FACTORS RELATED TO COMMUNITY PARTICIPATION BY STROKE VICTIMS SIX MONTH POST-STROKE

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Abstract. Participation in the community socially by stroke victims is an optimal outcome post-stroke. We carried out a cohort study to evaluate a model for community participation by Thai stroke victims 6 months post-stroke. Six standardized instruments were used to assess the patient's status 1, 3 and 6 months after stroke. These were the modified Rankin Scale, the National Institute of Health Stroke Scale, the Fugl-Meyer Assessment and the Berg Balance Scale. The performance of activities of daily living and community ambulation were measured using the Barthel Index and walking velocity. Participation in the community was measured by the Stroke Impact Scale. The outcomes demographics and stroke related variables were analyzed using the Generalized Estimating Equations. Of the 98 subjects who completed the follow-up assessment, 72 (86.5%) felt they had more participation in the community 6 months post-stroke. The level of disability, performance of independent activities and length of time receiving physical therapy were associated with the perceived level of participation in the community among stroke victims 6 months post-stroke. To achieve a goal of good participation in the community among stroke victims, health care planning should focus on improving the stroke victim's ability to independently perform daily activities. The average length of physical therapy ranged from 1 to 6 months, at 3 to 8 hours/month. Clinical practice guidelines should be explored to optimize participation in the community.

Keyword: stroke, community participation, the generalized estimating equations

INTRODUCTION

Stroke is a leading cause of disability

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and death in Thailand among persons > 45 years old (Ministry of Public Health, 2004). Post-stroke disabilities affect the daily life of survivors and their families, creating a major economic and social burden. The number of stroke survivors is likely to increase in the future because of increasing vascular risk factors and improved acute medical care (Hackam

and Anand, 2003; Sritara *et al*, 2003). Understanding the individual and societal burden of stroke is essential for health care planning and resource allocation.

A system for determination of the consequences of disease was proposed by the World Health Organization (WHO, 2001). The International Classification of Functioning, Disability and Health model is delineated into physical impairments, activities and participation in the community (Mayo *et al*, 2004). Each category has many functional outcome measures, including the Barthel Index, Berg Balance Scale, Rankin Scale and ambulation test (Schepers *et al*, 2007). Stroke survivors who are functionally independent are more likely to participate in the community than those who are dependent.

Increasing age, female gender and brain lesion in the dominant hemisphere are associated with poorer outcomes, less social participation and poorer health related quality of life (Kelly-Hayes *et al*, 2003; Glymour *et al*, 2007). Persons with mild to moderate stroke, as measured by the modified Rankin Scale and the National Institute of Health Stroke Scale have been shown to have a high degree of improvement in functional ability and activities of daily living (ADLs). Stroke survivors who receive physical therapy are more likely to live independently, have a significantly better quality of life and have lower mortality than those who did not receive it (Van Peppan *et al*, 2004; Jullamate *et al*, 2007).

Identification of factors associated with participation in the community may help to improve post-stroke morbidity. This study investigated factors associating with the participation in the community by stroke survivors, using a prospective six month cohort study.

MATERIALS AND METHODS

Participants

Stroke survivors who registered at neurological clinics at 5 sites were enrolled in the study. Inclusion criteria were having one of the following diagnoses: cerebral infarction, intracerebral, hemorrhage or subarchnoid hemorrhage, as defined by the World Health Organization (AHA, 1989). Patients with negative neuroradiological findings were excluded to avoid enrolling subjects with deficits due to uncertain causes. These included patients with transient ischemic attacks, subdural or extradural hemorrhages, and infarction or hemorrhages due to infection or malignancy. Patients with cognitive or psychological impairment, defined by a Modified Thai Mini Mental State Examination score < 16 with impaired ability to communicate were excluded from the study. Patients with serious comorbid conditions, such as serious cardiopulmonary disease, severe orthopedic problems or pain rated higher than 5 on a numerical rating scale (Duncan *et al*, 1999) were also excluded.

Procedure

Subjects were assessed three times after their stroke. The mean time of the 3 assessments were at 33 ± 21 days, 99 ± 11 days and 187 ± 12 days post-stroke. The study was conducted within one year of data collection (from May 2009 to June 2010). One hundred eighty stroke survivors were enrolled at the first assessment (Fig 1).

Demographics and stroke-related characteristics, including age, gender, stroke subtype, and the level of stroke severity as measured by the National Institute of Health Stroke Scale (NIHSS) were recorded at baseline. The NIHSS is
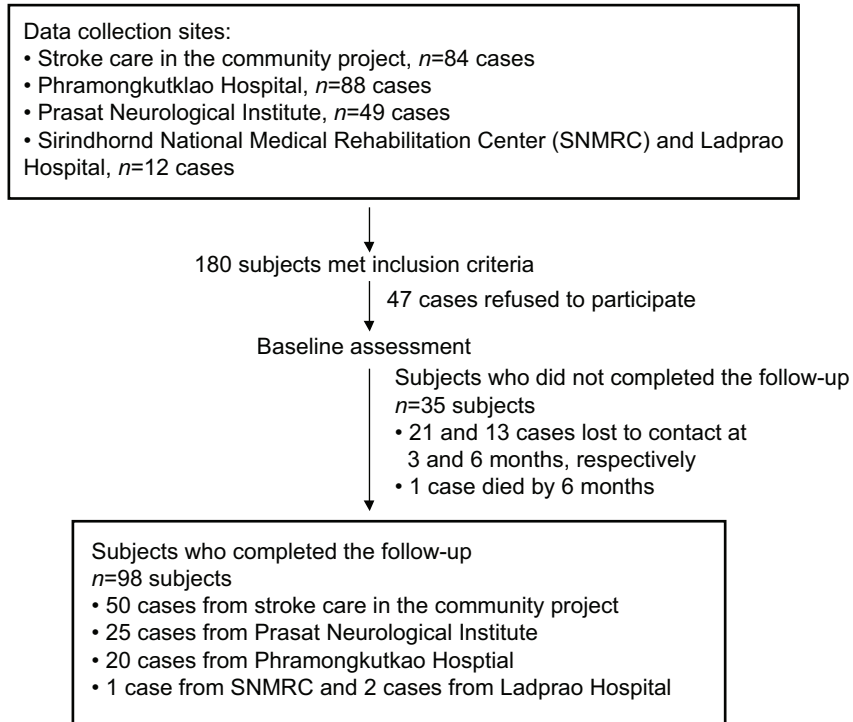
Data collection sites:
• Stroke care in the community project, n=84 cases
• Phramongkutklao Hospital, n=88 cases
• Prasat Neurological Institute, n=49 cases
• Sirindhornd National Medical Rehabilitation Center (SNMRC) and Ladprao Hospital, n=12 cases

180 subjects met inclusion criteria

47 cases refused to participate

Baseline assessment

Subjects who did not completed the follow-up
n=35 subjects
• 21 and 13 cases lost to contact at 3 and 6 months, respectively
• 1 case died by 6 months

Subjects who completed the follow-up
n=98 subjects
• 50 cases from stroke care in the community project
• 25 cases from Prasat Neurological Institute
• 20 cases from Phramongkutkao Hosptial
• 1 case from SNMRC and 2 cases from Ladprao Hospital

Fig 1–Distribution of subjects.

a quantitative measure of stroke-related neurological deficits that measures the level of consciousness, language function, neglect, visual fields, eye movements, facial symmetry, motor strength, sensation and coordination. Lower scores (<5) refer to fewer or no neurological deficits (Kasner *et al*, 1999).

All the participants were screened and their medical records were reviewed by 3 research assistants who were assigned to collect data at each site. The 6 functional outcome measures were the modified Rankin Scale (mRS), the Fugl-Meyer Assessment (FMA) for lower extremities, the Berg Balance Scale (BBS), the Barthel Index (BI) and walking velocity; each of these was carried out at each of the 3 evaluations. The mRS is a measure of global disability for evaluating recovery after stroke (Banks and Marotta, 2007). The scale ranges from 0 (no symptoms at all) to 5 (severe disability). The FMA evaluates movement, coordination and reflex activity to determine recovery of lower extremity motor control (Duncan *et al*, 1983). The BBS measures a person's balance during 14 daily activities, such as sitting, standing, leaning over and stepping (Belgen *et al*, 2006; Blum and Korner-Bitensky, 2008). The total score ranges from 0-56 points, with higher scores indicating better balance. The BI determines functional independence or disability following a stroke by evaluating 10 basic activities of daily living (ADL) (de Morton *et al*, 2008). Walking velocity is measured by having the patient walk 10 meters and dividing that distance by the time it took them to walk that far, this

also evaluates the ability to ambulate in the community (Rossier and Wade, 2001; Salbach *et al*, 2001; Schimd *et al*, 2007).

Information regarding physical therapy and self-perceived participation in the community was recorded at the end of data collection to reduce scoring bias. The amount of physical therapy was defined as the time the subject received physical therapy (in hours) by a physical therapist at a neurological clinic, physical therapy clinic or at their residence. Other treatments or physical activity provided by caregivers, relatives or medical teams were excluded. The perception of participation in the community among stroke survivors was determined using the Stroke Impact Scale (SIS) (Duncan *et al*, 1999, 2003). This contains eight items asking the subject to picture how the stroke has limited their performance relative to working, participating in social activities, quiet and active recreation, in their role as a family member or friend, in their ability to participate in spiritual or religious activities, and in their ability to control their life and to help others. The subjects rated their perception from all of the time (1 point) to none of the time (5 points). The score was generated with an algorithm which ranged from 0 to 100.

Statistical analysis

The Generalized Estimating Equation (GEE) was used to determine the effect of the variables on participation in the community at the 3 assessments. The results were evaluated with SPSS version 17 for GEE analysis of the time-dependent variables which accounted for responses among the subject (Ballinger, 2004).

Ethics

The study protocol was approved by the Institutional Review Board at each site of data collection and all participants were provided with written informed consent.

RESULTS

One hundred eighty stroke survivors who registered at the neurological rehabilitation units at 5 sites were included in the study. Of these, 133 met the inclusion criteria and agreed to participate in the study. Of these, 98 completed the study and 35 (26%) were lost to contact or died (Fig 1).

Table 1 shows the characteristics of the subjects who were enrolled in completed and did not complete the follow-up evaluations. Male stroke survivors who had an ischemic stroke accounted for > 60% of our subjects. Less severe strokes and less severe disability comprised the majority of the patients in our study.

The model of community participation

Our study assessed the subject's self-report of participation in the community over time as measured by the Stroke Impact Scale (SIS). The factors explaining participation in the community by these subjects were the main concern. To describe involvement in the community we analyzed the participation domain of the SIS (SISpart) over the 3 evaluations. The relationship between the SISpart and the related variables was assessed according to the delineation of the ICF model which encompassed the health condition, impairment and activity categories and personal and environmental factors, including demographics. Only variables with a significant correlation to participation in the community were entered to develop a predicting model (Table 2).

Stroke survivors who had mild disability, were able to perform ADLs and who received more physical therapy time had the perception they were more able

Table 1
Subject characteristics.

Characteristics	Subjects enrolled (n=133)	Completed follow-up (n=98)	Did not complete follow-up (n=35)
Age (years), mean (SD)	62.3 (11.52)	61.9 (11.02)	63.1 (12.93)
Body mass index, mean (SD)	24.7 (4.87)	24.8 (4.76)	24.6 (5.26)
Male, n (%)	81 (60.9%)	60 (61.2%)	21 (60%)
Ischemic stroke, n (%)	118 (88.7%)	87 (88.8%)	33 (94.3%)
Independent walking, n (%)	63 (47.4%)	50 (51%)	13 (37.1%)
Less severe (NIHSS ≤5), n (%)	88 (65.4%)	69 (70.4%)	19 (51.4%)
Modified Rankin Scale ≤3, n (%)	77 (58%)	63 (61.2%)	17 (48.6%)
Fugl-Meyer Assessment, mean (SD)	20.3 (9.03)	20.8 (8.46)	18.9 (10.48)
Berg Balance Scale, mean (SD)	31.0 (20.09)	33.1 (20.4)	25.3 (18.27)
Barthel Index, mean (SD)	68.0 (27.09)	71.8 (26.93)	57.4 (24.95)
Walking velocity[a], mean (SD)	0.6 (0.28)	0.7 (0.29)	0.5 (0.14)
Physical therapy time, mean (SD)	5.9 (8.12)	6.9 (9.1)	2.9 (2.69)

[a]Walking velocity was calculated for only subjects who could perform the test
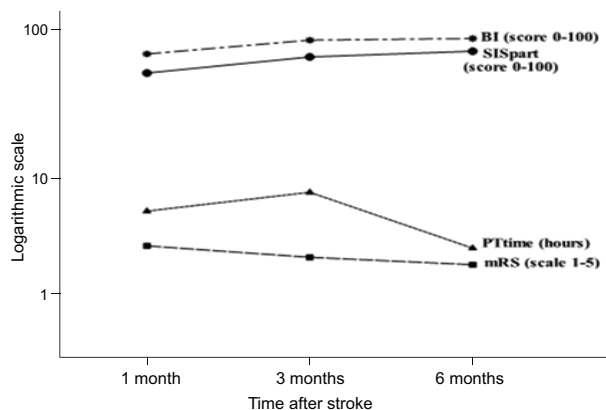

Fig 2–Participation in the community and related variables change over time; participation in the community (SISpart), Barthel Index (BI), physical therapy time (PTtime) and modified Rankin Scale (mRS).

to participate in the community 6 months after their stroke. The ability to participate in the community corresponded to improvement in the level of disability, the ability to perform ADL and physical therapy time (Table 3, Fig 2).

We based the analysis on a summary of the scores of the participation domain which ranged from 8 to 40 points. A score of 24 points distinguished between those who reported a limited or no participation in the community and those who had regular participation in the community. By 6 month, 72 of 98 subjects felt they had satisfactory participation in the community, with a score greater than 24. Using the SISpart 71.4% of subjects reported having little or no limitations on the ability to participate in quiet recreation, such as crafts and reading (Table 4), and 33.1% stated they were able to perform their work and volunteer for activities.

DISCUSSION

Our findings show improvement in the disability, ability to perform ADL and length of physical therapy influence self-perceived participation in the community 6 months after stroke. Age, gender and the

Table 2
Multivariate model of community participation over six months

	Community participation		
	Coefficient (β)	95% Confidence interval	*p*-values
Intercept	43.58	14.91, 72.24	0.003
Age	0.001	-0.21, 0.22	0.975
Gender	0.94	-4.31, 6.18	0.726
Stroke subtype	4.12	-3.32, 11.55	0.278
NIHSS	-0.07	-1.06, 0.91	0.882
Modified Rankin Scale	-8.12	-12.51, -3.72	<0.001[a]
Fugl-Meyer of LE	0.13	-0.37, 0.64	0.603
Berg Balance Scale	0.23	-0.10, 0.55	0.170
Barthel Index	0.32	0.07, 0.56	0.011[a]
Walking velocity	-0.21	-0.51, 0.09	0.178
Physical therapy time			
Time after stroke			
[Time = 1]	0.23	0.06, 0.41	0.008[a]
[Time = 3]	-4.41	-10.41, 1.60	0.150
[Time = 6]	-2.92	-7.34, 1.51	0.196

[a]*p*-values <0.05 analysed by the Generalized Estimating Equations (GEEs)

Table 3
Stroke impact scale and participation in the community post-stroke

	Time after stroke		
	Baseline (*n*=133)	Month 3 (*n*=112)	Month 6 (*n*=98)
Participation in community, mean (SD)	52.1 (29.64)	66.0 (26.46)	72.7 (32.37)
Mild disability (mRS ≥3), *n* (%)	77 (58%)	86 (77%)	81 (83%)
Barthel Index, mean (SD)	68.0 (27.09)	83.6 (21.99)	85.7 (22.53)
Physical therapy time, mean (SD)	5.9 (8.12)	8.0 (16.03)	2.9 (8.23)

level of stroke severity at baseline were not associated with participation in community. However, these variables have a complex interaction with social participation (Nichos-Larsen *et al*, 2005).

A reduction in mRS grade corresponded to improvement of performing ADL as measured by the Barthel Index (BI). A cut-off score of 75 on the BI among those with mild disability (mRS ≤ 3) was proposed by Uyttenboogarrt *et al* (2005) to differentiate subjects who could perform ADL from those who could not. Our results demonstrate the modified Rankin Scale is a potential predictor for self-perceived participation in the community in

Table 4
Limitation by Stroke Impact Scale domain.

During the past 4 weeks, how much of the time have you been limited by the stroke	Participation in the community (*n*=98)		
	All of the time (1 point)	Most of the time (2 points)	None or some of the time[a] (≥3 points)
1. Work, volunteer or other activities	42 (31.6%)	2 (1.5%)	54 (40.6%)
2. Social activities	21 (15.8%)	3 (2.3%)	74 (55.6%)
3. Quiet recreational activities (crafts, reading)	2 (1.5%)	1 (0.8%)	95 (71.4%)
4. Active recreational activities (sports, outings, travel)	29 (21.8%)	4 (3%)	65 (48.9%)
5. Role as a family member or friend	13 (9.8%)	2 (1.5%)	83 (62.4%)
6. Participation in spiritual or religious activities	32 (24.1%)	29 (1.5%)	64 (48.1%)
7. Ability to control your life as you wish	4 (3%)	14 (10.5%)	80 (60.2%)
8. Ability to help others in need	21 (15.8%)	5 (3.8%)	72 (54.1%)

[a]A single item score >3 indicates participation in the community.

stroke survivors 6 months post-stroke.

The effect of the number of hours of physical therapy on predicting participation in the community was investigated in this study. The greater the amount of physical therapy the greater the subject's perceived participation in the community. Studenski *et al* (2005) examined the effect of physical therapy on participation in the community. Subject who received home-based physical therapy had better social participation ($p = 0.0051$) than those who simply received rehabilitation advice by their physician. Physical therapy produced a greater improvement in physical and functional independence which appeared to improve participation in the community.

In our study 13.5% of subjects perceived limited participation in the community. The stroke survivors in our study perceived that the stroke affected their life relative to work (42 subjects), but performing quiet recreation, such as crafts and reading were less affected by stroke (2 subjects). This indicates the major burden of stroke survivors in the community and suggests a need for health care planning and resource allocation.

Our study was a hospital-based study which could skew the subject population toward those who access health care facilities. The results of this study may only be applied to those in this population group. This study was designed to investigate the effect of various factors on participation in the community by stroke survivors. Subjects who had physical therapy regularly achieved more functional recovery and participated more in the community. Physical therapy targets the subject's disability and functionality. Jette *et al* (2005) found more than 50% of treatment time focused on standing balance and gait training which have an affect on participation in the community.

This study focused on factors influencing participation in the community by using the SISpart. These results are not only valuable for providing information

regarding the burden of stroke survivors in the community but to help health care planner determine policies and allocate resources.

Participation in the community is a fairly new concept in stroke rehabilitation. Further studies are needed to determine the physical therapy techniques beneficial for improving the ability to participate in the community among stroke survivors.

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