term care	2
Walking assistive device	
Cane (any type)	5
Walker	1
Wheelchair	12

* Long-term inpatients undergo care and rehabilitation at the facility.

** Commuters can receive care and rehabilitation at daycare.

*** Short-term inpatients undergo care and rehabilitation while staying at the facility.

Table2. Basic information of each participant

Pseudonym	Sex	Years	Hemiplegia	Length from stroke to the first interview	Walking assistive device	Using service of the facility	Complications/previous diseases
Aoi	F	74	left	2 year 10 months	Wheelchair	Long stay	Coronary heart disease, High blood pressure
Osamu	M	61	left	3 years 6 months	Cane (any type)	Day Care (3 times a week)	Diabetes
Yuki	F	67	left	3 years 6 months	Cane (any type)	Day Care (3 times a week)	Diabetes, Aortic valve replacement
Tami	F	88	right	1 year 2 months	Wheelchair	Day Care (twice a week), Regular short stay	High blood pressure, Right side of the femoral neck fracture
Natsu	F	85	left	2 years 3 months	Wheelchair	Long stay	Chronic thyroiditis, High blood pressure
Kyoko	F	85	right	10 years	Walker	Day Care (twice a week)	High blood pressure
Kozue	F	76	left	11 years 8 months	Wheelchair	Long stay	High blood pressure, Thoracic compression fracture
Kota	M	74	right	1 year 3 months	Wheelchair	Day Care (3 times a week)	Nothing in particular
Tsutomu	M	69	left	2 years 11 months	Cane (any type)	Day Care (twice a week)	Diabetes
Tadashi	M	77	right	8 years 6 months	Cane (any type)	Day Care (twice a week)	Diabetes
Naoki	M	71	right	3 years	Cane (any type)	Day Care (twice a week), Regular short stay	High blood pressure
Kenji	M	62	left	1 year 10 months	Wheelchair	Day Care (3 times a week)	High blood pressure
Ryosuke	M	65	left	12 years	Wheelchair	Day Care (twice a week)	Nephrosis, Gastric cancer
Daiki	M	78	left	2 years 8 months	Wheelchair	Day Care (twice a week)	Atrial fibrillation, High blood pressure
Sumire	F	63	right	9 years 8 months	Wheelchair	Day Care (3 times a week)	Symptomatic epilepsy
Mayu	F	73	right	5 years 7 months	Wheelchair	Day Care (twice a week)	Colitis ulcerosa
Yayoi	F	69	left	6 years 4 months	Cane (any type)	Day Care (twice a week)	Cholecystectomy
Tomoka	F	76	left	4 years 9 months	Cane (any type)	Long stay	Atrial fibrillation, Diabetes