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Occupations after Stroke in Stroke Survivors' and Their Family Caregivers' Perception: Similarities or differences?

Jananya Panyamee Dhippayom* **Piyawat Trevittaya** **Phuanjai Rattakorn**

Occupational Therapy Department, Faculty of Associated Medical Sciences, Chiang Mai University, Thailand

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ABSTRACT

Background: Stroke is a leading cause of death and disability worldwide. Stroke survivors have to adapt to a life with restrictions on activities of daily living as a consequence of stroke. In Thai culture, family members generally take responsibility in providing help, care, and support to stroke survivors. Being family caregivers has been reported to be a burden. To equip families to promote better quality of life in stroke survivors in Thailand, an investigation of stroke survivors' and their family caregivers' perception on occupational performance after stroke is required.

Objectives: To examine and compare the perception among stroke survivors and their family caregivers on occupational performance of stroke survivors.

Materials and methods: Thirty stroke survivors living in the communities and their primary caregivers were recruited for the study. The 4th Edition Canadian Occupational Performance Measure (COPM) was used to assess stroke survivors' self-perception on occupations. They were asked to identify a maximum of five activities that caused difficulty to stroke participants. Stroke participants' performance and satisfaction of the reported activities were rated on a scale. The identified problems, and rated scores of performance and satisfaction were compared between two groups using Fisher's exact test and Wilcoxon signed-rank test.

Results: After stroke, participants had difficulty performing occupations by themselves, especially in the area of self-care which included personal care, functional mobility, and community management. When comparing the individual pairs, most activities were reported differently. Only 46 activities out of 157 activities (29.3%) were identified by both groups. Their perceptions on performance, and satisfaction scores of the same activities were not statistically different. The results of the study indicated that there were some similarities and discrepancies between the perceptions of the stroke participants and their caregivers on occupations after stroke even though they had close relationship.

Conclusion: For better quality of life among stroke survivors in Thai culture, occupational therapists need to use the client-centered approach focusing on both stroke survivors and their family caregivers in promoting a deeper understanding of stroke survivors' needs of care, what activity they cannot do by themselves and to what extent assistance is required.

* **Corresponding author.**
Author's Address: Occupational Therapy Department, Faculty of Associated Medical Sciences, Chiang Mai University, Chiang Mai Province, Thailand
** **E-mail address:** jananya.p@cmu.ac.th
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Introduction

Stroke is one of the major challenges of health care being the second leading cause of death and the third major cause of disability worldwide.[1] It was also reported to be the leading cause of death in Thailand.[2] The consequences of stroke depend on several factors, including the location and the size of the brain lesion, and personal factors. There are many devastating consequences after stroke, such as paralysis, numbness, perceptual and cognitive deficits, as well as emotional and behavioral changes.[3] Even though all these might improve over time and with rehabilitation, most stroke survivors still have some difficulties in performing occupations.

In occupational therapy, "occupation" means everyday activities that people do as individuals, in families and with communities to occupy time and bring meaning to life.[4] Occupations include things people need to, want to and are expected to do in the area of self-care, work, and leisure.[4] As an impact of stroke, stroke survivors need help and care from their caregivers in what they cannot perform. There are two common types of caregivers, including formal and informal. Formal caregivers are paid for trained care, whereas informal caregivers are not paid for providing care. Traditionally, an informal caregiver has an important role for stroke survivors who live in the community in Thailand.[5] It is generally the responsibility of family members to provide help and care for stroke survivors.[5] They take this duty because of obligation and their subjective choices derived from love, hope, and a sense of reciprocity.[6] Being an informal caregiver is also viewed as a form of suffering due to a lack of full understanding and preparation for the situation.[6, 7] This results in their development of physical symptoms, psychological/emotional problems, and social issues.[6] Also, unmet needs of care have been reported by stroke survivors.[8] However, family appears to increase stroke rehabilitation/outcomes by providing emotional and instrumental support as well as assistance with daily living.[9] Therefore, to preserve rehabilitation gains and the long-term well-being of the stroke survivors, the emphasis on stroke rehabilitation may need to shift from a patient-focused approach to a combined patient-caregiver-focused approach. The study aimed to investigate the perception of informal caregivers on occupations of stroke survivors whether there were similarities or differences when comparing with the perception of stroke survivors.

Materials and methods

This study had three research sites in Chiang Mai, Thailand. Thirty stroke survivors and their family caregivers volunteered to participate in the study. For the stroke participants, they were clients who lived in the service areas of Nakornping Hospital, Nong Pa Krang Rehabilitation Center, and Huay Kieng Rehabilitation Center. Purposive sampling was used to select the stroke participants who met the inclusion criteria, including having an onset of stroke of less than two years, being able to communicate, having no deficits of perceptual and cognitive functions, and having a family member as a primary caregiver. The 4th Edition Canadian Occupation Performance Measure (COPM) was used to measure the stroke participants' self-perception of performance in everyday living. They were asked to identify the priority of five most significant occupations that they could not perform by themselves and rate their performance and satisfaction scores of the identified occupations from 1 to 10, where 1 indicated poor performance and low satisfaction, while 10 indicated very good performance and high satisfaction.[10] Then, their family caregivers were asked to do the same procedure with the stroke participants. The perception of the stroke participants and their family caregivers on the occupations were compared using Fisher's exact test and Wilcoxon signed-rank test.

Even though the COPM was reported to be a suitable outcome measure for assessing patients with stroke in research and clinical settings,[11] there was no evidence of using the 4th edition COPM among Thai stroke survivors and their family caregivers who lived in the community. Therefore, the reliability of the 4th edition COPM had to be examined before it was used in the data collection process. Test-retest reliability was conducted with another group of 30 Thai stoke survivors who met the inclusion criteria as mentioned above and their 30 family caregivers. It was found that 96 and 97 activities were reported by the stroke survivors and by their family caregivers respectively. 100% of the problems reported by both groups were also identified for the second time with two weeks interval. The Spearman's rho correlation coefficient for the test-retest performance and satisfaction scores of the stroke survivors were 0.879 (p<.001) and 0.956 (p<.001) respectively. The Spearman's rho correlation coefficient for the test-retest performance and satisfaction scores of the family caregivers were 0.991 (p<.001) and 0.992 (p<.001) respectively. Therefore, the 4th edition COPM had high test-retest reliability for Thai stroke survivors and their family caregivers.

Results

Demographic data of the stoke participants and their primary caregivers are shown in Table 1. The age of the stroke participants ranged from 33 to 79 years old (Mean 60.33±11.77), and most of them were male (70%). For their family caregivers, their age ranged from 21 to 77 years (Mean 49.54±13.92). There were 20 females (66.7%) and 10 males (33.3%). Two majority groups of their relationship with the stroke participants were spouse (50%) and children (33.33%). All stroke participants and most family caregivers reported restriction on occupations after stroke. However, four family caregivers did not acknowledge any problems. The total numbers of activities reported by the stroke participants and by their family caregivers as an impact of stroke were 80 and 77 activities respectively. The identified activities were classified into three areas of occupation and nine categories of activity according to the COPM as shown in Table 2 and Table 3.

Table 1 Demographic data of the stroke participants and their family caregivers.

Aspects	Stroke participants (n=30)	Family caregivers (n=30)
Age range (Mean±SD)	33-79 years old (60.33±11.77)	21-77 years old (49.54±13.92)
Gender :		
Male	21 (70%)	10 (33.3%)
Female	9 (30%)	20 (66.7%)
Relationship to the stroke participants		13 wives (43.3%) 2 husbands (6.7%) 5 daughters (16.67%) 5 sons (16.67%) 1 sister (3.33%) 1 brother (3.33%) 2 fathers (6.67%) 1 sister-in-law (3.33%)
Numbers of activities as an impact of stroke		
0 activities	0	4
1 activities	12	8
2 activities	6	3
3 activities	1	4
4 activities	2	4
5 activities	9	7
The total number of identified activities	**80**	**77**

Table 2 Examination of the concurrence of identified activities.

Group	Total numbers of identified activities	Areas of occupation			Fisher's Exact Test (*p*)
		Self-care	Work	Leisure	
Stroke participants	80	55 (68.8%)	23 (28.8%)	2 (2.5%)	2.541 (0.265)
Family caregivers	77	61 (79.2%)	14 (18.2%)	2 (2.60%)	
Total	**157**	**116**	**37**	**4**	

Table 3 Classification of identified activities according to the areas of occupation and categories of activity.

Group	The numbers of identified activities									Total
	Self-care			Productivity			Leisure			
	Personal care	Functional mobility	Community management	Paid/Unpaid work	Household management	Play/school	Quiet recreation	Active recreation	Socialization	
Stroke participants	22	16	17	11	12	0	2	0	0	80
Family caregivers	32	14	15	8	6	0	2	0	0	77
Total	**54**	**30**	**32**	**19**	**18**	**0**	**4**	**0**	**0**	**157**

In Table 2, both stroke participants and their family caregivers had the same point of view that the stroke participants were confronted with difficulty in performing activities in all areas of occupation. Most limitation was in the area of self-care, followed by work, and leisure being least. There was no significant difference (Fisher's Exact Test=2.541, $p>0.05$) between the perception of stroke participants and their family caregivers on occupation restriction regarding the areas of occupation. In Table 3, personal care, community management, and functional mobility were the top three categories of activity that the stroke participants struggled with.

The numbers of similar activities between the individual pairs and the percentage of the similar activities according to the categories of occupation are shown in Table 4 and 5.

Table 4 Numbers of individual pairs according to the numbers of the same activities.

Numbers of the same activities (Activities)	Numbers of individual pairs (Pairs)
0	10
1	9
2	4
3	1
4	4
5	2

Table 5 Percentage of similar and different problems according to the categories of occupation.

Category of activity	Total activities	Similar activities	Different activities	% the same within the category	% the difference within the category
Personal care	54	19	35	35.18	64.82
Functional mobility	30	8	22	26.67	73.33
Community management	32	9	23	28.13	71.87
Paid/Unpaid work	19	6	13	31.57	68.43
Household management	18	3	15	16.67	83.33
Quiet recreation	4	1	3	25	75
Total	**157**	**46 (29.30%)**	**111 (70.70%)**		

When compare the identified activities between the individual pairs, most of the individual pairs tended to perceive a few of the same problems (0-2 activities). (See Table 4) Also, there were 10 out of 30 pairs reporting none of the same problems. In Table 5, there were only 46 out of 157 activities (29.30%) that the stroke participants and their family caregivers reported the same. The top three categories of activity being reported the same were personal care, paid/unpaid work, and community management with the percentage of the same problems of 35.18, 31.57, 28.1 respectively. For those 46 activities, the perceptions on occupational performance and satisfaction of occupational performance between the stroke participants and their primary caregivers were not statistically different as shown in Table 6 and 7.

Table 6 The comparison of occupational performance of stroke survivors between the perception of the stroke participants and their family caregivers (n=46 activities).

Group	Min/Max	Mean±SD	Wilcoxon Signed Ranks Test Z (*p*)
Stroke participants	1/9	3.78±2.42	-0.326 (.744)
Family caregivers	1/8	3.61±2.18	

Table 7 The comparison of satisfaction with occupational performance of stroke survivors between the perception of the stroke participants and their family caregivers. (n=46 activities).

Group	Min/Max	Mean±SD	Wilcoxon Signed Ranks Test Z (*p*)
Stroke participants	1/9	3.61±2.74	-1.252 (.211)
Family caregivers	1/8	4.35±2.49	

Discussion

This study's was aimed to investigate and compare the perception of 30 stroke survivors and their family caregivers on occupations after stroke. From the demographic data, most of the family caregivers were female. Most of them were spouses, and children were the next highest category.[6] This was in accordance with other studies.[5, 6] The COPM was an individualized, client-centered outcome measure.[10] It was designed to capture a client's self-perception of occupation performance in everyday living.[10] It could be used with family members or caregivers.[11] The results of assessment by the 4th edition COPM showed that the stroke participants and their family caregivers shared some similarities and differences in the perception of occupations after stroke.

Regarding similarity, both groups perceived that stroke had an impact on occupations, especially in terms of self-care activities (Table 2), including personal care, community management, and functional mobility (Table 3). Concerning occupational therapy, occupations occur in context and are influenced by the interplay among client factors, performance skills, and performance patterns.[12] Values, beliefs, and spirituality are the client factors influencing a person's motivation to engage in occupations and give his or her life meaning.[12] As self-care activity has an important role in maintaining health and wellness,[12, 13] people expect to regularly perform their self-care activities by themselves. Therefore, it is not surprising that the stroke participants and their primary caregivers expressed most of the problems in the area of self-care activity. However, there were some categories of activity that the stroke participants and their family caregivers did not report to have caused any problem. These included play/school activity, active recreation, and socialization. In the study, the stroke participants were adults or elders, and they did not need to do any activity in the play/school category. With regard to active recreation and socialization, this might be a result of the fact that the stroke participants and their family caregivers were asked to identify a maximum of five most significant occupations at the time of interview. Therefore, less significant activities were not reported. Moreover, having disability led to limitation of participation that was less diverse, limited in the home, involved fewer social relationships, and included less active recreation.[14] Thus, it might be possible that the stroke participants had significant disabilities that prevented them from doing less significant activities such as active recreation and socialization.

Even though the stroke participants and their family caregivers had close relationship (couples and parents-children), most of the stroke participants and their family caregivers perceived a few of the same problems (0-2 activities for each individual pair) (Table 4), or 46 activities out of total 157 identified activities (29.30%) (Table 5). When considering each category of activity (Table5), the highest three categories that both groups reported the same were personal care, paid/unpaid work, and community management. According to the nature of the activities in these categories, the stroke participants might not be able to perform them independently due to their decreased performance skills and physical barriers. They might need a great deal of assistance, or even had to ask their family caregivers for help. Therefore, both stroke participants and their family caregivers might perceive these activities much more the same than other groups of activity.

As the results of the study indicated the discrepancy of perception on occupations after stroke between the stroke participants and their family caregivers, this might lead to unmet care needs. The stroke participants might not receive any help in the significant activities that they needed or could not perform by themselves, or the family caregivers might provide the stroke participants with assistance in the activities that they did not want. Moreover, the discrepancy of perception of occupations after stroke might make their family caregivers overestimate or underestimate the performance and satisfaction of the stroke participants on those occupations. Unfortunately, the study did not design the methodology to proof this. There was only an analysis of the performance and satisfaction scores of the same activities reported by the stroke participants and their family caregivers (Table 6 and 7) indicating no differences of their perception on those scores.

Our finding confirmed the importance of understanding the needs of care in enabling the family caregivers to know the remaining functional capacity and satisfaction of the stroke survivors on those activities. Consequently, the family caregivers could provide the stroke survivors with appropriate and accordant assistance. Understanding the stroke participants' needs of care using occupations as a tool is not only beneficial to the stroke participants, but it can also relieve suffering among the family caregivers. The results of this study indicating the importance of understanding the needs of care in the family caregivers were in line with other studies concerning the uncertainty about stroke patients' care needs that caused a feeling of caregiving burden in the family caregivers.[5, 15] They did not have a good understanding of the role to which they were committed, and they were not well prepared to take on

even the basic tasks to meet the stroke patients' needs on discharge.[16] Therefore, early clarification of the stroke survivors' care needs is recommended for promoting better quality of life for the stroke survivors and their family caregivers. Thai occupational therapists should extend their expertise to the community to drive this crucial mechanism. The client-centered approach seemed to work well for promoting the understanding of occupations among Thai stroke survivors and their family caregivers. The outcomes of promoting the understanding about occupations among Thai stroke survivors and their family caregivers require further investigation.

Conclusion

The stroke survivors and their family caregivers had both similarities and discrepancies of the perception on occupations after stroke. To promote better health and well-being in the stroke survivors, the stroke survivors' and their family caregiver's perception should be adjusted to meet the same perception on occupations.

Conflict of interest

The researchers claimed no conflicts of interest.

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