

Patterns And Quality Of Long Term Care For The Bedridden Patients In Chandigarh, North India

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Abstract

Objective: To ascertain the quality and pattern of home based long-term care for the adult bedridden patients in Chandigarh, India.

Methods: This is a cross sectional study conducted during the calendar year 2004 and included 100 bedridden patients. The patients were enlisted through various sources. Their degree of disability was assessed using the Katz index of the activities of daily living. An interview schedule based on Craig Handicap Assessment and Reporting Technique (CHART) was used to assess the provision of care to the bedridden patients. Patients and families were interviewed about the patterns and quality of care.

Results: Mean age of subjects was 69 years. Sixty-eight patients lived in joint families. All subjects had total dependence in the domains of bathing, dressing, toileting and transfer. Most common cause of disability was neurological diseases. Predominantly, female family members were caring for the patients. Hired helps were also used by 54 % of the cases. Fifty-nine patients were consulting government hospitals for most part of the health care. In 35% cases unqualified practitioners were also consulted. Most patients (78) were given medicines on time and the physicians' advice for them was followed. Though the rates of complications like urinary tract infections (39%), pressure ulcers (54%) were quite high, 57% patients reported satisfaction with the quality of care they were receiving.

Conclusion: Bedridden people have high rates of medical complications. There is a need for formal training for the caregivers as almost of them were untrained.

INTRODUCTION

The demographic transition has resulted in increasing life expectancy and an increasing proportion of the elderly people all over the world. A parallel epidemiologic transition has led to a predominance of chronic diseases₁. Global life expectancy at birth was 65 years in the year 2000₂ while the health-adjusted life expectancy was 56 years. This means that on an average, every citizen of the earth will live about 9 years of their total life span with some disease or disability. Also, this means that an increasing proportion of people will suffer from chronic diseases. Many of such people need long term personal assistance in their activities of daily living of life due to severely disabling and chronic nature of their diseases.

Most of these patients are cared for at home, with family members and friends providing the bulk of the care₃. This

situation has lead to reorientation of health care systems in the developed countries from hospitals and nursing institutions to the domiciliary care arrangements that the chronically disabled prefer and use. Care in domiciliary settings has been found to be more cost effective, and the patients too, find domiciliary settings to be more comfortable_{3,4,5,6,7,8}. Shifting of long-term care provision in rich societies from institutionalized care to the home has brought into focus the quality of care available to the patients at home. While data about the quality of care being provided in hospitals, nursing homes, residential institutions is available directly or indirectly, data about the quality of long term care (LTC) provided to the severely disabled at their own homes is difficult to gather because of the multiple socio-demographic and interpersonal factors involved₉.

However, in India the situation is different. Hi-tech care for

the bedridden is practically non-existent. Hospital based care for the bedridden is also not available on a long-term basis. Data on quality of home-based LTC is scarce. Against this background the present study was conducted to measure, in terms of quality and pattern, the home based provision of care for the chronically bedridden patients in Chandigarh city, India.

MATERIAL AND METHODS

Chandigarh is a small compact well-planned city in northern India. The city is known for its planning and architecture, high literacy level (82%), pollution free environment, low crime rate, aware and active citizens and a high quality of life. Chandigarh, as a union territory, is also the regional seat of power and houses the governments of Punjab and Haryana states besides its own city administration. Also it is a regional center of commerce, education and health care. The populace is divided between the urban, rural and the slum areas, the largest being the urban component. Chandigarh is one of the fastest growing cities in the region with a decadal growth rate of 40% and has a high population density. Also a large percentage of people in the city are retired personnel who have made the city their home. As per the 1991 census 4.4% of the city's population was above 65 years of age.

This cross sectional study was conducted between January 2004 and May 2004 in the planned sectors of Chandigarh city. One hundred chronically bedridden patients above the age of twelve years and their key care providers were included in the study.

No random sampling was done to select the cases. The investigator accessed the data of a number of government and private hospitals in Chandigarh city regarding patients of chronically debilitating diseases treated during last year. Patients' addresses were taken from the record files. Those from Chandigarh were contacted and their current status was enquired about. All personal acquaintances of the investigator were also asked to report if they knew of any such patient. Senior Citizens Association of Chandigarh, Nevadac Center for prosthetic implants, Trauma Center run by the Western Command of the Indian Army, local private practitioners, physiotherapists, masseurs, chemists and suppliers of physical appliances were also contacted and asked to provide addresses of such patients in their records, if any. Maximum number of patients (35) was contacted through the private practitioners.

Only 118 of the total 242 cases contacted by the investigator

(TDS) fulfilled the study criteria (as given below). Of these, only the first 100 were included in the study to achieve the arbitrarily decided sample size. Only 67 of the cases answered the queries themselves. Head of the family were the respondents in 8 cases and key care givers in 25 cases (12 patients were very old and did not have the stamina to speak much and most of the queries were answered by the significant others. Four patients were of Alzheimer's, 3 of Parkinson's, 1 each of microcephaly, hydrocephaly, RHD with heart failure and depression. One patient had severe chest infection at the time of interview and could not speak. The remaining 9 subjects were all suffering from stroke). After contacting the patients, an appointment was made taking into consideration the patient's and the family's convenience. The subjects were then interviewed one by one. After obtaining the socio-demographic data, the patient and the key care provider/head of the family were interviewed about the pattern and quality of care provision. All available medical records of the patient's were also reviewed. A brief on the spot examination was also conducted by the investigator (a physician) to evaluate the current health status of the patient.

An interview schedule based on Craig Handicap Assessment and Reporting Technique (CHART)₁₀ was used to assess the care provision to the bedridden patients. Katz₁₁ index of activities of daily living was used to assess the degree of disability of the subjects. Scoring for quality of care was done by taking into account 4 structural, 5 process and 6 outcome indicators chosen for their representativeness of the care giving process as suggested by Donabedian₁₂. Presence of a positive indicator was given a score of one whereas its absence, or presence of a negative indicator was marked as zero. Out of the total maximum possible score of 15, patients having scores of 11 and above were considered as receiving good quality care, patients scoring 7-10 and below 7 were considered as receiving average and poor quality care respectively. EPI info version 2000 was used for analysis. Percentage, mean, standard deviation and Chi Square test were used for the interpretation of data.

OPERATIONAL DEFINITIONS

Bedridden Case: This included all cases above 12 years of age who had been confined to bed for 15 days or more, for 90% of the time during the day and who were unable to get out of bed without assistance₁₃.

Key caregiver: The person in the family who was primarily responsible for the care of the index case.

EXCLUSION CRITERIA

All ambulatory cases were excluded i.e. those who could get off the bed without assistance or those who could walk without assistance

ETHICAL CONSIDERATIONS

The subjects were informed about the purpose of the study. Only those willing for the study have been included. They were assured that all personal information would be kept confidential and used strictly for study purposes. Proxy consent was taken from the key care provider or the head of the family in cases who were not able to communicate.

RESULTS

Maximum numbers of patients were in age group of 16- 60 years and 71-80 years (29% each) followed by 26% in the above 81 years category. The mean age was 67 years. Seventy-one of the patients had education above the graduate level. Fifty-one patients were currently married, 43 were widowed / widowers and 5 patients had never been married. Sixty-eight of the cases were living in joint families whereas 32 were in nuclear families. No patient was living alone. Past history of smoking and alcohol use was given by 29 and 26 cases respectively. Two patients were still continuing with the habit of smoking while none were using alcohol now (Table-I).

Figure 1

Table 1: Profile of the bedridden cases (N=100)

Variable	N
Age >60 years	69 (mean age 67 years)
Sex	
Male	68
Female	32
Widowers	17
Widows	26
Joint family	68
Family size >5	26 (average size 4.8)
Per capita monthly income (>10,000, \$222.2)	47 (average Rs 9620, \$ 213)
Education (Graduate and above)	71
Causes of morbidity	
Neurological	38 (17 stroke cases)
Musculoskeletal	28 (8 hip fractures, 7 osteoarthritis)
Old age	17
Duration since bed ridden (>1 year)	43 (average time 16.4 months)
Own property	69
Currently working	8
Current smoker	2 (past use 27)
Current alcohol use	None (past use 26)
Use of sedatives	73
Dependent in activities of daily living	
Bathing	100 (87 assisted, 13 dependent)
Dressing	100 (assisted 90, dependent 10)
Toileting	100 (assisted 24, dependent 76)
Transfer	100
Contenance	42
Feeding	22

Neurological, musculoskeletal causes and old age were the predominant morbid conditions. Neurological disorders were concentrated (15/38) in the 71-80 years age group. While CVA, Parkinson and Alzheimer's disease were the main reason for morbidity of those above 60 years. Other causes like Gullian Barre Syndrome and Multiple Sclerosis predominated in those below 60 years. Fractures caused the bulk of morbidity due to musculoskeletal causes. Rheumatoid arthritis and fracture spine were the most frequent cause in those under age 60 years, while fracture hip and osteoarthritis were the main reasons in the above 60 years age group. There were 3 cases of severe disability due to paralysis after spinal tuberculosis (cured) (aged 37, 45 and 64 years).

Diabetes (19) and hypertension (31) were the most frequent comorbid conditions in the bedridden cases.

Mean duration of being bedridden was 16.4 months. Only 5 patients had been bedridden for more than 8 years. Two of these had been bedridden since birth. One had microcephaly and the other hydrocephaly. Of the rest three, 2 had Alzheimer's disease and 1 had Parkinson's disease.

PGIMER (Post Graduate Institute Of Medical Education And Research, Chandigarh, the parent institute of the investigator) (40) and private practitioners (PP) (19) were

the most frequent source of medical consultation. Two patients were taking treatment from non graduate registered medical practitioners (RMP) and one was consulting a traditional healer. Two patients, suffering from cancer, were consulting Rajiv Gandhi Cancer Institute (RGCI) in Delhi. Seventy percent of the people on bed due to old age were consulting private practitioners. Thirty five percent of all the bedridden had consulted someone other than the formally trained medical practitioners. Majority of the patients (61) had tried one or the other indigenous or traditional medicine at one point or the other during their illness. One of the common indigenous methods used was to inhale the smoke of green leaves of a climber, which was supposed to benefit people suffering from stroke and other neurological problems (9). Another was to take injections from certain "gifted" people (11). These too were for patients suffering from neurological afflictions particularly paralysis and stroke. Patients of musculoskeletal problems often used medicines prepared by local practitioners of indigenous systems of medicine (hakeems and vaid).

Fifty-eight of the patients had had contact with their current treatment providing agency within the last 1-week to 3 months. Forty-six patients were being visited by doctors at their homes and fifty-seven patients were in touch with their doctors over the phone. The usual pattern was to consult the hospital or specialist for the disease related problems (e.g. Parkinson's, Gullian Barre syndrome etc.) and to consult private practitioners for the day to day problems like bedsores, chest infection, urine infection etc. which were not related to cause of disability but were the complications of being bedridden.

Only 3 patients had severe limitation in feeding. One patient had Ryles tube in situ for feeding. Eighty-seven patients needed some assistance in bathing one or more parts of the body while 13 were totally dependent. Twenty-one patients had no control over bowel and bladder. Of these, 5 were disabled due to musculoskeletal reasons, 10 due to neurological reasons and 2 due to old age. Twenty-one patients experienced only occasional incontinence. Twenty-four patients were mobile with human and mechanical assistance. These 24 could also go to toilet. Rest of the patients (76) passed stools and urine on bed only and were totally bed bound. Ninety patients needed some assistance in dressing and 10 were totally dependent.

Analyzing by Katz Index, no case was found to be in categories A, B, C, D and H of disability. Almost half of the patients (49) were in class E of disability. Twelve patients

were in class G of disability. Mean monthly expenditure for the patients per month was Rs 3120 (69 \$). Average amount of total money spent on patient care since the beginning of period of being bedridden was Rs 1.55 lakhs/case (3444 \$), range of expenditure being from Rs 10,000 to Rs 7 lakhs (222 \$ – 15555 \$). Fifty one percent of the patients had spent less than Rs 1 lakh (2222 \$) since the onset of being bedridden. Twenty six percent had spent between 1-3 lakhs (2222 \$ - 6666 \$) (most of them being bedridden due to neurological reasons).

Overall, 305 caregivers were involved in caring for the 100 study cases with an average or 3.05 care givers per patient (range from 1 to 7).

Out of the 18 cases where restrictions about playing with children were reported, 7 were very old, 6 were suffering from neurological disorders, 2 from musculoskeletal complaints, 2 from cancer and one from depression. There were no such restrictions reported in people suffering from cardiovascular diseases and infection. Five patients with a neurological diagnosis were practically non responsive. Thirty-one patients said that friends visited them less than once a week, 43 were visited by friends 1-3 times per week. Friends visited 8 patients daily. No friends visited 11 patients and with the rest the frequency was variable.

Sixty-seven patients said that they did not feel that they were being blamed for any bad happenings in the family. Twenty-one did not answer the question. Sixty-eight said that they had someone to talk to when they wanted to, whereas twenty-two did not reply to the query. Sixty-four patients felt that they were still a significant part of their families, whereas 12 patients did not respond to the query. Majority felt that they were not a burden on their families with 15 refraining from answering the question. Fifty-seven patients said that they were involved in celebrations and mournings in the family whereas 55 said that their opinion was asked when taking major decision in the family. Twenty and 24 patients responded in negative for the two categories respectively. Rest of the patients did not respond to the questions. Only 13 patients had ever had a radiogram done to assess their bone mass since they had become bedridden. Three of these patients were bedridden due to old age, 7 were cancer patients, who also had bone scans done to detect metastases.

Ninety five percent of the cases said that they were given medicines on time and that the physicians' advice was being followed for them. Three patients in the old age group

complained that neither the medicines were given on time nor the physicians` advice for them was followed completely. One patient each in neurological and musculoskeletal groups had the similar complaints. Ninety-two of the patients said that their families had made arrangements so that they could pray. Only 30 patients responded that they had knowledge about government schemes to help the disabled. Twenty-seven did not respond. Fifty-four of the patients said they were satisfied with the care that they were receiving, while 29 of the patients did not respond to the question.

Only 47 patients said they had ready cash with them in case of emergency or for personal expenditure. Seventeen of them felt it was insufficient to make them feel comfortable. Eight cases were involved in earning process and one of them was still the main breadwinner in the family. This patient of rheumatoid arthritis took tuitions at home. One patient, of spinal trauma ran a Public Call Office booth from his bed placed near the window. The window formed the counter for public dealing. Another patient, again suffering from paraplegia due to spinal trauma, was involved in software development on a computer placed on a special table near his bed.

Sixty-five of the patients responded that they had some property in their names, either liquid assets in the form of fixed deposits, government pension, or solid assets like the house etc. Seventy-eight of the patients said that they had ready help at hand and did not have to wait for more than half an hour to be cleaned if they passed stools or wet their beds. However, 9 patients said that though ready help was available, the caregivers refused to clean stools or urine. The caregivers provided the materials required, but the patient had to clean himself/herself. Ninety-six patients said that they believed in God and prayed regularly.

Twenty seven percent of males and 18% of the females received good quality of care. Urinary infection was the most frequent complication (83). Twenty-seven patients had urine infection for more than 5 times while 53 had urine infection for 1-3 times. Eleven patients had urine infection 3-5 times since they became bedridden. Constipation was also very frequent (89). Overall, 54 patients had experienced at least one episode of bedsore. Chest infection (44) and urinary incontinence (39) were also very frequent complications. Six patients had at least one episode of deep venous thrombosis. Forty-two patients said that they had bad smell around them. In 78 cases, bed sheets were changed once in three days. In 13 cases, it was once a week. Six

patients reported that the sheets were changed as frequently as they wet their bed, which was sometimes more than once per day. In 3 cases bed sheets were changed daily

The mean expenditure on home environment modification was Rs 30250 (672 \$). The most frequent modification done in the house for the patients was clearing of rooms of all extra furniture so that there was enough space for care givers to move about and also to place wheelchairs or chairs with commodes (98%). Next two most frequent changes were use of chairs with toilets and bedpans. Use of bed tables was also quite frequent (37%).

Most frequent modifications in the bed were purchasing a mechanized bed (Rs 2500; 55 \$) in which both the head and foot ends could be raised as per desire (23). Also frequently done was raising the height of the bed so as to avoid caregiver back strain while bending to support the patient. One patient had special bed with holes in the top so that he could be bathed while lying in the bed only (Table II).

Figure 2

Table 2: Pattern of Care received by the bedridden cases (N=100)

Variable	N
Time spent on care per day >5 hrs	22 (average time 4.74 hrs)
Money spent per month (> Rs 4000, \$ 88.8)	13 (average Rs 3100, \$ 68.8)
Money spent till date (> Rs 2,00,000, \$ 4444)	27 (average Rs 160000; \$ 3555)
Last contact with doctor >3 months ago	26
Consultation of unqualified persons	35
Use of services of physiotherapist	36
Given medicines on time	78
Physicians advice followed	78
Waiting time to be cleaned (>30 minutes)	13
Current treatment providing agency	
PGIMER	40
Private practitioner	19
None	19
Care givers do not help in cleaning excreta	9
Modifications done in the house	
Readjustment of furniture	98
Chair with toilet/bed pan	48
Mechanized bed	23
Bed tables	37
New TV	15
Extra phone	22
Air / water beds	19
Costliest structural changes in house	Rs 60,000 (1333 \$)
Costliest mechanized wheel chair	Rs 34000 (755.55 \$)
Key care givers	
Blood relation	161(52.8%)
Spouse	36 (11.8%)
Hired help	55 (18%)

Nineteen patients were using water and airbeds to avoid bedsores. This was one of the most costly equipments bought for the patient to help in medical care, with alpha beds costing upto Rs 5,800 (128 \$). New TV had been bought or 15 patients with costs ranging from Rs 8000 - Rs 17000 (177 \$ - 377 \$). One patient had purchased mechanized wheelchair when she was not bed bound (cost

Rs 34000, 755 \$), but now this chair was no longer in use. No other high tech equipment had been purchased by any patient. Structural changes in the room consisted of leveling of floors wherever unevenness existed and widening the windows or doorways to allow patient to have better view of outside or to allow easy movement of heavy beds or wheel chairs. This was one of the costliest structural modifications with one family spending upto Rs 60,000 (1333 \$).

The patients, on an average, spent about seven hours in sleep daily (range 4-10 hours). Insomnia was quite frequent and most of the patients (73) were using sedatives off and on. Daily ablutions accounted for 3.5 hours. Seventy-nine patients enjoyed watching TV (mean - 3.5 hours). Eight patients, who were involved in work, spent, on an average, about 3 hours in work daily, (range 1-5 hours). Exercise and physiotherapy consumed about 2 hours of the patients who did exercise.

DISCUSSION

Conventionally, the “Dependency Ratio” is calculated as a ratio between the sum of proportion of population in the age group >60 years and <15 years divided by the productive age group i.e. 15-59 years. This ratio is calculated to estimate the productivity of nations and is used as an indicator for economic growth. Hence, if a population has a large number of disabled in the 15-59 years group, calculation of dependency ratio by age groups alone might not give a true picture of the needs of dependency in the community. In this study, 29% patients were in the age group of 15-59 years, the productive age group. One patient, now above 60 years of age, became disabled when he was below 60 years. Moreover, 79% of the caregivers belonged to 16-60 years age group forcing them to divert time from economically productive ventures to activities of care of the bedridden. Thirteen percent and 11.5% of the care givers were >60 years and <15 years of age respectively, the so called dependent populations. The younger segment, which is supposed to require family support for proper development, is already involved in care giving process to their elders. Thus, such disabilities modify the dependency ratio by altering both the numerator and the denominator. Modified “dependency ratio”₁ takes into account the proportion of total population who were dependent to the “working-age” population (total population aged 15-59 years). This represents the actual dependency more accurately as many care givers will be above 60, many will be children and many dependents will be in the “working-age” and not available for paid work. The dependency ratio

in India is projected to increase from the present 9% to over 12% by year 2050₁₃. The fact that out of the 35 care givers in < 15 yrs age group, 27 were hired helps and out of these only 8 were males means that children (esp. girls) from the lower socioeconomic group, are deprived of their care receiving years, and the time that they should be spending in education is put into the process of care provision for the upper classes. In fact, as far as the <15 years old hired helps are concerned, this is also in violation of the Labour Act.

Also there were some cases where the elders were involved in care of the younger generations. Here it should be noted that in their productive years, they looked after their parents and brought up their children. Now, when ageing and having a deteriorating health themselves, they are again called upon to provide care for their younger bedridden generations. This places double burden of care giving on the same generation. In face of this generation itself ageing and having health problems, the burden of care giving is likely to hasten the decline in health status leading them to be more dependent sooner than the natural ageing and disability process should make them.

The issue of who will provide for the disabled and aged is a matter of debate all over the world. In the liberal welfare states, the primary responsibility of care for the disabled persons lies with the individuals and their families and the government acts only as a payer for those unable to provide for themselves₁₄. In the corporate-statist welfare regimes in countries like UK, Switzerland, Germany, Austria, and Norway, the state takes responsibility for providing for acute as well as long-term care₁₄. In India the state does not intervene in the lives of its citizens in a large way. The role of the Indian welfare state is limited to providing facilities, which a community cannot provide on its own. Indian philosophy places high value on the intergenerational ties. Joint family system is still one of the common family forms and the family, friends, neighbors and volunteers share most of the actual burden of being a care giver. Our study revealed that 68 patients were living within a joint family system and that 82% of the caregivers were family members of the bedridden patients.

In the Indian patriarchal family system, the girls get married and go to their husbands' home. There, they are supposed to care for husbands' parents also. This shows that the traditional thinking of gender specific roles still prevails even in the educated urban setup. The women are also required to care for their children, and in most cases, are

pursuing active careers. Further, 32 females were caring for a spouse, 43 daughters-in-law were caring for their - in laws, and 35 of 55 hired helps were females.

Average monthly expenditure on LTC included the payments made to the hired helps and the medicines used for the patient. In 74 of the patients this was within 4000 rupees (89 \$), which they considered quite affordable on a monthly basis. One patient, disabled by osteoarthritis, had 3 hired helps for personal care. The patient spent Rs 8000-10000 / month (178-222 \$) on hired helps. The expenditure pattern was similar in all the other morbidity groups i.e. the major part of expenditure was on manpower. Hence in patients needing LTC, it appears that the monthly expenditure depends more on the intensity of needs of the patient and the ability of the family to provide care, and not on the nature of disease. The monthly expenditure rises steeply when the number of hired helps increase.

A large part of the overall total expenditure in caring for the bedridden patient is due to 2 reasons: - hospitalization and home structural modifications. In contrast to the western countries where a variety of costly and hi tech mechanized appliances are available for the convenience of the bedridden patients, in this study, even though most of the patients were from the upper social classes, the costliest appliance purchased was a mechanized wheel chair, which cost Rs 34000/- (755.5 \$). Even this was not being used now. This reflects the poor state of awareness of people about availability of enabling technological gadgets like splints, robotic hands, wheel chairs which are sensitive to falls and prevent collision with walls with the help of sensors, for the aid of bedridden patients. May be in India, human help is more valued and also cheaply available. Since human help is available or can be afforded, need might not be felt to purchase costly gadgets.

A majority of the patients took advice from the tertiary care hospitals for their acute care. Most of them also consulted private practitioners for their routine problems. Nineteen patients were consulting private practitioners exclusively. They preferred private practitioners because they found it difficult to go to the hospital and wait in queue to see the doctor. Moreover, even after waiting for a long time, meeting with the doctor was for a very short time, which left them dissatisfied. Private practitioners were more readily available, gave more personal attention, and were ready to make house calls. Hence, private practitioners share a considerable burden of caring for the aged and disabled. These practitioners can act as a bridge between the tertiary

care institutions, which provide acute care, and the long-term care rendered by the families and other informal caregivers.

A significant number of patients in the study had also consulted unqualified practitioners or traditional healers at one point or the other during their course of illness. In chronic diseases where the focus is not on cure but on limitation of disability and pain relief, the prospect of living in dependency and facing a slow downhill course of health is depressing. Patients become vulnerable to try out things, which promise improvement without any objective evidence for the same.

Fifty-eight of the patients had contacted their main health advisor within the last three months. This shows that there was concern on the part of the family for welfare of the bedridden. Of the rest, 19 were not consulting anyone, as they were familiar with most of the problems of being bedridden and indulged in self-medication.

The largest contribution to the total morbidity was of neurological disorders. CVA being the most common in the >60 years age group and LGB syndrome and multiple sclerosis being more frequent in the younger age group. Fracture spine (8) in 16-60 age group and osteoarthritis hip were the most common musculoskeletal diagnoses in the >60 age group. Thus, a large degree of morbidity in the older age group was preventable. Fractures of hip, the major cause of morbidity in the > 60 age group are mostly caused by falls on underlying osteoporotic bones. Maximum numbers of falls of elderly occur in the bedroom or slippery bathroom floors¹⁵. Simple modifications, as reported by 98% of cases in this study, included removal of extra furniture to avoid tripping, leveling of floor, making bathroom floors of non-slippery materials and avoiding use of marble. Similar modifications have also been reported from studies in other countries¹⁶. Use of non-slippery foot wear will also help.

Thirty-one patients had hypertension and 19 had diabetes. Both the diseases are preventable causes of CVA and hence better management can lead to lower burden of disability.

Neurological and musculoskeletal diseases were also the most expensive to manage in the long run. A large part of the total expenditure depended on the kind of modifications required for the person. Diseases like Alzheimer's & Parkinson's, Multiple Sclerosis are slow onset diseases and allow the expenditure to be spread out over time. In acute cases. e.g., fracture spine, there is a concentration of expenditure within a short time span, which causes a severe

strain on the financial resources of the family.

In 18 cases, there were restrictions about children playing with the patients. In case of 7 old people, children were restricted from entering the rooms so as not to cause disturbance. The 2 cancer patients had restricted entry of children into their room to prevent infection as they were undergoing chemotherapy. In 6 patients, suffering from neurological disease, the patients were almost non-responsive. Children were restricted from going to their room lest they unknowingly cause some damage to the patients. In no case was there a feeling that interaction of children with disabled adults was inauspicious.

Complications of being limited to bed for a long time are often taken as valid measures of quality of health care^{12,17,18}. A high frequency of medical complications was observed in this study. Urinary infections were the most frequent medical complication. The rate of bedsores was much higher than those observed in the nationwide survey conducted by IOM in the US¹⁸. Similarly, a high frequency of chest infections, bad smell and urinary incontinence shows that the technical quality of care provided to these patients was quite wanting. Bedsores, besides causing pain and infection, may also be a source of bad smell. In one case, presence of bedsores was the reason behind delay in surgery of spine.

Bad smell could also emanate due to passing of stool/urine by patients on bed. Though the bed sheets were changed frequently, the bedding as such was not changed. Also in cold weather, patients were not bathed daily. This bad smell emanating from the patients could also account for caregivers occasionally avoiding the patients in at least 42 cases. In 9 cases, the caregivers refused to clean the patient after the patient had passed stools. The patient was provided the materials to clean himself but the caregivers found the task distressing and unpleasant. Efforts to prevent bedsores were evident from the fact that 19 patients were using waterbed or alpha bed.

Most of the other modifications done within room or bathrooms were guided either by the comfort of the caregiver or comfort and safety of the patient. For example, lifting the patient up from lying position was felt to be a great strain by almost all caregivers (98%). Hence elevation to the bed was given, so that the angle at which back bent was reduced and hence back pain avoided. Also mechanized beds were purchased for 23 patients so that raising head end or foot end could be performed even by young children easily by simply turning the lever. Also frequently seen was

the attachment of side rails on bed. This was not only for the safety of the patient but also for support. The patient could hold the rails and pull himself/herself to sitting position. Use of bedpans was also a step in direction to help clean the patient while lying in the bed only. Head end elevation of the bed helped the patient sit up while eating rather than always being in a semi reclined or reclined state.

Occupying themselves during the day is a major problem for the bedridden patients. Patients have been known to become depressed and to express attention-seeking behavior during prolonged severe illness. The fact that new TV and phones were bought especially for the patients shows that the families were aware of the need to fill time with at least some activity. The other recreation activities were reading and encouragement of visits by friends. Talking to the family members and friends was also an activity most patients enjoyed for an average of 1.5 hours daily.

Old age and prolonged periods of restriction to bed leads to alteration of sleep wake cycles. This is a natural phenomenon and also stems due to the patient being in bed all the time¹⁹. Patients who sleep during the day remain awake and feel lonely and deserted at night while the rest of the family sleeps. To prevent this, intake of sedation is practiced so that sleeping time of the patient matches with that of the caregivers. In this study, sleeping was the single largest time occupying activity and 73 patients reported off and on use of sedatives. Next most frequent was watching TV, which although passive, still filled up time for the patient.

On an average, the patients spent 1.88 hours on prayers daily. This shows that faith was a source of strength for patients and helped coping with the problem of being disabled. This finding has also been highlighted in other studies²⁰. Patients spent average 2 hours daily on physiotherapy and exercises which come close to the recommended 2 hours daily in divided settings. This means that guidelines for good care of bedridden as regards physiotherapy were being followed in more than 50% patients. This reveals the awareness levels of the community about the hazards of inactivity.

All patients in the study sample were dependent in the domains of bathing, dressing, toileting and transfer. Total dependency in these areas makes the patient dependent for even minor alteration in the body position. Bathing and dressing of the patient required the presence of at least 2 caregivers. One to hold the patient while the other sponged

or bathed. Not only the cleaning of excreta of the patient was considered unpleasant but also the need for the same arose unpredictably throughout the day, the so-called 'critical interval' needs²¹. This was more so in case of patients who were incontinent. 'Critical interval' needs of the patient require that a caregiver be present almost throughout the day. Ninety-four of the patients were provided upto 6 hours of care daily. In 6 cases, more than 6 hours of care was rendered daily. Neurological morbidity accounted for 4 of these patients. This means that not only are neurological diseases a major cause of morbidity, but these diseases also require more care and hence also put a greater burden on the care giver. Though there was no significant difference between the numbers of hours of care received by different categories of severity of disability, category G (of Katz scale)¹¹ patients required higher number of hours of care numerically.

A large majority of patients said that they had someone to talk to and considered themselves a significant part of their family. A large number also felt that they were a burden on their family, despite the fact that most patients said that they were involved in family occasions and their opinions were asked in personal and family matters. This could mean that patients themselves had a feeling of worthlessness and of being a drain on family. The awareness that family members are making compromises for the patients while they lie in bed the whole day may give rise to self pity and a feeling of being a burden on others. Involvement of 8 patients in the earning process, on the other hand, shows a desire to be of use as much as they can. One patient, who was also the highest earning member of her family, was actually proud of her achievement, and though despondent about being diseased, expressed no feeling of self-pity or self-degradation. All the working patients were also in good spirits, though a feeling of sadness due to disability was perceptible.

Thus the present study reveals that in the upper social strata of Chandigarh, the labour intensive long term care is provided by family members of the patients at great personal costs. Although, the personal needs of the elders are well taken care of, the high rate of complications reveals that technical quality of care leaves much to be desired. Families, on their behalf, take great pains to make the patient feel loved and cared for. But lack of proper training in care and unfamiliarity with the dependency makes them apprehensive about the outcomes of whatever procedures they adopt.

In a city like Chandigarh, where most of the younger

generation people are working, it puts family ties under strain to have to care for a disabled person at home. Personal aspirations have to be sacrificed at the altar of care giving. Loss of income due to care giving to the bedridden places a great economic burden on the family. In a city where the cost of living is very high, this becomes even more piquant. Chandigarh was visualized by late Prime Minister Pt. Jawaharlal Nehru as a role model of planned city for urban areas. As a capital of 2 states, Chandigarh is home to a number of social organizations. A lot of efforts are being made by the Chandigarh administration to make the life comfortable for its citizens. Development of a comprehensive policy for care giving to the bedridden, from which other cities can also take initiative, will go a long way in making Chandigarh a 'Healthy City' in the real sense.

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