

THE APPLICATION OF COMMUNITY NEUROREHABILITATION USING A FAMILY-CENTRED APPROACH TO PERSONS WITH DISABILITY: A CASE STUDY IN STROKE SURVIVORS

Nomjit Nualnetr*, Waroonnapa Srisoparb**, Wichai Eungpinichpong***

ABSTRACT

This study aimed to evaluate changes in motor activity, and mental and social conditions of 10 stroke survivors after participating in the 12-week community neurorehabilitation using a family-centred approach. During the first four weeks, each client's problems, achievable goals, and a rehabilitation programme were discussed and cooperatively designed among the individual, caregiver and the investigator. Both client and caregiver were then instructed to perform the programme for four weeks with regular visits from the investigator, and were asked to continue the programme on their own for four more weeks. The outcomes were assessed at the baseline and every four weeks. The paired t-test revealed that neurorehabilitation using a family-centred approach significantly improved the client's mental and social conditions ($P < 0.05$). Future studies with a greater number of clients and randomised controlled trial design are needed to reveal further benefits of such a rehabilitation scheme on stroke survivors in the community.

INTRODUCTION

Stroke is a leading cause of death and disability for men and women of all ages, classes and ethnic origins. In Thailand, the number of stroke survivors increased from 62,757 in 2001 to 84,000 in the current year (1, 2). After being discharged from an inpatient setting, most stroke survivors have to live at home with their family because rehabilitation centres are not available nationwide. Furthermore, because of economic strain, most of them have not had the opportunity to continue their neurological rehabilitation at rehabilitation institutions. Therefore, the family has to play an important role in rehabilitation and in supporting the reintegration of stroke survivors into the community. The family needs to be viewed as the

primary team member in all stages of rehabilitation services across the life span (3). A study by Dowswell et al. (4) suggested that a rehabilitation programme with a family- or client-centred approach might be more suitable than that with a therapist-centred approach because it was relevant for individual stroke survivors. Tepdara and colleagues (5) also reported that the lack of a family's participation in the rehabilitation team was a cause of the inadequate rehabilitation services for stroke survivors. Thus, neurorehabilitation for stroke survivors in Thailand should move towards a home-based setting with a family-centred approach. The objective of this study was to evaluate changes in motor activity, and mental and social conditions of stroke survivors after participating in the 12-week community neurorehabilitation using a family-centred approach. This article is part of the full report published in Thai language in the Thai Journal of Physical Therapy, 2007 (6).

METHOD

Ten stroke survivors from a community in Khon Kaen Province, Thailand, were recruited to the study during December 2005 and July 2006. The inclusion criteria were having had a stroke more than six months previously, having a caregiver for supporting the subject in the rehabilitation programme more than 30 minutes per day throughout the study, having mobility problems such as supine to sitting, sitting to standing, walking, arm function and hand movement, and having good communication. The clients were excluded if they had severe unilateral neglect, had learning problems such as dementia, or had severe comorbidity that limited exercise such as severe hypertension, heart disease or pulmonary disease. Outcome measures were the client's motor activity, and mental and social conditions.

The motor activity of stroke survivors was assessed by the Modified Motor Assessment Scale (MMAS) (7, 8). It consists of eight items measuring functional capabilities: supine to side lying, supine to sitting over side of bed, balanced sitting, sitting to standing, walking, upper arm function, hand movements, and advanced hand activities. The items can be tested in any order. Each motor activity is rated on a seven point scale from zero (simple) to six (complex). The client performed each item three times, and the best performance was recorded.

The mental and social conditions were assessed by an interview schedule designed by the investigator (6). For the mental condition, a four point Likert-type scale ranging from one

(most terrible) to four (most happy) was established. The score ranges from seven to 28 with higher scores reflecting low increased tension and lower scores reflecting high increased tension. Rating of the social condition was defined with a four point scale. Total scores range from nine (worst social condition) to 36 (greatest social condition).

The study period in total was 12 weeks. During the first four weeks, each client's problems and achievable goals of rehabilitation were discussed among the client, his (her) caregiver and the investigator, and then a home-based rehabilitation programme relevant to the individual client was cooperatively designed. Two pre-programme assessments were conducted during this period. After that, each client and caregiver were instructed to perform the programme for four weeks with regular visits from the investigator, i.e. five days a week in the first two weeks, three days a week in the third week and once a week in the fourth week. The aims of each visit were to encourage the client and caregiver to keep practising the programme everyday, and to offer advice for an advanced programme. After completion of this four week period, each client underwent the first post-programme assessment in which all outcome measures were used. Thence, both client and caregiver were asked to continue the programmes on their own for four more weeks. The second post-programme assessment was conducted at the end of the study.

Descriptive statistics were drawn up to describe demographic and personal data of the individual clients. A paired t-test was used to analyse significant changes from the baseline scores of all outcome measures. The normality of the data set was assessed using the Shapiro-Wilk W test. All analyses were performed using the STATA statistical software package version 9.0. A value of $P < 0.05$ was used to decide the significance for all analyses.

This study was approved by The Khon Kaen University Ethics Committee for Human Research.

RESULTS

Ten clients (five men and five women) with an average age of 69.7 ± 6.8 years were recruited. Five of them were left hemiparesis and five were right hemiparesis. Their stroke duration ranged from seven to 84 months with an average duration of 45 ± 25.5 months. Their 10 caregivers (two men and eight women) had an average age of 56.1 ± 16.3 years. They were

the client's wife, husband or daughter. Of the 10 stroke survivors who attended pre-programme assessments, two withdrew from the study before the first post-programme assessment due to having a recurrent stroke and dementia, respectively. Eight subjects were thus included in the statistical analysis.

From the discussions between the clients, caregivers and the investigator, it was revealed that improved walking ability was prioritised as the main rehabilitation goal of most clients. An improvement in arm and hand control was another prioritised goal. Rehabilitation programmes were cooperatively designed to help the clients achieve their goals of rehabilitation as much as possible. In summary, the community neurorehabilitation programmes for stroke survivors in this study consisted mostly of walking training in various directions and surface areas; functional arm and hand training using activities in daily life such as taking food to the mouth, cooking, dressing, grooming, cleaning a table; reaching out to an object in various directions; and stretching exercises mainly on plantar flexor, back as well as lateral trunk flexor muscles. Local wisdom regimen such as exercise with a wooden stick, and application of a hot water bag and massage was also a choice of need.

Before determining the effects of community neurorehabilitation on outcome measures, the consistency of the two pre-programme assessment scores was examined.

Two pre-programme assessments were carried out with a time interval of four weeks between the first and second tests. The purpose of this design was to ensure that any changes exhibited in the study would be attributable to the rehabilitation programme. The results showed no significant differences between the first and second pre-programme assessments for all variables. The values obtained from the second pre-programme assessment were thus used to be the baseline scores for the analysis of the changes.

Table 1 shows the mean scores of the outcome measures at each assessment period. Small changes in the MMAS scores were found during post-programme assessments, but were of no statistical significance. The rehabilitation programme significantly improved the clients' mental and social conditions ($P=0.008$ and 0.04 , respectively) at the first post-programme assessment. However, these effects were not sustained for the further four week period.

Table 1. Mean (standard deviation) of outcome measures at each assessment period (N=8)

Outcome measures	Assessments		
	baseline	1st post-programme	2nd post-programme
MMAS (0-48)	26.3 (9.9)	28.1 (10.4)	28.1 (10.4)
Mental condition (7-28)	16.4 (4.9)	20.6 (5.3) *	18.3 (6.7)
Social condition (9-36)	28.1 (5.2)	30.0 (5.7) **	29.3 (6.9)

*P=0.008, **P=0.04

DISCUSSION

The current study failed to show a significant change in the clients' motor activity. Lack of significant improvement in this outcome measure may have resulted from too short a duration of the rehabilitation programme (9). As most clients were representative of most long-term survivors of stroke (average stroke duration of 45 ± 25.5 months), improvements in motor activity of such clients, especially in arm and hand functions, seemed to need a longer time than those of acute or sub-acute ones. Therefore, the rehabilitation programme's duration of this study may not have been long enough to improve the motor functions of the clients.

The other possible explanation for a non-significant change in the clients' motor activity is that the rehabilitation programme may not have been in harmony with the testing items of the MMAS. In this study, to improve arm and hand control, the rehabilitation programme designed for each client involved activities in daily life, not activities included in the testing items of the MMAS (e.g. continuous opposition of thumb and each finger, picking up the top of a pen and putting it down, drawing horizontal lines, making rapid consecutive dots on a sheet of paper by a pencil). A gradual increase in movement speed was also not emphasised in the subjects. Therefore, it is possible that following the rehabilitation programme, improvements in the client's motor activity may have occurred but were not assessed by the MMAS.

After completion of the first four weeks of the rehabilitation programmes with regular visits from the investigator, significant improvements were found in the clients' mental and social conditions. However, such benefits did not persist beyond this four week period. These findings are in accord with a study by Wade et al. (9). They are probably attributable to the fact that regular visits from the investigator during the four weeks may have provided some psychological support for the clients. In other words, improvements in such variables may have been influenced by the attention that the clients received from project participation. It is possible that, during a period of regular visits from the investigator, the clients felt that they had another person to talk with about their distress, or to help relieve their tension, and had more interactions with their family member and other persons. The investigator's visits may also have led to an increased relationship between individual clients and caregivers because they would have been assisted in spending time together for at least half an hour a day in order to perform the rehabilitation programme.

In the investigator's opinion, interpretation of a research study's findings only via statistical means may conceal some beneficial aspects of the study. In the current study, an interesting finding was observed. In order to follow the principle of a family-centred approach, the investigator paid much attention to tailoring the rehabilitation programme to each client's problems. Realistic achievable rehabilitation goals and programmes were cooperatively established through dialogue among individual clients, caregivers and the investigator. Although attention was paid specifically to ensure that the clients and caregivers would be greatly involved in these procedures, some of them rarely expressed their ideas and opinions regarding the programmes. They were likely to rely on the investigator's judgment. This may be due to a typically urban Thai culture that a person tends to respect professional suggestions rather than their own ideas. The clients might have adopted a passive role because they had become used to that culture. Such culture may not be obvious in Western countries. Moreover, it was observed that the participation of the clients in developing the rehabilitation programme was related to a number of factors such as education level, relationship in the family, experience in rehabilitation, and attitude to illness.

The other possible explanation of a low level of participation in developing the programme of some clients is that they were not ready to participate in rehabilitation services in a family- or client-centred manner. This is probably due to old age, poor health, or a negative attitude to

illness. The investigator then had to assist these clients as much as possible to involve them in developing their programmes. Such facilitation may have been inadequate because of the limitations of time and skill on the part of the investigator. Some clients' rehabilitation programmes may have been influenced by the investigator's suggestions, leading to small sense of ownership of the programmes in these clients. It was observed that the clients who had a low level of participation in developing the rehabilitation programme and quite relied on the investigator's facilitation had decreased mental and/or social condition scores after the investigator's visits ceased. Therefore, it could be suggested for further study that therapists should endeavour to engage clients in decision-making. They should evaluate a client's level of readiness and tailor interventions for participation accordingly. Matching an intervention to a client's level of readiness to engage in an activity should be more effective than the universal application of one particular intervention.

Because of the limitations of time and financial support, clients in this study were recruited only from one community. This resulted in a small sample size of 10 stroke survivors participating in the study. Further studies with a greater number of clients as well as a randomised controlled trial manner are essential. This would demonstrate whether stroke survivors who receive community neurorehabilitation with a family-centred approach improve their health status in comparison with the controls. In addition, the effects of a programme with a longer duration should be considered. Further detailed investigation of the cost implication of this rehabilitation scheme is also needed before it can be adopted unreservedly.

Furthermore, to achieve greater success in community neurorehabilitation with a family-centred approach, the clients' level of participation in developing the programmes needs to be considered and various strategies to approach the clients should be applied. As demonstrated in the current study, the clients who had a low education level, had no knowledge of exercise/rehabilitation, had a negative attitude to illness, had a poor relationship with their caregivers and mostly relied on the investigator's facilitation. Thus, the programmes may need to be modified for example, by increasing the number of therapist's visits, and organising a self-help group meeting for such clients. In addition, it seems that not only through the stroke survivors and their family, the neurorehabilitation should also be implemented through the combined efforts of the community, local government, and the appropriate health, education, vocational and social services, following the concept of a community-based rehabilitation (10, 11, 12, 13).

In conclusion, the rehabilitation programme designed with the participation of clients could positively affect stroke survivors. Future studies with a greater number of clients and randomised controlled trial design are needed to reveal further benefits of such a rehabilitation scheme on stroke survivors in the community.

* Address for Correspondence

Associate Professor, Department of Physical Therapy
Faculty of Associated Medical Sciences
Khon Kaen University, Khon Kaen 40002, Thailand
Tel/Fax: +66 43 202-085
Email: nomjit@kku.ac.th

** Lecturer, Department of Physical Therapy

Faculty of Allied Health Sciences, Naresuan University
Phitsanulok 65000, Thailand

*** Associate Professor, Department of Physical Therapy

Faculty of Associated Medical Sciences, Khon Kaen University
Khon Kaen 40002, Thailand

ACKNOWLEDGEMENT

This study was supported by the Graduate School and Faculty of Associated Medical Sciences, Khon Kaen University. The authors wish to thank Associate Professor Sopa Pichaiyongwongdee and Assistant Professor Orasa Kongtalin for their comments to the development, refinement, and completion of this work. Special thanks are given to all participants. Sincere appreciation is extended to Mrs. Shirley Edwards for having corrected the English in this article.

REFERENCES

1. Bureau of Policy and Strategy. *Thailand Healthy Lifestyle Strategic Plan 2007-2016*. Nonthaburi: Ministry of Public Health. [cited 2008 Aug 19]; Available from: <http://bps.ops.moph.go.th/Thailand.html>.
2. Vibulponprasert S. *Thai public health 1999-2000*. Nonthaburi: Ministry of Public Health; 2002.
3. Brown S, Humphry R, Taylor E. *A model of the nature of family-therapist relationships*:

- implications for education.* Am J Occup Ther 1997; 51: 597-603.
4. Dowswell G, Dowswell T, Lawler J, Green J, Young J. *Patients' and caregivers' expectations and experiences of a physiotherapy intervention 1 year following stroke: a qualitative study.* J Eval Clin Pract 2002; 8: 361-5.
 5. Tepdara S, Arayawichanon A, Thongmee L, Tannundaj N, Chaikul P, Siribulpipattana S. *The development of a continuous rehabilitation system for stroke patients with a cooperation of patients and their relatives.* Thai J Phys Ther 2001; 23: 14-23.
 6. Srisoparb W, Nualnetr N, Eungpinichpong W. *Home-based physical therapy program with family-centered approach for chronic stroke patients.* Thai J Phys Ther 2007; 29: 115-25.
 7. Carr JH, Shepherd RB, Nordholm L, Lynne D. *Investigation of a new motor assessment scale for stroke patients.* Phys Ther 1985; 65: 175-80.
 8. Loewen SC, Anderson BA. *Reliability of the modified motor assessment scale and barthel index.* Phys Ther 1998; 68: 1077-81.
 9. Wade DT, Collen FM, Robb GF, Warlow CP. *Physiotherapy intervention late after stroke and mobility.* BMJ 1992; 304(6827): 609-13.
 10. Cott C. *Client-centred rehabilitation: client perspectives.* Disabil Rehabil 2004; 26: 1411-22.
 11. World Confederation for Physical Therapy Keynotes Community Based Rehabilitation. *Changing concepts of CBR 2 – Implications for physical therapists.* http://www.wcpt.org/common/docs/wcpt_keynote_CBR2.pdf. [Accessed 2007 September 12].
 12. Bury T. *Primary health care and community based rehabilitation: implications for physical therapy.* Asia Pacific Disability Rehabilitation Journal 2005; 16: 29-61.
 13. Nualnetr N. *Physical therapy roles in community-based rehabilitation: a case study in rural areas of northeastern Thailand.* Asia Pacific Disability Rehabilitation Journal 2009; 20: 73-82.