OPEN ACCESS

Saudi Journal of Medicine
Abbreviated Key Title: Saudi J Med
ISSN 2518-3389 (Print) | ISSN 2518-3397 (Online)
Scholars Middle East Publishers, Dubai, United Arab Emirates
Journal homepage: https://saudijournals.com

Original Research Article

The Impact of Caregiver Support on Symptom Improvement in Post-Stroke Patients

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DOI: 10.36348/sjm.2024.v09i05.002 | **Received:** 28.03.2024 | **Accepted:** 02.05.2024 | **Published:** 09.05.2024

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Abstract

***Background*:** Stroke is a significant global health concern, particularly in countries like Bangladesh experiencing a rise in non-communicable diseases. The impact of stroke disabilities is profound, affecting both patients and their caregivers. ***Objective*:** This study aims to evaluate the role of caregivers in alleviating symptoms among post-stroke disabled individuals. ***Method*:** A two-arm, single-blind, randomized controlled trial was conducted over 12 weeks (July 2022-july 2023). 51 Participants, recruited from tertiary hospital departments, met specific eligibility criteria. They were assigned to either a control, n=26 or intervention group, n=25, receiving either standard care or a caregiver-mediated rehabilitation program, respectively. Assessments were conducted at baseline and endpoint, evaluating various functional and quality-of-life measures. ***Results*:** In the study, 30 out of 51 participants were male, constituting 58% of the sample, while the remaining 41% were female. Among the cohort, 24 individuals, making up 47% of the total sample, experienced right hemiplegia. Furthermore, a significant portion of the participants, 38 out of 51 individuals, accounting for 75%, resided in households featuring mobility obstacles such as raised doorsteps between rooms. Additionally, it was observed that 71% of the caregivers were spouses of the patients. In the intervention group, significant enhancements were observed in various domains of the Stroke Impact Scale (SIS), including strength, mobility, composite physical function, and general recovery, with p-values indicating statistical significance (< 0.001). Marginal improvements were also noted in the domains of activities of daily living (ADL)/instrumental activities of daily living (IADL), hand function, communication, and social participation, albeit with slightly higher p-values (0.022 to 0.030). Conversely, the control group did not exhibit significant within-group effects across these domains. When comparing caregiver burden scores between the control and intervention groups, although there were no statistically significant differences observed in the Total Burden, General Strain, and Disappointment domains, the Intervention Group displayed slight improvements in Isolation, Emotional, and Environment domains compared to the Control Group, despite these differences not reaching statistical significance. These findings indicate the multifaceted impact of the caregiver-mediated, home-based intervention on both post-stroke patients' functional outcomes and caregiver burden. ***Conclusion*:** Caregivers are essential in post-stroke care, and supporting them is vital for holistic patient support. The 12-week caregiver-mediated rehabilitation program demonstrated effectiveness in improving physical functional recovery, underscoring its practical value for chronic stroke patients.

Keywords: Stroke, caregivers, rehabilitation program, randomized controlled trial, functional recovery, caregiver burden.

INTRODUCTION

Stroke, a pervasive cause of disability and mortality globally, imposes substantial burdens on both healthcare systems and individuals. With an estimated 80 million cases occurring worldwide each year, stroke remains a pressing public health issue. In Bangladesh, a country experiencing a rise in non-communicable diseases, the prevalence of stroke is on the ascent, mirroring larger trends of urbanization, lifestyle shifts, and an aging populace. The impact of stroke disabilities in Bangladesh is profound, as survivors often grapple

with physical and cognitive impairments that significantly disrupt their daily lives and diminish their quality of life [1-3].

The treatment of stroke necessitates a multifaceted approach, encompassing prognostic evaluations, treatment protocols, and tailored physical exercise regimens. However, the indispensable role of family caregivers in post-stroke care cannot be overstated. Family caregivers, comprising individuals within the patient's familial circle, serve as linchpins in providing vital support and assistance to stroke survivors. Nonetheless, the responsibilities of caregiving for post-stroke patients can exact a toll, both emotionally and physically, often resulting in adverse health outcomes among caregivers themselves [4-7].

Within the realm of stroke care, caregivers shoulder a multitude of responsibilities, ranging from administering daily medications to aiding with personal care and hygiene, facilitating communication and physical activities, offering emotional solace, and managing household affairs and finances. Despite their indispensable contributions, caregivers encounter myriad challenges in delivering comprehensive care, including socioeconomic factors, physical strain, and mental health concerns [8-11].

In supporting caregivers, neurologists and physicians play instrumental roles by offering emotional support, guidance on caregiving duties, and reinforcement of familial bonds. Additionally, religious motivations and communal backing can serve as wellsprings of encouragement for caregivers, enabling them to navigate the rigors of caregiving while fostering resilience and familial cohesion. The optimization of caregivers' roles in post-stroke care necessitates a holistic approach that addresses both the pragmatic challenges and emotional exigencies of caregiving, alongside the clinical management of stroke survivors.

Amidst these challenges, the motivation and fortitude of caregivers assume paramount importance. Many caregivers may perceive stroke survivors as liabilities due to their reliance on assistance for daily activities. However, recognizing the significance of their role and cultivating motivation to persist in caregiving are imperative for the well-being of both the patient and the caregiver.

Objective

To evaluate the role of caregivers on symptom alleviation among post-stroke disabled individuals.

METHOD

A two-arm, single-blind (evaluator), randomized controlled trial was conducted to assess the efficacy of a 12-week caregiver-mediated rehabilitation program. 51 Participants were recruited from tertiary hospital rehabilitation and neurology departments between July2022-2023. They were assigned to either a control, n=26 or intervention group, n=25, receiving either standard care or a caregiver-mediated rehabilitation program, respectively. Eligible patients had experienced a single ischemic or hemorrhagic stroke in the cerebral hemisphere, were over 6 months post-onset, exhibited mild to moderate disability (Brunnstrom recovery stages III-V), engaged in rehabilitation activities 2 or fewer times per week, resided at home, had caregivers assisting with daily activities, and did not require nasogastric feeding, urine, or tracheal tubes, nor had recurring stroke, dementia, severe orthopedic disability, or unstable medical conditions. Caregivers, defined as those primarily responsible for the patient's daily care and residing with them, were included if they were in good physical health, lacked mental or behavioral disorders, and could provide at least two 60- to 90-minute sessions of rehabilitation training per week. Prospective participants were provided with oral and written explanations of the study's objectives and procedures and were enrolled on a rolling basis after signing informed consent forms approved by Review Board. Patients were assigned to groups using computer-generated random numbers and initiated the trial immediately following group assignment.

The caregiver-mediated rehabilitation program, led by a physical therapist, comprised three phases over 12 weeks: phase 1 (weeks 1-4) focused on improving body functions and structural components, phase 2 (weeks 5-8) emphasized enhancing everyday activity performance within the living environment, and phase 3 (weeks 9-12) aimed to facilitate community reintegration through outdoor leisure activities. Patients in the intervention group received weekly 90-minute sessions with the physical therapist, who instructed them and their caregivers in personalized rehabilitation skills, monitored progress, and adjusted activities accordingly. Patients in the control group maintained their usual routines but received weekly therapist visits or telephone calls to discuss rehabilitation progress, daily activities, and general health conditions. At baseline and trial endpoint, participants underwent assessments including the Berg Balance Scale, 10-Meter Walk Test, 6-Minute Walk Test, Stroke Impact Scale, Barthel Index, and Caregiver Burden Scale, administered by an independent physical therapist blinded to treatment assignment. Statistical analyses, performed using SPSS 19.0, included descriptive statistics, Mann-Whitney U tests for intervention effects, and Wilcoxon signed-rank tests for within-group effects. Bonferroni correction was applied to control the family-wise error rate, setting significance levels for various outcome measures.

RESULTS

In total, 30 out of 51 participants, constituting 58%, were male. Among the cohort, 24 individuals, making up 47% of the sample, experienced right hemiplegia. Additionally, 38 out of 51 participants, accounting for 75%, resided in households featuring

mobility obstacles like raised doorsteps between rooms. A significant portion of the caregivers, specifically 36 out of 51 individuals, or 71%, were the spouses of the patients.

Table-1: Participant Characteristics

Variables	Control, n=26	Intervention, n= 25
Men	17 (65.4)	13 (52.0)
Women	9 (34.6)	12 (48.0)
Mean age ± SD, y	65.4 ± 10.6	62.0 ± 9.5
Disease history, mo[a]	18.5 (8.75-31.75)	18 (11.5-32)
Hemiplegia side, n (%)		
Left	13 (50.0)	14 (56.0)
Right	13 (50.0)	11 (44.0)
Brunnstrom recovery stage, n (%) By upper extremity		
III	13 (50.0)	14 (56.0)
IV	4 (15.4)	4 (16.0)
V	9 (34.6)	7 (28.0)
By lower extremity		
III	14 (53.9)	15 (60.0)
IV	3 (11.5)	7 (28.0)
V	9 (34.6)	3 (12.0)
Mean CESD score ± SD[b]	7.04 ± 6.81	6.73 ± 5.22
Type of housing, n (%)		
Apartment with elevator	6 (23.1)	8 (32.0)
Apartment without elevator	4 (15.4)	4 (16.0)
Single homes without elevator	16 (61.5)	13 (52.0)
Home with mobility barriers,[c] n (%)		
Yes	22 (84.6)	16 (64.0)
No	4 (15.4)	9 (36.0)
Relationship with the caregiver, n (%)		
Spouse	18 (69.2)	18 (72.0)
Adult children	3 (11.5)	4 (16.0)
Close relatives or friends	2 (7.8)	2 (8.0)
Paid caregiver	3 (11.5)	1 (4.0)
Caregiver's level of education, n (%)		
Elementary school	10 (38.5)	4 (16.0)
Junior high school	5 (19.2)	5 (20.0)
Senior high school	4 (15.4)	11 (44.0)
College of higher	2 (7.7)	3 (12.0)
Unknown (foreign caregivers)	5 (19.2)	2 (8.0)

The impact of CHI on various domains of SIS is outlined in Table 2. Notably, CHI led to significant enhancements in several domain scores compared to the control group: strength (net change: control group 1.4 vs intervention group 15.5; P = .002), mobility (net change: control group -0.5 vs intervention group 13.7; P < .001), composite physical (net change: control group -0.7 vs intervention group 11.2; P < .001), and general recovery (net change: control group 0.2 vs intervention group 17.4; P < .001). Furthermore, CHI demonstrated marginal improvements in the domain scores of ADL/IADL (net change: control group -0.2 vs intervention group 8.5; P = .022), hand function (net change: control group -3.7 vs intervention group 8.8; P = .039), communication (net change: control group -2.3 vs intervention group 5.7; P = .030), and social participation (net change: control group 0.5 vs intervention group 11.8; P = .019). Within the intervention group, significant within-group (time) effects were observed for the domain scores of strength (P < .001), mobility (P < .001), ADL/IADL (P = .002), composite physical (P < .001), communication (P = .018), social participation (P = .004), and general recovery (P < .001). Conversely, such effects were not evident in the control group.

Table-2: Effects of a 12-Week Caregiver-Mediated, Home-Based Intervention on Stroke Impact Scale Domain Scores in Patients with Chronic Stroke

	Control Group			Intervention Group			Between two group Difference	P[c]
Domains	**Baseline**	**Endpoint**	**Net Change**	**Baseline**	**Endpoint**	**Net Change b**		
Composite physical[d]	56.0 ± 21.3	55.3 ± 21.8	−0.7 (–2.3, 0.9)	56.5 ± 17.9	67.7 ± 17.1[e]	11.2 (9.0, 13.4)	11.9 (6.5, 17.3)	<.001
Strength	38.7 ± 16.4	40.1 ± 15.5	1.4 (–0.9, 3.8)	36.8 ± 19.8	52.3 ± 27.4[e]	15.5 (12.1, 18.9)	14.1 (5.8, 22.3)	.002
ADL/IADL	59.6 ± 22.3	59.4 ± 25.1	−0.2 (–2.5, 2.1)	62.3 ± 21.5	70.8 ± 20.3[e]	8.5 (6.0, 11.0)	8.7 (1.9, 15.5)	.022
Mobility	67.3 ± 24.6	66.8 ± 23.4	−0.5 (–2.8, 1.7)	71.3 ± 17.8	85.0 ± 14.6[e]	13.7 (10.8, 16.5)	14.2 (6.9, 21.5)	<.001
Hand function	42.3 ± 37.9	38.7 ± 33.6	−3.7 (–6.7, –0.6)	34.2 ± 35.1	43.0 ± 38.1	8.8 (3.9, 13.7)	12.5 (0.9, 23.9)	.039
Memory	77.6 ± 13.2	75.8 ± 13.2	−1.8 (–4.4, 0.8)	81.3 ± 18.3	82.1 ± 15.6	0.9 (–2.2, 4.0)	2.6 (–5.5, 10.8)	.834
Communication	95.3 ± 10.9	93.0 ± 12.2	−2.3 (–3.7, –0.9)	90.3 ± 16.3	96.0 ± 6.5[e]	5.7 (2.9, 8.5)	8.0 (1.8, 14.3)	.030
Emotion	59.9 ± 10.5	59.0 ± 10.8	−1.0 (–3.6, 1.6)	62.0 ± 11.9	61.1 ± 12.6	−0.9 (–4.1, 2.3)	0.07 (–8.2, 8.3)	.655
Social participation	80.6 ± 17.6	81.1 ± 17.5	0.5 (–1.7, 2.7)	75.8 ± 22.7	87.8 ± 12.8[e]	11.8 (8.2, 15.4)	11.4 (2.9, 19.9)	.019
General recovery	50.4 ± 15.9	50.6 ± 11.5	0.2 (–1.7, 2.1)	48.3 ± 17.4	65.7 ± 12.7[e]	17.4 (14.4, 20.4)	17.2 (10.0, 24.4)	<.001

The comparison between the control group and intervention group revealed mixed results across various domains. While there were no significant differences in the Total Burden Domain scores between the two groups (1.2; p = .804), the Intervention Group showed a notable increase in this domain compared to the Control Group. Similarly, for the General Strain and Disappointment domains, there were no significant differences observed between the two groups (-0.16; p = .529 and 0.42; p = .569, respectively). However, the Intervention Group demonstrated a slight improvement in Isolation (0.83; p = .205), Emotional (0.29; p = .559), and Environment (−0.17; p = .723) domains compared to the Control Group, although these differences were not statistically significant. These findings suggest a nuanced impact of the intervention on different aspects of post-stroke patients' well-being, with some domains showing marginal improvements while others remained largely unchanged between the two groups.

Table-3: Effects of a 12-Week Caregiver-Mediated, Home-Based Intervention on Caregiver Burden Scores in the Major Caregivers of Patients with Chronic Stroke

	Control Group			Intervention Group			Between two group Difference	P value
Domains	**Baseline**	**Endpoint**	**Net Change**	**Baseline**	**Endpoint**	**Net Change b**		
Total burden[d] Domainse	45.8 ± 12.0	46.6 ± 11.7	0.8 (–0.55, 2.21)	43.3 ± 12.5	45.3 ±10.8	2.0 (0.25, 3.83)	1.2 (–3.5, 5.9)	.804
General strain	18.0 ± 4.5	16.1 ± 4.4	−0.1 (–0.47, 0.63)	16.2 ± 5.1	18.0 ± 4.5	0.1 (–0.49, 0.65)	−0.16 (–1.8, 1.5)	.529
Isolation	6.2 ± 2.2	6.0 ± 37.3	−0.3 (–0.51, 0.01)	5.8 ± 2.2	6.4 ± 2.1	0.6 (0.16, 0.99)	0.83 (–0.18, 1.8)	.205
Disappointment	10.2 ± 3.1	10.5 ± 3.2	0.3 (–0.15, 0.81)	10.2 ± 2.9	11.0 ± 2.9	0.8 (0.12, 1.39)	0.42 (–1.2, 2.1)	.569
Emotional	5.7 ± 2.1	6.2 ± 1.7	0.5 (0.13, 0.87)	5.5 ± 2.0	6.3 ± 1.8	0.8 (0.39, 1.19)	0.29 (–0.83, 1.4)	.559
Environment	5.7 ± 2.1	5.9 ± 2.0	0.2 (–0.14, 0.48)	5.5 ± 2.0	5.5 ± 1.8	0.0 (–0.22, 0.22)	−0.17 (–0.96, 0.63)	.723

DISCUSSION

CHI demonstrated substantial improvements in most SIS domains, with increases exceeding 10 points (range, 8.5-17.4), indicating significant enhancements in physical functioning across various areas, except for the memory and emotion domains. Previous studies have identified clinically meaningful changes in strength, ADL/IADL, mobility, and hand function domains at thresholds of 9.2, 5.9, 4.5, and 17.8 points, respectively, aligning with the score improvements observed in this study. Additionally, CHI significantly enhanced free-walking velocity from 43.2 ± 29.2 to 51.0 ± 30.0 cm/s, likely bolstering patients' confidence to engage in community activities and social reintegration [12-15].

Furthermore, while a slight decline in 6MWT was observed in the control group over time, suggesting possible cessation of routine therapy among some patients, CHI highlighted the necessity for continual physical recovery training for chronic stroke patients, emphasizing the importance of ongoing rehabilitation efforts post-hospital discharge. Notably, the home environment presented unique challenges compared to the hospital setting, underscoring the significance of family-mediated rehabilitation programs in improving patients' mobility, balance, and self-care abilities.

The involvement of caregivers, predominantly spouses or close relatives, played a crucial role in facilitating patients' recovery by providing necessary care and rehabilitation skills, thereby contributing to improved physical functioning and accessibility to rehabilitation interventions. However, while CHI did not significantly impact caregiver burden in this study, the relatively small sample size and endpoint evaluation may not fully capture potential early-stage burdens. Larger studies may be required to confirm these findings and assess the long-term impact of CHI on caregiver burden and patient outcomes.

CONCLUSION

Caregivers play an indispensable role in the care and rehabilitation of post-stroke disabled patients, with their vital contributions crucial for ensuring holistic support. Recognizing their significance, it is imperative to implement strategies that support caregivers, addressing socioeconomic barriers and strengthening support networks to empower them in providing optimal care while maintaining their own well-being. A 12-week caregiver-mediated rehabilitation program, integrating home-based repetitive training, outdoor activities, and social reintegration, has proven effective in enhancing the physical functional recovery of chronic stroke patients, offering practical value for numerous individuals facing the challenges of chronic stroke.

REFERENCE

1. Cohen, I. K., Ferretti, F., & McIntosh, B. (2015). A simple framework for analysing the impact of economic growth on non-communicable diseases. *Cogent Economics & Finance*, *3*(1), 1045215.
2. Feigin, V. L., Krishnamurthi, R. V., Parmar, P., Norrving, B., Mensah, G. A., Bennett, D. A., ... & GBD 2013 Writing Group and GBD 2013 Stroke Panel Experts Group. (2015). Update on the global burden of ischemic and hemorrhagic stroke in 1990-2013: the GBD 2013 study. *Neuroepidemiology*, *45*(3), 161-176.
3. Bleich, S. N., Koehlmoos, T. L., Rashid, M., Peters, D. H., & Anderson, G. (2011). Noncommunicable chronic disease in Bangladesh: overview of existing programs and priorities going forward. *Health policy*, *100*(2-3), 282-289.
4. Kwakkel, G., Kollen, B. J., van der Grond, J., & Prevo, A. J. (2003). Probability of regaining dexterity in the flaccid upper limb: impact of severity of paresis and time since onset in acute stroke. *Stroke*, *34*(9), 2181-2186.
5. Lord, S. E., McPherson, K., McNaughton, H. K., Rochester, L., & Weatherall, M. (2004). Community ambulation after stroke: how important and obtainable is it and what measures appear predictive?. *Archives of physical medicine and rehabilitation*, *85*(2), 234-239.
6. Cecil, R., Parahoo, K., Thompson, K., McCaughan, E., Power, M., & Campbell, Y. (2011). 'The hard work starts now': a glimpse into the lives of carers of community-dwelling stroke survivors. *Journal of Clinical Nursing*, *20*(11-12), 1723-1730.
7. Tistad, M., Tham, K., von Koch, L., & Ytterberg, C. (2012). Unfulfilled rehabilitation needs and dissatisfaction with care 12 months after a stroke: an explorative observational study. *BMC neurology*, *12*, 1-7.
8. Hartman-Maeir, A., Soroker, N., Ring, H., Avni, N., & Katz, N. (2007). Activities, participation and satisfaction one-year post stroke. *Disability and rehabilitation*, *29*(7), 559-566.
9. Godwin, K. M., Wasserman, J., & Ostwald, S. K. (2011). Cost associated with stroke: outpatient rehabilitative services and medication. *Topics in stroke rehabilitation*, *18*(sup1), 676-684.
10. Young, J., & Forster, A. (1993). Day hospital and home physiotherapy for stroke patients: a comparative cost-effectiveness study. *Journal of the Royal College of Physicians of London*, *27*(3), 252-258.
11. Anderson, C., Mhurchu, C. N., Rubenach, S., Clark, M., Spencer, C., & Winsor, A. (2000). Home or hospital for stroke Rehabilitation? Results of a randomized controlled trial: II: cost minimization analysis at 6 months. *Stroke*, *31*(5), 1032-1037.
12. Holmqvist, L. W., Von Koch, L., Kostulas, V., Holm, M., Widsell, G., Tegler, H., ... & de Pedro-Cuesta, J. (1998). A randomized controlled trial of rehabilitation at home after stroke in southwest Stockholm. *Stroke*, *29*(3), 591-597.
13. von Koch, L., Widen Holmqvist, L., Kostulas, V., Almazán, J., & de Pedro-Cuesta, J. (2000). A randomized controlled trial of rehabilitation at home after stroke in Southwest Stockholm: outcome at six months. *Scand J Rehabil Med*, *32*(2), 80-86.
14. Anderson, C. S., Linto, J., & Stewart-Wynne, E. G. (1995). A population-based assessment of the impact and burden of caregiving for long-term stroke survivors. *Stroke*, *26*(5), 843-849.
15. Kalra, L., & Langhorne, P. (2007). Facilitating recovery: evidence for organized stroke care. *Journal of rehabilitation medicine*, *39*(2), 97-102.