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Original Article

The long-term process of recovering self-leadership in patients with disabilities due to acquired brain injury

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ABSTRACT
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Objective: To create a model that makes it easier to understand the "process of recovering self-leadership (shutaisei)," which is linked to long-term improvement in the lives of patients with disabilities due to acquired brain injury.
Methods: We held the 18th Self-Leadership (Shutaisei) Research Conference comprising eighteen members that included patients, formal caregivers, medical personnel, and researchers. Results of semi-structured interviews with members related to "long-term recovery of daily activities at home" and "self-leadership (shutaisei)" in patients with disabilities due to acquired brain injury were qualitatively analyzed using a modified grounded theory approach.
Results: Forty-five concepts were generated after an analytical review of the analysis worksheet. Five recovery axes and five recovery stages emerged from the concepts related to individuals' progression courses. The cognitive element of understanding one's self and one's surroundings formed the base of the model, supporting the three elements of self-leadership (motivation, self-reliance, and confidence). It was shown that increased self-esteem can be expected to result from changes in personal values if self-leadership is recovered.
Conclusion: The model is considered to be useful as it is able to broadly assess the stages of patients with acquired disabilities, to grasp their characteristics, and to serve as a form of information that can be shared with others.
Key words: self-leadership, stroke, traumatic brain injury, life-stage rehabilitation, in-home rehabilitation

Introduction

Many patients with acquired disabilities due to cerebral stroke and other brain injuries have residual impairments and activity limitations. Treatment and rehabilitation for these acquired disabilities are usually initiated early in the post-stroke period under a physician's direction, while the patients have a passive, dependent role. However, in clinical practice, we encounter patients who actively rebuild a new life with enduring self-leadership and determination, whose long-term recovery may take place up to several years later, such that they may notice one day that they are capable of doing things that were previously difficult. In fact, some of these people with acquired disabilities may go on to become even more active than they were before the stroke [1, 2].

The patients' recovery in "reconstructing their life in their own way" despite the disabilities is as important as seeking functional recovery. To achieve this reconstruction of daily life, there must be a shift from a dependent relationship in which the medical personnel have the leading role and the disabled person has the passive role to one characterized by the disabled person as the leader and medical personnel as the formal caregivers [1].

The importance of "shutaisei" (self-leadership) in people with disabilities has been emphasized many times in the areas of healthcare, long-term care, and welfare [2–7]. However, the details of "shutaisei (self-leadership) associated with recovery of life in people with disabilities" have not been clarified. "Self-leadership" is the approximate translation of the Japanese term "shutaisei," which is more commonly translated as "autonomy" in English. Many reports

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have emphasized the importance of "autonomy" in discussing patient-centered nursing, long-term care, and rehabilitation [8−11]. However, we realized that a more complete definition of this word was required, as "autonomy" only reflects part of what "shutaisei" encompasses.

Although there are some cases in which the "shutaisei (self-leadership)" of the patient undergoes a change and concomitant long-term improvements in living occur after a long period of stroke, they are often discounted as exceptions, and no further investigation is performed.

The paths that individuals take to an active recovery from the desperation, anxiety and loss of confidence experienced in the early post-stroke period are not identical. However, there may be some common trends. It is understood that "self-leadership" serves a crucial role in rebuilding a new life, but the definition of "self-leadership" in individuals with disabilities is unclear and there are no indices for measuring it.

Generalizing the trends in the process of recovery from stroke and the types of interactions with surrounding people that promote this recovery will be useful for people with disabilities in care and rehabilitation settings and in their homes. We previously reported on the concepts of "shutaisei" (self-leadership) that lead to long-term recovery of community-dwelling patients with disabilities following stroke or brain injury [12].

The present study aims to create a clear model that illustrates the "process of recovering self-leadership" linked to long-term improvement in the lives of patients with disabilities due to acquired brain injury and to elucidate the manner and type of improvements that follow the recovery of self-leadership.

Our conferences yielded a wealth of information that exceeds the scope of a single study. The present report focuses on the model outlining the long-term process of recovering self-leadership. Other reports provide more detail on the concept of "shutaisei" (self-leadership) that promotes recovery [12] and the interactions with surrounding people that promote self-leadership.

Methods

This study was approved by the Ethics Committee of Aoi Medical Corporation.

1. Research participants

A Self-Leadership (Shutaisei) Research Conference was held once a month for approximately two hours per session starting in February 2015, with participants that included multidisciplinary medical personnel from multiple institutions (physicians, nurses, physical therapists, occupational therapists, and a speech/hearing therapist), formal caregivers (welfare and long-term care), researchers (sociology, psychology, education, and philosophy), and patients with disabilities. The topic of discussion was patients with disabilities due to acquired brain injury (cerebral stroke or other brain injuries) who made long-term recovery of functions, activities, and participation essential for living. Each conference session was held with around 20 participants, including 18 regular members representing 10 institutions and several guest participants.

2. Data collection

Anonymous, semi-structured interviews were conducted with the Self-Leadership Research Conference members during the period from February to June 2015 about the "recovery of life at home that took more than half a year" and "shutaisei (self-leadership)" of people with acquired disabilities due to cerebral stroke that the interviewees witnessed, heard about or experienced themselves. There were five to nine responses for each of the 10 questions. Seven cases were presented by members, and other cases were also shared in conference discussions. The questions are displayed in Table 1.

3. Analysis

Although various factors are reported to promote or interfere with recovery, focus was placed on the recovery (reacquisition) of self-leadership, which is thought to be associated with long-term rebuilding of life. The Delphi technique was used in the first six months of the conferences, i.e., collective feedback was provided to members by summarizing answers to the questions to allow experts to revise their opinions for the next conference. This process was repeated to facilitate the convergence of opinions. After this process was completed, common aspects of the patients' long-term recovery of life and the process of recovery of self-leadership were discussed to induce a model through "bottom-up" logic based on independent cases.

The modified grounded theory approach (M-GTA) was used for qualitative analysis [13, 14]. Discussion was conducted on the analytical theme "Elucidating the process of the recovery of self-leadership associated with people with acquired disabilities due to cerebral stroke, and their interactions with surrounding people," on the following subjects: "Patients who were able to achieve recovery in life over the long-term despite acquired disabilities caused by non-progressive acquired brain injury." The analytically-focused person was "People such as medical staff, specialists and family who interact with the people with the acquired brain injury" regarding "The patient's progress" and "Interactions with surrounding people." Furthermore, stabilization of acute symptoms and somewhat stabilized financial and social conditions were assumed as premises of the analysis.

Table 1. Questions and answers.

First request:
We ask that you relate anecdotes of "Episodes related to shutaisei (self-leadership)" as specifically as possible. There is no set format; please give them to us as they come to mind. Reported cases: 4 cases/7 examples
Second request:
Please give some examples deemed independent "behavior (actions or words)." There will be subsequent questions for discussing the "Preparation" stage and "Encouragement by others" later, but they can also be mentioned here. Answers: 7
Behavior with shutaisei (self-leadership), including actions and words, are understood to require a preparatory stage or antecedent factors. Please name these stages of "Preparation" (state of preparation and antecedent factors). Answers: 6
What "Encouragement by others" is required for behavior with shutaisei (self-leadership)? Please name them. Answers: 6
Please share any other opinions you may have regarding "shutaisei (self-leadership)." Answers: 5
Third request:
Tell us your thoughts on the "points in common of the stages and flow" of recovery (improvement) from disability. Answers: 7
Tell us your thoughts on the "points in common of the factors that promote" recovery (improvement) from disability. Answers: 6
Tell us your thoughts on the "points in common of the basis and preparatory stage" of recovery (improvement) from disability. Answers: 8
Tell us your thoughts on what is improved in the long run. Answers: 9
Share any other opinions you may have regarding "shutaisei (self-leadership)" or "improvement from disability." Answers: 6
Fourth request:
How do you determine that the patient has undergone a change of state from "desperation" to "having shutaisei (self-leadership)"? Your answers may include references to patients' words, utterances, behavior, and attitude. Answers: 6

Minutes were based on the written answers to the interview questions and answers from the conference recorded with a voice recorder. Cases that exemplified the process of the recovery of self-leadership in people with acquired disabilities were collected on the analysis worksheet and defined, and the concepts were named. These generated concepts were organized in chronological order along the timeline of the process and categorized by concept similarities; the relationships between the categories were structuralized and made into a final schema. Discussions were held on the model, which was peer reviewed and checked by the conference members. Furthermore, the accuracy and validity of the interpretations were discussed.

Results

A total of 18 conferences were held between February 2015 and September 2016.

1. Definition of "self-leadership" at the beginning of the study

"Shutaisei (self-leadership)" is defined as the attitude or characteristic of acting according to one's intentions and judgment and taking responsibility for it [15]; however, this definition was considered incomplete for the context of the debate on "self-leadership that links to the long-term recovery of people with disabilities." As long as the intention or motivation is aimed strictly at recovering the "functions" or "basic activities of daily living (ADLs)," it is difficult to reconstruct the emotionally meaningful aspects of daily life; thus, an amended definition was agreed upon at the first conference. The point of view of "living like oneself" was added in response to the idea that looking at intention or motivation was needed to redefine the term to "Attitude or characteristic of acting or making decisions with responsibility according to one's own intentions and judgment in order to live like oneself" for the purposes of the research.

2. Model of the recovery of self-leadership

2.1 Generating concepts and categories

Analysis worksheets and model-mapping began in March 2015. Opinions were exchanged, and revisions were made more than 30 times over the course of the conferences. Forty-five concepts were generated by means of the M-GTA analysis worksheets and the concepts were categorized by process, resulting in 16 concepts on "interactions with surrounding people" and 29 on "the patient's progress."

Concepts representing "the patient's progress," one of the analytical themes, were organized with some consideration for chronological order, with

"elucidating the process of recovery of self-leadership that affects the improvement of people with disabilities due to acquired brain injury" in mind. The recovery stages with actions as the keyword came in five stages. Five axes of recovery emerged from the concepts, and the model was based on them (Figure).

2.2 Stages of the recovery of self-leadership

Concepts describing "the patient's progress" were categorized into the following five consecutive stages: "Oblivion," "Inertness," "Preparation," "Readiness," and "Control" (Table 2) (Figure).

2.3 Five axes of recovery related to self-leadership

According to the subcategories generated from the concepts organized in chronological order, we found that "Vague recognition of the disabled self" and "Ability to see oneself objectively" corresponded to the recovery of "awareness;" "Apathy and sense of pointlessness" and "Urge to do things by oneself" corresponded to the recovery of "motivation (expectation of results);" "Reliance on others" and "Impression that results are determined by one's decisions and actions" corresponded to the recovery of "self-reliance (responsibility);" "Lack of confidence ('I don't think I can do it')" and "Budding confidence ('I feel like I can do it')" corresponded to the recovery of "confidence (self-efficacy);" and, finally, "Predominance of pre-disability values," "Gradual acceptance of changes to pre-disability values," and "Life under a new value system" corresponded to the recovery of "standards of values" [12]. That is, they were summarized into five Axes of Recovery (Table 3) (Figure).

Discussion

"Awareness" of the self or the environment that one is placed in (axis of recovery 0) is the base that supports the three elements of self-leadership linked to improvement, i.e., motivation, self-reliance and confidence (axes of recovery 1, 2 and 3). Once self-leadership begins to recover, feelings of self-respect also begin to increase based on new "values" (axis of recovery 4) (Table 3) (Figure). Close observation of the progress shows that changes in axis 1 "motivation" and axis 2 "self-reliance" seem to occur relatively quickly and without much hesitation. In contrast, axis 3 "confidence" is established gradually and with vacillation in stage 2. Similarly, axis 4 "values" also seems to waver with gradual changes throughout stage 3.

After a brain injury that is severe enough to impair ADLs, comprehensive recovery of the various facets of life is complex; needless to say, there are numerous factors that influence these in functional and environmental aspects. Here, we focused on the reacquisition of self-leadership because we believe it to be associated with the long-term recovery of life in individuals with acquired disabilities, with the premise that acute disease symptoms are stabilized and there is relative financial stability. In Maslow's hierarchy of five basic needs [16], these corresponded to having physiological and safety needs fulfilled while love and belonging and esteem needs were not yet met, which corresponded to stages 0 and 1 in the present model.

Stage 1 of the present model is similar to Erikson's concept of "identity diffusion," as articulated in his life-stage theory [17, 18]. Identity diffusion is a state in which an individual lacks the ability to define

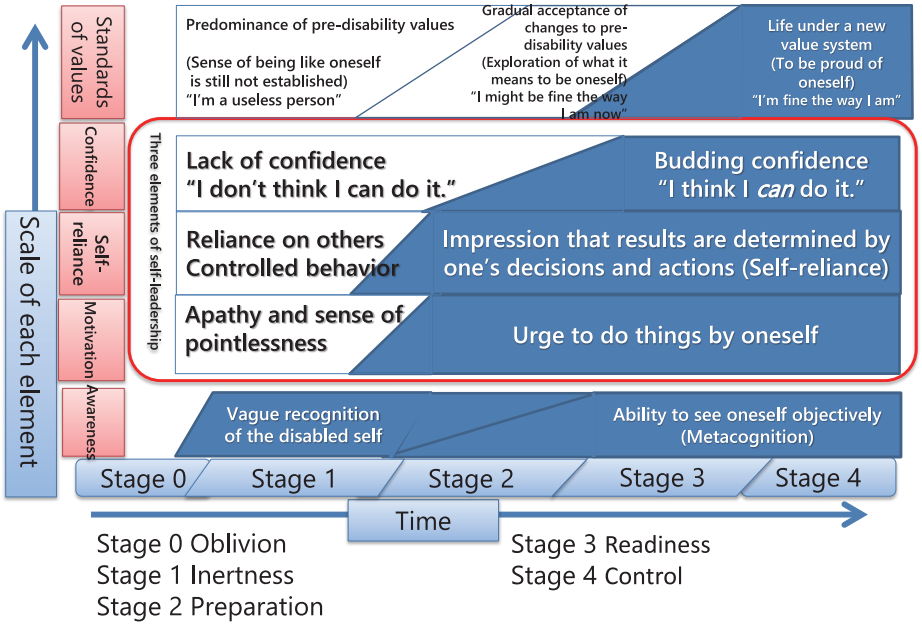

Figure Model of recovery of self-leadership for people with disabilities.

Table 2. Stages of recovery of self-leadership.

Stage 0: Oblivion, "Not recognizing what they can't do"

In this stage, patients are unable to recognize the current situation and the disability that is expected to persist. Patients are either unaware of the disability or they expect to recover completely.

Although the patients may have vague concerns that they may no longer be able to fulfill their roles, they are positive in a sense, and feel little anxiety about their disability. At this stage, the patients' goal is to return to their previous state through rehabilitation.

This stage is mainly expected to take place while still hospitalized. However, it may last longer in patients with lower awareness of their illness due to disorders of higher mental functions.

Stage 1: Inertness, "Having difficulty taking action"

Patients in this stage are filled with desperation, anxiety, and feelings of loss and isolation that impair the urge to take action. Taking action is a great challenge due to a lack of confidence and feelings of helplessness.

This stage starts from the patients' vaguely recognizing their profile as a disabled person and finding that they cannot live the same way as before. In this stage, patients are passive: tasks, even those that can be done by the patients themselves, are led and carried out by people around the newly disabled person, which can further disable the patients in a vicious circle of apathy, dependence, and lack of confidence. Rehabilitation itself easily becomes the goal.

Primarily takes place at home or after returning to the patients' social spheres, including work, roles in the community, hobby groups and volunteering activities, but some patients may enter this stage during hospitalization.

Stage 2: Preparation, "Preparation to take action"

Patients believe that a certain behavior will render desirable results (expectation of results, increasing motivation) and feel that certain results depend on their own actions (belief in self-reliance), which motivates the patients to take action. At this stage, patients break out of the passive attitude in which they are waiting for guidance. Patients in this stage are equipped with two of the three elements of self-leadership, but their confidence still fluctuates.

Patients also begin to gain the ability to compare their current self not to the pre-stroke self, but to a more recent post-stroke self. They begin to have values that are different from those before the stroke, begin to accept themselves as they are, and start to explore what it now means to "be themselves."

Stage 3: Readiness, "Readiness to take action"

Patients are motivated and have confidence in addition to the "belief in self-reliance," completing the three elements of self-leadership. Patients set specific and achievable goals themselves and begin to take actions that allow them to be like themselves. Their vision on interests also broadens at this stage.

The actual abilities or environment of the patients begin to match with their abilities and environment as the patients perceive them (metacognition), and they begin to make clear distinctions between the tasks that they can do on their own and those that require the help of others in order to live like themselves. Although their values gradually begin to shift to thinking that their self-assessment should be based on their own standards regardless of their disability, their search for a "sense of being oneself" continues.

Compared to the spatial realm of activity in Stage 2, which consisted of "familiar places," such as places the patients have been taken to, the patients in Stage 3 begin to explore places that they have never been.

Stage 4: Control, "Control over life"

Patients begin to take actions now with all three elements of self-leadership. Through that process, they begin to accept the things within and outside the reach of their capacity and begin to look around before planning their actions. These changes in their standards allow them to become aware of "the current self as the true self," "acceptance" and "sense of being oneself," which boosts their self-esteem and sense of self-respect. At this stage, patients are finally able to construct their entire lifestyle (control) within the new value system. The patients have become fully independent at Stage 4 and do not require further intervention.

Table 3. Axes of recovery around self-leadership.

Axis of recovery 0: Cognition

Patient transition from the state of "Inability to see the disabled self" to recognizing new things that they cannot do in their "vague recognition of the disabled self." The last step in this process, "Ability to see oneself objectively" (metacognition) is characterized by becoming able to assess their abilities, including factors such as the people surrounding them and the circumstances in which they are placed. This element establishes the underpinnings of self-leadership.

Axis of recovery 1: Motivation (expectation of results)

This axis is characterized by the shift from "Apathy and sense of pointlessness," or a sense that a particular action will not lead to the desired result, to the belief that a particular action does link to the desired result in "Urge to do things by oneself" (increased expectation of results).

Axis of recovery 2: Self-reliance (Responsibility)

Transition from the reliance on others, i.e., the "impression that results are determined by others' decisions and luck" to a belief centered on self-reliance and self-decision to rely on others, i.e., the "impression that results are determined by one's decisions and actions." Patients begin to believe that one is responsible for the results of one's own decisions. This axis is analogous to the transition from having an "internal" to an "external" locus of control.

Axis of recovery 3: Confidence (Self-efficacy)

Patients go from a state in which they feel like they "cannot do" anything, to having the confidence that tasks can be accomplished independently, or by asking for and receiving help from others. This axis characterizes an increase in confidence (self-efficacy).

Axis of recovery 4: Standards of values

A process of change from "disappointment in the changed self" and "plummeted sense of self-worth" to the "acceptance of self as is" and "positive image of the new self" so that the sense of being oneself can be regained once again. A shift in values: changes in the internal standards of values, increase in self-esteem and self-respect.

themselves and may not know what to do. The task for a person in this state is to construct or reconstruct a satisfying life that facilitates self-definition.

The importance of the "shutaisei (self-leadership)" of persons with disabilities has been repeatedly debated in the areas of health care, long-term care, and welfare [1−7]. However, it remains unclear what "self-leadership associated with recovery" exactly is. As described in 1. Definition of "self-leadership" in the Results section, self-leadership related to activities and participation "in order to live like oneself" is important if emphasis is placed on the recovery of life. Even when self-directed and purposeful, excessive fixation on the impairments is far from self-leadership that links to recovery [12]. Without clarifying this point, it is difficult to show this difference clearly in support settings.

The present model broadly assessed the stages of "self-leadership that links to recovery" in people with disabilities to understand their characteristics so that they can be communicated clearly. This can help lead to consistent approaches towards long-term recovery of life by professionals and families who assist people with disabilities.

Other models have been used to describe the complex process of identity shift related to physical changes. Okamoto [19] proposes a theory characterized by subjective efforts to adjust one's identity, i.e., that even after one's identity is established during middle age, it is revised at turning points of life in accordance with physical changes to more realistically reflect the person's abilities at that point in their life. She explains the process in four stages (Table 4), which almost correspond to the stages in the present model. In other words, the recovery of self-leadership may reconfirm the identity.

The process of recovery from disability has been debated with a focus on "acceptance of disability" and "life story" [20−24]. However, the broad interpretation and vague use of the term "acceptance of disability" by rehabilitation professionals has been a problem. For example, some interpretations, such as "disabled people should achieve changes in values while hospitalized" was criticized [25], giving rise to more confusion in rehabilitation settings [26].

The "acceptance of disability" theory and "recovery of self-leadership" model are similar in that both follow the progress in time and assume the final stage to consist of adaptation through a change of values. However, while the "acceptance of disability" theory divides stages 0 and 1 of the present model into more specific classifications, it treats stages 2 and 3 of our model only briefly, giving the impression that the course between the first and the fourth and final stage is a sudden jump (Table 4). That is, in the "acceptance of disability" theory, there is a wide gap and a lack of continuity between the final stage of adaptation and the steps preceding it. This can cause confusion and hesitation for the patient, medical personnel, and formal caregivers, which are likely to be the reasons underlying the criticism of this theory. Furthermore, the "recovery of self-leadership" model roughly

Table 4. Stages in the self-leadership recovery model compared to other theories.

Self-leadership recovery model (present study)	Cohn's stage theory [20]	Fink's stage theory [21]	Ueda's stages of acceptance of isability[22]	Okamoto's lifelong development of identity theory [19]
Stage 0: Oblivion Lack of awareness of the disability	(1) Shock (2) Expectations of recovery	(1) Shock (2) Defensive retreat (Retreat)	(1) Shock (2) Denial	
Stage 1: Inertness Presence of obstacles to taking action	(3) Mourning (4) Defense	(3) Acknowledgement (Renewed stress)	(3) Confusion	I: Crisis associated with recognition of physical changes
Stage 2: Preparation Preparing to take action	(4) Defense		(4) Efforts to find a solution	II: Re-evaluation of one's life and exploration of identity
Stage 3: Readiness Ability to take action			(4) Efforts to find a solution	III: Re-evaluation and modification of one's life-track
Stage 4: Control Ability to manage actions and life in general	(5) Adaptation	(4) Adaptation	(5) Acceptance	IV: Re-achievement of identity

assumes stage 0 to correspond to onset and hospitalization and stage 1 to hospitalization and early post-discharge period, which makes it easier to avoid the misunderstanding that the patient must arrive at stage 4 while still hospitalized. Another difference between this model and the "acceptance of disability" theory is that it assumes that the trajectory to the changes in values associated with stage 4 is difficult and emphasizes the importance of "recovery of self-leadership" preceding the adaptation stage.

As such, this model does emphasize the "recovery of self-leadership," but it is important to note that individuals with disabilities experiencing distress should not be compelled to set stage 4 (changes in standards of values) as a goal. The path to changes in values achieved at stage 4 is a difficult, long, and winding road, and in some cases, that stage may never be achieved.

Even in a stage of increased self-esteem characterized by "acceptance" under a new value system, it does not justify the illness or disability itself. This model was devised with the purpose of providing adequate support for people with disabilities; however, prompting a change of values in a coercive manner may hurt or offend the person with disabilities so it should be used with caution.

In actual practice, after making an assessment, it is important to determine what to do next. This model facilitates an understanding of "interactions with surrounding people that promote recovery of self-leadership" by stages and summarizes specific mechanisms for coping. In the future, we hope to develop an assessment scale for the self-leadership stage with this model as a point of origin, conduct quantitative studies, and investigate the effects of "self-leadership" on improving daily life.

Additional note

This study was based on "The Shutaisei (Self-Leadership) Research Conference". The members who participated in the conference significantly are as follows: Akira Ogawa (Nurse, Tokyo Metropolitan Rehabilitation Hospital), Setsuko Ogawa (Speech-Language-Hearing Therapist, JR Tokyo General Hospital), Daisuke Kawagoe (Occupational Therapist, Moriyama Rehabilitation Clinic), Jun Kawanabe (Social Worker, Social Welfare Corporation Setagaya Volunteer Association Care-Center Flat), Yoshikazu Goto (Occupational Therapist, Iki-iki Welfare Network Center), Ryuji Kobayashi (Registered Occupational Therapist, PhD, Professor, Division of Occupational Therapy, Faculty of Health Sciences, Tokyo Metropolitan University), Yukiko Komai (Chief Director, Iki-iki Welfare Network Center), Masahiro Sakakibara (CEO, Mono Well-Being Co., Ltd.), Yumi Tezuka (Representative Director, Kisuikai Incorporated Association), Sosuke Nagao (Registered Occupational Therapist, Long-Term Care Facility, Kunitachi Aoyagien), Suzumi Nakashima (Physical Therapist, Sangenjaya Rehabilitation Clinic), Masahiro Nochi (Professor, Graduate School of Education, The University of Tokyo), Yoko Nonoyama (Social Worker, Iki-iki Welfare Network Center), Sachiko Hasegawa (Former Vice Director of Nursing Service Department, Nippon Medical School Hospital), Hiroshi Hasegawa (Philosopher), Kayoko Fujii (Facility Director, Day Service Yumeko), Maki Fujita (Occupational Therapist, Sangenjaya Rehabilitation Clinic), Miwako Hosoda (Vice President, Seisa University), Kanchi Mishima (Standing Director, Kisuikai Incorporated Association), Takayuki Watabe (Occupational Therapist, Rehabilitation Center, Showa University Fujigaoka Rehabilitation Hospital), Toshiko Wada (Social Worker, Social Welfare Corporation Setagaya Volunteer Association Care-Center Flat).

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