

## ORIGINAL ARTICLE

# Comprehension and compliance with the discharge advice and quality of life at home among the postoperative neurosurgery patients discharged from PGIMER, Chandigarh, India

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## ABSTRACT

**Problem Statement:** Neurosurgical patients require special care not only in the hospital but also after their discharge from the hospital. Comprehension and compliance to the instructions given by the doctors/nurses at the time of discharge is important in home care of these patients. Many such patients suffer from various co-morbidities. Variable periods of convalescence affect health-related quality of life in these patients.

### Purpose of the Study:

- To determine the degree of compliance of neurosurgery patients and their family caregivers with the discharge advice given by the consultants
- To evaluate the quality of life of these patients
- To know the problems faced by these patients at home.

**Materials and Methods:** This cross-sectional interview-based descriptive study was conducted in 2010 in Chandigarh. These patients were visited at their home. A scale was evolved to evaluate comprehension and compliance to the advice given at the time of discharge, according to the criteria developed by Clark *et al.* Lawton Brody instrumental activity of daily life and Spitzer quality of life index were used to assess patients' quality of life after the operation. Verbatim responses were recorded for the purpose of qualitative research.

**Results:** Overall, 58 patients and their caregivers were interviewed at home. Mean age of the patients was 38.9 years. Out of 37 patients, 35 showed good comprehension and 33 patients had a good compliance with the instructions given for medication. The condition of 74.1% patients improved after the operation. Depression was reported in 31% of the patients. Many (36.2%) patients had to quit their job due to the disease. Almost half (47.4%) of the patients were independent in daily activities of their life while being evaluated on Barthel activity of daily life index.

**Conclusion and Recommendations:** It is in the long term that the true complexity and impact of operations become apparent. After operation, such patients are likely to have a range of physical, emotional, cognitive, behavioral, and social problems, which may result in difficulties for both patients and their family caregivers. Provision of mechanism of prioritized follow-up care to the operated bedridden neurosurgery patients should be made.

**Key words:** Comprehension and compliance, home-based care, narrative review, neurosurgery, quality of life

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## Introduction

Neurosurgery patients remain bedridden for quite a long time before and after operation. Co-morbidities are common after neurosurgical operations and patients need care for longer time.<sup>[1]</sup> Neurosurgical patients require special care not only in the hospital but also after their discharge from the hospital.

Home-based care of such patients is a difficult task for the families due to associated co-morbidities.<sup>[1]</sup> Many such patients have long-term sequelae. Some of them die due to fatal nature

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of the disease or due to the injury sustained by them,<sup>[2]</sup> and many of them who survive, develop various co-morbidities like bedsores, pneumonia, urinary infection, suppuration, etc.<sup>[3]</sup> They experience a variable period of convalescence. After initial neurosurgical management, the survivors are discharged with instructions. Comprehension and compliance to the instructions given by the doctors/nurses at the time of discharge is important for the caregivers in order to achieve better clinical outcome after neurosurgical operation. Poor compliance with follow-up instructions can lead to slow or no recovery and ineffective care. Non-compliance rates ranging from 20% to 67% are reported in different studies.<sup>[4-7]</sup>

Health-related quality of life (QOL) reflects the impact of disease and its treatment on the physical, social, and psychological well-being of a person.<sup>[8]</sup> Because of the nature of neurological deficit, independence in the daily life of patients is compromised.<sup>[9]</sup> A study from Sweden reported 91% self-care and 80% instrumental activity of daily life (IADL) independence among the discharged neurosurgery patients. Among self-care, 23% reported need of personal assistance. Leisure and vocational disabilities have been reported in 48% and 40% of cases, respectively.<sup>[10]</sup> A study from Denmark also reported similar results in terms of work-related dependency.<sup>[11]</sup> The co-morbidities in neurosurgery patients can easily be prevented and managed if proper nursing care is provided to bedridden neurosurgery patients. Many researchers have found that when patient and family have a better understanding of their diagnosis and treatment, they are more able to cope with their illness, use the health system more effectively, and have less psychological distress.<sup>[12]</sup>

Against this background, the present study was planned with the following objectives:

- To determine the degree of compliance of neurosurgery patients and their family caregivers with the discharge advice given by the consultants
- To evaluate the quality of life (QOL) of these patients
- To know the problems faced by these patients at home.

## Materials and Methods

This cross-sectional interview-based descriptive study was conducted in 2010 in Chandigarh. All patients (residents of Tricity Chandigarh, Mohali, and Panchkula) discharged from neurosurgical ward PGIMER within last 1 year and patients attending regular follow-up OPD and discharged within last 3 years were included in the study.

After taking the addresses of neurosurgical patients from discharge register in neurosurgery ward Nehru Hospital PGIMER and from the register of patients attending follow-up clinics in new OPD, PGIMER Chandigarh, attempts were made to contact them at their homes. Non-traceable patients were excluded from the study. Suitable appointments were sought from the patients and respondents (prime caregiver) for the

interviews. First of all, they were explained about the purpose of the study. Repeated visits were also made as per the need for this purpose. Relevant records of treatment were examined. After filling up demographic data, interview schedule based survey was done. In-depth interview of vocal respondents was done. Verbatim responses were also recorded. Key caregivers of patients were interviewed as proxy respondents in case subject was not in a condition to respond. All cases that were not available for three consecutive visits, non-cooperative patients, and patients/caregivers not ready to give consent were excluded from the study.

A scale was evolved to evaluate comprehension and compliance to the advice given at time of discharge, according to criteria developed by Clark *et al.*<sup>[13]</sup> An interview schedule based on Barthel index of QOL,<sup>[14]</sup> Lawton Brody IADL,<sup>[15]</sup> and Spitzer QOL<sup>[16]</sup> was used to assess patient's QOL after the operation. These are internationally validated tools to assess QOL of patients after the operation. An in-depth interview was also conducted with patients and caregivers for the purpose of qualitative research.

The person in the family who was primarily responsible for care of the patient at home was defined as key caregiver for the purpose of study. Textual analysis of the data was done. SPSS version 17 and Excel software were used for the analysis. Percentage, mean, standard deviation, tables, and graphs were used for the interpretation of data. The subjects were informed about the purpose of study. They were assured that all personal information will be kept confidential and used only for research and study purpose. Consent was also taken from patients as well as their key care providers. Ethical clearance was obtained from the institute's ethical review committee.

## Results

An attempt was made to visit 100 patients' homes. Their addresses were taken from neurosurgery department. Only 61 patients were traceable. Rest 39 patients either were non-traceable or had changed their residence due to retirement from job or some other reasons like marriage of girls, transfer, or were staying with relatives or were on rent for treatment purpose. Out of the 61 cases, 2 patients died within a month of their operation and 1 patient was not willing to participate due to some personal reason. So, 58 patients were included in the study.

Maximum number of patients were in age group of 36-50 years (34.48%) followed by 25-35 and above 50 years age group (22.41% each). The mean age was 38.9 years (standard deviation 15.42 years) (range = 4-75 years). Of the 58 patients, 36 were males and 22 were females.

Maximum number of caregivers were in the age group of 25-35 years (33.33%) followed by the age group of 36-50 years

(31.57%). Caregivers below the age group of 25 years formed just 14%. One patient did not have any caregiver (resides alone). Among all the age groups, primary caregivers were mainly females (33 out of total 57). The mean age of caregivers was 39.12 years (standard deviation 13.4 years). The minimum age among the caregivers was 18 years and maximum age was 73 years. Overall, majority of the care at home was provided by females (57.89%). Majority of the patients were males (61.40%). Out of total 57 (1 patient was residing alone) caregivers, maximum percentage was of spouse (45.6%). Only one patient had hired a caregiver/attendant.

Majority of the patients (41.4%) and caregivers (43.9%) were not in the job. They were either students/housewives or not able to do any kind of work. Many of the patients were graduates and above (31.6%), whereas caregivers (24.6%) had higher secondary education. Majority of the patients contacted from the study areas (72.4%) were from urban areas, whereas 27.6% were from the rural areas and slums. Almost one-third of the cases were due to trauma caused by road traffic injuries, falls, and assaults.

Out of total 58 patients, 37 were given instructions on follow-up care at home. Rest 21 were either unconscious at the time of discharge or were not able to understand properly. Out of 37 patients, 35 showed good comprehension and 33 patients had a good compliance with the instructions given for medication [Table 1].

Most (54) caregivers were instructed about medication. Of them, 52 showed good understanding and 49 caregivers showed good compliance [Table 2]. Comprehension and compliance for the instructions like physiotherapy was found to be very poor. Patients who could not follow the instructions given for physiotherapy revealed a range of problems. To quote the problem faced due to physiotherapy from one of the narrative in our study:

*"Physiotherapy vale kabhi dhang se check nahi karte. Bas tal matol karte hain. Private physiotherapist 200-300 Rs per hour (4-6 US\$/3-4 Euros per hour) leta hai. Hamein kaha hai 6 ghante ke liye Physiotherapy karo are kaise ho sakta hai 30000 Rs (60 US\$/44 Euros per day) mahine ka."* [Physiotherapy people in PGIMER never check properly. They shirk work. A private physiotherapist takes ` 200-300 per hour (4-6 US\$/3-4 Euros per hour). We are advised physiotherapy for 6 hours at least. This costs ` 30,000/month (60 US\$/44 Euros per day), which is nearly impossible].

The condition of 43 (74%) patients improved after the operation, whereas it deteriorated in 4 (6.9%) patients. In 11 (19%) patients, the condition remained the same after the operation.

Almost half (47.4%) of the patients were independent in daily activities of their life while being evaluated on Barthel activity of daily life index. They were performing all daily life activities

on their own; 8.7% of the patients were totally dependent on their caregivers for their daily life activities [Table 3]. Mean of activity of daily life [ADL] score was 80.35, with a range of 0-100 and a standard deviation of 29.09. Almost half of the patients were found to be independent.

Mean IADL score for males was 4.11 (standard deviation = 1.43), whereas the score for females was 5.27 (standard deviation = 3.02). Highest mean score in all dimensions of IADL was in the telephone use (0.91) and least mean score was for shopping (0.60). In the dimension specific for females, the lowest mean score was for food preparation (0.45).

More than one-third of the patients perceived that they were able to conduct all activities by their own, evaluated by Spitzer QOL index. Almost half (47.4%) of them said they needed some

**Table 1: Comprehension and compliance status for patients**

Instruction given regarding	Total	Comprehension		Compliance	
		Poor	Good	Poor	Good
Medicines	37	2	35	4	33
Follow-up	36	2	34	6	30
Diet	12	1	11	2	10
Dressing	4	1	3	1	3
Exercise	13	4	9	6	7
Constipation	2	1	1	1	1
Others	11	1	10	2	9

**Table 2: Comprehension and compliance status for caregivers**

Instruction given regarding	Total	Comprehension		Compliance	
		Poor	Good	Poor	Good
Medicine	54	2	52	5	49
Follow-up	54	3	51	11	43
Diet	20	3	17	5	15
Dressing	10	1	9	2	8
Exercise	21	9	12	11	10
Constipation	15	2	13	4	11
Others	39	7	32	13	26

**Table 3: IADL in patients for all dimensions**

Measure of IADL	Mean (SD) [range]
Functional measure	Male=4.11 (1.43) [0-5]
IADL scale	Female=5.27 (3.02) [0-8]
Telephone use	0.91 (0.285) [0-1]
Medication management	0.74 (0.444) [0-1]
Transportation	0.75 (0.434) [0-1]
Financial management	0.86 (0.350) [0-1]
Shopping	0.60 (0.495) [0-1]
Food preparation (F)	0.45 (0.50) [0-1]
Housekeeping (F)	0.77 (0.42) [0-1]
Laundry (F)	0.77 (0.42) [0-1]

IADL – Instrumental activity of daily life

assistance or can perform the normal activity at reduced level. Some (15.8%) of them were not able to work at all. Most of the patients were able to perform daily life activities on their own (42.1%) or with some assistance (45.6%) from their family members. Few of them (12.3%) were completely dependent on their caregivers. Majority of the patients (71.94%) felt that they were not well and lacked energy.

Most of the patients (84.22%) felt that they had strong relationship with their family and their family always supported them in all their needs. One of the patients felt that he was not supported by family members in his need. Most of the patients (57.9%) appeared to be calm and with positive outlook. Some of them (12.3%) were seriously confused and appeared to be very anxious. Almost one-third of the caregivers of the patients (29.8%) reported that sometimes their patients looked very anxious and frightened.

Mean score of all the dimensions of Spitzer QOL together was 6.79 (standard deviation 2.41) with a range of 0-10. QOL for half of the patients was found to be good.

Among the other problems which arise after the operation, bed sore as a complication was reported by almost 14% of the cases, urinary tract infections (UTIs) were reported by 12%, and pneumonia was encountered among 10% of the patients. Loss of sensation in the body parts was a cause of worry for 22% of the patients. Anxiety was also reported by 41% of the cases. Almost half of the patients and caregivers were apprehensive about the prognosis. Problem of vision and speaking was reported by 15% of the patients, and almost 28% reported regular vomiting and nausea. The other problems reported by patients included oral health, deafness, anorexia, and incontinence in almost 6% of the patients.

## Discussion

Neurosurgical operations may improve the patients' condition. Basic lesion may be treated. But it is in the long term that the true complexity and impact of operations become apparent. After operation, such patients are likely to have a range of physical, emotional, cognitive, behavioral, and social problems, which may result in difficulties for both patients and family caregivers.<sup>[17]</sup>

In India, most of the actual burden of care giving is shared by family, friends, neighbors, and volunteers.<sup>[18-21]</sup> Long-term care at home can be provided either by the family members of the affected individuals or by professional caregivers.

Comprehension and compliance to the instructions given to the patients was found to be good in our study. This means that advice given by consultants to patients was followed to a great extent. This is attributed to doctor-patient relationship in which the former is regarded superior. Complex social factors are implicated in doctor-patient relationship. Here, the

patient comes unbidden to a doctor and enters voluntarily into a contract by virtue of technical superiority, knowledge, and skills.<sup>[22]</sup> The relationship and process can also be analyzed in terms of social power relationships (e.g., by Michel Foucault) or economic transactions. Physicians have been accorded a higher status and respect. Outcome of treatment also depends upon the quality of nursing care patients get in hospital and at home. Primary role of nursing lies in the "care" process consisting of caring, helping, comforting, and guiding.

Many patients said that they should be properly instructed about diet, constipation, and exercise as well. However, many patients were unconscious at the time of discharge. So, instead of instructions being given to patients, in such cases, the doctors/nurses interacted with caregivers. They were mainly instructed about the medicines, follow-up, and the need for regular checkup of the patients. Still, many caregivers felt that they should be instructed about diet, constipation, exercise, and problems related to eyes and teeth. This perceived inadequacy of instructions by doctors to some of the caregivers regarding their patients can be attributed to lack of time, overburdened doctors, and load of patients in the department. Annual bed occupancy ratio in neurosurgery department of PGIMER is almost 100%. Many of the neurosurgery cases were from neighboring states. To decrease the load in PGIMER, efforts should be concentrated on strengthening the neurosurgery department in other institutions of these states.

In our study, compliance for medicine intake and follow-up was observed to be better than that for the instructions for other domains of discharge advice such as exercise. This can be explained in two ways. One is due to the prevalent health culture where pills are seen as a solution to a wide range of problems. Moreover, there is active marketing of medicines by pharmaceutical companies. Consequently, individuals in affluent, consumer-oriented societies are more inclined to feel that any medical problem they have can be solved by taking a pill.<sup>[23]</sup> They are socialized into expecting a "pill" prescription for every "ill." They start believing that pain or suffering need not be tolerated, and to seek medical help and get a medical prescription is important. Accordingly, they do not give much importance to intangible things like "exercise." They perceive this as a thing where doctor/nurse is not involved, and hence is "not a medicine!"

Neurosurgical problems/diseases involve a lot of disability. After operation also, patients have a varying degree of disability. Many of our respondents were dependent upon caregivers for their [ADL], which ranged from help in climbing stairs, bathing, and self-care to more severe dependency in emptying bowel, urination and transfer from bed in initial days, but majority recovered significantly. Half of the patients in our study were independent in daily life activities after operation, whereas another half was depended upon



caregivers, although the level of dependency varied from slight to total dependency. The patients who did not recover following operation, forces a lot of problems, and long-term dependency on the caregivers.

Long-term care opens the issues like physiotherapy, which is regarded as a must for the patients with head injuries, as observed by some of the caregivers. They told that patients' condition always improves after physiotherapy. Some other studies have also reported this finding.<sup>[24]</sup> However, in India, private physiotherapists are seldom available. In any case, they charge a huge fee, and further increase the financial burden on caregivers. There is an urgent need of strengthening physiotherapy care for better results of neurosurgery operation and rehabilitation process. Timely physiotherapy has been reported to solve many problems of operated neurosurgery patients, who can get back to normal life.<sup>[24]</sup>

QOL in patients varied in our study according to the nature and extent of morbidity. Some patients had poor and average QOL despite having good initial relief after the operation. This occurred because of their inability to comply with the instructions given due to financial and other problems of caregivers.

Support is an important dimension in QOL of patients. Majority (84%) of the patients felt that they had strong relationship with their family. This is an indication of respect for family values in Indian culture. These values are incorporated in social structure through socialization. Patients in difficult situation need support to cope up. Family support is necessary in improving the QOL of patients.<sup>[18]</sup> It saves patients from loneliness and from the psychological effects felt by them due to limitations in different dimensions of life.

Most of the patients appeared calm and had a positive outlook toward life. Majority (three-fourths) of the patients perceived their health as below par, and felt that they lacked energy due to weakness after the operation. Most (87%) of the patients were able to perform activities of daily living on their own or with some assistance from other family members. Almost half of the patients depended upon their caregivers for daily life activities. Dependency was more in activities like bathing, climbing stairs, transfer from bed to chair, mobility, and toilet use. This means activities which require physical effort (like lifting a bucket), concentration (such as hand eye coordination), and mental work were more severely affected. Most of the patients were independent in feeding, grooming, emptying bowel, and urination, but the condition of those who were suffering was really severe.

IADL scores in our study for patients suggested that movement and coordination are mostly affected in neurosurgery patients after operation. Patient often starts performing functions such as taking own medication, telephone use, and financial

management. But cooking and shopping are the most severely affected IADL activities. Patients were dependent upon caregivers for their transportation also.

QOL was also good in patients where the condition of patient was improving. It was linked to quality of care and degree of dependency in ADL. As patients became more independent in ADL, QOL improved. Thus, quality of care has a direct effect on improving the QOL of the patients. So, efforts need to concentrate on improving the quality of care to improve patient's QOL.

Constipation was the major problem affecting one-third of the patients. Some of the patients said that it was the biggest problem they faced at home after discharge from neurosurgery ward. The most common causes of constipation are poor diet and lack of exercise. Other causes include medications, irritable bowel syndrome, abuse of laxatives, and specific diseases.<sup>[25]</sup> In most cases, it can be prevented following simple remedial measures like eating a well-balanced diet comprising high-fiber sources like beans, fruits and vegetables. Drinking plenty of liquids, and doing exercises regularly may also help in preventing constipation. Some patients and caregivers felt that they should be instructed about diet and dietary pattern to be followed at home.

Bed sore is one of the avoidable complications, but it needs regular support of caregiver to the patient. Immobility is the number one cause of bed sore (also called pressure ulcer). Other causes can be irritation by urine and feces, lack of good nutrition or enough fluid, dryness, and old age. Bed sores are a serious complication and can be prevented if proper nursing care is given to the patient. Bed-bound person should change position two hourly.<sup>[26-27]</sup> Caregiver should clean feces and urine with warm water and soap.<sup>[27]</sup> Alpha bed is the other option suggested by some of the caregivers in our study. UTI, pneumonia, constipation, and bed sore reflect poor quality of care. These problems can be minimized to an extent if proper care and consultation is given to the patients and caregivers, respectively. Training of caregivers needs to be done to avoid these complications.

## Limitations

Most of the patients contacted were from the follow-up clinics in PGIMER OPD rather than being randomly selected. So, we cannot generalize the results. There is a possibility that those patients/caregivers who had worse experiences and the patients who chose to go for follow-up in some other clinics after the operation might not have been contacted.

Study was conducted in Chandigarh where most of the families are socioeconomically better than in other parts of India. Also, due to good awareness standards, expectations from the system are much more as compared to other similar settings.

Although repeated visits were made according to patients' and caregivers' convenience, due to a cross-sectional design, no follow-up interviews were done.

## Recommendations

### Physiotherapy

Provision of physiotherapy clinics and occupational rehabilitation centers in primary and secondary health care institutions is recommended.

### Psychological and dietary counseling

A proper dietary advice at the time of discharge is needed for the betterment of patients. In addition, provision of psychosocial support for patients is required.

### Financial support mechanism

Financial support to the needy patients should be arranged.

### Follow-up care

Provision of mechanism of prioritized follow-up care to the operated bedridden neurosurgery patients should be made.

### Future research

More efforts need to be done to find out the exact burden of care giving in terms of Disability Adjusted Life Years (DALYs) lost. Research in this area is needed to find out the adverse effects of strain on the health of patients.

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