

## ORIGINAL ARTICLE

# Stroke Survivors' Experiences and Needs during the Decision-making Process Considering Rehabilitation Options: A Pilot Descriptive Study in Japan

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**Objectives:** The purposes of the present study were to describe stroke survivors' experiences and to identify their support needs when faced with decisions about rehabilitation. **Methods:** Based on the Ottawa Decision Support Framework needs assessment, semi-structured interviews were conducted with 15 stroke survivors. The degree of participation in decision-making and anxiety were assessed quantitatively. All interview transcripts describing their experiences and emotions were qualitatively analyzed. **Results:** All participants had hemiplegia but could perform their daily activities unassisted. Most participants played an active role in decision-making, but 13 patients felt some anxiety when choosing chronic-phase rehabilitation programs. Qualitative analysis identified 19 codes, of which 13 were categorized into the four factors of knowledge, values, certainty, and support. The codes related to patient feelings of anxiety and insecurity about making decisions were "lack of information about options," difficulty in "selecting appropriate information," and "lack of support" from medical staff. Trustworthy specialist support and prior knowledge of rehabilitation were identified as factors that could help patients feel more secure about making decisions. **Conclusions:** To support stroke survivors in their decision-making about rehabilitation, each patient should be given a long-term perspective on stroke rehabilitation and sufficient information on rehabilitation options tailored to their individual needs. Decision aids for stroke survivors built on these findings will be used in clinical practice, and their efficacy will be verified in future studies.

**Key Words:** decision aids; decision support techniques; patient participation

## INTRODUCTION

The provision of support for patients to assist in their decision-making in various medical situations is becoming prevalent in clinical practice. Active participation of patients in medical decision-making and the ability to choose the appropriate treatment options based on appropriate information and patient values or preferences are important in maintaining patient engagement in treatment programs. However, due to the complexity of treatment options and the uncertainty of

clinical outcomes, patients can become conflicted and anxious when faced with making medical decisions. To relieve patients of such dilemmas, decision aids for some medical problems have been developed to help patients make decisions with confidence.<sup>1)</sup> Decision support is mainly required for patients with cancer,<sup>2)</sup> other life-threatening diseases, or psychiatric problems<sup>3)</sup> for them to choose between treatment or end-of-life care options. However, for many other medical problems, there are few practice reports dealing with decision support or decision aids.

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Stroke survivors are required to make a series of important decisions about treatment options during their transition from acute care to the treatment of chronic conditions. Choice of treatment options during rehabilitation is particularly important because of changes in the patients' functional status, rehabilitation needs, and social support systems. Such choices are inevitable for stroke survivors, and many may find the process challenging. It has been reported that the rehabilitation needs of many stroke patients remain unfulfilled.<sup>4)</sup> Another study, a review of qualitative studies dealing with the experience of inpatient stroke rehabilitation, showed that patients wanted information to help them understand stroke recovery and the rehabilitation processes, but they felt stressed if the information they received differed or conflicted among specialists.<sup>5)</sup> These previous studies convinced us that stroke patients need decision support using common and integrated tools (decision aids) when they choose rehabilitation options. However, despite these perceived needs, support tools for making decisions about stroke rehabilitation are not currently available.

The primary objective of this explorative study was to determine the experiences and emotions involved when patients with stroke make decisions about rehabilitation and to understand their needs for decision support. This study was guided by the Ottawa Decision Support Framework (ODSF).<sup>6)</sup> The Ottawa Hospital Research Institute provides steps for implementing patient decision support, and the first step is to 'identify decision needs by qualitative analysis,' which was the focus of this study. The findings of this study will help to build an appropriate decision support tool (decision aid) for stroke patients.

## MATERIALS AND METHODS

### Study Setting

Acute–subacute phase stroke rehabilitation is covered by the national medical insurance system in Japan. Acute-phase stroke rehabilitation begins while patients are undergoing treatment at acute care hospitals. Following emergency treatment, patients who require intensive rehabilitation after stroke are transferred to a *Kaifukuki* (convalescence) rehabilitation ward or hospital that offers inpatient rehabilitation for up to 150 days. Most stroke survivors who leave this ward or hospital are required to shift to home-based rehabilitation, which is covered by long-term care insurance.

Because of this medical and long-term care system, most patients who survive strokes are obliged to make major decisions about their rehabilitation twice during their recovery.

The first is made during the acute phase. Patients must choose a convalescence rehabilitation hospital, another facility, or immediate discharge home with or without home-based rehabilitation. For cases in which patients are transferred to rehabilitation hospitals, which is a major path for disabled stroke patients, the second decision is required upon discharge from the rehabilitation hospital. At this time, patients must select a home-based rehabilitation program.

### Participants and Settings

The study recruited consecutive stroke patients referred to Keio University Hospital for chronic-phase rehabilitation. Patients that met the following criteria were included: age 20–80 years, stroke onset at 6 months or more before the study, and sufficient communication capacity with Functional Independence Measure (FIM) scores of 5 or higher for comprehension and expression.<sup>7,8)</sup> Written, informed consent was obtained from each patient before their participation in interviews. The sample size was determined by saturation.

### Data Collection

The ethics board at Keio University Hospital approved the present study (approval number: 20160017). Patients were informed that participation was completely voluntary and that their treatment would not be affected regardless of whether they chose to participate in this study. Semi-structured face-to-face interviews based on the ODSF needs assessment were adapted to determine the decision-making processes of the patients regarding rehabilitation. A series of closed and open-ended questions were presented (see below). Given that most stroke patients make major decisions during the acute phase and the chronic phase, the same questions were used in each phase to determine the needs of patients according to the treatment phase. All responses and conversations were audio-recorded.

1. Please tell us about your experience when you selected a subacute-phase rehabilitation program during the acute phase of the stroke.

1) To what degree did you participate in decision-making? Answer on a scale from 0 (deferred decision-making to others) to 10 (fully participated in decision-making).

2) Did you feel any kind of difficulty or anxiety when you made the decision? If you felt some anxiety, how anxious did you feel? Use the visual analog scale to rate anxiety from 0 (none) to 10 (maximum anxiety).

3) Please tell us how you felt when you made the decision. What kind of support do you think would have been helpful for your decision-making?

2. Please tell us about your experience when you selected a chronic-phase rehabilitation program during the subacute to chronic phase of the stroke.

Questions 1) through 3) were the same as above.

### Quantitative Analysis

The degree of participation in decision-making and the level of anxiety were measured using a 100-mm visual analog scale (VAS) graduated in 10-mm marks and scored 0–10. Participants marked their responses on the VAS, with a mark at 0 mm indicating a score of 0 and a mark at 100 mm indicating a score of 10.

### Qualitative Analysis

Audio recordings were transcribed and segmented according to relevance. All transcripts from interviews were imported into NVivo 10 (QSR International Japan KK, Tokyo, Japan) for content analysis.

The main analysis involved the primary author, who coded the transcripts to identify general themes. The other authors then reviewed and modified the codes, taking a literal and reflective approach to assessing the data. Code sets of each treatment phase were categorized according to the decision-making factors specified by ODSF. To guarantee study consistency, every step of data analysis was shared among the research group members.

## RESULTS

### Participant Demographics

**Table 1** shows the demographics of the 15 consecutive patients who met the inclusion criteria. All had experienced a stroke between June 2016 and March 2017. Their median age was 56 years, and the median elapsed time from stroke was 14 months. All 15 patients achieved full comprehension

**Table 1.** Demographic characteristics of the 15 patients with stroke

Characteristic	n
Sex, male/female	7/8
Age, years	56 (38–71) <sup>a</sup>
Stroke type	
Cerebral infarction	6
Cerebral hemorrhage	9
Elapsed time from stroke, months	14 (8–55) <sup>a</sup>
Affected side, right/left	4/11

<sup>a</sup> Data given as median (range).

(FIM 7), 4 had mildly restricted expression capacity (FIM 6) because of aphasia or dysarthria, but all were capable of completing the interview. All participants had hemiplegia as a sequela of stroke, with a median motor Stroke Impairment Assessment Set<sup>9)</sup> score (possible range 0–25) of 12.3. At the time of the interviews, all participants could perform their daily activities without support. All patients had experienced transfer to and discharge from rehabilitation facilities. The median duration of interviews was 40 min.

### Participation in Decision-making

During the acute phase, two patients answered that they did not participate in decision-making (0/10), three played some part in decision-making (5/10), and ten indicated full participation (10/10). For the chronic phase, two patients indicated some participation (5/10), and the others perceived that they played a full (or nearly full) active role (10/10) in making decisions.

### Anxiety Associated with Decision-making

Feelings of anxiety over decision-making were measured using a VAS (0–10). The median anxiety level was 0 during the acute phase and 5 (interquartile range 1–10) during the chronic phase. Six of the 15 participants reported that they felt some anxiety regarding rehabilitation during the acute phase. In contrast, 13 participants reported some anxiety and 5 reported high anxiety regarding decisions about rehabilitation during the chronic phase.

### Qualitative Analysis of Interviews

A total of 448 transcripts were obtained from 15 interviews. Transcripts that stated only facts and those with duplicate information were eliminated, leaving 206 transcripts for analysis. Seventy-two transcripts were about decision-making during the acute phase and 134 concerned the chronic phase.

### Coding and Analysis Using Decision-making Factors

Nineteen codes were determined from the 206 transcripts after analysis according to meaning and context. Thirteen codes were categorized into the factors of knowledge, values, certainty, and support that were associated with medical decisions made by the patients (**Table 2**). The remaining six codes were not related to any of these factors but were considered to have some influence on decision-making.

**Table 2.** Coding and analysis of the factors related to decision-making

Factor	Code	Participants (n)	
		Acute phase	Chronic phase
Knowledge	Lack of information about options	6	10
	Selecting appropriate information	0	6
	Prior knowledge of stroke rehabilitation	4	0
Values	Unsure about what is important	4	0
	Good functional recovery	7	5
	Continuing same rehabilitation program	0	10
	Family burden	4	4
	Preferences	0	2
Certainty	Certain about the necessity of rehabilitation	4	10
	Uncertain about choices of rehabilitation options	0	6
Support	Recommendations from family members or friends	4	5
	Recommendation from trusted medical staff	0	5
	Lack of support	0	6
Others	Lack of options	5	11
	Anxiety about the future	8	0
	Anxiety about activities of daily living at home	0	3
	Anxiety about stroke recurrence	0	1
	Anxiety about decline in function after stroke	0	6
	Hopes and expectations for subsequent rehabilitation	3	1

### Factor 1: Knowledge

The code “lack of information about options” was identified during both the acute and chronic phases and was more prevalent during the chronic phase. Four patients commented that “prior knowledge of stroke rehabilitation” helped them to make decisions during the acute phase. Another code about knowledge was identified during the chronic phase regarding “selecting appropriate information.”

### Factor 2: Values

During the acute phase, four participants stated that they were “unsure about what is important.” Seven participants noted that they clearly valued “good functional recovery.” During the chronic phase, all participants knew what mattered to them, and their values became more definite, such as “continuing the same rehabilitation program.” “Family burden” was identified in both phases. Only two participants stated that they based their decisions on their personal “preferences.”

### Factor 3: Certainty

“Certain about the necessity of rehabilitation” was a common theme during the acute and chronic phases. However, six participants stated that they were “uncertain about the

choices of rehabilitation options” during the chronic phase.

### Factor 4: Support

The results showed that “recommendations from family members or friends” played an important role in decision-making during both phases. In contrast, the code “lack of support” became evident during the chronic phase. Support from medical staff at the rehabilitation hospital or from home-care specialists was often considered insufficient. One code that helped participants feel safer and more confident in their decision-making was “recommendation from trusted medical staff.”

### Other Codes

A few other codes did not fall under the above factors but were relevant and influential in the decision-making processes of the participants. “Lack of options” was a prominent code identified during the acute and chronic phases, and it was associated with dissatisfaction with medical or local care.

The code “anxiety about the future” was identified during the acute phase, and the participants remarked that they could not free themselves from general anxiety despite having enough information. Sources of anxiety became more

specific during the chronic phase, including “anxiety about activities of daily living at home,” “anxiety about stroke recurrence,” and, most commonly, “anxiety about functional decline after discharge.”

The code “hopes and expectations for subsequent rehabilitation” was relatively prevalent during the acute phase, but this code decreased during the chronic phase.

## DISCUSSION

This is the first known study to qualitatively analyze the needs of stroke patients when making decisions about rehabilitation in Japan. Participants were recruited from a single hospital, but the areas and hospitals where they underwent rehabilitation were all different, which helps to generalize the findings. However, the present study group was relatively young, with preserved abilities in daily activities, which should be taken into consideration when interpreting the results and making a decision aid based on these results.

The preliminary quantitative findings showed that stroke survivors played an active role in making decisions about rehabilitation. One study found that over half of Japanese hypertensive outpatients preferred a passive role.<sup>10)</sup> However, in the present study, over 80% of stroke survivors actively participated in decision-making and gave strong statements such as “my rehabilitation should be my choice”, which indicated that the desire to participate in decision-making was much deeper than the medical staff had expected. During the acute phase, some participants complained that they were “too confused to think” and had low physical tolerance, which would explain their lower rate of participation than during the chronic phase. Patients should receive support to participate in meetings and care conferences with medical professionals regarding continued rehabilitation and play active roles in making decisions while considering their physical and cognitive functions. Another finding is that many stroke patients felt strong anxiety about making decisions about rehabilitation, particularly during the chronic phase. Levels of anxiety in decision-making felt by stroke patients in their chronic phase were similar to or stronger than those felt by cancer patients in their treatment decision-making.<sup>2)</sup> Previous studies reported that patients with chronic conditions continued to experience uncertainty in decision-making because of ongoing treatment without the certainty of good consequences.<sup>11)</sup> These chronic care decisions were thought to have a greater need for an ongoing partnership between patients and the clinical team,<sup>12)</sup> and the present study showed that this might be true for stroke patients considering

rehabilitation.

Factors associated with decision-making and the accompanying anxiety were assessed qualitatively. Nineteen codes obtained from the qualitative analysis were organized based on knowledge, values, certainty, and support, which are the decision-making factors that reportedly contribute to decisional satisfaction and conflict.<sup>1)</sup> These factors also constitute the essential structure of the Ottawa decision aids.

Of the four factors, “knowledge” was the most powerful determinant of decision-making, because it was mentioned by most participants and correlated with other factors. “Lack of information about options” was commonly identified during both treatment phases and is frequently involved in decision-making situations for other medical problems such as depression<sup>13)</sup> and osteoarthritis.<sup>14)</sup> A previous study of the perspectives of medical staff and patients regarding information about treatment options showed that medical staff tended to restrict the availability of information based on the belief that information overload would confuse the patients. That study found that such an approach made the patients feel poorly informed.<sup>14)</sup> Stroke patients in the present study made efforts to obtain specific and accurate information about rehabilitation options, such as session time, frequency, and quality, beyond what is usually shared by healthcare specialists or rehabilitation facilities. Insufficient information would make patients perceive that they lacked support from healthcare specialists, which ultimately led to codes with negative connotations such as “uncertain about choices of rehabilitation options.” Furthermore, the code “selecting appropriate information” showed that patients were also concerned about the quality of information. Being aware that stroke impairment varies among individuals, many participants expressed the need for information specific to them and wanted help finding exactly what they needed from a large volume of information. Some participants regarded healthcare specialists who were familiar with their functions and rehabilitation options as “trustworthy” and considered shared decision-making with these specialists to be a powerful supportive factor. “Prior knowledge” was thought to be another important supportive factor, which explained the difference in anxiety levels during the two treatment phases. Eight of the participants in the present study indicated that they knew the rehabilitation system for convalescent patients before they were informed by medical staff because they themselves, their family members, or their friends had some knowledge or experience with rehabilitation during the convalescent phase after stroke. They mentioned that such knowledge helped them feel at ease in making decisions and

to have subsequent high hopes and expectations for rehabilitation. This showed that having “prior knowledge” is an important supportive factor in decision-making. In contrast, no patient was already familiar with or knew anyone nearby with prior knowledge about chronic-phase rehabilitation, and this contributed to their anxiety. A previous study also identified the lack of not only information, but also of knowledge about rehabilitation programs as a major barrier to accessing the services.<sup>15)</sup> Patients with no prior knowledge would have difficulty processing the information provided by medical practitioners and may be hesitant to choose unfamiliar options. Time might be needed to educate the public but spreading knowledge about stroke rehabilitation with focus on its chronic phase would be effort well spent, given that stroke is highly prevalent in Japan. Furthermore, there appears to be an urgent need to inform stroke patients about the optimal long-term perspective on stroke treatment and rehabilitation in the early treatment phase before they face making decisions about chronic-phase rehabilitation.

Individualized and appropriate information must be organized based on the values of individual patients. “Values” played a vital role in medical decision-making, and “good functional recovery” was a value associated with both treatment phases. Another specific value, “continuing the same rehabilitation program,” was identified. This value was often tied to another code with a negative connotation, namely “anxiety about decline in function after stroke.” The confidence of patients about rehabilitation during the convalescent phase changed to anxiety when they had to modify their program after leaving a rehabilitation hospital. To satisfy patients in this regard, it is important to have them learn and practice ‘self-rehabilitation’ including self-care, exercises, and adequate levels of physical activity to manage impairment while participating in inpatient rehabilitation. Repeatedly practicing and acquiring such ‘self-rehabilitation’ techniques, which patients can continue in the same way after discharge, would help them reduce anxiety associated with changes in their rehabilitation situations after discharge from hospital. Because many patients were anxious about changes in the transition and felt insecure with regard to making decisions about home-based rehabilitation service options, providing opportunities for them to take enough time to discuss these concerns with trustworthy professionals might be important. Discussion about home-based rehabilitation should start in the early part of a patient’s stay in rehabilitation hospital and should be repeated after discharge; however, the supporting professionals will not always be the same between these time periods. For consistent support to make patients feel secure,

their values and actual processes of decision-making should be noted, and appropriate information passed on to professionals taking over the support role.

The code “family burden” that was identified in acute and chronic phases has also been recognized in another study regarding home-based stroke rehabilitation,<sup>16)</sup> but relatively few participants in the present study touched upon this theme. Despite a lack of information about rehabilitation *per se*, participants thought that social workers or home-care specialists tended to focus on matters associated with reducing family burden. This is supported by the fact that most Japanese articles<sup>17,18)</sup> describing support and guidance for the discharge of stroke survivors emphasize “reducing family burden” as a key topic. Medical practitioners must be conscious of this tendency and make efforts to identify and respect the values of each patient. These outcomes obtained by qualitative analysis were not in major conflict with the preliminary quantitative findings, which supported this study’s validity.

## STUDY LIMITATIONS

One major limitation of this study was that the present study group was relatively homogeneous. Some commonalities, such as age and functional status, might influence the results, especially in relation to the code ‘value.’ The study participants were relatively young, were independent in activities of daily living at the time of interview, and were focused on functional recovery and maintenance. Other values, such as returning to daily life and life-recovery balance, which were mentioned in a previous descriptive study of rehabilitation,<sup>19)</sup> were not identified in the present study. Other values could have been explored among more severely disabled patients. Therefore, the present findings can be applied to stroke patients of a similar age group and functional characteristics, but further studies of patients with different backgrounds, especially age and functional status, are needed.

## CONCLUSION

In the present study, stroke survivors played active roles in decision-making regarding rehabilitation. However, the process involved anxiety, especially during the chronic phase, which meant that they had greater needs for decision support at that time. This support would include not only providing sufficient information about rehabilitation options, but also helping to select appropriate information based on their clinical status and individual values. Sharing a long-

term perspective on stroke rehabilitation in the early phase would help patients feel secure when they actually have to make decisions about chronic phase rehabilitation.

The efficacy of decision aids built on these findings will be verified in clinical practice and future studies. The needs of stroke patients with different characteristics should also be explored. Interfaces for decision aids need to be developed. Ideally, an electronic interface should be designed to facilitate the gathering and storage of relevant information for easy access by patients and medical practitioners.<sup>20</sup> Records of patients' values and decision-making processes with their decision aids would be helpful for consistent discussion and support.

### CONFLICT OF INTEREST

The authors report no conflicts of interest.

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