

The effect of family-supportive therapy on the burden of caregivers and Activities of Daily Living among stroke patients

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Abstract

The role of family members in providing care for stroke patients at home is associated with heightened stress and burden on caregivers. Therefore, this study aimed to analyze the effect of family-supportive therapy on the burden of caregivers and Activities of Daily Living (ADL) among stroke patients. A quasi-experimental method was used with a pre-test and post-test control group. The intervention of family-supportive therapy was given to the treatment group, while the control group received home visits. Samples of 40 caregivers in two primary health care centers in Surabaya were recruited using a multi-stage sampling method. The variables were the burden of caregivers and ADL of stroke patients, while Zarit Burden's Interview Schedule and Katz Index of Independence in ADL were used as instruments. Data analysis was carried out using a Paired t-test and a Manova test. The results showed that the burden of caregivers in the treatment group decreased, but there was a re-increase after 2 weeks of therapy, and the burden in the control group also decreased. ADL of stroke patients in the treatment group increased and tended to persist up to 2 weeks after therapy, while the value in the control group decreased. Furthermore, family-supportive therapy did not have a significant effect on the burden of caregivers (p-value 0.12) and ADL (p-value 0.21). To address this challenge, modifying services through the implementation of community health programs, individual health efforts for stroke patients in the hospital and at home, group services for families providing primary health care, and home visits could be a comprehensive effort. The study found that family-supportive therapy and health education through home visits reduced caregiver burden.

Introduction

Family is recognized to play a crucial function in health care, particularly during the acute period of disease to the recovery and rehabilitation phase. This is specifically true for non-communicable diseases such as stroke, which currently tend to increase in prevalence both in urban and rural areas. However, the responsibility of providing care for stroke patients at home can lead to persistent stress and burden for caregivers.

According to the 2018 Basic Health Research of Indonesia (Riset Kesehatan Dasar), East Java ranked third in stroke prevalence.¹ Weakness, physical disability, psychological problems, and depression cause obstacles to Activities of Daily Living (ADL) and even a decrease in Quality Of Life (QoL).² A previous study stated that 50% of stroke patients' caregivers had mild to moderate burden, and 5,8% showed moderate to severe burden.³

Persistent distress eventually strains and burdens both stroke patients and caregivers, in the emotional, social, and financial aspects.⁴⁻⁶ The high burden felt is manifested in the form of symptoms of anxiety, depression, and low physical health.⁶ Caregivers often neglect personal health and are generally ignored by health-care professionals while family members pass through the recovery phase. To address this challenge, caregivers should also receive attention from health service providers in the form of informational, emotional, and instrumental support, as well as rewards to mitigate burden.^{7,8}

The inability to cope with a crisis capable of causing strain or burden due to a stroke leads to low function and further increases the stressor experienced by family. A valid initial assessment of stroke patients, caregivers, and all family members is crucial for better preparedness to provide care at home. In this context, the assessment of experiences, perceptions, beliefs, and family support is used as the basis for determining appropriate collaborative nursing interventions to make the coping mechanism of caregivers and family adaptive. Consequently, the crisis is resolved, and family welfare is achieved.⁹

Interventions currently provided by health services in the acute phase and rehabilitation for stroke cases tend to be patient-centered care. For example, during the rehabilitation phase, interventions including therapeutic counseling, psychoeducation, and skills training have proven effective in reducing burden of care as well as increasing satisfaction, welfare, and quality of life among caregivers.^{4,10} All forms of therapy have the primary objective of providing help to individuals by eliminating or reducing suffering. Although several studies did not state the most effective therapy, several experts mentioned three interventions that reduced burden of mild to moderate care, namely psycho-educational, psychotherapy, and supportive. Family and group supportive interventions can also reduce burden of care and anxiety, while also increasing the ability to care for families with chronic disease, including

Significance for public health

Caring for stroke patients at home represents a significant source of stress for family members. This study indicates that the implementation of family-supportive treatment led to a temporary reduction in caregiver burden and a positive improvement in stroke patients' daily activities. To further optimize the program's effectiveness, incorporating community health programs is recommended. This could involve prioritizing individual health initiatives for stroke patients with in-hospital and home settings, providing group services for families focusing on primary health care, and conducting home visits.

stroke, chronic kidney disease, and mental disease.^{7,11} Supportive therapy is one of the psychotherapy models that can be applied in the community and hospitals. This therapy is a form of family empowerment aimed at building relationships based on shared understanding and empathy with caregivers by focusing on strengths to help identify resources in the community. It is expected to help family, specifically caregivers effectively resolve problems when caring for family members who are sick, provide motivation and change in behavior, as well as carry out adaptive coping strategies.¹¹⁻¹³ Therefore, this study aimed to analyze the effect of family-supportive therapy on burden of caregivers and ADL among stroke patients.

Materials and Methods

A quasi-experimental design was used, with a pre-test and post-test control group. Treatment group was given family-supportive therapy, and the control group received home visits. Samples were 40 caregivers in Surabaya recruited from July to September 2018 with multi-stage sampling. Caregivers from Pegirian and Pucang Sewu primary health care served as treatment and control group, respectively. The inclusion criteria included i) primary care provider, ii) family members who provided follow-up care at home, and iii) caregivers living at home with the treated stroke patients.

The instruments used were Zarit Burden's Interview Schedule^{6,14} and Katz Index of Independence in ADL.^{15,16} Zarit Burden's Interview Schedule consists of 22 statements and scoring is carried out using the Likert scale comprising 0=never, 1=rarely, 2=sometimes, 3=often, and 4=always. The assessment of burden caregiver includes scores of 0-20 = no/little, 21-40 = light-moderate, 41-60 = moderate-heavy, and 61-88 = very heavy.

Katz Index of Independence in ADL has six closed statements covering bathing, dressing, defecating, moving, continental, and feeding. The scoring uses a dichotomy scale (0=dependent and 1=independent). ADL assessment depends on whether patients can perform with or without supervision, direction, assistance, or total care. The previous questionnaire was tested on families who met the criteria but were not selected as respondents and the next step was to test the validity and reliability. All statements in Zarit Burden's Interview Schedule were valid (p-value >0.30) and reliable (p-value 0.923). Similarly, all Katz Index of Independence in ADL statements were valid (p-value >0.30) and reliable (p-value 0.870). This study was conducted using two groups, namely the control, and treatment, which received family-supportive therapy in four sessions. On the other hand, the control group received standard intervention of health education through home visits by health care providers. Burden of caregivers and ADL of stroke patients in the control group were measured twice, while in treatment group, measurement was carried out three times.

Family-supportive therapy was implemented through four sessions with a duration of 50 minutes and spanning 4 weeks. Measurement for burden of caregivers and ADL of stroke patients was performed in the first session, fourth session, and about 2 weeks after the fourth session. Caregivers in the control group received two-session home visits, with a span of about 2 weeks from the first. A therapy-caring module for stroke patients was used, while burden of caregivers and ADL were measured at the first and second home visits.

The variables assessed were burden of caregivers and ADL of stroke patients, while analysis was performed using a paired t-test

and a Manova test by SPSS 21st edition. The paired t-test analyzed the relation between burden of caregivers and ADL of stroke patients pre-test and post-test. Manova test analyzed the more substantial impact of family-supportive therapy on changes in burden of caregivers or ADL. Ethical approval letter was received from the Health Research Ethics Commission of Health, Ministry of Health, Surabaya, number 194/S/KEPK/V/2018, on 8th June 2018.

Results and Discussion

Burden of caregivers in caring for stroke patients in treatment group was reduced but there was a re-increase after 2 weeks following family-supportive therapy. Similarly, burden of caregivers in the control group also decreased. ADL of stroke patients in treatment group increased and tended to persist until 2 weeks after therapy, while the value in the control group decreased. In general, family-supportive therapy did not have a significant effect on burden of caregivers (p-value 0.12) and ADL of stroke patients (p-value 0.21).

Table 1 shows that caregivers of stroke patients in treatment group are mostly aged 46-55 years or early elderly (42.2%), women (82.5%), had elementary school education (40%), unemployed (55%), and have family relationships (57.5%). In addition, the majority had length of caring 1-2 years (40%) and 1-2 hours per day (57.5%), as well as had 1-2 health problems (47.5%). In the control group, a significant proportion of caregivers were aged 46-55 years or early elderly (35%), women (65%), had senior high school education (42.5%), unemployed, and entrepreneurs (42.5%). Furthermore, the majority had a length of caring 1-2 years (67.5%) and 1-2 hours a day (70%), had 1-2 health problems (49%), and worked as housewives (50%). Table 2 shows the two heaviest indicators for burden of caregivers, namely physical and financial.

Table 3 shows a decreased burden of caregivers in the control group before and after following family-supportive therapy (p-value 0.063; d 2.75). However, 2 weeks after following up the therapy, burden increased (p-value 0.103; d -3.7). In the control group, burden of caregivers before and after home visits showed a decrease (p-value 0.000; d 8.525). Table 4 shows that the lowest independent fulfillment of ADL for stroke patients in treatment and control group was bathing.

Table 5 shows an increase in ADL of stroke patients in treatment group after following family-supportive therapy (p-value 0.006; d -3.5). However, 2 weeks after, stroke patients had a decreased ADL (p-value 0.401; d -0.1). In the control group, the decrease in ADL occurred after 2 weeks of home visits (p-value 0.668; d 2.633). Manova test results are shown in Tables 6, 7, and 8.

Table 6 shows a variance in burden of caregivers variable between treatment and control groups (p-value 0.061). ADL of stroke patients between treatment and control group had the same variant (p-value 0.693). Table 7 shows that Box's M tested the null hypothesis stating that the observed covariance matrices of the dependent variable, namely burden of caregivers and ADL of stroke patients were the same across both groups (p-value 0.212). Table 8 shows that family-supportive therapy did not affect burden of caregivers (p-value 0.12) and ADL of stroke patients (p-value 0.21). The partial eta squared value for burden of caregivers was slightly more significant than ADL. Specifically, the partial eta squared value on burden of caregivers was 0.031, implying that the effect of family-supportive interventions reached 3.1%. On the other hand, the impact of family-supportive therapy on ADL was

low, estimated at 2% (partial eta square 0.02). Burden felt by most caregivers of stroke patients at home comprises both physical and financial, which are often perceived as more significant compared to emotional, timing, and social. The strain and burden of caregivers are influenced by gender (female), age (elderly), low education, job (retired), length of care, and mental health. Meanwhile, the influential factors of stroke patients are physical impairment/weakness of motor and cognitive function, depressive symptoms, decreased verbal ability, difficulty walking, and neurological deficits.^{17,18}

The condition of stroke patients who have sequelae contributes to the degree of dependence, which consequently adds to the physical burden of caregivers. The sequelae of stroke patients show mainly in the form of stiffness, weakness, and extremity paralysis (88.75%). Furthermore, the age factor can also increase the dependency level, which has an impact on burden of caregivers. Based on the results, 77.5% of stroke patients were in the elderly age group (46-65 years) and 23.75% were more than 65 years. The physiological aging process of the neuromuscular system potentially decreases the limbs' physiological functions, specifically the extremities, including a decrease in ADL ability.^{17,18}

The financial burden is the second major burden of caregivers

and is associated with the change in the major role of stroke patients being the head of family, who acts as the main financial source. The data showed that 63.75% of stroke patients were male and the head of family. This condition is in line with a previous study, stating that all families of stroke patients experienced changes in the economy, acting as a high stressor.^{8,19}

Caregivers feel stress due to stroke attacks on family members from the acute therapy period at the hospital to the follow-up phase of care at home. Many stressors during rehabilitation are associated with physical assistance to meet the daily needs of patients.^{2,20} A significant proportion of caregivers were in early elderly category (46-55 years) and 73.75% were women, with the majority being wives of patients. In terms of education, 7.5% were uneducated, and 32.5% had only primary school education. Almost half (48.75%) were unemployed (homemakers), while some made efforts to find additional income by becoming entrepreneurs or selling food at home up to 2 years after stroke attack on husbands. Most of caregivers (73.75%) had cared for family members suffering a stroke for ≤ 2 years, with a therapy duration of 1-4 hours (87.5%).

Health problems experienced by caregivers of stroke patients can affect burden. Based on the results, most of caregivers

Table 1. Demographic characteristics regarding caregivers of stroke patients (n=40).

Demographic characteristics	Category	Treatment		Control	
		n	%	n	%
Age (year)	17-25 years old	4	10	3	7.5
	26-35 years old	5	12.5	5	12.5
	36-45 years old	12	30	5	12.5
	46-55 years old	17	42.5	14	35
	56-65 years old	2	5	10	25
	>65 years old	0	0	3	7.5
Gender	Male	7	17.5	14	35
	Female	33	82.5	26	65
Education	Not school	4	10	2	5
	Elementary school	16	40	10	25
	Junior high school	4	10	9	22.5
	Senior high school	14	35	17	42.5
	Diploma or bachelor's	2	5	0	0
	Postgraduate	0	0	2	5
Employment	No employee	22	55	17	42.5
	Government employee	2	5	1	2.5
	Private employee	5	1.5	5	12.5
	Entrepreneurship	10	25	17	42.5
	Others	1	2.5	0	0
Family relationship	Husband	2	5	8	20
	Wife	23	57.5	20	50
	Child	8	20	10	25
	Others	7	17.5	2	5
Length of caring (year)	< 1 year	11	27.5	6	15
	1-2 years	16	40	27	67.5
	3-4 years	9	22.5	5	12.5
	≥ 5 years	4	10	2	5
Duration of caring (hour/day)	1-2 hours	23	57.5	28	70
	3-4 hours	10	25	9	22.5
	5-6 hours	4	10	2	5
	≥ 7 hours	3	7.5	1	2.5
Health problem	No problem	10	25	15	37.5
	1-2 problems	19	47.5	16	40
	3-4 problems	11	27.5	8	20
	5 problems	0	0	1	2.5

Table 2. Indicators regarding burden of caregivers for stroke patients.

Group	Indicators for burden of caregivers	Mean		
		Pre	Post 1	Post 2
Treatment (n=40)	Physical burden	1.35	1.17	1.4
	Timing burden	0.66	0.55	0.54
	Financial burden	1.33	1.05	1.5
	Emotional burden	0.70	0.58	0.74
	Social burden	0.23	0.2	0.28
Control (n=40)	Physical burden	1.85	1.33	-
	Timing burden	0.59	0.33	-
	Financial burden	1.80	1.60	-
	Emotional burden	1.28	0.86	-
	Social burden	0.19	0.06	-

Table 3. Burden of caregivers of stroke patients (treatment and control group).

Burden of caregivers	Treatment (n=40)		Control (n=40)		p (paired t-test)
	Mean	SD	Mean	SD	
1. Pre-test burden	17.30	11.697	26.23	8.069	
2. Post-1 burden	14.55	10.195	17.70	7.532	
3. Post-2 burden	18.25	12.689	-	-	
4. Different pre-post one burden	2.750	7.990	8.525	7.310	Treatment 0.036 Control 0.000
5. Different post-1-post-2 burden	-3.700	14.008	-	-	Treatment 0.103

Table 4. Indicators of ADL among stroke patients.

Group	Indicator of ADL	Mean		
		Pre	Post 1	Post 2
Treatment (n=40)	Bathing	0.55	0.65	0.68
	Dressing	0.68	0.83	0.88
	Toileting	0.78	0.83	0.83
	Transferring	0.9	0.95	0.95
	Continent	0.98	0.95	0.95
	Feeding	0.88	0.9	0.93
Control (n=40)	Bathing	0.53	0.4	-
	Dressing	0.78	0.88	-
	Toileting	0.73	0.83	-
	Transferring	0.85	0.75	-
	Continent	0.9	0.98	-
	Feeding	0.8	0.88	-

Table 5. Differences in ADL among stroke patients between treatment and control group.

ADL of stroke patient	Treatment (n=40)		Control (n=40)		p (paired t-test)
	Mean	SD	Mean	SD	
Pre ADL	4.75	1.548	4.58	4.7	
Post -1ADL	5.10	1.317	1.947	1.506	
Post -2 ADL	5.20	1.224	-	-	
Different pre-post 1 ADL	-0.35	0.77	2.633	1.828	Treatment 0.006 Control 0.668
Different post-1-post 2 ADL	-0.1	0.744	-	-	Treatment 0.401

(68.75%) reported experiencing health problems including fatigue, certain diseases, and irritability. This condition is in line with a previous study, stating that burden of caregivers manifests in the form of anxiety, depression, and low physical health.^{6,21-23}

Common diseases experienced by caregivers include hypertension, diabetes mellitus, gastritis, hypercholesterolemia, and hyperuricemia. These diseases are included in the non-communicable category, which often require regular and long-term management of therapy to avoid complications. Caregivers tend to ignore personal health problems while caring for stroke patients.²⁴

Caregivers feel burden while caring for stroke patients who need help both physically and emotionally. This statement is a value/belief embraced and influenced by family culture in major Asian countries including Hong Kong. Moreover, it is a religious/religious value system with the principle that caring for sick family members, specifically the elderly, is a service from younger to older family members, specifically parents, as well as wives' devotion to husbands/partners.²⁵

Based on the results, caregivers of stroke patients who adhered to family-supportive therapy experienced a decrease in burden. However, after 2 weeks, there was an increase in burden of care. Health education provided to caregivers through counseling using modules of care can also reduce burden. Family-supportive therapy and health education through home visits in families with stroke cases are among the interventions recommended in several previous studies.^{4,10,26} Based on several reports, family-supportive therapy is widely used in family with mental, congenital, and chronic diseases.^{11,12,20} The objective is not limited to providing support and complementing the experience of isolation but also to plan, organize, and respond positively to pressure, anxiety, burdens, and unpleasant circumstances. Furthermore, this therapy can increase strength, coping skills, and resources, improve autonomy in decision-making, enhance the ability to achieve optimal independence, as well as reduce subjective distress and maladaptive coping responses.²⁷

Evaluation of burden 2 weeks after family-supportive therapy showed an observable increase. Several studies showed that when

social support was reduced, some families experienced increased psychosocial burdens and problems. To effectively manage burden and anxiety while caring for stroke patients, supportive therapy needs to be followed up on an ongoing basis with various methods. For example, this can be achieved through the use of information technology that enables health professionals and other therapy members to continually communicate and provide mutual support.^{11,28}

Family-supportive therapy and home visits did not show a different effect on burden of caregivers for stroke patients. Family-supportive intervention is a new therapy for caregivers that requires sufficient time to develop mutual trust and empathy between the therapist and members. During session 1, most of therapy participants were not able to assertively convey personal experiences and opinions about caring for stroke patients. Active participation of new therapy participants was observed in session 2, underscoring the need for pre-therapy readiness, specifically by health workers who play the role of a therapist. This is crucial to achieve the objective of therapy in four sessions.

Most stroke patients are unable to achieve independence in fulfillment of bathing, dressing, toileting, mobility, and feeding. The commonly experienced weakness or paralysis of the upper extremities causes stroke patients to feel difficulty in fulfilling ADL, specifically bathing and dressing, leading to the need for care assistance from family members. This inability to fulfill ADL is reportedly associated with sequelae. Based on the results, most stroke patients (88.75%) experienced stiffness, weakness, and extremity paralysis, specifically in the upper limbs. A previous study in Purwokerto (Central Java, Indonesia) reported that in 1-3 months after the attack of stroke, 51.3% achieved mild to minimal independence based on the Barthel Index.²⁹ In contrast, another study found that stroke patients at 6-24 months after occupational therapy achieved an independent activity of 7.7% and 92.3% of non-independent activities.³⁰ A previous investigation at Tugurejo Hospital Semarang stated that 30%, 45%, and 20% of patients were partially, highly, and totally dependent, respectively.¹⁵

The decline in ADL ability could also be influenced by age, as

Table 6. Manova-test (Levene's test of equality for error variances).

Variable	F	df1	df 2	sig
Burden	3.609	1	78	.061
ADL	.157	1	78	.693

Table 7. Manova-test (Levene's test of equality for error variances).

Group	N	Box's M	F	Box test df1	df 2	sig
Treatment control	80	4.636	1.502	3	1095120.000	0.212

Table 8. Manova analysis (tests of between-subjects effects).

Variable	Mean square	F	Sig	Partial Eta Squared	Observed Power
Burden	198.450	2.470	.120	.031	.342
ADL	3.200	1.600	.210	.020	.239

demonstrated by the results in which 77.5% of stroke patients were 46-65 years old, and 23.75% were older than 65. The decline in the physiological function of the body systems, specifically the neuro-muscular system, impacts the independence of elderly patients to meet daily needs.^{17,18}

ADL of stroke patients whose caregivers followed family-supportive therapy slightly increased and tended to persist for up to 2 weeks. Health education provided to caregivers through counseling using care modules did not increase ADL. Family-supportive intervention helped increase individual roles, as motivators for patients. Caregivers convey not only the need to provide physical assistance but also to motivate patients to actively fulfill ADL. Gradual efforts to independently meet daily needs, specifically in the aspect of neuro-muscular function, are required in the rehabilitation phase to reduce the residual symptoms in the form of weakness or paralysis. According to a previous study, stroke patients are advised to continually carry out routine control to monitor the improvement or deterioration in the condition.³¹ Efforts to increase independence in activities not only affect motor skills but also enhance self-esteem and confidence as well as reduce anxiety due to feelings of helplessness.³²

Home visits intervention by health care providers to provide health education for stroke patients and caregivers did not help achieve independence. These home visits, which were carried out two times, had not yet achieved the purpose of establishing a stroke family as the focus of community healthcare activities proclaimed by Puskesmas. This was because the frequency of visits was still one-third of the normal (about six visits).

Currently, home visits remain at the stage of family identification to recognize health problems. In this context, obstacles are in the form of difficulty meeting the primary care provider for stroke patients who might be working outside home. This condition was supported by the employment data, with almost half of caregivers having no employees (42.5%). Therefore, efforts to follow up on the next home visits are needed to achieve the objectives of family independence, including the fulfillment of ADL. The conditions of stroke patients also contributed to the low ADL ability, specifically in the home visits group. This was supported by the data showing that the majority of caregivers were in the elderly age category, and most patients were in the rehabilitation phase of 1-2 years (82.5%).

Family-supportive therapy and home visits did not show a different effect on ADL in stroke patients. The similarity can be attributed to the shared focus of both interventions, primarily targeting caregivers in the early stages. Consequently, the initial impact of these interventions is largely directed towards achieving objectives related to support for caregivers, rather than ADL ability. The independence of stroke patients in fulfilling ADL is influenced by several factors, including age, sequelae, frequency of attacks, duration of disease, rehabilitation, and patient motivation.^{17,33-34} Caregivers play a significant role as motivators during long-term care at home. Therefore, these individuals should also be targets of public healthcare activities to achieve independent and prosperous family.

Conclusions

In conclusion, family-supportive therapy decreased burden on caregivers immediately but increased after 2 weeks. In addition, health education activities carried out through home visits also reduced burden. Both of these interventions were recommended to prevent and reduce burden on caregivers, although the most effective

method is yet to be proven. Family-supportive therapy and health education through home visits did not directly increase the independence of stroke patients in ADL. Therefore, it was necessary to modify several interventions and strengthen patient factors to achieve independence in ADL.

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