PROFILE, UNMET NEEDS AND STRESS AMONG CAREGIVERS OF TOTALLY BEDRIDDEN PATIENTS IN NORTH KERALA: A COMMUNITY BASED STUDY

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ABSTRACT

Unmet needs of caregivers can lead to burden based on inadequacies in caregiver knowledge, lack of communication between patient, caregiver and service provider, lack of finances, physical, psychological and social problems of the caregiver, limited respite care options, lack of public awareness about caregiver issues and lack of technical training.

METHODOLOGY

A cross-sectional study was done among caregivers of bedridden patients receiving home-based care by the Palliative team of our college to assess their unmet needs and stress.

RESULTS

There were 104 caregivers of totally bedridden patients who participated, out of which 96% were women and 98% belonged to the low socio-economic group. Unmet needs like lack of recreation, sleep, total responsibility for the patient, insufficient money and no scope for respite care were seen in more than 50% of the caregivers. Most unmet needs were associated with physical stress while lack of recreation, being totally responsible and insufficient income was associated with social stress and lack of recreation with psychological stress. Impending death of the patient was a cause of mental stress among most caregivers irrespective of unmet needs. Lack of initial technical training (99%) was not associated with stress since communication exists between caregivers and the palliative team including a doctor.

DISCUSSION

Services to be aimed primarily at informal caregivers may be designed to increase the level of knowledge and emotional support of caregivers, provide relief from the unending burden of caring or provide financial benefits to those who take on this responsibility.

KEYWORDS

Caregiver, Unmet Needs, Caregiver Stress.

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INTRODUCTION

Informal care is the most important form of care of disabled persons throughout the world. Paid services play a relatively small role in a few developed countries where modern society has smaller families, greater longevity, separate and independent living situations for older people and greater freedom for women.

Informal care is by far the most prevalent form of long-term care. In a developing country like India, it is not cost effective to provide care in nursing homes or by paid homecare workers.[1]

A caregiver is an unpaid person who helps the patient with his physical care and management of the disease. Normally, the caregiver is a family member or a friend. Informal caregivers take on caregiving tasks voluntarily for many different reasons like family obligation, traditional values, poor quality care in institutions in spite of high costs, personal satisfactions such as feeling needed, sense of accomplishment, expressing love and responsibilities, feeling appreciated by family members and the disabled relative.[1,2]

Despite these positive aspects, prolonged care giving has negative effects on the physical health of caregivers such as interrupted sleep, chronic fatigue, myalgia and irregular eating.[2] Psychological health is also severely affected. As compared to the general population, primary caregivers are frequently depressed and anxious, having symptoms of psychological distress.[2,3,4]

Unmet needs of caregivers can be classified into domains namely inadequacies in caregiver knowledge, lack of communication between patient, caregiver and service provider, weak social support, lack of financial support, physical, psychological and emotional setback of the caregiver, little or no respite care options and lack of public and technical awareness about caregiver issues.[5] Unmet needs over a period of time leads to caregiver stress or burden.

Caregiver burden, one of the consequences of care giving has been defined as "the physical, psychological or emotional, social and financial problems that can be experienced by family members caring for impaired relatives." Care giving is an engaging task, which may result in subjective feelings such

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as abandonment, entrapment and demoralisation.[5] Therefore, treating care givers becomes important, since stress holds back the quality of support they can give to the patient. In developing countries where the backbone of the long-term health care system is informal care givers, strengthening support for family caregivers becomes essential. In order to do so, the most pressing unmet needs and burdens of family caregivers must be addressed.

Caregivers will benefit from information about patient prognosis, measures to improve quality of life and end of life issues which may result from enhanced direct relationship with clinicians. Technical training may further decrease burden. Studies on caregiver stress are very few in India and no such study has been done in this part of the country. Thus, it was decided to study the extent of unmet needs and burden among caregivers.

METHODOLOGY

The palliative care unit functions under the Community Medicine Department and conducts visits to homes of selected sick patients on a regular basis, the selection criteria being families belonging to low socioeconomic class, having no manpower to transport the sick person to the hospital, living in difficult terrain with low connectivity to hospitals. Four panchayats around our medical college have been getting this service from our department since 5 years. There are around 300 patients identified, among which there are 110 totally bedridden patients. A cross-sectional study was conducted among caregivers after obtaining informed consent using a pretested semi-structured questionnaire based on specific local and cultural situations to assess the profile, unmet needs and the stress factors of caregivers of totally bedridden patients.[6] Unmet needs were assessed by asking the patient to answer in the affirmative if there was an unmet need. Different aspects of stresses-physical, social, psychological and entrapment were assessed on a 5-point scale. Overall stress was assessed on 10-point scale where 0 was taken as having no stress, 1-3 mild stress, 4-6 as being moderately stressed and 7–10 as being severely stressed.[7]

RESULTS

One hundred and four primary caregivers of totally bedridden patients were interviewed.

Table 1: Disease Profile of the Patients being looked after by the Caregivers

Out of the 104 caregivers, 100 (96%) were females.[8] The mean age of the caregivers was 51.07±13.94 years.[8]

Table 2: Profile of the caregivers.

Table 3: Socioeconomic status of the study population

While 49 caregivers were availing social scheme pension of the government, 20 were employed with an income ranging between Rs 1500 and 15000 and another 6 were utilising retirement pension of the patient's or their own.

Table 4: Unmet need of the Caregivers

Stress among caregivers was classified into 7 domains namely physical stress, emotional and psychological stress, social stress, feeling of entrapment, technical skill and physical environment. In these various aspects answers no, rarely, sometimes, frequently and always were obtained.[7]

Table 5: Physical stress in caregivers.

Table 6: Emotional and psychological stress in caregivers.

Table 7: Social stress in caregivers.

Table 8: Feeling of entrapment in caregivers.

Table 9: Stress due to Technical Uncertainty and Physical

Environment of the Caregivers

Physical stress, psychological stress and social stress were assessed using a 10-point scale. One was taken as nil, while 2 to 4 was taken as mild stress, 5–7 was taken as moderate stress and 8–10 was taken as severe stress.[7]

Table 10: Level of Stress among the Caregivers

The mean physical stress level was 6.59±1.76, mean psychological stress was 5.83±1.70 and the mean social stress level was 5.66±1.73.

Nil and mild stress were considered as normal, while moderate and severe stress were taken as being stressed and association sought between unmet needs and stress.

Table 11: Association between unmet needs and type of stress.

Disease Profile of the Patient	No. (%)
Disease	
Stroke	41 (39)
Old age with comorbidities (Contractures, dementia, diabetes, hypertension, etc.)	32 (31)
Cancer	11 (10.5)
Fractures	9 (8.5)
Parkinsonism	4 (4)
Cerebral Palsy	4 (4)
Multiple sclerosis	1 (1)
Transverse myelitis	1 (1)
Diabetes with above knee amputation	1 (1)
Duration of being Bedridden	
<1 year	43 (41)
1 – 5 years	40 (38)
5 – 10 years	13 (13)
>10 years	8 (8)

Table 1: Disease Profile of the Patients being Looked After by the Caregivers

Profile of the Caregivers	Number (%)
Age (In years)	
21 – 30	12 (11.5)
31 – 40	13 (12.5)
41 – 50	26 (25)
51 – 60	26 (25)
>60	27 (26)
Relationship with the Patient	
Daughter	33 (32)
Wife	31 (30)
Daughter-in-law	21 (20)
Mother	5 (5)
Husband	4 (4)
Grand daughter	4 (4)
Sister	3 (3)
Mother-in-law	2 (2)
Sister-in-law	1 (1)
Marital Status	
Married	89 (85)
Unmarried	5 (5)
Widowed	9 (9)
Separated	1 (1)
Religion	
Hindu	75 (72)
Muslim	19 (18)
Christian	10 (10)

Table 2: Profile of the Caregivers

Socio-Economic Status	No. (%)
Education	
Illiterate	7 (6.7)
Primary	21 (20.1)
Secondary	35 (33.7)
High school	27 (26)
Plus 2	12 (11.5)
Semi-professional	2 (2)
Occupation	
Nil	84 (80.7)
Unskilled	14 (13.3)
Skilled	2 (2)
Clerical	2 (2)
Semi-professional	2 (2)
Monthly Family Income (In Rs.)	
≤ 5000	21 (20)
5001 – 10000	25 (24)
10001 – 20000	37 (36)
20001 – 40000	19 (18)
>40000	2 (2)
Social Scheme Pension Availed by CG or Patient	
Old age	32 (31)
Widowed	4 (4)
Caregiver	5 (5)
Farmer's	7 (7)
Disability	1 (1)

Table 3: Socioeconomic Status of the Study Population

Unmet Needs	Yes Number (%)	No Number (%)
Lack of recreation	68 (65)	36 (35)
Lack of sleep	65 (62)	39 (38)
Totally responsible for the patient	69 (66)	35 (34)
Lack of respite care	89 (86)	15 (14)
Technically untrained	99 (95)	5 (05)
Ill themselves	55 (53)	49 (47)
Have no time/inclination to see a doctor	36 (35)	68 (65)
No source of income for themselves	29 (28)	75 (72)
Income insufficient for themselves	66 (64)	38 (37)

Table 4: Unmet Need of the Caregivers

Physical Stress	Nil No. (%)	Rarely No. (%)	Sometimes No. (%)	Frequently No. (%)	Always No. (%)
Feel tired	11 (11)	18 (17)			
Single person Responsible	13 (12)	32 (31)	25 (24)	46 (44)	4 (4)
Deterioration of health	21 (20)	28 (27)	24 (23)	26 (25)	9 (9)
Find no time to relax	6 (6)	22 (20)	23 (23)	20 (19)	12 (11)
			32 (31)	5 (5)	39 (38)

Table 5: Physical Stress in Caregivers

Emotional and Psychological Stress	Nil No. (%)	Rarely No. (%)	Sometimes No. (%)	Frequently No. (%)	Always No. (%)
Have a constant feeling that you are not taking enough care of the patient	25 (24)	34 (32)	35 (34)	9 (9)	1 (1)
Feel mentally tired	12 (11)	18 (17)	12 (11)	54 (53)	8 (7)
Worry about relative's death	8 (8)	21 (20)	20 (19)	43 (41)	12 (12)

Table 6: Emotional and Psychological Stress in Caregivers

Social Stress	Nil No. (%)	Rarely No. (%)	Sometimes No. (%)	Frequently No. (%)	Always No. (%)
Feeling of isolation	29 (29)	34 (32)	18 (17)	17 (16)	6 (6)
Feel that social life has been affected	13 (12.5)	37 (36)	13 (12.5)	29 (28)	12 (11)
Feel embarrassed in front of visitors	40 (38)	16 (15.5)	29 (28)	16 (15.5)	3 (3)
Find time for social activities	13 (12.5)	11 (11)	29 (27.5)	40 (38)	11 (11)

Table 7: Social Stress in Caregivers

Entrapment	Nil No. (%)	Rarely No. (%)	Sometimes No. (%)	Frequently No. (%)	Always No. (%)
Feel that you can no longer take care of the relative	24 (23)	38 (36.5)	29 (27.5)	12 (12)	1(1)
Feel that the patient is unnecessarily dependent on you	62 (59)	20 (19)	9 (9)	10 (10)	3 (3)
Feel like running away from the whole situation	59 (57)	9 (9)	16 (15)	18 (17)	2 (2)

Table 8: Feeling of Entrapment in Caregivers

Technical Uncertainty	Nil No. (%)	Rarely No. (%)	Sometimes No. (%)	Frequently No. (%)	Always No. (%)
Uncertain about technical skills	48 (46)	9(9)	16(15)	27(26)	4(4)
Patient affected relationship with other family members	63(61)	9(9)	18(17)	13(12)	1(1)

Table 9: Stress Due to Technical Uncertainty and Physical Environment of the Caregivers

Stress Level	Nil-to-Mild No. (%)	Moderate No. (%)	Severe No. (%)
Physical stress	14 (13%)	59 (57%)	31 (30%)
Psychological and emotional stress	18 (17%)	77 (74%)	09 (9%)
Social stress	30 (29%)	58 (55%)	16 (15%)

Table 10: Level of Stress among the Caregivers

Unmet Needs	Physical Stress Yes no	p value	Psychological Stress Yes no	p value	Social Stress Yes no	p value
Lack of Recreation						
Yes	65 3	0.001*	55 13	0.035*	57 11	0.001!
No	25 11		31 5		17 19	
Lack of Sleep						
Yes	61 4	0.006 *	56 9	0.174	47 18	0.452
No	29 10		30 9		27 12	
Total Responsibility						
Yes	66 3	0.001*	54 15	0.072	56 13	0.002!
No	24 11		32 3		18 17	
Lack of Respite Care						
Yes	80 9	0.029 *	73 16	0.496	62 27	0.315
No	10 5		13 2		12 3	
Technically Untrained						
Yes	87 12	0.075	82 17	0.379	71 28	0.449
No	3 2		4 1		3 2	
Illness						
Yes	40 9	0.137	43 6	0.152	35 14	0.564
No	50 5		43 12		39 16	
Insufficient Income						
Yes	65 1	0.001*	54 12	0.490	55 11	0.001!
No	25 13		32 6		19 19	

Table 11: Association between Unmet Needs and Type of Stress

* Fisher Exact test

! Pearson Chi Square test

DISCUSSION

Out of the 110 totally bedridden home-based care patients, 104 caregivers participated. All of them were family members of the patient. India lacks a formal social support scheme and therefore patients have to depend on intergenerational support and services from relatives. Besides this informal care is also related to factors such as filial piety, traditional sociocultural norms and wealth transfer.

Out of the 104 caregivers, 100 were women. Women dominate over men as caregivers because it is defined in the traditional division of labour between sexes. The reasons mentioned by them were because they were expected to do this traditionally due to love and affection and also because they had no other option. Home based care usually means care by women, because it is assumed that women should look after the family and because men get higher wages should work for the family.[8,9] The few studies done on caregiver burden in India also show that mostly caregivers are women.[8,9]

The mean age of the caregivers was 51.07 years. There are studies which show mean age of caregivers to be between 45 to 60 years.[1,8,9]

The common relation of the caregiver to the patient was a daughter followed by a wife. Two were second wives married to look after the patient in his old age and in the event of an illness. Daughters-in-law constitute 20% of the caregivers, again keeping up with the traditional norms of India. In a study done on caregivers in North India, spouses- and daughters-in-law were the main caregivers.[1,4,10]

There were 7 caregivers who did not go to school, 21 of them studied up to primary level, 35 up to secondary and 27 up to high school level.

Twenty caregivers were employed. Out of the 20, 14 were unskilled labourers and 2 each were skilled, clerks and semi-professionals. Another six were utilising retirement pension of the patient's or their own. Forty nine pairs of the caregivers and patients were drawing a social scheme pension for either one, which was being utilised by the caregiver for both self and patient needs. Thus out of the 104 caregivers, 75 had an income of their own either as social or job pension or as wages and this ranged between Rs. 1500 and Rs. 15000.

Most of the working caregivers were not able to work to their fullest capacity to earn a livelihood. The unskilled labourers did not work on all days of the week or worked lesser number of hours per day.[11,10,12] Those few (Clerks and semi-professionals) who could not compromise on the hours or days of work had someone else to look after the patient while they were gone.[10] In these cases, the burden actually was higher since they were multitasking by looking after the patient at night.[10,12,13] Though caregivers, by taking care of the bedridden patients at home are saving the nation's economy, they themselves are financially devastated.[2,12,14]

Monthly family income ranged from Rs 1500 to 40000. There were 2 families with income more than Rs 40000. The families with a higher income range had more than 1 person generating income (2 earning members in 8 families and 3 earning members in one family) or had a relative working abroad. One very poor family was supported by a mosque and another poor family was supported by a relative not living in the same house. Ninety eight percent of the 104 families belonged to the lower socioeconomic strata.

Informal caregiving creates several unmet needs among the caregivers, especially women and brings with it several unintended and undesirable outcomes, stress and ill health being the most important of them all.[11] Stress is both a cause and effect of a disease. The stress caused by the disease and the poor quality of life in the patient is perceived to be more by the caregivers than the patient himself. Taking care of a chronically ill patient demands a lot of patience, compassion, commitment and kindness. Bedridden patients, due to helplessness tend to lose their patience and take out their

frustrations on their primary caregivers. The physical act of looking after patients, mental worries regarding their prognosis, the social isolation faced, expectations and criticisms of other family members, other responsibilities in the family, technical and financial insufficiencies are all factors that cause stress in the caregivers and eventually lead to disease amongst them.[14]

This study made an attempt to study the unmet needs of the care giver. If the variable asked seemed to be a problem, they were asked to answer in the affirmative. Thus 65% did not have time for recreation, 62% did not get enough sleep, 66% were totally responsible for the patient and 64% said that they did not have sufficient money for themselves, 86% did not have a scope for respite care and 95% were not technically trained initially.

In various aspects of physical stress, emotional and psychological stress, social stress, entrapment, technical skill and physical environment, answers no, rarely, sometimes, frequently and always were obtained while total physical, psychological and social stress were obtained on a 10-point scale, 1 being nil, 2-4 mild, 5-7 moderate and 8–10 severe.[7]

Lack of recreation, lack of sleep being totally responsible, being ill and insufficient income were factors associated with moderate-to-severe physical stress, while lack of recreation being totally responsible and insufficient income were factors associated with moderate-to-severe social stress. Lack of recreation was associated with psychological stress.[4]

Although, more than half of the caregivers said they frequently or always worried about their relative's death or they were mentally tired; this stress was seen among all caregivers irrespective of the unmet needs.

Keeping up with the expected socio-cultural norms of India, very few caregivers felt they were trapped to do the work of care giving. Majority had a sense of inborn responsibility and had a positive attitude towards caregiving.[12] For the same reason, they also did not blame the patient for strained relationship with other relatives. The very few who agreed were the younger women who had young children to look after.[9,10,11]

The palliative team has been visiting these patients since 5 years and training for minor techniques is given to the caregivers. Lack of initial technical training (Among 99%) is not associated with stress since communication exists between caregivers and the team which includes a doctor.

Informal care is the dominant mode of helping people with disabilities with their long-term care needs. Services to be aimed primarily at informal caregivers may be designed to increase the level of knowledge and emotional support of caregivers, provide relief from the unending burden of caring for a disabled person or provide financial benefits to those who take on this responsibility.[13,14]

REFERENCES

1. Brodsky J, Habib J, Miriam J. Key policy issues in long-term care. World health organization collection on long term care. Hirschfel (Ed). Publishers: WHO 2003. Available from http://apps.who.int/iris/handle/10665/42604.
2. Goodhead A, McDonald J. Informal caregivers literature review. Report prepared for the national health committee, health services research centre. Victoria University of Wellington 2007. Available from: http://www.docfoc.com/informal-caregivers-literature-review.
3. Gray L. Caregiver depression: a growing mental health concern. Policy brief. Family caregiver alliance, national centre on caregiving 2003. Available from: https://caregiver.org/sites/caregiver.org/files/pdfs/op_2003_caregiver_depression.pdf.
4. Reinhard SC, Given B, Petlick NH, et al. Supporting family caregivers in providing care: patient safety and quality. In Hughes RG (ed). An evidence-based handbook for nurses. Rockville: agency for health care research and quality (US) chapter 14, 2008.
5. Schulz R, Sherwood PR. Physical and mental health effects of family caregiving. The American Journal of Nursing 2008;108(9):23-7.
6. Selected caregivers assessment measures: a resources inventory for practitioners 2nd ed. Family caregiver alliance 2012 Available from: https://www.caregiver.org/sites/caregiver.org/files/pdfs/SelCGAssmtMeas_ResInv_FINAL_12.10.12.pdf.
7. Kulkarni P, Kulkarni P, Ghooi R, et al. Stress among care givers: the impact of nursing a relative with cancer. Indian journal of palliative care 2014;20(1):31-9.
8. Women and caregiving: facts and figures, family caregiver alliance: national center on caregiving. Available from: https://caregiver.org/women-and-caregiving-facts-and-figures.
9. Caring for/ caring about: women, home care and unpaid caregiving. Health care in Canada series, In Karen R (ed). York University, garamond press aurora, Ontario 2004.
10. Bains P, Minhas AS. Profile of home-based caregivers of bedridden patients in north India. Indian Journal of Community Med 2011;36(2):114-9.
11. Neal MB, Wagner DL, Program development issue brief. Working caregivers: issues, challenges, and opportunities for the aging network: administration on aging, U.S. Department of health and human services 2002. Available from: https://www.towson.edu/chp/departments/interprofessional/documents/working-caregivers.pdf.
12. Caregiver burden of terminally ill adults in the home setting. Best practice: evidence based information sheets for health professionals. Published as Joanna Briggs Institute 2011;15(6):1-4. Available from: http://connect.jbiconnectplus.org/viewsourcefile.aspx?0=7117.
13. Brazil K, Bainbridge D, Rodriguez C. The stress process in palliative cancer care: a qualitative study on informal caregiving and its implication on the delivery of care. Am J Hosp Palliat Care 2010;27(2):111-6.
14. Averting the caregiving crisis: why we must act now, an update: rosalynn carter institute for caregiving 2012. Available from: http://www.rosalynncarter.org/UserFiles/File/PositionPaperUpdate3-19-12.pdf.