Profile of Home-based Caregivers of Bedridden Patients in North India

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ABSTRACT

Background: Caregiving to bedridden patients in India is set to become a major problem in future. Objective: To ascertain the profile of caregivers for the adult bedridden patients in Chandigarh, India. Materials and Methods: This cross-sectional study was conducted on 100 purposively selected bedridden people. The Katz Index of the activities of daily living was used to ascertain their degree of disability. Patients and families were interviewed about the patterns of care provision. Results: The mean age of subjects was 69 years. A majority (68%) of them lived in joint families. A lid of them required assistance in bathing, dressing, toileting, and transfer. In 54% of the cases someone was hired to look after the subjects. A majority of the caregivers (82%) were family members. All caregivers were untrained. In 35% of the cases unqualified practitioners were consulted, while in 59% of the cases government hospitals were consulted. Most patients (78) were given medicines on time. Complications like urinary tract infection (39%) and pressure ulcers (54%) were reported; 57% of the patients reported satisfaction with the care provided. Conclusion: The main source of caregivers for the bedridden was the family. Bedridden people had high rates of medical complications. There is a need for formal training for the caregivers.

Keywords: Bedridden, caregiver, geriatrics, long-term care, quality of care

Introduction

The Indian aged population is currently the second largest in the world. The absolute number of the elderly (over 60) population in India will increase from 76 million in 2001 to 137 million by 2021.¹

The recent demographic trend shows that in 1950, 5.6% of the India’s population was classified as elderly, which by 1990 rose to 7.1%, and by 2025 it is likely to reach 12.3%. In the industrialized countries of the west, the elderly population in the 1990s was 7 – 15% of the total population, and is expected to reach 25% by the year 2020.²

Many of the elderly have various degrees of disability. They are often dependent on others for their activities of daily living. Some of them remain bedridden due to various causes. Clearly, in view of such a demographic trend, caregiving to the rising number of dependent elderly is a major problem that India is going to face in the near future. Against this background, in the present study, we have tried to ascertain how the caregivers provide home-based care for the adult bedridden patients in Chandigarh, India.

Materials and Methods

This cross-sectional descriptive study was done in Chandigarh on 100 purposively selected families with bedridden patients. For enlisting the cases the investigator, a postgraduate student in community medicine, accessed the data of a number of government and private hospitals in Chandigarh city with regard to patients with debilitating diseases. Those in Chandigarh were contacted and their current status was sought. Information about such families was also sought from various sources, namely, personal acquaintances of the investigator, senior
citizen associations of Chandigarh, Nevedac Center for prosthetic implants, a trauma center run by the western command of the army, local private practitioners, physiotherapists, masseurs, chemists, and suppliers of physical appliances, and so on. The addresses of the families were noted. The subjects and their caregivers were interviewed individually by the investigator. After obtaining the sociodematic data, the respondents were interviewed about the pattern and quality of care provided. The family members and caregivers within the families were asked about their involvement in the caregiving process and its impact on their lives. An interview schedule based on the Craig Handicap Assessment and Reporting Technique (CHART)\(^{(5)}\) was used to assess the care provision to the bedridden patients. The Katz Index of activity of daily living was used to assess the degree of disability of the subjects.\(^{(4)}\)

EPI info version 2000 was used for the analysis. Percentage, mean, and standard deviation were used for the interpretation of data. Bedridden cases were defined as those people who had been confined to the bed for 15 days or more, for 90% of the time during the day, and who were unable to get out of bed without assistance.\(^{(5)}\) The subjects were informed about the purpose of study and consent was taken. Proxy consent was taken from the key care provider or the head of family, in cases where they were unable to communicate.

**Results**

Overall 305 caregivers were involved in caring for the 100 study cases, with an average of 3.05 caregivers per patient [Figure 1].

Forty-six cases were provided personal care by their families only. Help, if any, was hired to perform other household chores. In 54 cases hired help was involved in providing personal care. Of the total 55 hired helps employed, 35 were females. None of these hired helps had received any formal training for case provision. They learnt as they performed under the supervision of the family members.

In most of the cases (291; 95%) the key caregiver lived in the same house as the patient. In case of the 24 untrained, hired nurses who lived in the same house, generally, accommodation was given in the annexes or the servants’ quarters of the house. Sometimes, the whole family of the untrained nurse was given accommodation in the house, to ensure the availability round the clock. In all, 18 untrained nurses slept in the same room as the patient; seven nurses were hired to cater to the needs of the disabled only during the night. Four of the children, eight daughters-in-laws, two grandchildren, three parents, and thirty-five spouses slept in the same room as the bedridden patient. Out of the eight daughters-in-law who slept in the same room as the patient, five took care of their mothers-in-law, whereas, three took care of their fathers-in-law [Table 1].

In case of the 38 female bedridden patients, 28 were looked after by male as well as female caregivers and 10 by a female caregiver exclusively. Among the 62 male bedridden cases, two were looked after by female caregivers exclusively and six by male caregivers exclusively. For the rest both male and female caregivers provided their services. Fifty-four percent of the key caregivers were blood relations of the patients. For example, 29% were children (71 sons and 19 daughters). Untrained hired help was the next most frequent source of caregiving. Daughters-in-laws and grandchildren were involved in equal proportions (14%). No son-in-law was involved in caregiving. Only one grandparent was involved as a caregiver. Two hundred and seven

![Figure 1: Profile of the caregivers](image_url)
of the caregivers had education up to the graduate and postgraduate levels. Fifty-five were illiterate, 23 of them being untrained hired help [Table 1].

Moreover, 79% of the caregivers belonged to the 16 to 60 years age group, forcing them to divert their time from economically productive ventures to care for the bedridden. Thirteen percent and 11.5% of the caregivers were >60 years and <15 years of age, respectively, the so-called dependent populations.

A relatively high complication rate was seen in the bedridden cases, for example, constipation was reported in 89 patients, urinary infection in 83 cases, bedsores in 54 cases, bad smell due to passing of urine/stools in bed was reported in 42 cases, chest infection in 44 cases, and urinary incontinence in 39 cases.

Some of the comments made by the caregivers during the interview were:

- “Why doesn’t he understand we have our needs too.”
- “I think it would be good if someone who knows how to give care to such cases could come sometimes and see if everything is ok.”
- “Why can’t he sleep at night?”
- “I need someone as a caregiver whom I can trust the patient with while I’m gone”
- “I need at least some break”

<table>
<thead>
<tr>
<th>Variable</th>
<th>Number</th>
<th>%</th>
</tr>
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<tbody>
<tr>
<td>Profile of Caregivers</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;15 years</td>
<td>35</td>
<td>11.5</td>
</tr>
<tr>
<td>&gt;60 years</td>
<td>39</td>
<td>12.8</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>137</td>
<td>45</td>
</tr>
<tr>
<td>Female</td>
<td>168</td>
<td>55</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Illiterate</td>
<td>55(23 hired helps)</td>
<td>18</td>
</tr>
<tr>
<td>Graduate and above</td>
<td>207</td>
<td>67.8</td>
</tr>
<tr>
<td>Relation to the patient</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Children</td>
<td>90 (m = 71, f = 19)</td>
<td>29.5</td>
</tr>
<tr>
<td>Son/Daughter-in-law</td>
<td>43 (m = 0, f = 43)</td>
<td>14.1</td>
</tr>
<tr>
<td>Grandchildren</td>
<td>44 (m = 27, f = 17)</td>
<td>14.4</td>
</tr>
<tr>
<td>Parents</td>
<td>27 (m = 10, f = 17)</td>
<td>8.8</td>
</tr>
<tr>
<td>Spouses</td>
<td>36 (m = 4, f = 32)</td>
<td>11.8</td>
</tr>
<tr>
<td>Untrained Nurses</td>
<td>55 (m = 20, f = 35)</td>
<td>16.3</td>
</tr>
<tr>
<td>Place of residence</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Same house as patient</td>
<td>291</td>
<td>95.4</td>
</tr>
<tr>
<td>Different house than patient</td>
<td>14</td>
<td>4.6</td>
</tr>
<tr>
<td>Formally Trained</td>
<td>None</td>
<td></td>
</tr>
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</table>

“For if we could be put in touch with other people facing similar situation we could form a club and help each other. Right now everyone is fighting his own battle”.

Discussion

The fact that out of the 35 caregivers in the <15 years age group, 27 were hired helps and out of these only eight were males, means that children (especially girls) from the lower socioeconomic group were being deprived of their care receiving years, and the time that they should be spending in education was spent in the process of care provision for the bedridden patients from upper classes. In fact, employment of <15-year-old children as hired helps is in violation of the Child Labor Act of India.

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 aging and having a deteriorating health themselves, they are again called upon to provide care for their younger bedridden generations. This places a double burden of caregiving on the same generation. In the face of this generation itself aging and having health problems, the burden of caregiving is likely to hasten the decline in their health status, leading them to be more dependent sooner than the natural aging and disability process should make them. Moreover, these elderly caregivers were the family members of the bedridden. All the hired caregivers were in the younger age group.

The issue of care of the disabled and bedridden is basically of the financial burden it entails. Essentially, the bedridden cases are dependent on the family for their immediate needs of day-to-day care, especially the hygiene-related aspects. The issue of who will provide for the disabled and aged is a matter of debate all over the world. In countries like UK, Switzerland, Germany, Austria, and Norway, the State takes the responsibility of providing for acute as well as long-term care. In India, family, friends, neighbors and volunteers share most of the actual burden of being a caregiver. Long-term care institutions have not yet become the norm here.

Our study revealed that 68% of the patients were living within a joint family system and that 82% of the caregivers were family members of the bedridden patients. Of the total, 32 females were caring for a spouse and 43 daughters-in-law were caring for their in-laws. Moreover, 35 of the 55 hired help were females.

In the Indian patriarchal and patrilineal family system, the girls get married and go to their husband’s home. There, they are supposed to care for their husband’s...
parents also. This shows that the traditional thinking of gender-specific roles still prevails, even in the educated urban setup. In urban areas, women are required to care for their children, while pursuing active careers. The family spends Rs. 8000 – 10000/- month (178 – 222$) on hired helps.

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 require the presence of at least two caregivers. One to hold the patient, while the other sponged or bathed him/her. Not only was cleaning of the excreta of the patient considered unpleasant, but also the need for the same arose unpredictably throughout the day, the so-called ‘critical interval’ needs. This was moreso in the case of patients who were incontinent. Ninety-four of the patients were provided up to six hours of care daily. In six cases, more than six hours of care was rendered daily.

A lot of efforts were being taken by the family members for the care of their disabled. However, there was also evidence of caregiver burn out. Also, there was concern that perhaps what they were doing was not enough. The comments made by the family members about their problems, show that the caregivers were very much stressed by the small, but continuous demands of the patients, and were compromising their own needs. This also shows that the caregivers want someone with technical training to visit and see whether what they are doing was correct and whether there was any scope of improvement. None of the hired caregivers had undergone any formal or vocational training in caregiving. All hired caregivers were informally trained by the family caregivers. This also required a lot of effort on the part of family members.

In our study, most of the family caregivers expressed a need for respite from caregiving. Also strongly expressed was the desire to have some training for caregiving and formation of support groups to help them cope with the strain of caregiving. In situations where there are multiple caregivers, the burden gets diluted. In nuclear families, where a single or only two-to-three caregivers share the caregiving process, this is likely to result in a greater burden on the caregivers, and hence, a higher chance of caregiver burnout and weakening of ties between the patient and the caregiver. The slow build up of frustration due to caring for long durations has been found to be detrimental to the quality of care as well as interpersonal ties.

The diversion of resources for caregiving is likely to compromise on the needs and aspirations of the other family members, which often leads to a feeling of resentment against the patient over a period of time. In 12 cases, the proxy interviewey responded that there was no such feeling. The caregiving process places a severe strain on the caregiver. In our study, almost all the caregivers felt that caring was a physical and emotional strain. Caregivers felt irritable due to lack of sleep, as the demands of the patient kept them awake at night. Also, backache was caused by need of repeatedly lifting the patient into sitting position. Drag on family resources forced many caregivers to alter their budget outlays and in one case the plan of the family to buy property was shelved. Similar findings have been reported in other studies also.

Bad smell emanates due to the passing of stool/urine by patients on bed. Although 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 nine cases the caregivers refused to clean the patient after the patient had passed stools. The patient was provided the material to clean himself but the caregivers found the task distressing and unpleasant.

In the present study, each patient on an average, received care from 3.06 caregivers. This reflects the high intensity of the needs of patients. The number of female caregivers was higher than males. This is in accordance with the predominance of involvement of female caregivers in the caregiving process all over the world. A significantly higher number of females cared for females. The number of males caring for males exclusively was significantly higher than females caring for males. Although two males were being cared for by females exclusively, no females were being cared for by males exclusively. This brings out the sharp gender definition and limitations placed by society on gender-based personal interaction. Even where males and females together acted as caregivers for males, the role of males was more in the nature of providing muscle and gender sensitive roles like cleaning excreta. Females acted more as nurturers by playing roles in feeding, changing sides, and talking with the patient, although in some cases the females did clean the patient. In case of female patients, it was deemed necessary that a female only provided the more intimate kind of care like bathing, changing clothes, and cleaning excreta. This laid stress on the fact that more females would be involved in caregiving, as the statistics showed that a lot more disabled in the older age group were women.

Thus, the present study reveals that in the upper social strata of Chandigarh, the labor-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 reveal that the technical quality of care leaves much to be desired.

The concept of trained caregivers in India is yet to be introduced on a large scale. The family has been providing care to bedridden cases on an informal basis. Actually, in developed countries the models of institutional long-term care have been tried for a long time. These were found to be quite expensive. Emphasis is now again on home-based, long-term care, with involvement of the family members. To encourage it they have a well-developed caregiver support system, in countries like Australia, New Zealand, United Kingdom, Germany, Sweden, and so on. For example, in Germany, Long-Term Care Insurance program has long been established. Various countries have initiated schemes to help or compensate the caregivers. This has been done so that family members do not feel burdened or stressed due to caregiving.\(^{12-14}\)

Thus, in the rich western countries the governments have initiated measures to encourage caregiving by the family itself. In the last decade, a number of specific programs and strategies have also been initiated by the Government of India, for the welfare of the elderly and disabled. However, there are only a handful of reputed institutes that train caregivers; namely, the National Institute of Social Defense (NISD) [Table 2]. Even these have started recently. Therefore, we do not have an established program of training caregivers in India. The caregiving institutes have just started picking up.\(^{12-14}\)

Under the aegis of the Ministry of Human Resource Development, the National Policy for Older Persons (NPOP) was announced in January, 1999. In the Ministry of Social Justice and Empowerment — the Social Defense Division has been activated. It provides for the need of older persons through its various programs and initiatives. For example, the government has constituted a National Council for Older Persons (NCOP) under the Chairmanship of the Minister for Social Justice and Empowerment, to advise and aid the government on policies and programs for older persons and also to provide feedback to the government on the implementation of the NPOP, as well as on specific program initiatives for older persons. The NCOP is the highest body to advice and coordinate with the government in the formulation and implementation of policy and programs for the welfare of the aged.

India is also now slowly moving toward creation of a formal cadre of professional caregivers. A cadre of educated and vocationally trained young adults is being prepared so that they can work with social organizations or for individual persons. Various degree and diploma courses on physiotherapy are being contemplated. Along with the teaching material, vocational courses have been developed for this purpose by the National Institute of Technical Teachers Training and Research Institute (NITTI), Chandigarh.

Therefore, in future, it is expected that in India, long-term care to elderly bedridden patients will continue to be provided by the family with the support of a cadre of trained caregivers, available on a payment basis. This

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<tr>
<th>Variables</th>
<th>USA</th>
<th>Doubebo</th>
<th>Bvetubjeb</th>
<th>UK</th>
<th>Gbodj</th>
<th>Ofutaftboe</th>
<th>Txefo</th>
<th>Jsbf</th>
<th>Hfnboz</th>
</tr>
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<tbody>
<tr>
<td>65 years and older</td>
<td>12.4</td>
<td>13</td>
<td>12.6</td>
<td>16</td>
<td>16.3</td>
<td>13.6</td>
<td>17.3</td>
<td>9.8</td>
<td>18</td>
</tr>
<tr>
<td>65 + institutionalized and requiring long care</td>
<td>5.7</td>
<td>7.5</td>
<td>6</td>
<td>5.1</td>
<td>6.5</td>
<td>8.8</td>
<td>8.7</td>
<td>4.3</td>
<td>6.8</td>
</tr>
<tr>
<td>GDP spent on LTC</td>
<td>1.32</td>
<td>1.08</td>
<td>0.9</td>
<td>1.3</td>
<td>0.5</td>
<td>2.7</td>
<td>2.7</td>
<td>NA</td>
<td>0.82</td>
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<tr>
<td>Women care givers</td>
<td>46</td>
<td>46</td>
<td>44</td>
<td>44</td>
<td>45</td>
<td>41</td>
<td>49</td>
<td>41</td>
<td>42</td>
</tr>
</tbody>
</table>

Figures in parenthesis are in percentage
of course will be applicable to the people in the upper
and middle class. For the lower social strata of people,
the government will have to spend money to provide
the requisite services.

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Author Queries???
Q.1 Table 3 not cited in the text ???
Q.2 Please check "Labor" or "Labour"???