

Original Article

The long-term process of recovering self-leadership in patients with disability due to acquired brain injury: II. Interactions with surrounding people that promote recovery of self-leadership

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ABSTRACT

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Objective: To create a model of interactions with surrounding people that promote recovery of self-leadership leading to long-term improvements in patients with disability due to acquired brain injury.

Methods: We held the 18th Self-Leadership (Shutaisei) Research Conference comprising about 20 members, including patients, formal caregivers, medical personnel, and researchers. The results of semi-structured interviews with members related to “long-term recovery of daily activity at home” and “self-leadership” in patients with disability due to acquired brain injury were qualitatively analyzed using the Modified Grounded Theory Approach.

Results: The model was created from 16 concepts related to caregiver interactions generated from an analysis worksheet. “Gaining the patient’s trust” was the starting point of this model. It was found that patients seem to progress more smoothly when the people surrounding them “suggest tasks and roles set at the appropriate level,” then “provide support to gain successful experiences,” and then close the cycle by “creating opportunities to reflect on each experience.”

Conclusion: The model illustrates the flow of interactions that effectively promote recovery of self-leadership and has the potential to be developed into a standardized

rehabilitation method for patients with disability due to acquired brain injury.

Key words: stroke, acquired brain injury, life-stage rehabilitation, in-home rehabilitation, self-leadership

Introduction

The importance of self-leadership is frequently emphasized in the areas of healthcare, long-term care, and welfare for helping with long-term improvements when patients with acquired disabilities due to cerebral stroke and other brain injuries have residual impairments and activity limitations [1–7]. However, self-leadership cannot be measured, and outcomes related to the recovery of self-leadership have not been identified. Existing knowledge is insufficient for elucidating the long-term process of recovery of self-leadership in people with acquired disabilities, and requires a qualitative exploration of new aspects of the conditions and new theories.

This study aims to elucidate the process of recovery of self-leadership for long-term improvements in people with disabilities due to acquired brain injury, and to develop a model that effectively represents the interactions with surrounding people that promote recovery in this population.

Earlier parts of this qualitative study series focused on the concept of self-leadership that promotes recovery in people with disabilities [8], and the process of long-term recovery of self-leadership for people with disabilities due to acquired brain injury (Figure 1) [9]. This study documents and categorizes the elements of interactions with surrounding people that promote the recovery of self-leadership.

Methods

1. Study design

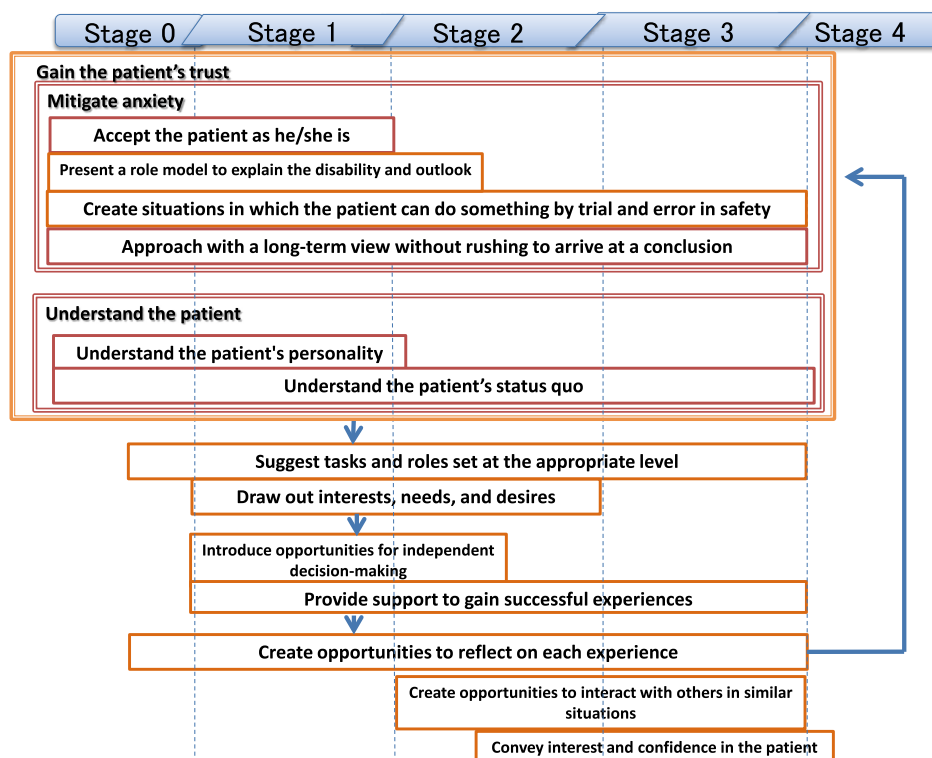
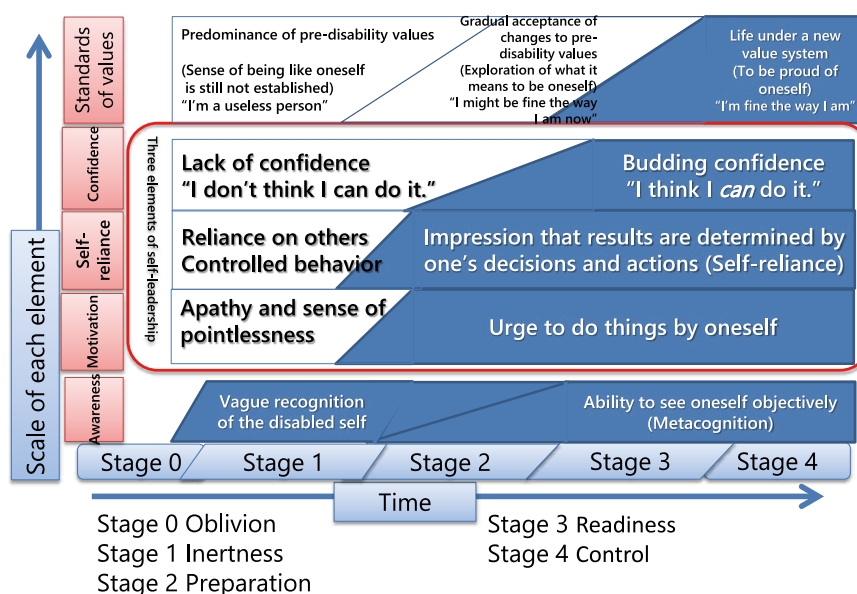
Three research questions were raised: 1) How do people with disabilities recover (regain) their self-

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This study was approved by the Ethics Committee

2. Research participants

Starting in February 2015, a Self-Leadership (Shutaisei) Research Conference was held once a month for approximately two hours per session to discuss the topic of long-term recovery of abilities essential for living for patients with disability due to acquired brain injury. Participants with experience and knowledge were represented among multidisciplinary

medical personnel from multiple institutions (physicians, nurses, physical therapists, occupational therapists, and a speech-language-hearing therapist), formal caregivers (welfare and long-term care), researchers (sociology, psychology, education, and philosophy), and patients with disabilities. Each conference session was held with around 20 participants, including several guest participants and 18 regular members representing 10 institutions. The members who participated in multiple conferences had a mean of 20.2 ± 10.7 years (median: 19 years) of experience. On the other hand, some guest participants had no experience or knowledge of patients with disabilities who had made a long-term recovery.

3. Data collection

During the period from February to June 2015, members of the Self-Leadership Research Conference completed anonymous, semi-structured interviews about witnessing, hearing about, or personally experiencing “recovery of life at home that took more than half a year” and “self-leadership” of people with acquired disabilities due to cerebral injury. We gathered five to nine responses for each of the 10 questions, such as “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.” Seven cases were presented by members, and other cases were also shared during conference discussions. The questions have been included in the previous articles [9].

4. Analysis

Focus was placed on the recovery (reacquisition) of self-leadership, which is thought to be associated with the long-term rebuilding of life. The Delphi technique was used during the first six months of the conferences: i.e., collective feedback was given to the members by summarizing answers to the questions, thus allowing experts to revise their opinions for the next conference.

The Modified Grounded Theory Approach (M-GTA) [10, 11] was adopted for the following analytical theme: “Elucidating the process of the recovery of self-leadership associated with people with acquired disabilities due to cerebral stroke or other brain injuries, and interactions with surrounding people.” Subjects were “Patients who were able to achieve recovery in life over the long term despite disabilities caused by nonprogressive acquired brain injury.” The analytically focused person was “People such as medical staff, specialists, and family who interact with the person with the acquired brain injury.” The focus was “The patient’s progress” and “Interactions with surrounding people.” Conditions of stability of acute symptoms and somewhat stabilized financial and social conditions were assumed as premises of the analysis.

Data was collected from the written answers to the questionnaires and from the recorded minutes of the

conferences. Cases that exemplified the process of the recovery of self-leadership in people with acquired disabilities were collected on the analysis worksheet and the concepts were defined and named. Concepts generated in this way were organized in chronological order and categorized by similarities, and the relationships between categories were structuralized. To perform member checking, discussions were held with various participants during the conferences on the following: whether the analysis was coherent with the data or interpretation; whether there were any major inconsistencies; to which contexts the findings applied; and to what extent they contributed to insight or understanding by the people surrounding the person with the brain injury to develop the model. For peer debriefing, discussions were also held with guest participants, and the workers engaged in caring for people with disabilities were also updated on these findings to debate the strengths and problems of this study from multiple perspectives of other experts to ensure the accuracy and validity of interpretations.

The first author handled “collecting cases for the analysis worksheet, naming and defining concepts, categorizing concepts, structuralizing relationships between categories, and drafting the model” to propose an agenda for the conferences. Revisions and questions were discussed in the conferences and revisions were made as they were discussed. The first author prepared the draft revisions through consultations with qualitative researchers and persons engaged in caring for people with disabilities before the following conference, at which they were discussed again. These cycles were repeated until there were no more questions or points for revision.

Results

A total of 18 conferences were held between February 2015 and September 2016. Analysis worksheet and model preparation was initiated in March 2015. Conferences were held as described in Methods. Concepts were defined, named and categorized, relationships between categories were structuralized, and the model was drafted and revised multiple times per conference to prepare an agenda for the following conference. When there were objections and counterarguments, all participants ultimately agreed by summarizing the opinions and making sure that they did not diverge from the analytical theme and were easily understood as pertinent to “the process of the recovery of self-leadership associated with the improvement of disability due to acquired brain injury and interactions with surrounding people” and the analytically focused person, “People such as medical staff, specialists and family who interact with the person with the acquired brain injury.” Revisions were made at least 30 times.

Details of the results on the “Concept of self-

Table 1. Fundamental interactions that promote recovery of independence (Starting point).

Category	Gain the patient's trust				
Subcategories	Understand the patient		Mitigate anxiety		
Concepts	Understand the patient's personality	Understand the patient's status quo	Accept the patient as he/she is	Present a role model to explain the disability and outlook	Create situations in which the patient can do something by trial and error in safety
Definitions	Gain a detailed understanding of the patient's personality, the things he/she likes, pre-stroke environment and the things he/she valued, such as background, past, and things that do not change	Understand (recognize) the patient's current disease, disability, psychological state, and environment and examine his/her strengths and weaknesses in detail. Limited in terms of time and space (Present)	Attitude that accepts the patient as he/she is, including emotions, how he/she perceives the disability, etc. Avoid denying, ordering or judging.	Explain about using the role model so the patient can have an idea of his/her current and prospective condition (Storytelling)	Availability of places and opportunities that allow trial and error of individual challenges in safety
Most pertinent stages	Stages 0-1	Stages 0-3	Stages 0-1	Stages 0-2	Stages 0-3
Details	Explore what the patient likes through everyday conversation or interactions with him/her. Ask the patient and his/her family and friends about how he/she was before the stroke and his/her life history. When visiting his/her home, ask the patient about things that may provide hints about his/her personality, such as photographs, things he/she made in the past, etc. Use tools such as the Interest Checklist [22].	Check factors that may affect the future life of the patient, such as physical function, mental state, high mental function, ADL, IADL, living environment, and social environment from various perspectives with the help of professionals and family. Record the patient's comments related to how he/she perceives the disability and the patient's notable demeanor in settings where he/she was observed. Check for differences between the patient and his/her supporters' perceptions of the patient's disease and state of disability. Determine the patient's degree of acceptance by observing his/her reactions and body language, such as nodding. Speak slowly with the patient so that you can notice his/her true feelings through facial expressions and strong talking.	Listen without approval or denial with receptiveness to both the positive and negative aspects. At this point, accept all input about the patient's emotions or how he/she perceives the disability. Record the details as told. Do not give criticism or advice before building a relationship of trust. Acknowledge the patient's efforts thus far.	Tell the patient that there is possibility of further change and explain the predicted prognosis. It is possible to change positively despite the disability as long as life in its entirety is well planned out. People with disabilities have difficulty making independent decisions without understanding the current situation or knowing what may happen, and they feel confused about the future. The patient is not aware of his own state of confusion in Stage 0, but becomes aware of it in Stage 1.	Introduce situations and opportunities for gaining successful experiences, such as situations where the patient feels listened to, that his value as a person is acknowledged, and he is given permission to try things out. The supporter's attitude is one of thinking collaboratively with the patient to figure out how things can be done. Activities in groups and places and opportunities provided with support to enable things may make it possible for the patient to accomplish things that he/she may feel anxious or insecure about or incapable of doing alone. This may also make him/her realize that there are ways to perform the tasks, as well as allow him/her to share the fulfillment of accomplishing the task together.
					Approach with a long-term view without rushing to arrive at a conclusion Take time so that the patient is on the same page as you, and work together on the challenges with a long-term approach. Do not rush to arrive at a conclusion.
					Avoid trying to convince the patient; instead, wait for a spontaneous change in his/her attitude. Keep in mind that it takes a long time for the patient to digest his/her physical state and other changes and listen patiently. Try to observe small changes in the daily interactions. Remind the patient that changes will eventually occur. Do not become preoccupied with big goals and hopes that may take a very long time to achieve. Working with the patient, shift the focus onto shorter-term goals that he/she may be able to accomplish more easily.

Table 2. Concepts and interactions by stage that promote recovery of independence.

Concepts	Suggest tasks and roles set at appropriate levels	Draw out interests, needs, and desires	Introduce opportunities for independent decision-making	Provide support to gain successful experiences	Create opportunities to reflect on each experience	Create opportunities to interact with others in similar situations	Convey interest and confidence in the patient
Definitions	Suggest tasks and roles that are at slightly higher levels for the patient and support them.	Draw out specific and realistic wants, needs, and interests that are achievable and are matched to the patient's abilities and situation. Have the patient shift from apathy to having an interest in making changes in his/her behavior.	Have the patient make a habit of independent decision-making for things that may seem trivial for people without disabilities in this stage where the patient may have difficulty making decisions independently.	Encourage the patient to gain successful experiences in the near past, present, and future. Think together with the patient about how he/she can accomplish what he/she wants to, and provide support.	Focus on individual accomplishments and compare them to the patient's immediate post-stroke phase to encourage objectivity in the patient's own self-evaluation. Reflect upon successful experiences in the near past and re-acknowledge them.	Create opportunities for interactions with others in similar situations so that the patient can see others accomplishing things successfully and feel encouraged that he/she may be able to do the same thing.	Tell the patient that you are interested and have confidence in him/her so that he/she is encouraged to act proactively in order to fulfill the expectations of the surrounding people.
Most pertinent stages	Stages 0-3	Stages 1-2	Stages 1-2	Stages 1-3	Stages 0-3	Stages 2-3	Stages 2-3
Interactions by stage Stage 0	The patient is not aware of or may be in denial about his new challenges. Start with difficulties that he/she already somewhat acknowledges as a starting point for the interventions.			(Encourage the patient to try things out without assistance to allow him/her to identify difficulties.)	Check the patient's degree of awareness about his/her difficulties or disabilities, and perceptions afterwards.		
Stage 1	Avoid unrealistic goals and wishes. Focus on small, realistic goals and temporarily narrow down the perspectives. Suggest achieving small and immediate goals one by one that lead to the achievement of bigger goals.	Use tools such as the Interest Checklist [22] to start the conversation. However, it is often difficult for the patient to verbalize what he/she wants to do in this stage. Start by providing information related to activities that the patient may be interested for an impetus. At the beginning, ask the patient to participate ("I want you to try this activity with me."). Take sufficient time for broad suggestions.	Guide the patient to making autonomous decisions, even for things that may seem trivial. If the patient seems capable, create a situation where he/she selects from among the options to acclimatize the patient to thinking and making decisions autonomously. Visualize the three steps: (1) Ask the patient—(2) Patient chooses from among the given options—(3) Patient begins to initiate own propositions.	Rather than assuming that the patient is unable to do something, think with the patient about how he/she would be able to do it. Be consistently faithful to this stance through both words and actions. Allow the patient to have the experience of succeeding with just a little help in accomplishing things that he/she believed were difficult to achieve with the new state. Have the patient experience success in small increments: Start with small parts of tasks that the patient is confident about accomplishing, and having such efforts recognized by others.	Train the patient to have objectivity in perception. Encourage him/her to compare the current self not to himself/herself before the stroke, but several months earlier, if not just after the stroke. Allow the patient to reflect and recognize that he/she was surprisingly capable of doing something he/she believed was impossible. Recognize the disparity between the goal and status quo and arrive at common grounds on how much the patient has accomplished. Reflecting on something that was "fun" or accomplished allows the patient to enjoy things.	(A patient in Stage 1 who sees somebody else who is active and vigorous tends to reject it ("That person is a special case, so it means nothing to me.") At this stage, limit references to the introduction of past cases or lifestyles of other patients who had developed a similar disability earlier.)	(Patients in Stage 1 do not have confidence that they can meet others' expectations or do certain things to get better. Conveying to patients the hopes and expectations of others tends to shut them out more adamantly.)
Stage 2	Broaden perspectives and lay down longer-term goals in gradual steps.	Interact in ways to gradually broaden the patient's perspectives by supporting what he/she wants to try doing. Encourage setting long-term goals.	The supporter should always encourage the patient to think about what he/she wants, rather than give suggestions. Have the patient express what he/she wants to do.	Same as the above. Encourage the patient to actually go out and try and experience things that he/she would never have imagined possible with his disabilities.	Same as the above.	Patients in Stage 2 and later begin to feel that they want to try things because they realize that things are in an individual's control. Exchanges and interactions with people who have longer experience in their post-stroke lives (peer support, etc.) allows them to move forward.	
Stage 3	Broaden goals and roles: include things and places the patient has never experienced before.			Same as the above.	Same as the above. Have the patient evaluate himself/herself in the present in comparison to before the stroke. Have the patient describe what defines him/her.	Same as the above.	

leadership” [8] and the “Model of Recovery of Self-Leadership” (Figure 1) [9] are discussed in other parts of the series. This article focuses on the results on “interactions with surrounding people that promote the recovery of self-leadership.”

1. Concept generation and categories

As mentioned above, analysis worksheet and model preparation was started in March 2015. Revisions were made repeatedly in the conferences with the analytical themes and analytically focused person in mind, and 45 concepts were generated from the M-GTA analysis worksheet [9].

An example of the concept generation process is presented below. For instance, the process for finalizing the concept “Accept the patient as he/she is” consisted of first extracting 14 specific cases such as “Value the process of working together through things that the patient cannot do until he/she can either accept this or do it to his/her satisfaction,” “Accept the patient as an autonomous being; that is, wait for the patient to accomplish tasks within his/her capacity instead of doing it for him/her, and respect the person as an equal” from the interview text data, and then debating the most appropriate definition at the conferences. This concept was defined as having an “Attitude that accepts the patient as he/she is, including emotions, how he/she perceives the disability, etc. Avoid denying, ordering or judging.” The concept was initially named “Acceptance.” However, several participants argued that the term “acceptance” was potentially misleading because it has already been used by experts from various other fields who have attached meanings to the term that are different than those intended here. Through repeated discussions at the conferences to come up with a more common expression that is easier to understand, agreement was ultimately reached on “Accept the patient as he/she is.”

The concepts generated were categorized by process. Sixteen concepts were related to “interactions with surrounding people” (Tables 1, 2) and the model of “interactions with surrounding people that promote recovery of self-leadership” was investigated based on them.

2. Model of interactions with surrounding people

Concepts representing the “interactions of surrounding people that promote the self-leadership of people with acquired disabilities” were organized in chronological order and categorized according to the analytical theme, the analytically focused person and the stages of recovery of the patient. The concepts were integrated into a model that illustrates suitable interactions according to each stage of recovery (Figure 2).

2.1 Interactions with surrounding people that promote recovery of self-leadership: Foundations (Origin)

The dynamics of the 16 concepts of “interactions of surrounding people” to encourage the transition from inertness (Stage 0 and 1) to rebuilding a self-led life were discussed. The six concepts, two subcategories and one category presented in Table 1 were consolidated as being prerequisite and fundamental to the other concepts related to “interactions with surrounding people” through the course of discussion in the conferences.

We observed a spontaneously wide range of degree of abstraction that the concepts represented; some concepts were specific while others were comprehensive. This spread made it easier to draw a comparison between the concepts. Consequently, two of the concepts were elevated to subcategories and one to a category. This process is described below.

There were no objections to the conclusion that “Understanding the patient” was fundamental to the interactions at the preliminary stage of promoting recovery. “Understanding the patient’s personality” was chosen to summarize the patient’s past and “Understanding the patient’s current status” to describe the present. These were relatively more specific ideas, as well as two of the most important requirements for understanding a patient, and were therefore merged under the subcategory “Understanding the patient.”

The importance of “mitigating anxiety” was also discussed repeatedly as being fundamental for having people with disabilities accept various approaches. The four concepts “Accept the patient as he/she is,” “Present a role model to explain the disability and outlook,” “Create situations in which the patient can do something by trial and error in safety” and “Approach with a long-term view without rushing to arrive at a conclusion” depict relatively specific actions by surrounding people that would be grouped under the more abstract subcategory “Mitigate anxiety.”

The category “Gain the patient’s trust” is at the highest level of abstraction, overarching all the other concepts. It is also the fundamental starting point of all interactions and none of the approaches could be effective without it. Some of the discussions that led to this conclusion are excerpted below.

First, participants shared 18 specific examples of situations that encouraged a gradual development of self-leadership; these brought up the concept that was eventually named “Gain the patient’s trust.” Examples included “staff members that the patient is friendly with and speaks to often provided encouragement and worked together with the patient” and “the patient initially did not have the confidence to leave his/her home and was nervous about commuting to the center, so the staff started by encouraging communication with other users to familiarize the patient with the community so that he/she could enjoy and be motivated

to come to the center.” This would make the analysis coherent and prevent major inconsistencies, because the ideas of “Understand the patient” and “Mitigate anxiety” are implied. These would be applicable in the preliminary stages of interactions to promote the initiation of action. Since the other interactions are not possible without first gaining the patient’s trust, this type of interaction would be indispensable in Stages 0 and 1. Participants reached an accord at the conferences that these results would promote understanding and insight in the people surrounding patients with a brain injury.

The definitions and details of the concepts of “Gain the patient’s trust” are shown in Table 1.

2.2 Flow of interactions with surrounding people that promote recovery of self-leadership

The remaining seven concepts represented the types of interactions that promote recovery of self-leadership after gaining the patient’s trust. The seven concepts that were determined to be at equal levels of abstraction were organized to obtain results, as shown in Figure 2. The definitions and details of the concepts are shown in Table 2.

A consensus was reached through discussions and revisions at conferences on the flow of interactions that are described below. People with disabilities will be open to listening only when the surrounding people interact with them in ways that “gain the patient’s trust.” The two concepts “suggest tasks and roles set at the appropriate level” and “draw out interests, needs, and desires” are preliminary to initiating actions, and were believed to represent approaches that incite action after building a trusting relationship.

Next, two concepts that promote actual behaviors were developed. “Introduce opportunities for independent decision-making” was founded on 17 specific examples from the text data of the interviews, such as “Guide the patient to make his/her own decisions and judgments,” “Formulate options and create a situation where the patient makes a selection on his/her own to acclimatize the patient to thinking and making decisions autonomously.” Specifically, patients should decide from among the available options even for things that may seem trivial, particularly in Stage 1 when it is especially difficult for the patient to initiate actions. “Providing support [for the patient] to gain successful experiences” offers a chance for the patient to experience that he/she is capable of doing certain things. These two concepts were believed to promote recovery of self-leadership by encouraging the patient to experience control over his/her own behavior.

Furthermore, “Create opportunities to reflect on each experience” was believed to be a concept that follows action. Reaffirming the accomplishment of something that the patient failed at in the recent past was considered to promote a clearer recognition of the able self. This reflection and confirmation would also

mean to “understand the patient” at present, which in turn would lead to “mitigating anxiety” and “gaining the patient’s trust,” to complete the cycle of interactions that constitute this model.

There are also two concepts that were not included in this cycle. Both were highly likely to be ineffective in the inert Stage 1, and would only be effective in Stages 2 and onwards. “Create opportunities to interact with others in similar situations” introduced to a person in Stage 1 rarely led to self-led actions due to rejecting attitudes, such as “It does not apply to me because I am different from that person.” Thus, it was believed to only help patients in Stage 2 or later to move on to the next stage. “Convey interest and confidence in the patient” also led to the reverse effect in Stage 1 patients, who often shut themselves off more adamantly, and would only be helpful in prompting patients in Stage 2 or later to progress to the next stage.

Discussions and revisions were repeated with consistent focus on the analytical themes, subjects of analysis, analytically focused person and focus to achieve results that were approved as pertinent by those experienced in long-term caring for people with disabilities.

Discussion

Through the discussions, we hypothesized a flow that promotes the recovery of self-leadership by understanding patients with disabilities, mitigating their anxiety, and gaining their trust as a precondition for other interactions initiated by the people surrounding them. Furthermore, real experiences gained in response to appropriate suggestions and confirmation by reflection led again to understanding within the patient, which completes the cycle that comprises this model.

This model schematizes behavioral changes that promote self-leadership and allow individuals to act and live in their own way. The validity of this model is discussed in the following section with reference to other established theories that also elucidate behavioral change.

The finding that “Gaining the patient’s trust” is the fundamental starting point for the interactions parallels the approach used in coaching [12], specifically that the preliminary stage of coaching most requires the formation of a solid rapport/relationship of trust. The other interactions are not possible without gaining the patient’s trust; thus, it was considered a required concept for Stages 0–3. There are also other similarities between the flow of the present model and the coaching process. In terms of flow of approach, this model forms a cycle that starts by understanding the patient, making appropriate suggestions to prompt real experiences, recognizing through reflection, and coming back to understanding the patient. The coaching process has many things in common with the present

model in that it promotes desired behaviors by understanding the current status, setting goals, clarifying the disparity between the current status and envisioned goal, planning the actions, and following up. However, the present model distinguishes itself from the coaching process in that it is structured according to the patient's stage of recovery of self-leadership (adaptation stage), how "Understanding the patient" fits under "Gaining the patient's trust," and how "Opportunities for independent decision-making" and "Support for successful experiences" are incorporated into the process rather than being considered a skill. In that sense, this model is more specialized for the recovery of self-leadership in people with acquired disabilities.

The interactions promoted in this model are not instructive, but are supportive in nature and can be considered similar to responses in motivational interviews [13, 14]. Motivational interviewing is a method of supporting people to make desired changes in various contexts. The interventions are not intended to instruct by providing solutions or advice, but are based on the premise that people can find solutions only in a safe atmosphere of positive empathy where they are free to explore their experiences [13, 14]. Empathy draws out the capacity for recovery [15], and explains the effectiveness of supportive interactions in this model. "Create situations in which the patient can do something by trial and error in safety," "Approach with a long-term view without rushing to arrive at a conclusion," "understand the patient's current status," "suggest tasks and roles set at the appropriate level," "provide support to gain successful experiences" and "create opportunities to reflect on each experience" are not instructions, advice, or proposed solutions, but are intended to promote safe and supportive settings in which the patient is repeatedly exposed to situations in which he/she perceives that success is attainable. Motivational interviewing theorizes that constructive behavioral changes are fostered in an atmosphere that promotes acceptance and confidence in which the patient can explore the disparities between the current status and personal ideals and values without fear [13, 14]. It is believed to promote changes that can foster self-led actions for patients throughout Stages 0–3 of the Model of Recovery of Self-Leadership.

"Provide support to gain successful experiences" is the only type of interaction mentioned above that is valid in Stages 1–3. This is because patients in Stage 0 believe that they are capable of doing things that they are actually not capable of doing. Patients in this stage first need to become aware of their incapacities before entering the subsequent stages that boost their self-efficacy by achieving successful experiences. Stage 0 promotes awareness of the divide between the current status and desired state to lead patients to Stage 1, in which they begin to gain a "Vague recognition of the disabled self." In this period, the patient is very

"ambivalent," the corresponding notion in motivational interviewing. Ambivalence refers to having conflicting attitudes of desiring change and defending the current status [13, 14]. Awareness of the importance of change is associated with the degree of disparity between the "current status" and "desired future state." A certain contradiction is necessary for motivation, and a larger contradiction would also strengthen the awareness of the importance of change. Furthermore, ambivalence will not be present without some disparity between the "current status" and "desired future state." The first step to change is to "enter the state of ambivalence." Larger disparities intensify the ambivalence, and greater ambivalence also increases the potential for change [13, 14]. Interactions in Stage 0 are intended to promote recognition of the difference between the current status and the desired future state by "Presenting a role model to explain the disability and outlook," and prompt awareness of the contradiction by "suggesting tasks and roles set at the appropriate level" and "creating opportunities to reflect on each experience."

The present model is similar to the "Staging and processes of change" model [16, 17] in that it focuses on staging and approaches in human behavioral changes. "Present a role model to explain the disability and outlook" in the present model is effective in Stages 0 and 1 of the Model of Recovery of Self-Leadership [9], which is characterized by resistance to taking action, but decreases in importance in Stage 2 and later. Similarly, the Stages of Change model teaches that education to raise awareness about the benefits of changing behavior is important in the transition period from the Precontemplation to Contemplation stage, but education does not promote the subsequent steps of behavioral change [17]. "Presenting a role model to explain the disability and outlook" in the present model corresponds to education, and the Stages of Change model supports its effectiveness up to Stage 1.

The tasks and roles in "suggest tasks and roles set at the appropriate level" refer to tasks and roles with clearly defined levels of difficulty that are neither too easy nor too difficult for the patient, and there is some commonality with the concept of "Skills and Challenges" in the flow theory [18, 19]. Flow is a state of mind characterized by sustained concentration, absence of slowness and sense of control under specific conditions including a clear goal, immediate feedback and balance between challenge and skills, filled with excitement and not wanting that state to come to an end [18–20]. In other words, activity on the verge of the balance between skill and the size of the challenge is something that can be accomplished with some effort. Thus, there is believed to be an appropriate level of difficulty that advances gradually in tasks in Stages 0–3 in the Model of Recovery of Self-Leadership. Furthermore, the immediate feedback produced by "creating opportunities to reflect on each

experience” in this model promotes flow and links to the patient’s self-motivated behaviors.

“Introducing opportunities for independent decision-making” promotes motivation and self-reliance to foster self-leadership, thereby promoting intrinsic motivation [20]. Intrinsic motivation is associated with activities that are goals in themselves and psychological states in which we are completely engrossed in the activity itself. Even a small opportunity for choice increases intrinsic motivation, and engages us in the activity with more passion and fun [20]. In terms of behavioral change for the management of chronic diseases, people experience a stronger sense of determination when they are given two options instead of one [17]. People in Stage 1 or early in Stage 2 with less motivation of the three elements of self-leadership have little intrinsic motivation. This indicates why “Introducing opportunities for independent decision-making” is most important in these stages.

The relationships between the people with disabilities and the professionals surrounding them are compared to the Physician-Patient Relationship model [21] according to the stages of the Model of Recovery of Self-Leadership. In the early stages of developing the disability, the relationship is characterized by paternalism because it is difficult for the patient to act in self-led ways. Transitioning from Stage 0-1 to later stages is more likely to follow the interpretive model, as it requires elucidating the values of the patient, presenting a role model, conversing in non-instructive ways to assist in decision-making, and communicating supportively through “reflecting on each experience” in the successful accomplishment of actions. In Stage 3 and onwards, the medical staff convert to the informative model, in which their job is to provide information to the patient and act according to the patient’s choices.

To summarize, the interactions of surrounding people that promote self-leadership are reviewed by stage. Stages 0 and 1 start with “support.” In Stage 2, the preparatory stage to taking action, surrounding people advance expectations in tandem with the patients’ capabilities. In Stage 3, in which actions are accompanied by confidence, surrounding people engage in standby support in which they provide help as needed but generally remain as supportive observers. Finally, people surrounding the patients with disabilities learn from them in Stage 4, when they have become capable of living within a new value system. While the surrounding people “accept patients as they are” in the initial stages, the patients begin to accept themselves the way they are as they advance through the stages.

As the qualitative stage of the study on self-leadership ends, we plan to develop a self-leadership staging assessment scale, integrate specific measures, and initiate a quantitative study derived from this model to investigate the effects of “self-leadership” in

improving daily life for individuals.

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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