IMPACT OF PHYSICAL THERAPY ON BURDEN OF CAREGIVERS OF INDIVIDUALS WITH FUNCTIONAL DISABILITY

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ABSTRACT

Advances in medical science have resulted in a concomitant increase in the life span of persons with disabilities. The prevalence of chronic disease, an aging population and the ongoing shift of the site of care from institutions to the community, have resulted in a significant increase in the informal care provided by family members and friends of those living with chronic illnesses. This in turn increases the burden on the family, by way of physical and psychological stressors.

The objectives of this study were to identify the burden perceived by caregivers of individuals with functional disability, and to evaluate the effects of a tailored physical therapy intervention, or caregiver education, on the caregivers' burden. Ninety seven persons were deliberately assigned, based on their accessibility, to the control group, caregiver education group and intervention group.

Although there was no statistically significant difference between the groups, among caregivers of persons affected by moderate to severe disability, there were trends showing greater reduction in caregiver stress and burden in the intervention group.

These trends and comments from individual participants point to an improvement in caregiver burden with physiotherapy intervention. Hence, it can be suggested that physiotherapy management of persons with disabilities must also include caregiver health.

Key words: Physical therapy, burden of caregivers, functional disability, India

INTRODUCTION

Advances in medical science have resulted in a concomitant increase in the life span of persons with disabilities. In the area of the present study, the conditions that most often give rise to long-term disability are cerebrovascular accident (CVA), cerebral palsy (CP), spinal cord injury (SCI), traumatic brain injury (TBI), dementia, Parkinson's disease, rheumatoid arthritis and chronic obstructive

pulmonary disease. The prevalence of chronic disease, an aging population and the ongoing shift of the site of care from institutions to the community, have resulted in a significant increase in the informal care provided by family members and friends of those living with chronic illnesses. In the rural Indian cultural context, the majority of persons with disabilities tend to live at home with their families, rather than in institutions. This increases the burden on the family, by way of physical and psychological stressors. Once the affected person is discharged from hospital, the family is left to cope on its own. These factors are evident from affected person/ family reports. Added to this are economic factors that preclude availability of caregivers / aids to assist in activities. The cumulative effects of all this can be devastating for the whole family.

Caregivers are people who take care of the affected individuals, and are most often parents or spouses, who may be ill or persons with disabilities themselves. The people who receive care usually need help with basic daily tasks. There are three types of caregivers. "Formal caregivers" are volunteers or paid employees connected to the social service or health care systems (1, 2). "Informal caregivers" are family members and friends, who are the primary source of care for nearly three-quarters of the affected individuals who live in the community (1,2).The third type, the "family caregiver'', refers to care provided by close relatives. Caregivers assist or provide most of the care for people who need help in activities of daily living, such as bathing, dressing, preparing meals, transfers, ambulation and shopping (3). Some of them have the added responsibilities of administering medication, making sure that an immobile person is turned frequently to avoid developing pressure sores, and other tasks related to the older person's illness or disability, in addition to managing household finances (1,3).

There is evidence to show that most caregivers are ill-prepared for their role, and provide care with little or no support (3,4,5), yet more than 1/3rd of the caregivers continue to provide intense care to others while suffering from poor health themselves (3,6).

A substantial body of research shows that family members who provide care to the individuals with chronic or disabling conditions, are themselves at risk. Emotional, mental and physical health problems arise from complex care-giving situations, and the strains of caring for relatives who are frail or with disabilities (3).

Research has also revealed that care giving affects the workplace because family caregivers either make changes at work, modify their schedules, alter their work-

related travel or give up their jobs (3). This can lead to financial burden, which in turn can increase stress.

The effects of caring for persons with chronic illness/disabilities, and the accompanying burden of care that falls on caregivers, make it imperative to address caregiver needs.

The study had two objectives:

1. To identify the burden perceived by caregivers of individuals with functional disability.
2. To evaluate the effects of a tailored physical therapy intervention or caregiver education, on caregiver burden.

METHOD

The study design was interventional, based in the community setting. Ninety seven individuals with functional disability, aged 18 years or older, were included in the study, selected through a convenience sampling method.

Exclusion criteria were: where primary caregiver (>2) could not be identified; and where more than one member of the family required care giving from the same person.

Procedure

The study was approved by the college Research Committee. Individuals with functional disability were selected as per criteria, either prior to discharge from the hospital or after getting addresses from the medical records department of Kasturba Hospital, Manipal, India and various hospitals in Hubli, India. Informed consent was obtained from all persons who were included and the caregivers. The subjects were then assigned, based on their accessibility to either the control group, caregiver education group or intervention group.

The families were interviewed to decide who was/were the primary caregiver/caregivers. Demographic data of the affected persons (age, sex, type of disability, community) as well as the caregivers (age, sex, pre-existing medical condition) were obtained. FIM (7) scores were used to determine the degree of disability.

Prior to discharge from the hospital, or once identified in the community, the Caregiver Burden Scale (8) and Caregiver Strain Index (9) were administered

to the caregiver/caregivers, in an interview session. The questionnaires were translated into the local regional language, using parallel back translation.

Interventions for group b (education) and group c (intervention) were carried out for for one month. After that the questionnaires were re-administered to find out if the intervention had made any difference to the caregiver's burden. Two months later, a follow-up was done by re-administering the questionnaires, in order to see carry-over effect of the intervention, if any.

Data analysis

Statistical analysis of the data was done by using the SPSS statistical package version 11.0. Non parametric tests (repeated measures ANOVA) of comparison were used as the outcome measures for ordinal/nominal scales.

A "p" value of ≤ .05 was considered as significant. Spearmans correlation was done to determine correlation of Caregiver Burden Scale (CBS) and Caregiver Strain Index (CSI), with the degree of disability.

RESULTS

A total of ninety seven affected persons and their caregivers (participants) who met the inclusion criteria, were part of the study. Of the ninety seven subjects, sixty six completed the study. The demographic characteristics of these subjects and their caregivers (participants) are as shown in Table 1.

Table 1. Demographic characteristics of participants and affected persons (n=66)

		Intervention (n=21)	Caregiver education (n=22)	Control (n=24)
Age of affected person - mean ± SD yrs		40.57 ± 14.85	54.77 ±14.73	51.33 ±20.53
Age of caregiver - mean ± SD yrs		41.09 ± 13.64	46.13 ±13.61	46.16 ±13.78
Sex of the caregiver	Male	8	6	4
	Female	12	16	20
Sex of the affected person	Male	11	12	15
	Female	9	10	9
Type of disability (n)	CVA*	9	9	10
	SCI**	-	2	3
	Childhood disabilities	2	0	1

	Orthopaedic	4	4	4
	Amputation	1	3	1
	Old age	1	2	0
	Miscellaneous	0	3	5
Community	Rural	14	17	18
	Urban	6	5	6
FIM Median (IQR)		80 (49-85)	79 (44-84)	75 (43-80)

*Cerebrovascular accident; **Spinal cord injury

As evident from Table 1, the groups showed heterogeneous baseline characteristics. The median FIM scores were similar in all groups. Caregivers of victims of CVA made up the largest population in all groups. The majority of participants were from the rural area.

Correlation was done between the severity of disability of the affected person as measured by FIM, and the burden and stress perceived by the caregivers as reported on the scales. There was a weak negative correlation between the scales and the FIM; CBS and FIM (r=0.57) and CSI and FIM (r=0.5). There was a good correlation between CBS and CSI (r=0-8).

Analysis of the burden and stress across the time of the study, showed a statistically significant improvement (reduction) in both scales over time. This was consistent in all three groups ($p < .000$). However, there was no difference between the groups ($p = .78$).

Further analysis of sub groups based on disability was done. A FIM score of 39 was taken as the cut-off point to classify persons affected by mild disabilities (>39) and moderate to severe disabilities (<39). This classification resulted in the large majority of subjects fitting into the mild group. Scores on the Caregiver Burden Scale and Caregiver Stress Index, as distributed in the three study groups of persons affected by mild disabilities, are depicted in Tables 2a and b.

Table 2a. Change in scores on Caregiver Burden Scale (CBS) and Caregiver Strain Index (CSI) over time, among caregivers of persons with moderate/ severe disabilities

Groups	CBS1 median (IQR)	CBS 2 median (IQR)	CBS 3 median (IQR)	p	CSI 1 median (IQR)	CSI 2 median (IQR)	CSI 3 median (IQR)	p
Control (n=10)	40 (30-51)	38 (27-49)	38 (28-49)	>.000	9 (6-11)	8 (5-11)	6 (3-11)	>.000
Intervention (n=9)	45 (35-59)	35 (23-54)	30 (20-51)		8 (7-11)	5 (4-7)	5 (3-6)	
Caregiver education (n=8)	34 (25-45)	30 (18-41)	30 (18-39)		7 (4-10)	5 (2-10)	5 (2-10)	
P	.77				.54			

As can be seen from the above Table, the CBS scores at baseline were dissimilar between groups. This was not so for the CSI scores. All groups showed a decline in caregiver burden and stress over time, but no effect of intervention was seen.

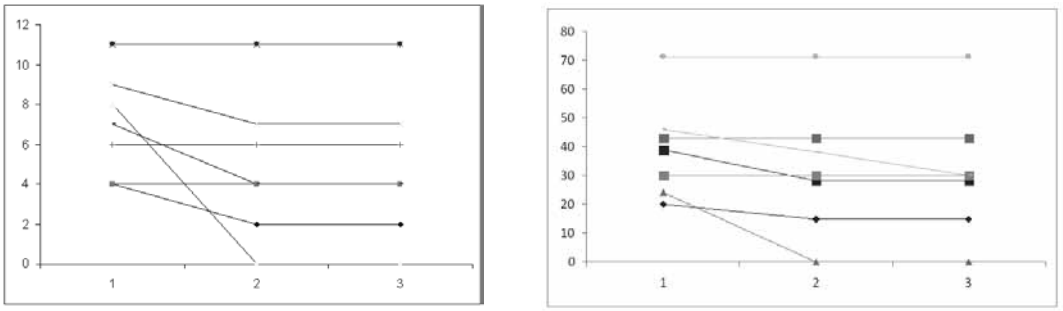
Table 2b. Change in scores on Caregiver Burden Scale (CBS) and Caregiver Strain (CSI) over time, among caregivers of persons with mild disabilities

Groups	CBS1 median (IQR)	CBS 2 median (IQR)	CBS 3 median (IQR)	p	CSI 1 median (IQR)	CSI 2 median (IQR)	CSI 3 median (IQR)	p
Control (n=14)	7 (0-17)	4 (0-14)	10 (0-14)	>.000	2 (0-5)	2 (0-4)	2 (0-4)	>.000
Intervention (n=12)	45 (39-59)	35 (23-54)	30 (20-51)		8 (7-11)	5 (4-7)	5 (3-6)	
Caregiver education (n=14)	34 (25-45)	30 (18-41)	30 (18-39)		7 (4-10)	5 (2-10)	5 (2-10)	
p	.77				.92			

The baseline scores were greatly dissimilar in this group as well, with the control group having a much lower score on the scales than the other two. As can be seen from Table 2b, there was an improvement in all three groups, but there was no significant difference noted because of the intervention.

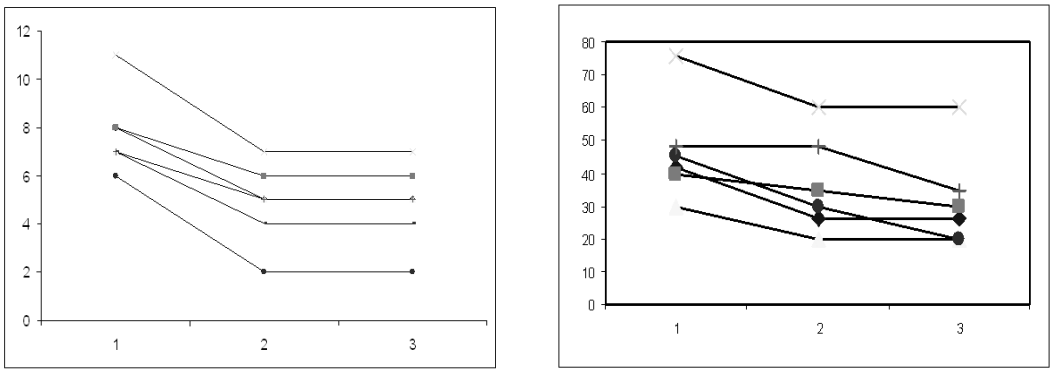
Although there was no statistically significant difference between groups among caregivers of persons affected by moderate to severe disabilities, there were trends showing greater reduction in caregiver stress and burden in the intervention group. The following figures depict individual differences.

Figure 1. CSI and CBS scores in the caregiver education group



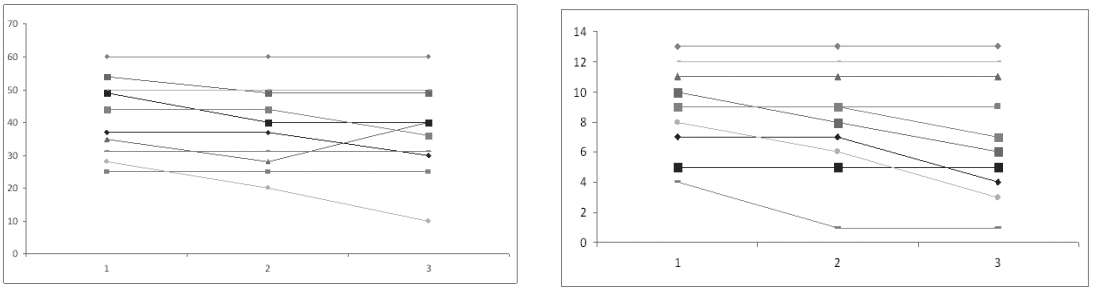
Only three out of the seven showed decrease in burden in both scores, after caregiver education was given to the participants. These participants were caregivers of persons affected by stroke, brain fever, and total knee replacement.

Figure 2. CSI and CBS scores in the intervention group



All showed a decrease in the burden scores. However, one participant showed increase in burden scores in the follow-up period. The diagnoses in this group were mixed.

Figure 3. CBS and CSI scores in the control group



Many of the samples showed no difference; only three showed considerable decrease from the first to the second score. However, more participants showed decrease in the follow-up period. In this group, the affected persons who improved had a diagnosis of CVA. An interesting observation is that one subject showed an increase in the scores on the CBS from the second to the third time, but there was no corresponding increase in the CSI scores.

DISCUSSION

Demography, affected person and caregiver characteristics

The groups were heterogeneous with respect to diagnoses, age, gender and living situation. It needs to be kept in mind that the comparison between groups would have been influenced by these characteristics. Although the purpose of the study was to achieve homogeneity regarding the extent of disability, the functional prognosis was partly dependent on the diagnosis. This, as well as individual characteristics, may have played a confounding role.

The fact that all groups improved over time, with respect to the extent of caregiver burden, may be attributed to coping strategies developed over a period of time, and recovery in functional status even if the diagnosis did not change. The fact that no demonstrable difference was found between groups, might be due to the lack of cultural context seen in the scale. This may have decreased the sensitivity of the scales, a fact which was voiced by a few of the participants. This is also evident from the incongruity observed in the one participant depicted in Figure 3. The authors had not controlled for confounders like therapy sessions, other than what was provided during the study .This may also have influenced results.

Due to the convenience sampling method used for this study, most affected persons fitted into the mild disability group. Hence the caregiver burden may

not have been a factor to begin with. Perhaps quota sampling to include equal numbers of persons with varying severity of disabilities would have helped.

Hand dominance may have played a role in influencing the results, as more than 50% of persons affected by CVA had right hemisphere affectation with left-sided hemiplegia. Due to this, the affected persons were able to perform most of their daily activities, except for mobility skills and bilateral activity. Hence the care giving requirement was minimal.

Age

It was noted in this study that most of the caregivers were much older than the affected persons. Many of them had health concerns of their own, not related to care giving. This may have acted as a confounding factor, and accounted in part for the lack of significant effect on the burden scales. Perhaps intervention aimed at the health of the caregiver, in addition to the ergonomic advice, may have contributed to a greater sense of well-being. This warrants further research.

Gender

Fifty one out of sixty six affected persons were female caregivers. Financial issues and physical differences in characteristics, add to the burden of female caregivers, as suggested in literature (2). Often the affected persons were the breadwinners of the family, and the caregivers had also been contributing to the income. With a person being affected by disability, there was a great loss in income as both affected person and caregiver became unemployed. Over a period of time, when the affected person improved and the caregiver was able to return to work, there was a concomitant decrease in burden as well. This factor was often voiced by the participants. Hence burden was not necessarily attributable to physical stress.

Other issues

Many of the participants lived in extended families and hence the burden may have been shared by several family members. This factor has not been taken into account. Some participants reported that physically demanding chores were performed by someone other than the primary caregiver. This constituted respite care which was part of the intervention. However, this factor is not reflected in the scores as the primary caregivers had never participated in these chores. Also, the groups were dissimilar in baseline CSI and CBS scores.

The influence of the caregivers' reluctance to confess to strain or burden, as these factors are considered taboo, cannot be discounted. This was demonstrated in statements made by individuals. Some people were offended when they were asked if caring for the family member was a burden.

Treatment

When looking at the moderate to severe group of disabilities, individualised programmes were tailored for affected persons, according to diagnosis and physical attributes.

Although conclusive statements cannot be made, there were clear trends that physical therapy intervention influenced caregiver burden. The magnitude of decrease in the scores was greater in this group than in the other groups. Looking at diagnoses, this was evident in subjects with SCI and CVA, where intervention was most often aimed at improving transfer and mobility skills, along with emphasis on coping strategies in persons affected by CVA. In the caregiver education group, compliance with ergonomic advice was questionable. Some of the caregivers of persons with chronic disabilities had adopted various compensatory strategies which they were reluctant to change. Adherence to advice and treatment were not assessed, and hence these cannot be commented on.

Scales

Many of the participants in the mild group did not show any difference at all. This may also have been due to the characteristics of the scale. Some of the questions on the scale are ambiguous when considered from an Indian perspective. Though some questions were explained in the local language, the information understood may have been dissimilar to that of the base questionnaire. Though both scores tested different domains, they had correlation when compared. This may be due to more emphasis on the mental strain rather than the physical stress. An assumption of this study was that physical stress played a strong role in caregiver burden. However, it can be argued that mental stress has many other components, none of which were addressed in this study.

Mode of interview

The questionnaires were administered to the participants, either face to face or via telephonic interview. This may have influenced the results. As reported in literature (10,11), response rates were higher, more credible and genuine in

face-to-face interview compared to telephonic interviews. Another factor is that when interviews were conducted over the telephone, it was difficult to determine whether the person being interviewed was indeed the primary caregiver.

One of the other factors that needs mention is a deviation in the FIM scoring. There were a number of affected persons who had no alternate device for toilet activities. In this case, the ambulation required for the short distance to the bathroom was considered as part of the toilet transfer, when the patient did not otherwise engage in walking.

Limitations of the study

1. The groups were assigned maintaining the homogeneity of disability groups, and not diagnosis.
2. There was lack of context in some aspects of the scales pertaining to the Indian population.
3. The telephonic interview method may have affected the responses.

CONCLUSION

The comments from individual participants and trends pointing to improvement in caregiver burden with physiotherapy intervention, are encouraging. Hence, it can be suggested that physiotherapy management of individuals with disabilities must also include caregiver health.

Since this pilot study demonstrated clear trends of decrease in caregiver burden with Physical Therapy intervention, further studies with more stringent design and procedure are warranted.

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REFERENCES

1. Cifu DX, Carne W, Brown R, Pegg P, et al.. ***Caregiver distress in Parkinsonism.*** Journal of Rehabilitation Research and Development, 2006; .43(4):499-507. In ProQuest Medical Library [cited 23 March 2003], available http://www.proquest.com/:Document ID:1144946271
2. National Family Caregivers Association and Family Caregiver Alliance. ***Prevalence, Hours and Economic Value of Family Caregiving,*** 2006: Updated State-by-State Analysis of 2004. [cited 2009 Mar 23]. Available from: www.caregiver.org/caregiver/.../State_Caregiving_Data_Arno_20061107.pdf.
3. Family Caregiver Alliance, National Alliance for Caregiving. 2009 Mar 16 [cited 2009 Mar 16] Available from: http://www.caregive.org/caregiver/jsp/conent_node.jsp?nodeid=1822.
4. Alzheimer's Association and National Alliance for Caregiving. ***Families Care: Alzheimer's Caregiving in the U.S.*** Chicago, IL:, 2004. Alzheimer's Association and Bethesda, MD: National Alliance for Caregiving [cited 2009 Mar 16] Available from: http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=1822.
5. Maryam NW, Feldman PH., Gould DA., Levine C, Kuerbis AN, Dolenan K. ***When the caregiver needs care: The plight of vulnerable caregivers.*** American Journal of Public Health 2002; 92(3): 409-413. PMid:11867321 PMCid:1447090
6. Women's Health in the Department of Health and Human Services (2006).[Cited 2009 Mar 16] Available from: www.cdc.gov/nchs/data/hus/hus06.pdf.
7. Wright J.. ***The FIM*** (TM). The Centre for Outcome Measurement in Brain Injury. 2000. [cited 2009 April 16] Available from: http://www.tbims.org/combi/FIM.
8. Montogomery RJD, Gonyea JG, Hooyman NR. ***Caregiving and the Experience of Subjective and Objective Burden.*** Family Relations 1985;34:19-26.
9. Robinson B. ***Validation of a Caregiver Strain Index.*** Journal of Gerontology. 1983. 38:344-348.
10. Jackle, A Roberts C, Lynn P. ***Telephone versus Face-to-Face Interviewing: Mode Effects Data Quality and Likely Causes. Report on Phase II of ESS-sallup Mixed Mode Methodology Project,*** ISER Working Paper 2006-41. Colchester: University of Essex, 2006. [cited 2009 Mar 16] Available from: www.iser.essex.ac.uk/publications/woking-papers/iser/2006-41.pdf
11. De Leeuw E, van der Zouwen J. ***Data Quality in Telephone and Face-to-Face Surveys: A Comparative Meta-Analysis,*** in Groves, R. Biemer P, Lyberg L, Massey J, Nicholls II, W, and Weisberg J. (eds), Telephone Survey Methodology, pp.283-299, New York: Wiley, 1988.