

**Original article:**

**Adherence to Home-based Neuro-rehabilitation Exercise program in Stroke survivors**

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**Abstract**

**Background:** Post discharge, Home-based exercise program (HEP), prescribed by physiotherapist is an integral part, to plan effective stroke rehabilitation, with the intended goal of maintaining functional motor performance and enhancing functional progress. Earlier studies have shown that many factors attribute to adherence and barriers for structured group based exercise program.

**Objective:** This study was designed to identify the factors in stroke subjects, which may influence the adherence and barriers to individually tailored HEP post-discharge, in stroke subjects. **Method:** An analytical cross-sectional study, with non-random sampling, consisting of first onset stroke subjects who had received acute stroke rehabilitation from tertiary care hospitals. Post-discharge, seventy-four participants were followed up and their responses related to adherence and barriers to the prescribed HEP by administering a self-reported adherence to home exercise questionnaire. **Results:** 63.5% were adherent and 36.5% were non-adherent to HEP, among 74 subjects. The adherent group had performed exercises for at least 5-6 times in a week, for 31-45 minutes each day. Intrinsic factors related to self-efficacy and perceived level of anticipated recovery had found an association with adherent and non-adherent groups. The most common barriers for adherence to HEP were fear of fall or injury and fatigue for both adherent and non-adherent subjects. **Conclusion:** This present study helped to put an insight, onto socio-demographic and intrinsic factors, with the level of adherence and to identify the barriers for adherence to individually tailored HEP.

**Keywords:** stroke; hemiparesis; home exercise program; adherence; barriers

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**Introduction**

Worldwide 15 million people suffer a stroke each year out of which 5 million die and another 5 million live with permanent disability<sup>1</sup>. In India, it has been one of the leading causes of death and disability with an estimated prevalence rate of 84-262/100,000 in rural and 334-424/ 100,000 in urban areas and the incidence rate of 119-145/100,000 based on the

recent population based studies. A recent study from India has also stated that young stroke, aged less than 45 years, accounts for the 5 to 10% of all the strokes, which can lead to loss of the productive years and long term disability<sup>2-4</sup>.

In recent advances of stroke management, the use of thrombolytic therapy in acute care, has found to reduce the mortality rate in ischemic stroke and

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also, there has been considerable improvements in their functional outcomes<sup>5</sup>. Though, the post-stroke survival rates have increased due to the advanced acute care management, there are residual physical and psychological impairments, resulting in functional impairments<sup>6</sup>. Hence, development and implementation of strategies in stroke rehabilitation, is important to enhance recovery in different stages of stroke and also to improve functional status and optimize the quality of life, in young stroke subjects.

Traditionally, the physiotherapy management, in acute stroke rehabilitation includes, training for basic mobility, self-care and improving functional capabilities, in activities of daily living. This early initiation of rehabilitation has shown to improve functional outcomes<sup>7, 8</sup>. Post-discharge, the stroke subjects may become physically inactive, due to secondary health conditions associated with stroke, decreased mobility and barriers in the community<sup>9</sup>. Thus, physical inactivity, which leads to physical deconditioning, may decline the functional status of these subjects<sup>9-11</sup>. Rehabilitation in later stages of stroke care, therefore should focus on improving the physical activity of the subjects and making them independent in activities of daily living. In developing countries, after discharge from the acute care, the rehabilitation is continued in patient's home or in out-patient facilities<sup>2,7</sup>.

Home-based exercise program (HEP) prescribed by physiotherapist, is an integral part of post-discharge rehabilitation planning, with the intended goal of maintaining functional motor performance and enhancing functional progress<sup>7</sup>. Earlier studies have shown that high level of exercise adherence is important for HEP<sup>12,13</sup>. Adherence is defined as 'An active, voluntary, collaborative involvement of the patient, in a mutually acceptable behavior, to produce a desired preventive and therapeutic result'<sup>14</sup>. The studies on structured group based exercise program have shown that many factors, which contributes for adherence to exercise are, self-confidence, motivation, depression, psychosocial support, biophysical issues, knowledge about exercise, environmental factors and self-efficacy<sup>15-18</sup>. Studies on barriers for adherence to physical activity, as reported by stroke subjects are lack of time, lack of adequate supervision, patient discomfort like pain or fatigue, personal barriers and lack of accessible transportation<sup>9,19,20</sup>.

The primary aim of this study was to identify the factors in stroke subjects, which may influence the

adherence and barriers to individually tailored HEP, post-discharge in stroke subjects. Our secondary objective was to study the various factors associated with the level of adherence, to individually tailored HEP, in stroke subjects.

### **Method**

This study is a questionnaire-based, descriptive, cross-sectional study, in which results were extracted from subjects, who have undergone acute stroke rehabilitation, tertiary care hospitals Mangaluru, Karnataka, India. Stroke subjects were recruited, using purposive non-random sampling. The specific inclusion criteria were: (1) Post-stroke subjects, who have undergone neurological rehabilitation in the inpatient department for more than two weeks; (2) Subjects, with Mini Mental State Examination (MMSE) score equal to or more than 23. The exclusion criteria were: (1) Stroke subjects, with sensory aphasia; (2) Other diagnosed neurological conditions, such as Parkinson's disease or Multiple Sclerosis; (3) Concomitant severe musculoskeletal, cardio-pulmonary or other medical conditions, which may hinder the HEP, for the subjects.

### **Development of Adherence Questionnaire**

A self-administered questionnaire "Adherence to Home Exercise Questionnaire" (English version) for individually tailored HEP, was developed after exploring the literature regarding various questionnaire's on adherence and barriers for structured group based HEPs, for various medical conditions including stroke<sup>13,15,19,20</sup>. A pilot study was conducted for face and content validity of the questionnaire, the original version in English, consisted of 9-components which includes socio-demographics, stroke severity and level of disability, satisfaction to prescription of HEP, anticipated recovery post HEP, practice patterns of HEP, participant's self-efficacy level using Stroke Self-efficacy Questionnaire (SSEQ)<sup>21</sup>, global impression of recovery following HEP using global perceived effect scale<sup>22</sup>, motivators and barriers for adherence to HEP and each component comprising of one or more questions.

### **Exercise Program and Measurement of Level of Adherence**

At the time of the discharge from the inpatient department of the hospital, each stroke patient was screened for the inclusion and exclusion criteria. The primary investigator, collected demographic variables from the subject. Medical records and severity of

stroke was scored by National Institutes of Health Stroke Scale (NIHSS) and the level of disability was scored by Modified Rankin Scale (MRS). The detailed HEP was explained and taught to the subject and their caregiver, which was tailored according to the subject's functional abilities and motor recovery. HEP attempts to improve the performance of basic mobility and personal care tasks, together with muscle strength, coordination, balance, and gait activities. The subjects and the caregivers were instructed to follow the HEP, each day in a week and at least for 45 minutes, to improve the individual's functional abilities. The check lists and individually tailored HEP, was explained to 220 stroke subjects and 138 subjects met the inclusion criteria, out of which 74 subjects attended for the follow up. The reasons for the loss of follow up were lack of time, ignorance regarding the condition, reported death, ongoing rehabilitation by the community physiotherapist, financial problem and improvement in their post-stroke condition.

On the day of follow-up, principal investigator, briefed about the purpose of the study, to the stroke subjects and their caregivers. A written consent was obtained from the subjects and the interested subjects were asked to complete the questionnaire, based on their language preferences. In case, if the patient was unable to attend the follow-up after 1 month, he/she was telephonically reminded by the principal investigator and was encouraged to attend the follow-up within two weeks' time and complete the questionnaire. As per the current guidelines recommended for physical activity in stroke subjects<sup>23</sup>, we presumed in our study that the stroke subjects, which followed the individually tailored HEP, for at least five to six times or more in a week and for 31-45 minutes or more each day, were considered as adherent to individually tailored HEP.

### **Data Analysis**

The collected data was coded and entered in Statistical Package of Social Sciences (version 16 for Windows). The results were expressed as proportions and summary measures. Chi-square test was used, to find association with socioeconomic demographics, intrinsic factors, and barriers across adherent and non-adherent groups. The p-value of less than 0.05 was considered statistically significant.

**Ethical clearance:** The study was approved by the scientific and institutional ethics committee of Kasturba Medical College, Mangaluru, Manipal

Academy of Higher Education, India.

### **Results**

A total of 74 stroke subjects, comprising 59.5% (N=44) men and 40.5% (N=30) women, filled the "Adherence to Home Exercise Questionnaire". Among these subjects, 62.2% (N= 46) belong to the upper and middle class and 37.9% (N=28) belong to lower socioeconomic class. With respect to comorbid conditions, the subjects having hypertension were 73.1% (N=54) and diabetes mellitus were 29.9% (N=22). Level of stroke severity using NIHSS had shown 59.5% (N=44) had mild stroke and 40.6% (N=30) had moderate stroke. 74.3% (N=55) had moderate disability and 20.3% (N=15) with slight disability in Modified Rankin Scale. The above findings are presented in Table 1.

In the domain of satisfaction level in prescribed HEP, all the subjects were reported to be satisfied, with the prescribed HEP. But, among the 74 stroke subjects, 95.9% (N=71) followed the HEP more than a week from the day of discharge and 4.1% (N=3) reported to not to follow the HEP. Under the domain perceptions of stroke subjects about participation in HEP, entire study population (100%) agreed that the HEP was beneficial and important for their recovery and functional independence in activities of daily living. Among the 74 subjects, about 26.2% (N=21) reported they performed HEP with the goal of walking independently, 21.9% (N=16) for improvement in strength, and 35.6% (N=26) for functional independence and for performing activities of daily living. About 93.2% (N=71) also reported no adverse effects from HEP, only 12% (N=9) of them are able to modify the prescribed HEP as described in Table 2.

In reported practice patterns, it was found that in 32.4% (N=24) assistance for performing HEP was by spouse and in 62.2% (N=46) assistance was given by relatives. Only 5.4% (N=4) of the 74 stroke subjects were found to perform exercises, without assistance. 65% (N=48) of the stroke subjects performed the HEP, minimum for 5-6 times in a week or more and 77.2% (N=57) of subjects performed for at-least 31-45 minutes. In this study, 63.5% (N=47) stroke subjects were found to be adherent who performed exercises, for at least 5-6 times in a week for 31-45 minutes each day as mentioned earlier and 36.5% (N=27) were non-adherent to HEP among 74 subjects explained in Table 3.

Self-efficacy is an important domain considered for exercise adherence. In this study, participants reported

with 100% and above in SSEQ were considered as high in self-efficacy. 83% (N=39) had reported highly confident in adherent group compared to 22.2% (N=6) in non-adherent group. Participants responded with any scores from +3 to +5 in global perceived effect numeric scale was considered as positive change and scores from +2 to 0 are considered as no change, -5 to -1 as negative/worsening to address global recovery following HEP. 93.5% (N=43) are reported with positive change in adherent group, compared to 59% (N=16) in non-adherent group. Association between level of adherence and socio-demographic variables there was no statistically significant difference for age groups, with p-value as 0.589, gender with p-value of 0.339, socio-economic status with p-value of 0.06 and severity of stroke with p-value of 0.312. Self-efficacy and Global perceived effect scale had found statistically significant association with level of adherence with p value as <.001 as described in Table 4.

The most common reported barriers among the personal factors were fear of falling and fear of injury with 16.2% (N=12) and fatigue with 16.2% (N=12), lack of energy with 12.2% (N=9), in both adherent and non-adherent subjects. Among the non-adherent group, exercising is boring and monotonous and fatigue was commonly reported barriers. "Exercising is too difficult" showed significant difference and was reported by 11.1% (N=3) amongst the non-adherent group, with  $p < 0.05$  are presented in Table 5.

### **Discussion**

The primary aim of our study was to find, the level of adherence and barriers for adherence to HEP, in stroke subjects followed post-discharge from the inpatient rehabilitation, by administering a self-reported adherent questionnaire. The questionnaire has categorized the potential factors associated with exercise adherence into four domains; (1) Socio demographic (2) Personal factors including self-efficacy and perceived HEP benefits (3) Practice Patterns and (4) Barriers. Subjects were asked to respond the extent to which they adhere to the prescribed HEP and their barriers using 'Yes' or 'No' and few open ended questions. The level of adherence in our study was found to be satisfactory and there was an association between intrinsic factors such as self-efficacy and global perceived effect for adherent and non-adherent groups.

In the present study, 86.48% were between the age group of 40-80 years and the reported cases of

young stroke (<40 years of age) was 9.46%. These results are similar to previous study that there is an emerging trend of young stroke in India<sup>2,3</sup>. 73% were found to have hypertension, as the most common comorbidity amongst the stroke subjects. With respect to severity and disability in stroke subjects, 59% had mild severity and 74.3% had mild-moderate disability, following stroke, which may attribute for very less (5%) subjects, to use assistive devices for mobility as reported in this study.

In the current study, the HEP was individually tailored for the stroke subjects, according to their clinical presentation, residual impairments and functional abilities. We also believe that variations between patients that occur in real clinical practice, a pragmatic approach involving physical therapy interventions could provide a maximum level of flexibility, applicability and generalizability in structuring acute stroke rehabilitation program. For every stroke subject, the therapist, who provided the inpatient rehabilitation during the hospital stay, explained and demonstrated the HEP, following discharge. One to one interaction between the therapist and the stroke subject, adequate and precise HEP instructions at the time of discharge, positive interpersonal relationship and also boosting their morale, motivation, confidence would have been few of the possible factors, which attributed to 100% satisfaction for all the subjects, who participated in this study; as it is reported in a recent study that these factors may influence the level of adherence<sup>24</sup>.

96% of the stroke subjects reported that they follow prescribed HEP and they also perceived that individualized HEP; enhance their functional recovery and independence in activities of daily living. The majority of subjects reported that the primary reason to perform the HEP regularly was to improve walking, strength and ADL activities. These results were similar to the finding of the previous studies, which reported that gait recovery and improvement in strength are the major goals, for the stroke subjects, in stroke rehabilitation<sup>25,26</sup>. 93% of the subjects felt that HEP does not resulted any adverse effects such as pain, muscle spasm and joint swelling. Hence, HEP found to safe and many factors could have contributed for such findings which includes therapist knowledge and training skill to teach the care giver, educational level of participants and social support. In addition to the above, they also reported poor knowledge to modify or challenge the prescribed HEP exercises. Such a finding suggests

that there is a need, for the therapist, to follow up these subjects, to modify the prescribed HEP.

In this study, the rate of adherence was high and found to be 64% for the prescribed HEP, compared to previous studies on adherence to group based structured program<sup>15,27</sup>. Earlier results have shown that the support from family and relatives were shown to increase the adherence in exercise program<sup>28</sup>. The reported practice patterns of HEP, in this study, showed that availability of spousal support and by family members may attribute one of the factor for high adherence, in our prescribed HEP.

The role of perseverance is an important construct that impact health behavior. In our study the intrinsic factors addressed to the level of self-efficacy and perceived HEP benefits related to stroke recovery are found to be high and positive in adherence group. This association between intrinsic factors with the level of adherence and non-adherence were in accordance with the previous studies which shown a strong association between these characteristics in exercise participation among other neurorehabilitation conditions<sup>29,30</sup>. 62% of our participants are upper and middle class with higher educational attainment which could attribute to better knowledge and translating them with increased goal and aspiration to recover post stroke functional status<sup>31</sup>.

The most common reported barriers, amongst the stroke subjects, were fear of falling or fear of injury, lack of energy and fatigue. As reported in earlier studies that post-discharge stroke subjects experience fear of fall, which may thereby attribute to the physical and emotional consequences of falls<sup>32-34</sup>. Amongst the non-adherent subjects, "Exercising is boring and monotonous", was the most common reported barrier, which is due to the earlier reported low level of knowledge, amongst the stroke subjects, to modify the exercises, in terms of modifying it, by making it easier or harder. There was an association between the barriers "Exercising is too difficult", with the non- adherence, as it was only reported by the 11.1% of the non-adherent subjects. Similar to earlier study on barriers associated with exercise, our study also reported lack of time, lack of interest, lack of motivation and the lack of personal attendant to help to do exercise are the barriers for adherence to home-based exercise program (HEP)<sup>9</sup>. Some

studies have revealed the relationship between family support and quality of life and caregivers' burden for caring the stroke survivors further, recommended for strategic home based rehabilitation programs.<sup>35-8</sup> This study highlighted the experiences by the caregivers in HEP for the stroke survivors and understanding these experiences may help the service providers to provide better support and resources for caregivers in caring for stroke survivors.

This study has following limitations; (1) this study period was brief and only could include post-discharge stroke subjects from the acute rehabilitation. (2) The stroke subjects, which fulfilled the inclusion criteria were subjects with mild to moderate severity of stroke, according to the NIHSS, so furthermore, we can explore level adherence with respect to severe stroke (as per NIHSS). (3) The subjects who filled the questionnaire, might have different experience and perceptions towards HEP, so the results cannot be generalized for stroke population. Future implications include, to identify the predictive factors for exercise participation in HEP, encouraging optimism and promoting self-efficacy should be considered in designing exercise trails. There is also a need to explore the effects of implementing individualized tailored HEP, on motor recovery, functional outcomes and quality of life in stroke subjects.

### **Conclusion**

This present study helped to put an insight, into socio-demographic and intrinsic factors, with the level of adherence and to identify the barriers for adherence to individually tailored HEP. The findings of the study, suggest that there was a high level of satisfaction and adherence with individually tailored HEP, for the stroke subjects.

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**Conflict of interest statement:** The authors declare that they have no competing interest

**Individual authors contribution:** Conception and Design-VK, AJ, PB; Data Acquisition-PB

Resources and Supervision –CM, MZK; Analysis and Interpretation of Data – VK,AJ

Writing Publication- VK,PB; Critical Revision and Final approval of Publication-AJ,CM,MZK

**Table 1: Demographic Characteristics of Participants (N=74)**

Variables	Description	N (%)
Age (years)	<40	7 (10)
	40-60	32 (43)
	60-80	32 (43)
	>80	3 (4)
Gender	Men / Women	44 (59.5) / 30 (40.5)
Diagnosis	Ischemic / Hemorrhagic	48 (65) / 26 (35)
Co-morbidities	HTN / DM	54 (73.1) / 22 (29.9)
Side of paresis	Right / Left	47 (63.5) / 27 (36.5)
Socioeconomic status	Upper / Lower	46 (62.2) / 28 (37.9)
NIHSS for severity of stroke	Mild / Moderate	44 (59.5) / 30 (40.5)
Modified Rankin Score	No significant disability	1 (1.3)
	Slight disability	15 (20.3)
	Moderate disability	55 (74.3)
	Severe	3 (4.1)
Assistive devices	Cane	1 (1.3)
	Walker	2 (2.7)
	Wheelchair	1 (1.3)
	None	70 (94.7)

HTN-Hypertension, DM-Diabetes Mellitus, NIHSS-National Institutes of Health Stroke Scale

**Table 2: Reported level of satisfaction and perceived HEP benefits (N=74)**

S No	Characteristics	Yes	No
1	Was the HEP explained to you before discharge satisfactory?	74 (100)	-
2	Was the HEP sufficiently explained and demonstrated to you?	74 (100)	-
3	Was it possible to understand the HEP taught to you by the physiotherapist?	74 (100)	-
4	Did you follow the HEP as instructed by Physical therapist at least for 2 weeks from the day of discharge?	71 (95.9)	3 (4.1)
5	Do you believe that the home exercises are beneficial to improve your recovery?	74 (100)	-

S No	Characteristics	Yes	No
6	Do you believe that the HEP helped you to be functionally independent and improve activities of daily living?	74 (100)	-
7	During HEP did you experience any adverse effects such as shoulder pain, back pain, spasm, and swelling?	5 (6.8)	69 (93.2)
8	Do you know how to make exercises easier or harder?	9 (12.2)	65 (87.8)
9	What made you to perform the exercises regularly		
	To walk independently	21 (26.2)	
	For better health or recovery	07 (9.7)	
	For improvement / improvement in strength	16 (21.9)	
	To carry out ADL's	13 (17.8)	
	To be functionally independent	13 (17.8)	
	Advised by consultant	01 (1.4)	
	Return to work	01 (1.4)	

**Table 3: Reported practice patterns and adherence of HEP (N=74)**

S No	Characteristics	Response	N (%)
1	Who is assisting you to perform the HEP?	Self	4 (5.4)
		Spouse	24 (32.4)
		Relatives	46 (62.2)
2	In a week, how many times or sessions did you perform the HEP?	1-2 times	12 (16.2)
		3-4 times	14 (21.7)
		5-6 times	29 (39.4)
		7 or more times	19 (25.7)
3	How long do you perform the exercises per session?	<15 mins	2 (2.7)
		15-30 mins	9 (12.2)
		31-45 mins	57 (77.2)
		> 45 mins	6 (8.2)
4	Participants adherence to HEP	-	47 (63.5)
5	Participants non-adherence to HEP	-	27 (36.5)

**Table 4: Association of demographic variables and intrinsic factors with adherence and non-adherence groups (N=74)**

Variables		Adherent (N=47)	Non-adherent (N=27)	Total (%) (N=74)	<i>p</i> value <sup>#</sup>
Age groups (years)	< 40	5 (71.4)	2 (28.6)	7 (9.5)	0.589
	41-60	22 (68.8)	10 (31.3)	32 (43.2)	
	61- 80	19 (59.4)	13 (40.6)	32 (43.2)	
	>80	1 (33.3)	2 (66.7)	3 (4.1)	
Gender	Men	26 (59.1)	18 (40.9)	44 (59.5)	0.339
	Women	21 (70.0)	9 (30)	30 (40.5)	
Socio-economic status	Upper	33 (71.7)	13 (28.3)	46 (62.2)	0.06
	Lower	14 (50)	14 (50)	28 (37.8)	
Severity of stroke	Mild	30 (68.2)	14 (31.8)	44 (59.5)	0.312
	Moderate	17 (56.7)	13 (43.3)	30 (40.5)	
Stroke Self-efficacy questionnaire (SSEQ)	High	39 (83)	6 (22.2)	45 (61)	0.001*
	Low	8 (17)	21 (77.8)	29 (39)	
Global perceived effect scale	Positive	43 (91.5)	16 (59)	59 (79)	0.002*
	No Change	4 (8.5)	11 (41)	15 (21)	
	Negative	-	-	-	

# Chi-square test \*Significant

**Table 5: Comparison of Barriers with Adherence and Non-adherent groups (N=74)**

Barriers †		Adherent	Non- adherent	Total (%)	<i>p</i> value <sup>#</sup>
Personal	Fear of falling or fear of injury	8 (66.7)	4 (33.3)	12 (16.2)	1
	Lack of energy	5 (55.6)	4 (44.4)	9 (12.2)	0.716
	Exercise is boring and monotonous	2 (28.6)	5 (71.4)	7 (9.5)	0.092
	Exercising is too difficult	-	3 (11.1)	3 (4.1)	0.045*
	Lack of motivation	2 (2.7)	-	2 (2.7)	0.530
	Lack of interest	-	1 (100)	1 (1.4)	0.365
	Lack of time	-	1 (100)	1 (1.4)	0.365
	I feel depressed	-	1 (100)	1 (1.4)	0.365
Emotional	Lack of personal care attendant who can help me to do exercise	-	2 (100)	2 (2.7)	0.130
Health-related	Get fatigued easily	7 (58.3)	5 (41.7)	12(16.2)	0.749
	Pain prevents me from exercising	2 (40)	3 (60)	5 (6.8)	0.348
Educational	Lack of knowledge about benefits of exercise	1 (50)	1 (50)	2 (2.7)	1

, # Chi-square test \* Significant

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