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Providing Care Beyond the Hospital: Perspective of a Tertiary Care Hospital from a Developing Country

Saad Akhtar Khan¹, Muhammad Waqas¹, Badar Uddin Ujjan¹, Adnan Salim², Gohar Javed¹, Syed Ijlal Ahmed¹, Malikah Surani¹, Marium Khan¹

■ **BACKGROUND:** Neurorehabilitation is an important aspect of continuing care for neurosurgical patients with functional disability. In developing countries, where formal home nursing frequently is unavailable, ensuring care after discharge is a difficult task. Training attendants to provide nursing care is an alternate option. In this study, we compared the outcomes of patients nursed by family members versus those looked after by a professional nurse.

■ **METHODS:** This was a retrospective observational study conducted at the Aga Khan University Hospital Karachi. The study consisted of 2 groups. Group 1 (consisting of patients cared for by a professional nurse) included 94 patients and group 2 (patients cared for by family members) included 102. All these patients had activity of daily living score of ≥ 3 . Glasgow Outcomes Scale score, time to decannulation, development/worsening of bedsores, and mortality were recorded and compared between the groups at follow-up.

■ **RESULTS:** The study included 196 patients. Traumatic brain injury was the most common diagnosis. Nursing requirements were similar between the 2 groups and included tracheostomy care, percutaneous endoscopic gastrostomy tube care, peripherally inserted central catheter line care, care of patients with no bone flap, and log-rolling. The outcomes of the 2 groups were comparable and included bed sore development/worsening of grade, Glasgow Outcomes Scale score at follow-up, time to decannulation, and 30-day mortality.

■ **CONCLUSIONS:** There was no statistically significant difference in outcomes of patients nursed by family members compared with the patients looked after by professional nurses.

INTRODUCTION

Neurorehabilitation is an important aspect of continuing care for neurosurgical patients with functional dependence. Long-term quality nursing care is critical to the achievement of optimal outcomes in such patients. In developing countries, this aspect of management often is overlooked and studied inadequately. This is a multifaceted problem that includes several factors, such as lack of awareness among general population, financial constraints, and lack of an integrated health care system. Most of the developing countries including Pakistan lack institutes for the rehabilitation of patients with functional dependence or diseases that need specialized nursing care. As one of the leading centers of clinical neurosciences in the country, we are faced with a challenge of providing adequate care and rehabilitation once these patients are discharged to ensure achievement of optimal neurologic recovery and surgical outcomes.

Training attendants to be caregivers is an alternate option that has been studied, especially in the context of end-of-life care. Attendants are taught nursing care, and once adequately trained, take over the role of a professional nurse. This alternate option ensures nursing care at home when professional nurses cannot be hired or afforded. There have been studies on patients suffering from chronic illnesses that suggest that home care is cheaper compared with hospital or nursing home care¹⁻⁶; however, some

Key words

- Disability
- Neurosurgery
- Nursing
- Rehabilitation

Abbreviations and Acronyms

- GOS:** Glasgow Outcome Scale
PCC: Patient care coordinator
PEG: Percutaneous endoscopic gastrostomy
TBI: Traumatic brain injury

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researchers suggest that the cost of home care is greater if family labor is included.⁷⁻¹⁰

There are limited data that compare outcomes of neurosurgery patients cared for by professional nurses compared with those cared for by trained family members. Therefore, we decided to look at our own data to assess the difference in the 2 groups. The objective of this study was to compare the 2 groups on parameters that reflect the quality of nursing care.

METHODS

This was a retrospective cohort study conducted at Aga Khan University Hospital over a period of 5 years (2009–2014). Aga Khan University Hospital is a Joint Commission International Accreditation–accredited tertiary care referral center and a teaching hospital with well-established neurology and neurosurgery units.

We included adult neurosurgery patients (16–70 years) with activity of daily living score of ≥ 3 who needed nursing care at home irrespective of sex or pathology. Patients who were looked after by both nursing and family members simultaneously or at different times were excluded. We also excluded patients with a follow-up of less than 1 month and those who received nursing care at other hospitals after discharge.

Data were collected through a proforma report. Variables such as age, sex, comorbidities, presenting diagnosis, presenting Glasgow Coma Scale score, procedure performed, severity of deficit, stay in the intensive care unit, type of home nursing care provided (trained attendant or professional nurse), and Glasgow Outcome Scale (GOS) at discharge were recorded. Nursing parameters studied were tracheostomy care, feeding via percutaneous endoscopic gastrostomy (PEG), bedside care, and administration of intravenous antibiotics. Outcome assessments were obtained, including GOS at follow-up, time to decannulation, development/worsening of bedsores, and mortality.

At our institute, neurosurgical patients with a major deficit (defined as one due to which the patient cannot perform routine activity independently) and functional dependence are identified during hospital stay and options of home nursing are discussed with family. Nursing care required at home and support system are identified by the patient care coordinator (PCC). The family decides the type of nursing (trained attendant or professional nurse). The option of training a family member was initiated by identifying a family member. The family member was then trained in basic nursing and rehabilitation by the nursing and physiotherapy team. Family members were trained for basic tracheostomy care, nasogastric/PEG feeding, chest and limb physiotherapy, and bedside and basic urinary catheter care. Nursing care was started before discharge by both groups of caregivers. Quality of care given by both group was assessed by the PCC during his/her rounds and the patient was discharged once the PCC and the primary attending found the care provided satisfactory. GOS at discharge was noted. Patients were discharged and followed in clinic, and feedback was taken regarding the nursing care; quality of care given was further assessed on follow-up. Outcomes including time to decannulation, bedside development, mortality, and GOS at follow-up were compared.

Categorical data were described with frequencies and percentages. Continuous data with normal distribution were reported as

mean and SD, and skewed data were presented as median and ranges. Categorical variables were compared between the 2 groups with the χ^2 test whereas the independent t test was used for continuous data. A P-value of less than 0.05 was considered significant. The data were analyzed using SPSS version 17 (SPSS Inc., Chicago, Illinois, USA).

RESULTS

The number of patients included in this study was 196. They were divided in 2 groups at discharge based on type of nursing care provided. Group 1 consisted of patients who were looked after by professional nursing staff ($n = 94$), whereas Group 2 included 102 patients who were taken care by trained family members. A total of 77% had traumatic brain injury (TBI), 7.1% had tumors, and 12.2% presented with vascular lesions (such as arteriovenous malformations and aneurysms). A total of 22.4% had hypertension and 7.1% had diabetes mellitus. In patients with TBI, 38.8% had contusion, 5.1% had diffuse axonal injury, and 17.9% had intracranial/intraventricular hemorrhage. A total of 19% of the patients who could be assessed had major focal deficits. Demographics and clinical characteristics of patients in each group were comparable and are presented in [Table 1](#).

At the time of discharge, 34.7% of patients required tracheostomy care, 23% needed PEG tubes feeding and care, whereas 18.4% had a peripherally inserted central catheter line. Intravenous antibiotics were required by 40.3% and log rolling by 51.5%. Nursing requirements were similar between the 2 groups and included tracheostomy care, PEG tube care, peripherally inserted central catheter line care, care of patients with no bone flap, and log-rolling ([Table 1](#)).

The outcomes of the 2 groups were comparable and included bedside development/worsening of grade, GOS at follow-up, time to decannulation, and 30-day mortality. These results are presented in [Table 2](#). In Group 1, 17 patients had died at follow-up compared to 13 in group 2; however, the P value was not statistically significant. The number of vegetative patients in each group also was comparable (23 and 17, respectively); 91.3% patients had at least 1 year of follow-up.

DISCUSSION

Neurosurgery deals with some of the most devastating illnesses in the form of TBI, cerebral infections, and brain tumors. Despite all the advancements in basic and clinical neurosciences, most of these conditions carry significant morbidity, mortality, and functional impairments. According to estimates, 5.3 million people are living with TBI-related disability alone.¹¹ Similarly, up to 78% of patients with brain tumors may have motor deficits.¹² According to a report, 127 million Europeans are living with a brain disorder in a population of 466 million.¹³ The total annual cost of brain disorders in Europe was estimated to 386 € billion in 2004.¹³ Although the reported proportion of patients suffering from neurosurgical disorders in that study was small, nursing care requirements of patients with disability due to brain disorder do not differ significantly.

Neurorehabilitation is therefore a vital component of long-term management of these patients. In 1995, there were 16,700 nursing homes nationwide with 1.5 million residents in United States. Strahan et al. reported a 9% increase in number of beds during the

Table 1. Demographic and Clinical Characteristic and Nursing Care Requirements of Study Population

Variables	Trained Nursing (Group1)	Family Members (Group 2)	P Value
Age	38.49	31.16	0.008
Male, %	78	74	0.24
LOS	25.62	19.67	0.097
Diagnosis			
Trauma	80	73	
Tumor	8	6	
Vascular	6	18	
GCS score at the time of admission			
13–15	10	14	0.242
9–12	28	20	
3–8	56	58	
Procedure			
Decompressive craniectomy	30	21	0.001
Craniotomy	40	26	
Laminectomy	2	2	
Comorbidity			
HTN	18	14	0.166
Diabetes	0	2	
HTN + diabetes	4	8	
CRF	2	0	
Other	4	6	
None	60	70	
Major focal deficits	15	22	0.414
GOS at the time of discharge			
2	23	17	0.397
3	33	35	
4	31	37	
5	7	13	
Nursing care			
Trach tube	36	32	0.522
PEG	20	25	0.591
Log roll	54	47	0.082
PICC	22	14	0.080
No bone flap (DEC CRANI)	30	21	

LOS, length of stay; GCS, Glasgow Coma Scale; HTN, hypertension; CRF, chronic renal failure; GOS, Glasgow Outcome Scale; PEG, percutaneous endoscopic gastrostomy; PICC, peripherally inserted central catheter; DEC CRANI, decompressive craniectomy.

Table 2. Differences in Outcomes Between the 2 Groups

Variables	Group 1	Group 2	P Value
Time to decanulation, days	23.29	19.69	
GOS at follow-up			
1	17	13	0.020
2	3	3	
3	8	13	
4	22	31	
5	44	42	
Mortality	17	13	0.300
Bed sores			
Absent	46	62	
Grade I	8	12	
Grade II	8	6	
Grade III	2	2	
Grade IV	2	2	

GOS, Glasgow Outcome Scale.

past 10 years.^{14,15} There are several obstacles to providing long-term nursing care in developing countries, like Pakistan, which, according to the World Bank Report, is a low middle-income country. The concept of nursing homes is nascent and as a result, long-term arrangements of nursing care are difficult. Therefore, educating and training family members to take care of these patients becomes essential.

Many studies have demonstrated that home care is cheaper and more favorable than institutional care for patients with chronic illnesses.^{1,6,16} This study explores this important aspect of management of these patients at a single private hospital in a developing country. Contrary to the results from previous studies, our study did not show any difference in outcomes between the 2 groups.

We observed no significant difference in outcomes between the 2 groups; however, there is a great unmeasured economic burden and psychological stress on family who take care of their functionally dependent relatives. This factor, although important, was not studied by us; however, several previous studies has addressed this topic.^{9,17-23}

To the best of our knowledge, this is the first study on this subject from this region. It highlights the importance of long-term nursing care and lack of adequate facilities. We also highlight that trained family members can care adequately for these patients; however, the apparent burden of such arrangement needs to be weighed against the potential benefits.

The most important caveat is the retrospective design with all its inherent pitfalls. Because of a lack of detailed documentation, an extensive scoring system measuring functional status and outcomes could not be applied; however, we had sufficient information to apply GOS and adequately assess nursing care related parameters.

CONCLUSIONS

Long-term nursing care and rehabilitation is an important aspect in management of neurosurgical patients, and where professional nurses or nursing homes are not available, family members can be

trained for providing comparable nursing care; however, investigations into the economic and emotional implications of such arrangement are necessary. Such studies can guide authorities in designing and implementing health care system.

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