

## REVIEW ARTICLE

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# Role of Caregivers Training as Predictor of Outcome in Stroke Survivors – A Review

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### Abstract:

*There are many predictors of poor functional outcome in stroke survivors. Need of caregivers training to address the discharged patients for their home care management is often overlooked. Early discharge, lack of post-acute management facilities including home or community based services are other important predictors of poor functional outcome. Most of the patients are discharged home directly from hospital neurology unit after acute care management for inability to pay hospital costs. Rich patients who reside in the city can afford to receive treatment from trained nurse or physiotherapist at home but poor patients go home without any preparation for home care management of the patients. Hospital based rehabilitation management of stroke survivors are scarcely available in our country but thousands of inadequately treated patients are discharged home without any training to the caregivers. They come back to the outpatients department for next visit with multiple complications. This review article tried to find out the need and impact of caregivers training on outcome of stroke survivors.*

### Introduction:

Stroke is the leading cause of adult disability in the world as well in Bangladesh. Many variables have an impact on disability and quality of life after stroke including age, comorbidities, severity of neurological deficit, state of mind and social risk<sup>1</sup>. Stroke rehabilitation in Bangladesh is inadequately addressed mostly due to resource constraints. Most patients go to their remote villages after acute care management in the hospital with incomplete recovery and profound disability. Care givers to manage the patient at home are usually not trained or briefed on physiotherapy or nursing care. Most of the patients return to next visit with many complications.

Stroke has a profound effect on the lives of patients, their spouses and family members. These effects include role and relationship changes, psychological distress and the challenge of coping with long-term disability<sup>2,3</sup>. Family carers provide most post-discharge care to patients but often receive little preparation for this. Long-term caring can result in increased stress and burden for caregivers<sup>2,3,4</sup>.

A single-center individually randomized trial reported by the London Stroke Carers Training Course (LSCTC), a structured competency-based training program, decreased caregiver burden and anxiety, and improved psychological outcomes for patients. Overall costs were reduced, due largely to earlier discharge in the LSCTC group compared with usual care<sup>4,5</sup>. One of the most important interventions is the training of families and other caregivers in specific care techniques to prevent complications, perform physical functions, and encourage patients to perform any activities they are capable of doing. Training in problem-solving techniques can help family members provide effective support in the home environment. Additional teaching focuses on the dissemination of knowledge about strokes, their consequences, and use of medications, stroke prevention, and other care aspects<sup>6</sup>. Evidence now exists that both education and counseling significantly improve caregiver knowledge and stabilize some aspects of family functioning. Family education has been found to contribute to the long term maintenance of rehabilitation gains<sup>7,8,9</sup>.

Education of family and caregivers: Families and caregivers should be educated in the care of these patients. The family and caregiver education may include; preventing recurrent stroke, signs and symptoms of potential complications and psychological dysfunction, medication administration, assisted ADL tasks (e.g., transfers, bathing, positioning, dressing, feeding, toileting, and grooming), swallowing techniques, nutrition and hydration, care of an indwelling bladder catheter, skin care, contractures, use of a feeding tube, home exercises (range of motions) and sexual functioning<sup>10</sup>. The patient and family/caregivers should be given information and provided with an opportunity to learn about the causes and consequences of stroke, potential complications, and the goals, process, and prognosis of rehabilitation. The presence and effectiveness of large social support networks can have a positive influence on the physical recovery and quality of life of the stroke survivor.

**Review of relevant studies:** A National Stroke Association survey in USA found that stroke survivors often do not reach their rehabilitation goals, and lack of information is a major barrier to continued recovery: 38% of 523 long-term stroke survivors reported a lack of information about community and rehabilitation resources<sup>11</sup>. Inadequate provision of information is predictive of poor quality of life in stroke patients and their families<sup>12</sup>.

Forster and colleagues reviewed nine studies of educational intervention. There is some evidence that combining information with educational sessions improves knowledge and is more effective than providing information alone<sup>13</sup>. As the patient progresses from hospital-based rehabilitation to the community, involvement of caregivers in rehabilitation becomes increasingly important. Formal training of caregivers in delivery of care reduces personal costs and improves quality of life<sup>4</sup>.

The systematic review and one meta-analysis looked at caregiver support interventions and found that social support improved patient outcomes and family functioning. A comparison of passive versus active information intervention determined that there was no significant effect on the number of cases of anxiety or depression in patients, carer mood or satisfaction or death. A qualitative analysis found no strong evidence of an effect on other outcomes. Meta-analyses showed a significant effect from

information therapy on patient and carer knowledge, one aspect of patient satisfaction, and patient depression scores<sup>14,15</sup>.

An evidence-based educational program for stroke survivors after discharge home described 39 comprehensive educational guidelines. The program recommended that educational programs provided to stroke survivors and their families be interactive, interdisciplinary, and focused on identified needs<sup>16</sup>.

The first few weeks after discharge from an inpatient stay after a stroke are difficult as the patient attempts to use newly learned skills without the support of the rehabilitation environment or team. Adequate support from family and caregivers is critical to a successful outcome. It is also important to ensure that all necessary equipment and support services are in place.

Evans et al after noting that rehabilitation services are effective in improving short-term survival, functional ability, and the most independent discharge location, have suggested that “the lack of long-term benefits of short-term rehabilitation may suggest that therapy should be extended to home or sub-acute care settings, rather than being discontinued at discharge. These services should be organized and in place at the time of discharge”<sup>17</sup>.

Clinicians should work with the patient and caregivers to avoid negative effects, promote problem solving, and facilitate reintegration of the patient into valued family and social roles. Preexisting organizational and functional characteristics of the family may have important effects on a successful transition to community living. A caregiver is more likely to give adequate support if he/she is a spouse who is knowledgeable about stroke and its disabilities, is not depressed, and lives in an otherwise well-functioning family unit<sup>18</sup>.

#### **Conclusion:**

Prognosis in stroke survivors depends on many factors. A home or community based management should be addressed timely and adequately. Caregivers training or briefing during hospital stay for home management are helpful and brings better outcome. Patients and caregivers should be educated throughout the rehabilitation process to address patient's rehabilitation needs, expected outcomes, procedures and treatment as well as

appropriate follow-up in the home/ community. Patient and caregiver education should be provided in both interactive and written formats. Caregivers should be provided with a variety of methods of training based on their specific needs, cognitive capability, and local resources; Training may be provided in individual or group format, and in community-based programs. Hospital based rehabilitation management of stroke survivors are scarcely available in our country but thousands of inadequately treated patients are discharged without any training to the caregivers. They come back to the outpatients department for next visit with multiple complications. This review article intends to highlight the importance of caregivers training to stroke survivors especially at low resource setting in Bangladesh.

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