

Research article

A Study on Development and Short-term Evaluation of a Self-Management Support Program for Post Stroke Survivors and Families

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Abstract

In recent years, in the control of chronic diseases, not only prevention but also care of patients with chronic diseases has become an issue in public health. In this study, we developed and implemented a self-management support program to enhance social life support for patients and families with various problems after stroke, and verified the effectiveness before and after the intervention by questionnaire survey. Respondents (n=25) were family (68.0%), women (64.0%), age 60.1 ± 10.6, living with spouse (72.0%), and 56.0% respondents had jobs with income. Comparison before and after the intervention by Wilcoxon's signed rank test showed that the post-intervention group tended to show a lower value in the item BP (bodily pain) than the pre-intervention group (p=0.024). Though this program was suggested to be effective for "reducing the impact of pain on behavioral restrictions", it was considered it will be necessary to be improved so that participants can learn how to do so by themselves.

keywords: post stroke survivors, sequelae, disabilities, self-management support program, interventional study, social support

Purpose

In recent years, the increase in the number of chronically ill patients and the accompanying effects have become a problem worldwide, and in chronic disease control, not only prevention but also care of chronically ill patients are issues in healthcare and public health [1]. The number of elderly-onset epilepsy patients in Japan is expected to increase to 439-549,000 in 2030, [2] and countermeasures for post-stroke epilepsy, which frequently occurs in elderly patients' stroke, are an issue. In the future, it is important to enhance measures to effectively support the community life of home care patients. Tachibana has pointed out that there is a need to promote the development of a self-management support system in a mature society Japan [3,4]. We developed and carried out a self-management support program for patients with sequelae such as symptomatic epilepsy complicated after stroke, with the aim of enhancing social life support. The purpose of this study is to verify the effectiveness of the program by assessing the physical and mental health and health-related quality of life of the course participants before and after the intervention. "Sequelae complicated after stroke" means epilepsy, depression, higher brain dysfunction, physical dysfunction, etc.

Methods

Program development and "Self-management support courses for various post-stroke issues"

Self-Management Education (SME) refers to the teaching of task-solving skills so that patients can take appropriate actions to become healthy from their own perspective [5]. In this study, we developed a prototype

program based on this principle and conducted two series of "Self-management support course for post-stroke problems (hereinafter simply referred to as "course")". The interval between each course is two weeks, and the outline of the developed program is as shown in Table 1.

The first course was held on January 25, 2020, and the second of the series took place on February 8, 2020, both of which were held in a conference room at the TMG Asaka Medical Center (Saitama prefecture, Japan). Participants of the courses were recruited for patients of stroke and their families, by posters at both medical institutions with epilepsy centers, and NPO organizations in the nearby areas in Saitama prefecture, Japan. With a view to fostering social capital surrounding patients, [6] the course participants were set as "patients with stroke and their families" ranging from 18 to 25 years across states. In 2000, India became one of the few countries to ban advertising of alcoholic beveragesⁱⁱ. However, to circumvent the legislation there has been an increase in 'Surrogate Advertising' whereby alcohol companies advertise products such as non-alcoholic beverages, or sponsor events, under the same brand name. Surrogate advertising has been challenged in the courts with some cases being upheld [4].

Objects and survey methods

The subjects of the survey are the participants of the first and second courses, who gave the consent to answer and cooperate. In the survey, self-administered questionnaires were distributed in each course and collected on the spot. The pre-intervention survey was conducted before the start of the first course, and the post-intervention

Table 1. Overview of the developed program. The "Self-management support course for post-stroke problems" was held twice in a series, whose interval was two weeks. Both of the first and second courses were held in a conference room at the *TMG Asaka Medical Center* (Saitama prefecture, Japan).

	Program theme	Contents	
1st course Jan 25, 2020 (150 minutes)	Understanding issues after stroke and draw positive self-management image	<ul style="list-style-type: none"> • Orientation • Small lecture ① • Small lecture ② • (Coffee break) • Self-introduction (by group) + Group work ① • Group work ② • Exercise (stretch) • Home work • For the next time 	<ul style="list-style-type: none"> • Problems after a stroke • What is "self-management" for post-stroke issues? • Do you have any problems in your daily life after the stroke? What is it? • Are there any "feelings you can't do" or "what you want to change" about the various issues after the stroke? What is it? • Dance for children and adults with disabilities • Self-configuration of what to try
2nd course Feb 8, 2020 (150 minutes)	Thinking about a positive self-management method for post-stroke issues	<ul style="list-style-type: none"> • Self-introduction (by group) + Group Work ③ • Small lecture ③ • Group work ④ • (Coffee break) • Small lecture ④ • Group work ⑤ • Exercise (stretch) • Closing 	<ul style="list-style-type: none"> • Oral practice report of homework • Problems after stroke; Self-management and what is needed for self-management support. • How did you feel the previous small lecture? • What is needed for self-management & for realization • "Realization of self-management support," and what you can do and make creative" etc. • Dance for children and adults with disabilities

Available at <https://www.asakadai-hp.jp/> (2020-2-27)(in Japanese)).

The participants (Fax./Tel./email) were mailed with explanatory documents related to the course and the survey. In addition, we asked for a pre-course answer to a questionnaire on health conditions and matters requiring special consideration, and requested a pledge on "protection of personal information" when participating in the course. Participants wore a nameplate with their own nickname, selected one of the four round tables prepared for each course, and sat down. At the start of each course, a booklet describing the time allocation of the programs for the day and the challenges of group work was distributed. During the "exercise (stretch)" time, the upright participants stood around each round table and moved their bodies under the guidance of the participants who had dance experience. In the first course, "Home Work", each participant set an initiative entitled "What I would like to try until the next time", such as exercise and improvement of daily life. The second course started with an oral report on the practice of "home work" in the first course.

** This program is an original version designed and created by the authors with reference to programs already conducted in clinical settings in Japan and programs of the Japan Association for the Management of Chronic Diseases.

Table 2. Composition of the Questionnaire and Scales Included in the Analysis

<p>Respondent's position, age, and gender, Japanese version of GHQ12 scale version [* 1], SF-12v2 Japanese version [* 2], chronic disease status (presence of illness / disability, Japanese version of modified Rankin Scale (mRS) [* 3], self-efficacy[*4], etc.</p> <p>[* 1] Japanese version GHQ12 scale version: The Japanese version of the General Health Questionnaire (GHQ) (12-scale version) was used to evaluate mental and physical health. In recent years, GHQ has been used not only to detect neurotic patients but also as an index of mental health of the general population and as a degree of stress response. The cutoff of the 12 scale version is 3/4 point and the confidence coefficient (Cronbach's α) is 0.85 [6].</p> <p>[* 2] SF-12v2 Japanese version: The quality of life was measured using a health-related quality of life scale, SF-12v2 [7]. 8 subscales (1. physical function: PF, 2. daily role function (body): RP, 3. bodily pain: BP, 4. general health view: GH, 5. vitality for 12 question scales : VT, 6.Social role: SF, 7. Daily role function (mental): RE, 8. Mental health: MH) and component summary based on factor structure ([Physical component summary (PCS: Physical component summary)], [Mental component summary (MCS)] and [Role / Social component summary (RCS)] were scored and analyzed.</p> <p>[* 3] Japanese version of the modified Rankin Scale (mRS): (1) The Japanese version of the modified Rankin Scale (mRS) [8] was used as a measure of the independence of living after the onset of stroke.</p> <p>[*4] Six scale questionnaire measuring self-efficacy against diseases, sequelae, and disabilities. A score from zero (No confidence) to ten (Very confident) is used for each scale.</p> <ul style="list-style-type: none"> • Self-Efficacy_1: How confident are you to be able to do what you want to try, even if you are tired from your illness? • Self-Efficacy_2: How confident are you to do what you want to do, even if you have physical discomfort or pain due to illness? • Self-Efficacy_3: How confident are you to do what you want to do, even if you have mental distress due to illness? • Self-Efficacy_4: How confident are you to do what you want to do, despite other symptoms and health problems? • Self-Efficacy_5: How confident are you that you can do the various things you need to manage your own health so that doctors do less? • Self-Efficacy_6: How confident are you that you can do more than just take medicine to reduce the impact of your illness on your daily life?
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survey was conducted after the completion of the second course.

Questionnaire composition and statistical analysis

The composition of the questionnaire (in the pre-intervention survey and post-intervention survey) and the scales included in the analysis are as shown in Table 2 [7-9]. The pre-intervention survey and the post-intervention survey were completed by the participants in the first course and the second course respectively. The subjects of the analysis were participants who answered both the questionnaires.

R version 3.5.0(The R Foundation for Statistical Computing, Vienna, Austria) was used for statistical analysis, and Wilcoxon signed rank test was performed before and after the intervention to calculate “mean ± SD” and quartiles. Considering the multiplicity of the test, the significance level was adjusted to 0.05/7=0.007 by Bonferroni adjustment.

In addition, when performing the non-parametric test, reports such as quartiles should be added to the summary value of every score in Table 4, but since this is exploratory study by small population, those have been omitted, and only “mean ± SD” has been listed.

Ethical considerations

This study was approved by the National Institute of Public Health Sciences Research Ethics Review Board (Certificate of approval number: NIPH-IBRA # 12262).

Results

Of the 33 participants in the first course, 32 (97.0%) responded to the pre-intervention survey, and 28 (100%) among the 28 participants in the second course responded to the post-intervention survey. The subjects of the analysis are 25.

Baseline characteristics of the respondents

The baseline characteristics of the respondents (n=25) were as shown in Table 3. Families (68.0%) and women (64.0%) accounted for the majority and ages ranged from 37 to 77 years.

The spouse was the most common (72.0%), followed by children (60.0%). 56.0% had a job with income, and the majority of respondents answered for the Satisfaction in Life as "Satisfied (neither somewhat satisfied nor Not satisfied)".

Comparison before and after the intervention by the course program

Table 4 shows a comparison of responses (n=25) before and after the course program intervention. The values of the SF-12v2 subscale were higher than the national standard values in all scales in both the pre- and post-intervention groups. On the other hand, in the comparison before and after the intervention, the post-intervention group tended to show a lower value in the scale BP (bodily pain) than the pre-intervention group (p=0.024). The scale BP was distributed as [Min_0, Q1_75, Q2_100, Q3_100, Max_100] before the intervention, and [Min_0, Q1_25, Q2_75, Q3_100, Max_100] after the intervention. For other scales, post-intervention values compared to pre-intervention values tended to be lower in mRS, lower in self-efficacy 1, 2, and 5, and higher in GHQ12 score and PF of SF-12v2.

Considerations

In this study group, the scale with the most significant difference before and after the program intervention was SF-

12v2 BP (bodily pain). BP is a measure of the answer to the question, "Was your regular work (including housework) hindered by pain in the past week?" The higher the rank variable scale, the higher the degree that the behavior was hindered by pain. Before the intervention, stroke patients may have had thalamic pain, pain from cranial surgery, and pain from elevated intracranial pressure. Some of these pains may disappear automatically during the recovery from the acute stage, but they may worsen.

The overall pain relief effect of self-management education is reported as follows: Pain and discomfort are common problems in many chronic diseases. As the causes can be as diverse as pain from the disease itself, "muscle tension or weakness," "lack of sleep," "stress, anxiety, discouragement, anger, fear, dissatisfaction, etc.", so, medication is not always the only use.[10] Therefore, it was thought that participation in the program in the self-management support course of this study for stroke may have led to “improvement of behavior restrictions due to pain” through awareness of self-management and reduction of stress. It was considered necessary to improve the program so that we could identify “types of pain” and participants could learn “how to reduce pain by themselves”.

Table 3. Baseline Characteristics of respondents (n=25)

Characteristic	Respondents (n=25)	% (ALL=25)
Position		
Patient	5	(20.0%)
Family	17	(68.0%)
Others	3	(12.0%) volunteer 1
Sex		
Male	9	(36.0%)
Female	16	(64.0%)
Others	0	(0.0%)
Age		
Mean± SD	60.12±10.61	
Min	37	
Q1	52	
Q2	62	
Q3	69	
Max	77	
Housemate (Multiple answers allowed)		
None	2	(8.0%)
Spouse	18	(72.0%)
Child	15	(60.0%)
Parent	3	(12.0%)
Brother or sister	1	(4.0%)
Grandchild	1	(4.0%)
Grandparent	1	(4.0%)
Others	0	(0.0%)
Getting paid jobs		
Yes	14	(56.0%)
No	9	(36.0%)
Do not want to answer	2	(8.0%)
Satisfaction in life		
Very satisfied	0	(0.0%)
Somewhat satisfied	7	(28.0%)
Satisfied	11	(44.0%)
Not satisfied	6	(24.0%)
Not satisfied at all	1	(4.0%)

In recent years, many studies on self-management of chronic diseases have been reported in Japan and overseas. Sato

et.al. summarized and examined 15 high-evidence randomized controlled trials abroad on the self-management of stroke patients through literature reviews, while pointing out the shortage of intervention studies in Japan [11-26]. On the other hand, the symptoms and sequelae of stroke have been pointed out as one of the difficult factors of self-management, compared with the other chronic diseases, such as diabetes, mental illness, cancer, kidney disease, respiratory disease, heart disease, etc. [27]. From now on in Japan, it seems necessary to promote the developing, implementing, and evaluating self-management programs such as this study, which will not only prevent the recurrence of stroke but also improve the quality of life of patients with disabilities and illness.

Limitations of this Study

In this study it was an exploratory study for a small group, so we 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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Authorship Contribution

Lead author Dr. Tachibana oversaw the work, and worked on the idea and design of the study, planning and implementation of the program, data collection, data analysis and interpretation, writing the dissertation, and making important revisions to the dissertation. Dr. Motoyama and Dr. Otaga planned and implemented the program, collected data and approved the final draft.

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Table 4. Comparison before and after the intervention by the course program (n=25). Wilcoxon's signed rank test.

	Before the intervention	After the intervention	p	W
	mean ± s.d.(n=25)	mean ± s.d.(n=25)		
modified Rankin Scale (mRS)	1±1.35	0.84±1.21	0.679	333
Self-Efficacy_1	7±2.65	6.44±2.66	0.457	351
Self-Efficacy_2	6.52±2.77	5.76±2.65	0.273	369
Self-Efficacy_3	5.92±2.80	5.60±2.68	0.698	337
Self-Efficacy_4	5.84±2.87	6±2.60	0.919	307
Self-Efficacy_5	7±2.16	6.56±2.08	0.310	364.5
Self-Efficacy_6	6.72±1.95	6.72±2.34	0.934	317
GHQ12 total	4.96±4.51	3.48±3.16	0.352	36.05
Likert method	15.8±8.18	14.16±6.05	0.423	353.5
SF-12v2 subscale				
1. Physical Function: PH	85±23.94	92±18.71	0.166	252.5
2. Role Physical: RP	80±21.35	75.5±27.59	0.658	335
3. Bodily Pain: BP	82±25.54	58±39.34	0.024	422.5
4. General Health: GH	57.2±21.54	55.2±21.53	0.773	325
5. Vitality: VT	59±27.84	58±22.5	0.659	334.5
6. Social Functioning: SF	75±25	74±31.02	0.872	304.5
7. Role Emotional: RE	75.5±24.07	81±20.13	0.460	275.5
8. Mental Health: MH	64.5±24.92	66.5±19.67	0.926	307.5

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