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Original Article

Changes in demands of primary caregivers for stroke patients during the golden period of rehabilitation

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Purpose: To explore the changes in demands of the primary caregivers for stroke patients during the golden period of rehabilitation.
Methods: This longitudinal research study assessed 60 primary caregivers of stroke patients at a regional hospital in central Taiwan. We collected clinical and sociodemographic data, and administered the Family Needs of Stroke Patient Questionnaire to the primary caregivers at the third months and sixth months of the golden period of rehabilitation. Data were analyzed by descriptive statistics and inferential statistics.
Results: Primary caregivers had significantly greater demands for health information, professional support, community networks, substantive support, and participation in patient care at the third month than sixth month (P<0.05); their demand for emotional support did not significantly change (P>0.05). Generalized estimation equation analysis found the associated factors of high demand over time among primary caregivers at the early stage time point (3 months),the patient having an indwelling nasogastric tube, and the Taiwanese caregiver.
Conclusions: Health professionals should understand that primary caregivers for stroke patients have more diverse care demands in the early stages during the golden rehabilitation, which can change over time. In addition, special attention should be paid to patients with the care of the in-dwelling NG tube and the type of manpower to assist in caring. The results of this study can provide references for health professionals and provide continuous care for stroke patients and their primary caregivers in the golden period of rehabilitation.

Keywords: Stroke, Rehabilitation, Caregiver, Demand

1. Introduction

Stroke is the second most common cause of mortality and disability worldwide (1). Cerebrovascular diseases were ranked as the fourth leading cause of death in Taiwan in 2020 (2). About 17,000 people are functionally disabled in Taiwan due to stroke every year; stroke is the main cause of adult disability in the region, and about a third of patients will have sequelae (3-4). After a stroke, patients must rely on others for help in daily life, which not only affects their executive ability, but also places a great burden on their family and society, and can negatively impact the future life of the patient and his family members. In Taiwan, more than half of the 790,000 demented and disabled families are still cared for by their

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families alone (5). The average caregiver experience is 7.8 years, with an average of 11.1 hours of care per day, and 51.4% of them have no substitute care (6). Family members who play the role of primary caregiver frequently have psychological reactions such as depression, anxiety, frustration, anger, emotional instability, and may experience physical, mental, financial, and social pressures. However, the literature indicates that providing effective care information can improve patient knowledge and satisfaction and reduce psychological stress (7). Stroke and caregivers can have different demands at each stage of patient recovery. According to the Taiwan Stroke Association, post-stroke rehabilitation can be divided into three stages (8). The first stage is the acute stage, which is within 3 months of the onset of the stroke. The lack of understanding of the disease will cause many emotional reactions and care demands. The main concern of this stage is to meet the needs of physical health care. The second stage is the late acute stage, usually 3 to 6 months after stroke. In this stage, active rehabilitation treatment is required. Caregivers must pay attention to the recovery of limb movement functions and hope to restore the patient's daily life functions as much as possible. The caregivers will also want to know future care information, prognosis and emotional support, etc. The third stage refers to the recovery status of patients 6 months after the stroke. Some patients can return to work or remain in the rehabilitation system, while others return home to be taken care of by their family members or transferred to long-term care institutions (9).

Caregivers' experiences from hospitalization to after discharge, usually the first few months after discharge are the most difficult in terms of caring. Coupled with the lack of caring skills and care-related information, caregivers will be under great pressure (10). The demands of respite care and emotional support may be acquired at this stage. The primary caregivers are concerned about clinical care, prevention and treatment of stroke, and functional recovery (11). The most urgent care demands of the caregivers of patients with stroke are related to their patient's activities, exercise, psychological changes, and nutrition. Caregivers expect customized information (7). Hafsteinsdo'ttir et al. (2011) found that the information provided to stroke patients and caregivers was not specific to their needs (11), and this issue needs to be improved. A clinician's inability to meet caregivers' needs may lead to incompetent or inadequate care after a patient is discharged, which could increase the degree of disability and affect the overall quality of life of the patient and their family(12).

Three to six months after the onset of stroke is the golden period of rehabilitation. Provision of active rehabilitation care in the first three months after a stroke significantly improves patients' recovery in terms of daily living activities (13). However, clinical observations suggest that patients and caregivers mainly focus on treatment. The primary caregivers often find that they are not ready to provide care when the patient returns home from the hospital, and the resulting problems often make caregivers feel under pressure. The golden period of rehabilitation care for stroke patients is also a very important turning point that connects long-term care and family life. Thus, during this crucial stage of rehabilitation, it is very important for clinical healthcare providers to understand the needs and care demands of family members, design continuous care plans, and provide individual assistance as soon as possible so that caregivers can cope with their future care work and reduce their care load.

Therefore, the purpose of this study was to explore the changes in and predictors of the demands of the primary caregivers of patients with stroke in the golden period of rehabilitation. We expect these research results to provide a reference for clinical healthcare providers to design individualized measures and provide relevant information tailored to caregivers' needs at different stages of patient recovery; that is, to grasp the golden period of rehabilitation and provide the most correct direction and care, to enable patients and caregivers to improve their quality of life and successfully return to family life.

2. Methods

2.1. Research design

This longitudinal research study assessed stroke patients hospitalized at a hospital in Central Taiwan between January 2018 to December 2018 and their primary caregivers. The researchers screened the

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stroke patients and primary caregivers for eligibility. The primary caregivers were defined as the family members who spend the most time and mainly make decisions on the care of the patients. We explained the purpose and methods of the research to the caregivers. After the primary caregivers agreed to participate in the study, they still retained autonomy and could decide to withdraw from the study at any time. A total of 60 patient/primary caregiver pairs were recruited when the stroke patient was admitted to the rehabilitation ward.

The inclusion conditions were the primary caregivers of (1) patients who had suffered a stroke for the first time and were transferred to the rehabilitation ward for the first time; (2) who were the primary caregivers of the patient before and after rehabilitation; (3) who speak Taiwanese fluently; and (4) who were willing to complete the questionnaire. The exclusion conditions were: (1) patients with a history of stroke and (2) primary caregivers with mental health issues.

Structured questionnaires were used to collect data, including a basic data sheet on the features of the patients and primary caregivers, and the demand scale for the primary caregivers. The golden period of rehabilitation for stroke patients is 6 months. The same primary caregiver for each patient filled in the questionnaire at two-time points: the early stage of the golden period of rehabilitation (the third month after the onset of stroke) and the late stage (the sixth month after the onset of stroke). If the primary caregivers were illiterate or unable to read the questionnaire, the researcher orally assisted the caregivers to complete the questionnaire, and analyzed and compared the two questionnaires before and after. Before recruiting participants, this study was reviewed and approved by the institutional review board (IRB) (No. csl7131).

2.2. Basic data sheet on patients and primary caregivers

The basic data we collected on the patients included sociodemographic features and disease characteristics. The sociodemographic features of the patients included gender, age, and education and the disease characteristics included stroke type, chronic disease, and body indwelling tube. The data collected on the primary caregivers included sociodemographic features, type of care delivery, and Self-rated health status. The category variables involved gender, education, type of care delivery, relationship with the patient, religion, and self-rated health status. The continuous variable was age in this study.

2.3. Family Needs of Stroke Patient Questionnaire

The Family Needs of Stroke Patient Questionnaire was adopted in this research (14). Before the study began, an approval letter was obtained from the author, who authorized and agreed to modify the original scale according to the purpose of this study. The Family Needs of Stroke Patient questionnaire contains 43 questions. According to the current long-term care policy of Taiwan and the current situation of care manpower, 45 questions were added and revised to maintain six aspects. Topics 1-13 are health information needs (13 questions), Topics 14-17 are community networks needs(4 questions), Topics 18-21 are professional support needs (4 questions), Topics are 22-31 substantive support needs(10 questions), Topics are 32-39 emotional support needs(8 questions), and Topics are 40-45 patient care needs (6 questions). Each question is scored using a four-point Likert quartile method: very necessary (3 points), necessary (2 points), neutral (1 point), unnecessary (0). For each topic, the score range is 45-180 points. The higher the score, the higher the demand. Six experts conducted an expert validation to verify the appropriateness and importance of the content. The CVI (content validity index) values of the appropriateness and importance of the content were 0.94 and 0.92 respectively.

2.4. Data analysis

SPSS 22.0 statistical software was used for statistical analysis. The basic attributes of the patients and primary caregivers were described as numbers, percentages (%), and means and standard deviations for descriptive statistics. The changes in two-stage care demands of the primary caregivers were assessed using paired *t*-tests. A uni-variable variance analysis of the care demands of primary caregivers at different stages was analyzed using independent sample *t*-tests or one-way ANOVA. The variables of time-related care demands were identified using generalized estimating equation (GEE) analysis.

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Table 1. Descriptive data on stroke patients and primary caregivers (*N*=60)

Variable	*N*	%	Mean±SD
Demographic data on patients			
Gender			
Male	44	73.30%	
Female	16	26.70%	
Age (mean, SD)			59.25±15.17
Education			
≧Senior high school	29	48.40%	
≦Junior high school	31	51.60%	
NG tube			
No	36	60.00%	
Yes	24	40.00%	
Urine catheter			
No	54	90.00%	
Yes	6	10.00%	
Stroke type			
Bleeding	36	60.00%	
Infarction	24	40.00%	
Chronic disease			
Hypertension			
No	17	28.30%	
Yes	43	71.7.%	
Diabetes			
No	44	73.30%	
Yes	16	26.70%	
Heart disease			
No	53	88.30%	
Yes	7	11.70%	
Other			
No	48	80.00%	
Yes	12	20.00%	
Demographic data on primary caregivers			
Gender			

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Male	16	26.70%	
Female	44	73.30%	
Age(mean, SD)			46.62±10.25
Education			
≧College	23	38.40%	
≦Senior high school	37	61.60%	
Person who delivered care			
Taiwanese caregiver	20	33.30%	
Primary caregiver	16	26.70%	
Foreign caregiver	16	26.70%	
Family rotation	8	13.30%	
Relationship to patient			
Spouse	26	43.30%	
Children	28	46.70%	
Parent	6	10.00%	
Religion			
Taoism	28	46.70%	
Buddhism	20	33.30%	
Christianity	2	3.30%	
None	10	16.70%	

Table 2. Changes in care demands of primary caregivers between 3Ms and 6Ms after stroke (N=60)

	Month 3		Month 6			
	Mean	SD	Mean	SD	t^a	*P*
Health information	3.503	0.422	3.153	0.399	7.238	<0.001
Professional support	3.500	0.472	3.171	0.445	5.046	<0.001
Community networks	3.138	0.642	2.863	0.515	3.553	<0.001
Substantive support	2.933	0.576	2.775	0.418	2.253	0.028
Emotional support	2.614	0.645	2.600	0.475	0.169	0.866
Participate in patient care needs	2.544	0.803	2.142	0.570	4.367	<0.001
Total scores	3.057	0.456	2.811	0.350	4.851	<0.001

3. Results

3.1. Demographic features, disease characteristics, and physical status of the stroke patients

The demographic characteristics of the 60 stroke patients are shown in Table 1. The majority of patients were male (73.3%), their average age was 59.25 ± 15.17-year-old, and 51.6% of patients had a level of

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education below junior high school. Hemorrhagic stroke accounted for 60% of cases, and hypertension accounted for 71.7%. In terms of indwelling pipelines, 40% of patients had a nasogastric tube in the third month of the golden period of rehabilitation, and 13.3% had a nasogastric tube in the sixth month of the golden period of rehabilitation.

3.2. Demographic features of the primary caregivers

Basic information on the primary caregivers is shown in Table 1; 73.3% of the primary caregivers were female, and the majority of caregivers were the children of the patient (46.7%). The average age of the primary caregivers was 46.62 ± 10.25-year-old, 61.6% had a level of education below high school, and 83.3% had religious beliefs. During hospitalization, 33.3% of the patients were taken care of by Taiwanese assistants.

3.3. Changes in the care demands of the primary caregivers between 3Ms and 6Ms after stroke

The six major care demands of the primary caregivers are ranked from high to low as shown in Table 2. The caregivers had the highest demand for health information and professional support in the third month of the golden period of rehabilitation, and had the highest demand for professional support in the sixth month. The care demands of the primary caregivers changed significantly between these two stages: the caregivers had significantly higher demands for health information and professional support in care in the third month than in the sixth month ($P< 0.05$), though there were no significant changes in the caregivers' demands for emotional support over time ($P> 0.05$).

3.4. Factors related to care demands of primary caregivers at different stages

Independent sample *t*-tests and one-way ANOVA were used to analyze the care needs of the primary caregivers at the two stages of the golden period of rehabilitation. Significant differences were observed in the patients diagnosed with hemorrhagic stroke and the patients with an indwelling nasogastric tube at three months ($P< 0.05$). At six months there was no significant difference in any variables(Table 3).

3.5. Time-related factors influencing care demands during the golden period of rehabilitation

Furthermore, the associated factors of changes in primary caregivers' care demands during the golden period of rehabilitation were analyzed using the generalized estimation equation. The results showed that in the third month of the golden period of rehabilitation, patients with an indwelling nasogastric tube and Taiwanese caregivers were significantly associated with caregiver demands Table 4. The B score for caregivers' demands in the sixth month was -0.12 compared to the third month ($P< 0.05$), indicating that the caregivers' demands were higher in the early stage than late stage of the golden period of rehabilitation. Moreover, the care demands scores were significantly higher for caregivers caring for patients with an indwelling nasogastric tube than for patients without a nasogastric tube ($P< 0.01$). Additionally, the B score for the care demands of caregivers caring for patients with foreign caregivers (-0.22) was significantly lower than that of caregivers of patients with Taiwanese nurses ($P< 0.05$).

4. Discussion

This research shows that the primary caregivers of stroke patients have different care demands in the early and late stages of the golden period of rehabilitation, and the level of care demands in these stages are also different. Similarly, the results of a systematic review showed that stroke patients and their caregivers have a high demand, and these demands vary at each stage of rehabilitation (11). We analyze the care demands of the primary caregivers in two stages of the golden period of stroke rehabilitation. The Family Needs Scale for Stroke Patients showed that caregivers' average demand decreased between the third and sixth month of the golden period of rehabilitation. After the patient has just suffered a stroke, acute care is mainly to stabilize his life. Immediately after stabilization of the condition, acute medical treatment is transferred to the rehabilitation period. Most caregivers focus on stroke or physical care needs, so they focus on the patient's current health care information at this stage (14). Caregivers can access more specialized care-related resources and medical staff can provide

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Table 3. A uni-variable variance analysis of the care demands of primary caregivers at different stages (N=60)

		Month 3 Total care needs scores				Month 6 Total care needs scores			
		N	Mean	SD	p[a]	N	Mean	SD	p[a]
Gender (patient)	Male	44	137.14	21.72	0.790	44	127.52	17.07	0.409
	Female	16	138.75	17.40		16	123.69	11.32	
Education (patient)	≧Senior High school	29	137.97	18.51	0.886	29	125.62	14.68	0.679
	≦Junior high school	31	137.19	22.55		31	127.32	16.87	
Stroke type	Bleeding	36	142.67	18.39	0.017	36	127.08	13.54	0.728
	Infarction	24	129.92	21.54		24	125.63	18.86	
Hypertension	No	17	142.71	19.23	0.226	17	125.00	15.01	0.647
	Yes	43	135.53	20.88		43	127.09	16.16	
Diabetes	No	44	137.57	20.99	0.999	44	125.30	16.39	0.330
	Yes	16	137.56	19.84		16	129.81	13.74	
Heart disease	No	53	138.38	20.84	0.405	53	126.25	14.80	0.733
	Yes	7	131.43	18.18		7	128.43	23.10	
NG tube	No	36	131.36	17.88	0.003	52	125.13	16.33	0.087
	Yes	24	146.88	21.06		8	135.38	6.41	
Urine catheter	No	54	135.94	19.77	0.066	59	126.36	15.84	0.590
	Yes	6	152.17	23.29		1	135.00		
Gender/caregiver	Male	16	137.38	20.39	0.966	16	129.38	18.64	0.398
	Female	44	137.64	20.81		44	125.45	14.65	
Education/caregiver	≧College	23	136.96	20.83	0.858	23	126.91	14.75	0.874
	≦Senior high school	37	137.95	20.61		37	126.24	16.52	
Religion	Yes	50	137.34	21.48	0.850	50	126.56	15.87	0.948
	No	10	138.70	15.73		10	126.20	15.94	
Relationship to patient	Spouse	26	136.23	18.72	0.861	26	122.54	13.09	0.203
	Children	28	139.14	22.35		28	130.21	18.35	
	parent	6	136.00	22.24		6	126.33	9.54	
Person who delivered care	Taiwanese caregiver	20	142.80	20.30	0.475	20	133.40	15.49	0.098
	Primary caregiver	16	132.88	21.88		16	123.38	16.04	
	Foreign caregiver	16	134.63	21.05		16	124.38	13.89	
	Family rotation	8	139.75	17.43		8	119.75	15.86	
Self-rated health status	Good	17	139.53	25.81	0.645	13	130.54	24.04	0.469
	Acceptable /Bad	43	136.79	18.33		47	125.38	12.70	

*: $P<0.05$; **: $P<0.01$; ***: $P<0.001$.
a. *t*-test or ANOVA.

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Table 4. GEE analysis of time-related factors influencing care demands

Variable	B	SE	*P*-value
Intercept	277.37	9.02	0.001
Time point			
Time point2(month 6)	-0.12	0.06	0.038
Time point 1(month 3)	0[a]	.	.
Type of stroke			
Bleeding	-0.13	0.09	0.167
Infarction	0[a]	.	.
NG tube			
Yes	0.24	0.08	0.002
No	0[a]	.	.
Urine catheter			
Yes	0.24	0.13	0.069
No	0[a]	.	.
Person who delivered care			
Family rotation	-0.20	0.12	0.090
Foreign caregiver	-0.22	0.10	0.028
Primary caregiver	-0.16	0.09	0.076
Taiwanese caregiver	0[a]	.	.

a:reference group

care during hospitalization. The primary caregivers of stroke patients are more able to cope with care difficulties during this period of time. Therefore, the average care demands decreased by the sixth month of the golden period of rehabilitation. A longitudinal study constructed by Tsi et al. (14) found that the care demands of caregivers of stroke patients also decreased significantly from ICU transfer to 3 months after discharge. Lin, Chen, and Yen (2012) discussed the care demands of chronically disabled elderly and their families and concluded that the most urgent care demands of chronically disabled people are similar to those of medical services (15).

In terms of the six aspects of care demands, we observed significant differences in the aspects of health information, professional support, substantive support, community networks, and the needs of patients participating in care at three and six months, while the aspects of emotional support were not significantly different at three and six months. The primary caregivers of stroke patients continued to need emotional support at six months; their demands for these aspects did not decrease with time. Stroke is a chronic disease that requires long-term treatment and care (16). For the primary caregivers who take care of them, long-term care makes them exhausted, socially restricted, and even emotional situations such as depression, sadness, and depression (17). As the degree of disability of the patient is higher, the caregiver lacks care experience and family support, and the role and psychological and emotional load of the caregiver will become more evident (18). The primary caregiver is concerned about the patient's condition and plays a caring role. Therefore, when

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providing care during hospitalization, clinical staff should cross-disciplinary team evaluation, comprehensively assess physical and mental status, stress index, and care demands of family caregivers, screen high-risk primary caregivers and follow up regularly for a long time, assist in referring relevant professionals in a timely manner, and provide psychological support services such as provide emotional support and stress relief by means of support groups, psychological consultations to reduce the physical load, psychological pressure, and emotional load of caregivers to improve the overall quality of life of the caregivers(19).

GEE analysis of time-related factors that influence care demands, we found that the predictive factors of the care demands of the primary caregivers were the third month (early stage) of the golden period of rehabilitation, patients with an indwelling nasogastric tube, and Taiwanese caregivers. Caregivers of patients with an in-dwelling nasogastric tube have higher demands. Clinical nurses should provide information on pipeline care skills and precautions ask questions and provide practical demonstrations to ensure caregivers can provide safe pipeline care (20-21).In terms of the type of nursing, there is a higher demand for employing Taiwanese caregivers than foreign caregivers. When patients need long-term care, families must bear a lot of responsibility and pressure. Hiring Taiwanese caregivers is not a long-term plan for many families, as the costs of employing Taiwanese caregivers are huge. For family members, the demand for care is relatively higher than that of foreign caregivers. Furthermore, it is more difficult for Taiwanese caregivers to provide round-the-clock care, thus the primary caregivers still have to bear the responsibility of care at other times and even need to adopt rotation care. In contrast, family members need more help and are exhausted. Due to financial factors, foreign caregivers remain the preferred long-term care providers for most families (22). Additionally, improving the training of foreign caregivers in medical institutions and returning to family care together is one of the most important needs for families. Nursing staff should actively assist foreign caregivers to improve their nursing knowledge and skills during hospital care. The literature highlights that foreign caregiver skills can be improved through complete teaching and matching with appropriate teaching tools to improve the quality of care (23).

This study was limited to a regional hospital in central Taiwan and could not be generated for the primary caregivers of all stroke patients. There may be sampling bias and limited generalizability. In addition, the demands for care are a dynamic and continuous process. The time point of this study is limited to the third and sixth months of the golden period of rehabilitation, and it is impossible to understand the continuous care demands of the primary caregivers. It is recommended to expand the collection of cases and collect data in more stages in the long term to provide more complete care.

5. Conclusion

The care demands of stroke the primary caregivers of patients vary during the golden period of rehabilitation. As a result, the care demands of the primary caregivers changed in the two stages of the golden period of rehabilitation of stroke patients. Overall, during the golden period of rehabilitation for stroke patients, the top three primary caregivers' demands are health information, professional support, and community networks, but the demands have declined over time. However, emotional support demands remained consistent. The most important factors that affect the demands of the primary caregiver are the early stage of stroke, the nasogastric tube, and the type of care delivery. When providing care, clinical medical staff should first assess the demands and burden of the primary caregiver, and only by providing the necessary care information can they truly provide a complete quality of care. Stroke is a major factor that causes disability and mortality. Long-term care policies should focus on prevention. If a patient suffers from a stroke, they must master the treatment and rehabilitation during the golden critical period, understand the demands of the primary caregiver, and provide care tailored to their needs.

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