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#### Research Article

# A Study on Evaluation of Post-Stroke Self-Management Support Program for Social Life Support. Towards Building Supporting Systems for Self-Help/Mutual-Help in Communities

#### Tomoko Tachibana

Center for Public Health Informatics, National Institute of Public Health, Japan

Corresponding author: Tomoko Tachibana, MD, MPH, PhD 2-3-6 Minami, Wako city, Saitama prefecture 351-0197, Japan, Tel:+81-48-458-6206; Fax: +81-48-469-0326

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#### **Abstract**

In this study, I focused on the "treatment" of medical institutions as a public health issue in chronic disease control. The purpose of this study was to investigate the ideal way of supporting social life for post-stroke epilepsy patients and their families by adding the qualitative analysis results to our quantitative evaluation results of the development programs that were already published. The survey target was 29 respondents to a self-administered questionnaire that took part in the development program. The homework task "What I want to try" was imposed, and free answers were gathered from the impressions that were experienced and "impressions and opinions on the course/program", and a narrative analysis was performed. The following items were extracted as program evaluations: "Specific goal setting and execution experience," "Amusement," "Opportunity for participants to set their own opportunities and places," "Interchange of patients, families, supporters, etc." "Face various obstacles by recognizing 'what (the patient) can do' that can be discovered by devising and supporting without prejudice or first "impression," "Minimize texts distribution," "Relaxed group work," "Participants themselves set their own "self-management" and "think about their own way." The program we developed seemed to have been accepted by the target group and provided an opportunity and a place to think about how to live a sick life and life as oneself. In Japan, access to medical care is guaranteed and the transition to a comprehensive community care system is in progress. In the future, the "self-management support program" such as this study used should be promoted, to utilize for "self-help/ mutual-help support measures" in each region in order to ensure a healthy and safe independent life.

Keywords:post-stroke epilepsy, community-based integrated care system, chronic disease control, self-management support program

#### Introduction

In chronic disease control, not only prevention but also care of patients with chronic diseases has become a public health issue in recent years [1,2]. The author has discussed the public health system that Japan needs to strengthen in the future, based on a wide range of medical experience and achievements [3-5]. Providing participants (patients,families,etc.) with the program developed in the "Self-Management Support Course for Post-Stroke Problems (hereinafter "Course")" and the effect of "reducing behavioral restrictions due to pain" by quantitative effect evaluation I have reported [6, 7]. In this study, we will analyze the free answers in the survey. The purpose of this study is to explore the ideal way of social life support for post-stroke epilepsy patients by conducting a program evaluation together with the above quantitative evaluation results.

#### Methods

# Program development and holding "Self-management support courses for various problems after stroke"

In this study, the purpose of the program development was set as "to help the patient think so that the patient can take appropriate actions to be healthy from his/her own point of view." The 1st and 2nd "Problems after Stroke Self-Management Support Course (hereinafter simply referred to as "course")" were held. The survey method was carried out according to Reference [7]. A self-administered questionnaire was used for the "homework survey" in this study. The contents consist of "record of home-work task," "question item 1\_impression of experiencing home-work task," and "question item 2\_impression/opinion on course/programs."

#### Methods

The study subject is 29 respondents who participated in either the 1st or 2nd course. Recruitment of course participants was publicized through the use of hospital epilepsy centers and social capital. At the end of the 1st course program, a homework task of "practicing and recording "what you want to try" that you set" was imposed. During the two weeks between the end of the first course and the start of the second course, participants worked on their own homework tasks. Then, while recording the efforts, the answers to the homework survey were recorded in a timely manner. Answers were collected after the second course and analyzed using narrative analysis [8].

#### **Ethical considerations**

This study was approved by the Research Ethics Committee of the National Institute of Public Health. (Approval number: NIPH-IBRA #12262).

#### Results

- 1. Study subjects: [Table 1] shows the breakdown of 29 respondents to the homework survey.
- 2. The setting contents of the homework task "I want to try" were analyzed into the following categories: "Challenges to solve challenges related to work (work/hobbies etc.)" "Types of leisure (distraction etc.) matters" "Efforts to in-crease the number of times" "Challenges for new matters (Web family meetings etc.)."
- 3. Question item 1)The categories of "Impressions I experienced" were analyzed as "Understanding the significance of setting goals," "I thought it would be easy to achieve a goal, which was unexpectedly difficult." [Table 2]
- 4. Questionnaire 2) The main summaries of "impressions/ opinions on courses/programs" were analyzed as follows: "It was fun," "A better understanding of self-management" "Patients/family/supporters, I was glad to hear the stories of each of them," "The matter shared in the group work is that each person has their own disability, but people should face each other without prejudice or first impression. With a little ingenuity and support, we can do a lot of things," "I think that I was able to think about myself in a relaxed group work and make it my own way about self- management.

Though, by only getting the materials, people tend to be satisfied, such a course like this was fresh." [Table 3].

#### **Considerations**

Stroke is the third leading cause of death for Japanese, and is a general term for "cerebral hemorrhage", "subarachnoid hemorrhage", and "cerebral infarction" [9]. Until the mid-1960s, Japan had extremely high levels of cerebral hemorrhage due to high blood pressure, which resulted in stroke mortality rates that were twice as high as in the West. At present, cerebral hemorrhage has decreased due to progress in the development of antihypertensive drugs that can control blood pressure well, and in recent years, cerebral infarction accounts for 75% of strokes. Strokes often have sequelae, which is a major cause of bedridden and other conditions requiring nursing care. Therefore, coping with post-stroke epilepsy that frequently occurs is an issue.

In the course program evaluation that has already been conducted, we reported the trend of decreasing the SF-12v2 Japanese version BP (bodily pain) (p=0.024) by comparing the participant responses before and after the Wilcoxon signed rank test (significance level 0.007) [7]. We conducted an exploratory analysis, and detected the effect that "pain tends to reduce behavioral restriction" in the study. Therefore, in order to improve the program itself, it will be necessary to further explore "types of pain and relief measures" as well as "pain relief measures" together. We would like to further improve the program in the future.

On the other hand, most of the participants in the course program developed and implemented this time were patients and families who live in a social life while visiting a medical institution. Therefore, it seems that most of the people who have completed rehabilitation treatment in hospitals to a certain extent and are expected to live independently in the area. "Reconstruction of rights [10]" and "reconstruction of life [11]", which are the ideals of rehabilitation for patients and families to accept illnesses and disabilities after leaving the protected environment "in the medical institution," should be achieved in his/her own region. In order to realize this, it will be necessary to provide "opportunities and places" so that patients and families can think of "living with illness and life in their own way." It is expected that medical institutions have already applied medical profes-

**Table 1.** Breakdown of homework survey targets (n=29) [unit: name (%)]

Q 1 Course participation status	Participants only in the 1st course	Participants only in the 2nd course	Participants in the 1st and 2nd courses	Unknown
	6(20.7)	3(10.3)	19(65.5)	2(6.9)
Q 2 Respondent's position	1. Patient	2. Patient family	3.Others	Unknown
	6(20.7)	17(58.6)	4(13.8)	2(6.9)
Q 3 Sex	1.male	2.female	3.others	Unknown
	9(31.0)	18(62.1)	0	2(6.9)
Q 4 Age	Mean ± SD=60/9±10.6 (N=27,Excluding 2 unanswered)			

Q 5 Family living together (Multiple answers pos- sible)	1. Not living together	2. Spouse	3. Children (including children's spouse)	4. Father/Mother (including father/mother of spouse)	5. Brothers and sisters	6. Grand- children	7. Grandparents (including grandparents of spouses)	Unknown
	2(6.9)	20(69.0)	17(58.6)	3(10.3)	1(3.4)	2(6.9)	1(3.4)	2(6.9)
6 Work with income	1.Yes	2.No	3.Others	Unknown				
	14(48.3)	11(37.9)	2(6.9)	2(6.9)				
7 Wealthness for living	1. Very wealthy	2. A little bit wealthy	3. Neither wealthy/ poor	4. Not so wealthy	5. Not wealthy at all	Unknown		
	0	8	11	7	1	2(6.9)		

Table 2. Question item 1\_"Impression that I tried

category	Individual description example				
Comments that "discov	very" was obtained, such as the significance and utilization of experience and learning				
	I understood the significance of setting goals				
	In many cases, "it is difficult for one person, and it is necessary to work from others". It is important not to force it, to clarify the effects and outcomes, to lower the threshold, and to extend daily life.				
	I thought it important to continue to do it and to set goals that could continue.				
	I have set the task "Securing sleep". Execution proceeded by recording. By devising and trial and error to carry out, it led to motivation for the next goal.				
	It wasn't possible to achieve it just by setting the goal in mind, but I felt that "writing it" on paper changed the way I faced.				
	I was able to reconfirm the importance of working with a goal. To set goals, you need to understand your strengths. If there is a target value, the result will be easy to understand and I will be able to work hard.				
Comments on the prog	ress of setting/experience itself				
	I thought it would be easy, but I struggled unexpectedly.				
	After the onset, there were many criticisms from the patient to his family, which made him feel negative. For 25 years, I was blaming myself and just worried. I tried to laugh and I thought I would keep laughing in the future.				
	I tried to run with "dash", and made trial and error like the story of a rabbit and a turtle. Thank you for the opportunity to have a valuable experience.				
	I thought it was important to always be aware.				
	I realized the importance of keeping my promise.				
	I did my best.				
	I would like to continue to practice stretching and vocalization in the future.				
	I thought I could read while I was in the hospital, but that was not the case.				
	It didn't go as expected. I want to make an effort to review my lifestyle.				
	It didn't go as planned. I want to go at my own pace.				
	I was getting fat, but I lost 4.7 kg. You can do it if you do your best.				
	Depending on the weather, daily walking was difficult. I want to continue.				
	I would like to continue working on what I could not do in the future.				
	I couldn't quite do it. I couldn't concentrate on multiple things.				
	In the first half, I couldn't achieve my goal due to poor physical condition, but in the latter half, I happened to be able to achieve it with fun.				
	It's about 180,000 yen if I save 500 yen for one year. I can travel with my family. I have a lot of fun.				
	I decided to solve three questions a day. I think it would have been zero if no goals were set.				

sional guidance on diseases and medical treatment. Therefore, the provision of expertise and technology would not be the main responsibility of local health and welfare. With the transition to a comprehensive community care system in progress by 2025 [12,13], I think that intervention in the community should be "support for self-help/mutual help" based on an understanding of family medical care.

Hamamura. et al. have been developing regional rehabilitation activities centering on hospitals in Kitakyushu [14], and have proposed social inclusion [15]. In addition, Hamamura notes that "the functions of hospitals (medical care/nursing institutions)

can also be utilized for community development that supports independent living, and there are local needs" [16]. From this, it can be said that in the future it will be necessary to have an institution that carries out regional comprehensive activities and an institutional mechanism to evaluate those activities. In Japan, access to medical care is guaranteed by the universal insurance system. For this reason, independence living of diverse residents will require not only the provision of existing services, but also more detailed "support" for the lives of the residents who are connected to the community. The "self-management support program" verified in this study was considered to have been ac-

Table 3. Question item 2\_"Comments/opinions on the course/program

Category	Individual description example						
"It was fun."							
	It was very fun. I didn't think I could do it easily, so I had a hard time. I want to make the most of it when I was motivated.						
	It wasn't clear what to learn, but I noticed on the way and learned the importance of self-management. I wanted to know more about the concrete method. "Gymnastics" in the program was good. Smiles came out from everyone.						
	Family position. In order to spend a day by day, I am noisy, but I realized that it is important to have a good life.						
"My understand	ing of self-management has advanced"						
	I not only listened to the story, but also tried it out and got a concrete understanding. I thought that self-management was difficult, but I thought I could do it if I was conscious of it with a little chance. It was a good opportunity to learn new things.						
"It was nice to l	ear the stories of patients, their families, supporters, and their respective positions."						
	It was nice to be able to interact with various people. I am happy that I can exchange information. It was a very meaningful time. I want to participate again.						
	Patient family. I didn't talk to people, I was withdrawn. I participated in the course this time and once again realized that it was not only me that was difficult. I will go out as much as possible.						
	I felt that feeling and consciousness are important. If you have prints in addition to slides, it will be more memorable. Thank you for your valuable time.						
	Although I am doing something right now with the help of my family at home and the person in charge at work, I am worried about my income after my parent's death and retirement. In need of public support.						
	The instructions for sitting "please sit freely" were quite difficult. The content was learned. I want to participate again. We will cooperate in research as much as we want for research.						
	ing shared in the group work are: "Each person has different disabilities, but they should face each other without prejudice based on their prejudice or first impression. things that can be done with a little effort and support."						
	I think it was good that we could have a discussion at each table.						
	I was encouraged by the courage to hear from a family member who had a similar experience in a similar environment. I'd like to get the materials of the lecture.						
	Family 3 months after discharge. My family are understand the disability, but I am worried about how much I will understand if I return to the company in the future.						
"I think that I w such a course is	as able to think about myself in a relaxed group work, and have made it my own thing about self-management. Even if I get the materials, I tend to be satisfied, but fresh. was."						
	Supporter. I couldn't imagine what kind of course it was. I think that I was able to think about myself in a relaxed group work and make me understand self-management. Although I tend to be satisfied just by getting the materials, such a lecture was very fresh and meaningful.						
	I want a lecture by a social worker.						

cepted to a certain extent as a tool that met its purpose from the results of this study, so it can be expected to be used as a support tool. It was thought that in the future, the promotion of policies in the form of "support for self-help/mutual-help" should be aimed at ensuring healthy and safe independent living.

#### Limitations of this Study

In this study it was an exploratory study for a small group, so I did not know what kind of pain the participants suffered. And, as a method for evaluating patients and families who may have memory impairment, a self-administered questionnaire survey mainly based on memory recall might not have been optimal, and further study is needed in the future.

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#### **Disclosure of Conflicts of Interest**

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