

# Differences in understanding and subjective effects of home-visit rehabilitation between user families and rehabilitation providers

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**Abstract.** [Purpose] This study aimed to clarify differences in understanding and subjective effects of home-visit rehabilitation between user families and rehabilitation providers. [Subjects] The subjects were home-visit rehabilitation providers and user families. [Methods] Home-visit rehabilitation providers and user families completed a self-administered questionnaire regarding the content and subjective effects of home-visit rehabilitation. For statistical analysis, the McNemar's test was used. [Results] Fifty pairs of responses met the inclusion criteria. The mean age of user families was  $65.0 \pm 11.2$  years, and 58.0% (29/50) were spouses of users (user mean age,  $77.7 \pm 10.2$  years; 48.0% (24/50) female). With regard to home-visit rehabilitation content, user families thought that paralysis improvement exercise, massage, and self-care activities were implemented to a greater degree than did rehabilitation providers. With regard to the subjective effects of home-visit rehabilitation, a higher proportion of user families noticed "maintenance/improvement" effects on symptoms and sequelae, as well as pain and suffering, compared with providers. [Conclusion] User families believed that rehabilitation would also improve users' symptoms and pain. Care providers should explain the aims of home-visit rehabilitation to users and their families, both of which require a strong understanding of home-visit rehabilitation in order to achieve rehabilitation goals.

**Key words:** Home-visit rehabilitation, Family's subjective effects, Rehabilitation program

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## INTRODUCTION

Japan's rapidly aging society has become a major issue in recent years<sup>1)</sup>. In 2000, a universal long-term care insurance system was established in Japan<sup>2, 3)</sup>, allowing access to publicly insured services such as home-visit rehabilitation. Home-visit rehabilitation encompasses exercise, training, and advice for users, as well as family education, provided in the home by physical therapists, occupational therapists, and speech-language therapists. Sharing of functional goals of home-visit rehabilitation among all parties involved is critical in determining the course of rehabilitation<sup>4)</sup>.

To improve the quality of care, care providers should pay close attention to client-centered views with respect to issues that are relevant to clients<sup>5)</sup>. Moreover, comprehensive geriatric assessment for each user is necessary<sup>6, 7)</sup>. Geriatric care assessment has been developed to be comprehensive and efficient<sup>8)</sup>, and care providers understand the importance

of individual needs of elderly people<sup>9)</sup>. While some studies have found that care providers and recipients differ in their views of care<sup>10-13)</sup>, little is known about the specific differences in perspectives.

Understanding the perception of each patient (client or user) is important in care settings<sup>5)</sup>. Care providers listen to the needs of care recipients and their families and then provide explanations regarding rehabilitation goals and plans using various documents created for this purpose. Specific rehabilitation goals and programs should be explained according to the level of each user's understanding. Our previous study found differences between users and providers in their understanding of home-visit rehabilitation programs<sup>14)</sup>. However, whether user families understand what home-visit rehabilitation entails and whether the awareness of user families is equal to that of care providers have yet to be determined.

In this study, we examined differences in understanding and subjective effects of home-visit rehabilitation between user families and care providers.

## SUBJECTS AND METHODS

Previously, six home-visit rehabilitation practitioners (three physical therapists and three occupational therapists) and one researcher (occupational therapist with home-visit

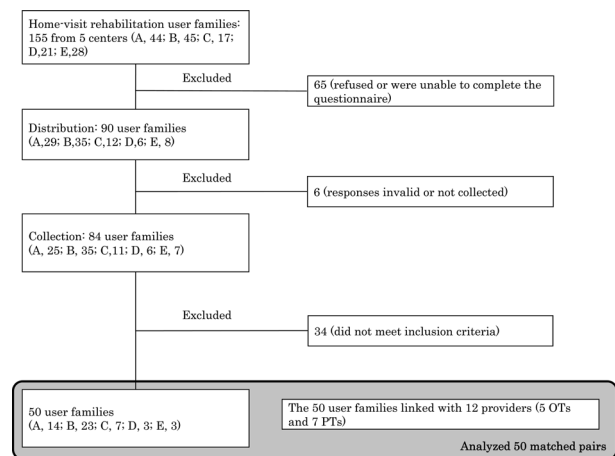
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rehabilitation experience) created a questionnaire consisting of 18 items pertaining to the content of home-visit rehabilitation and 17 items pertaining to its subjective effects in the areas of physical and mental function, basic movement, applied movement, and environmental improvements, as well as other items such as difficulties before home-visit rehabilitation<sup>14</sup>). As this questionnaire targets users and home-visit rehabilitation providers, we modified the items to target user families in this study. In this study, the families were asked about subjective care burden and subjective time of care giving time and free time<sup>15</sup>). All families received an explanation specifying that their responses would not be revealed to those in charge of home-visit rehabilitation and that traceable anonymity was provided for families as well as users.

We focused on differences between user families and care providers with regard to (1) understanding of home-visit rehabilitation content and (2) its subjective effects. To evaluate (1), we asked each user family and provider to “Please choose the level of implementation of the home-visit rehabilitation content within approximately the last month.” Possible answer choices included “implemented,” “not implemented,” and “do not know.” In the analysis, the responses of those who had engaged in home-visit rehabilitation within the past one month were labeled as implemented, while responses of those who had not engaged in home-visit rehabilitation or had chosen “do not know” were labeled as not implemented/unclear. To evaluate (2), we asked each user family, “How has the user’s condition changed since beginning home-visit rehabilitation?” We also asked each provider, “Have you noticed a difference in the condition of your user as compared with that when you began home-visit rehabilitation?” Possible answer choices included “It has gotten better,” “no change,” and “it has gotten worse.” In the analysis, changes occurring after initiation of home-visit rehabilitation were labeled as maintenance/improvement for “it has gotten better” and “no change” and as deterioration for “it has gotten worse.”

Among 155 user families making use of five home-visit rehabilitation centers for over a month, the self-administered questionnaire was distributed to 90, while paying due attention to issues such as mental and psychological burden and sudden deterioration of cognitive function. In terms of basic information about users, data were collected on gender, age, medical condition, cognitive function (the revised version of Hasegawa’s Dementia Scale<sup>16</sup>), activities of daily living (Barthel Index<sup>17</sup>), instrumental activities of daily living (Tokyo Metropolitan Institute of Gerontology Index of Competence<sup>18</sup>), and user services. In addition, characteristics of user families (e.g., age, gender, living conditions, and care burden) were collected by each questionnaire. Twelve home-visit rehabilitation providers from 5 centers answered the questionnaire for 155 users.

For the analysis, the inclusion criteria were families of users who were over 40 years of age, no missing data on family characteristics, and <10 items answered for the 18 items pertaining to content or 17 items pertaining to subjective effects. We analyzed responses to the 18 items pertaining to home-visit rehabilitation content and 17 items pertaining to subjective effects from families and linked them to the re-



**Fig. 1.** Participant selection process

Ninety pairs of home-visit rehabilitation providers and user families were given self-administered questionnaires. The final analysis utilized data from 50 pairs that met the inclusion criteria.

sponses of their care providers. Responses with missing data (i.e., characteristic data,  $\geq 10$  items on content or subjective effect) were excluded from the analysis. The McNemar’s test<sup>19</sup>) was used to compare proportional differences between user families and care providers, with statistical significance set at  $p < 0.05$ . Analyses were performed using IBM SPSS Statistics 20.

The study protocol was approved by the Research Ethics Committee of Seijoh University (2011C0007). The director of each center approved the study, since none of the five participating home-visit rehabilitation centers had an ethics committee. We provided an explanation of the protocol concerning data management as well as study objectives on the cover of the questionnaire. Specifically, it stated that the questionnaire envelope would be opened only by the researcher (i.e., not by the home-visit rehabilitation provider), and that not participating in the study would not in any manner confer a disadvantage in service use. No identifiable information of any user (name, medical record number, etc.) was taken out of the centers.

## RESULTS

Responses were received from 81 pairs of user families and providers of five home-visit rehabilitation centers. Of these, 50 pairs that met the inclusion criteria were analyzed (Fig. 1). Providers provided an explanation of the home-visit rehabilitation planning document concerning rehabilitation goals and programs for 46 (92.0%) of the 50 user families. The mean user age was  $77.7 \pm 10.2$  years, 48.0% (24/50) were female, and 62.0% (31/50) were living with their spouse. The main medical condition was cerebrovascular disease in 32.0% (16/50) of users, and the mean frequency of use during the month the survey was conducted was  $5.8 \pm 2.7$  times. The mean age of user family members was  $65.0 \pm 11.2$  years, and 84.0% (42/50) were living with the users (Table 1).

With regard to the content of home-visit rehabilitation,

**Table 1.** Characteristics of users and user families

	Users (N=50)			User families (N=50)		
	N	%	Mean ± SD	N	%	Mean ± SD
Gender						
Female	24	48.0		35	70.0	
Living conditions						
Alone	4	8.0				
With spouse	31	62.0				
With children's family	12	24.0				
Other	3	6.0				
Living together				42	84.0	
Living apart				8	16.0	
Main disease						
Cerebrovascular	16	32.0				
Bone and joint	10	20.0				
Neuromuscular	11	22.0				
Disuse syndrome	2	4.0				
Dementia	3	6.0				
Other	7	14.0				
Unknown	1	2.0				
Age			77.7±10.2			65.0±11.2
Frequency of going out* (Number of times/week)			2.0±1.8			
Barthel Index			52.6±32.5			
HDS-R (N=30)			20.1±8.6			
TMIG			3.5±3.9			
Times of HR/month			5.8±2.7			
Relationship with user						
Spouse				29	58.0	
Son				7	14.0	
Daughter				13	26.0	
Daughter-in-law				1	2.0	
Care burden (current)						
Fair				11	22.0	
Little				28	56.0	
Some				8	16.0	
No burden				3	6.0	

\*Including day care, day service, going to hospital, etc.

HDS-R: Revised version of Hasegawa's Dementia Scale, TMIG: Tokyo Metropolitan Institute of Gerontology Index of Competence, HR: home-visit rehabilitation

user families tended to think that the following three items were being implemented to a significantly greater degree than did providers ( $p<0.05$ ): paralysis improvement exercise, massage, and self-care activities (Table 2). With regard to the subjective effects of home-visit rehabilitation, a higher proportion of user families were aware of maintenance/improvement effects on symptoms and sequelae, as well as on pain and suffering, compared with care providers ( $p<0.05$ ; Table 3).

## DISCUSSION

The present study analyzed responses from 50 pairs of user families and care providers who met the inclusion

criteria, and found that user families tended to think that home-visit rehabilitation comprised paralysis improvement exercise, massage, and self-care activities to a greater degree than did providers. On the other hand, a higher proportion of user families thought that home-visit rehabilitation was effective for the maintenance/improvement of symptoms and sequelae, as well as pain and suffering, compared with providers. We also found differences between user families and care providers in their awareness of subjective effects regarding maintenance/improvement of symptoms and pain. These findings suggest the need for providers to better explain the aims of home-visit rehabilitation to user families and to incorporate the aims based on an understanding of the family's awareness.

**Table 2.** Contents of home-visit rehabilitation within the past one month

	Analyzing pairs	User families		Providers		
	N	N	%	N	%	
Stretching and exercise of range of motion	47	43	91.5	39	83.0	
Muscle and physical strength	44	37	84.1	32	72.7	
Paralysis improvement exercise	40	30	75.0	7	17.5	*
Massage	43	26	60.5	10	23.3	*
How to move	47	35	74.5	30	63.8	
Floor sitting and standing	47	12	25.5	6	12.8	
Self-care activities	46	12	26.1	4	8.7	*
Indoor movement	49	34	69.4	30	61.2	
Outdoor movement	48	20	41.7	18	37.5	
Climbing stairs and entranceway	46	16	34.8	13	28.3	
Breathing	42	12	28.6	8	19.0	
Choking and swallowing	43	5	11.6	3	7.0	
Speaking, reading, and writing	44	11	25.0	8	18.2	
Self-training and advice	45	32	71.1	28	62.2	
Housing repair and devices	46	18	39.1	12	26.1	
Consultation for anxiety and worries	46	23	50.0	16	34.8	
Housework and leisure activities	45	5	11.1	5	11.1	
Working	49	1	2.0	0	0.0	

An “analyzing pair” consisted of a user family response and a provider response. Incomplete pairs were excluded from the “analyzing pairs” in each item.

McNemar’s test (binomial distribution) was used with statistical significance set at  $p < 0.05$ . \* $p < 0.05$

**Table 3.** Maintenance or improvement of user’s condition since beginning home-visit rehabilitation

	Analyzing pairs	User families		Providers		
	N	N	%	N	%	
Symptoms and sequelae	48	45	93.8	33	68.8	*
Pain and suffering	47	44	93.6	36	76.6	*
Risk of falling	50	47	94.0	43	86.0	
Decline of physical strength and fatigue	50	41	82.0	39	78.0	
Muscle weakness	49	42	85.7	39	79.6	
Decreased frequency of going out	45	37	82.2	42	93.3	
Choking and swallowing	48	45	93.8	45	93.8	
Forgetfulness	49	46	93.9	44	89.8	
Walking and moving	49	42	85.7	38	77.6	
Climbing stairs	47	38	80.9	41	87.2	
Use of public transportation	43	36	83.7	43	100.0	
Self-care activities	49	43	87.8	44	89.8	
Housework	37	30	81.1	36	97.3	
Work and hobbies	43	38	88.4	43	100.0	
Family relationships	48	48	100.0	48	100.0	
Friendship	44	42	95.5	44	100.0	
Anxiety about the future	48	45	93.8	44	91.7	

An “analyzing pair” consisted of a user family response and a provider response. Incomplete pairs were excluded from the “analyzing pairs” in each item.

McNemar’s test (binomial distribution) was used with statistical significance set at  $p < 0.05$ . \* $p < 0.05$

In Japan, where care is significantly influenced by the family, thorough explanations regarding care are required for both care receivers and their families. Thus, there is a need for the development of strategies to improve and promote communication between rehabilitation providers and user families. Hagino M et al. pointed out that users expect items related to functional training, basic operations, and movement to be incorporated into home-visit rehabilitation<sup>20</sup>. Previously, we reported differences between reasons for service use and daily life goals in the same study population<sup>21</sup>. In addition, from the family's perspective, "personally meaningful activities" were included among users' daily life goals<sup>22</sup>.

This study has some limitations worth noting. First, our results may not be generalizable to the general population. For instance, other regions may have different numbers of home-visit rehabilitation centers and manpower, and regional cultures and characteristics of local residents are also likely to be different. However, the present study targeted five different home-visit rehabilitation centers that remained anonymous, and the analysis was performed by matching the providers with each user and his/her family. Therefore, our results will likely provide insight that will be helpful in clinical practice.

In conclusion, the present study suggests that user families may overestimate the role of home-visit rehabilitation (e.g., physical function improvement, massage), as well as the effects of rehabilitation on symptoms and pain, more than providers do. Therefore, providers should pay attention when providing explanations regarding the content and aims of rehabilitation to each user as well as his/her family.

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