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## Caregiver burden in family members of patients undergoing Rehabilitation

Mirza Obaid Baig<sup>1</sup>, Muhammad Masood Khokhar<sup>2</sup>, Anam Pervez Qureshi<sup>1</sup>, Maham Malik<sup>1</sup>, Zarlish Ayan<sup>1</sup> and Marrium Batool<sup>1</sup>

<sup>1</sup>Faculty of Rehabilitation & Allied Health Sciences, Riphah International University, Islamabad, **Pakistan**

<sup>2</sup>Islamic International Medical College, Riphah International University, Islamabad, **Pakistan**

\*Correspondence: [obaaid.baig@riphah.edu.pk](mailto:obaaid.baig@riphah.edu.pk) Received 05-10-2021, Revised: 14-12-2021, Accepted: 17-12-2021 e-Published: 20-12-2021

The study aimed to assess the extent or prevalence of anxiety and depression in caregivers of long-term, physically disabled patients. Cross Sectional. A questionnaire comprised of the Caregiver Burden Scale and the Hamilton Anxiety and Depression Scale were distributed among caregivers at the Riphah Rehabilitation and Research Center. A total of 200 participants participated in the current study. There were 106 males and 94 female caregivers. There were 27 (23.5%) caregivers were categorized in 'moderate to severe' or 'severe' burden. A total of 97 (48.5%) participants had abnormal levels of anxiety as well as depression. The correlation was found to be strong and positive between caregiver burden and anxiety (Correlation coefficient = 0.682). The correlation between caregiver burden and depression (correlation coefficient – 0.542) was moderately positively correlated. Caregiver's burden is positively associated with not only anxiety but also depression.

**Keywords:** Anxiety, Caregiver burden, Depression

### INTRODUCTION

The World Health Survey found that an estimated 650 million people around the world suffer from some form of disability. Rehabilitation is defined by the World Health Organization as a set of measures that assist individuals who experience, or are likely to experience, disability to achieve and maintain optimal functioning in interaction with their environments (WHO, 2011). Rehabilitation services help patients cope with physical disabilities and assist them in learning to perform activities of daily life independently. Life-threatening ailments are commonly associated with diminished physical activity. Patients with stroke, chronic lower back pain, cerebral palsy, cancer and many other musculoskeletal and neurological disorders require physical therapy services. Critically ill patients who are on bed rest are strongly associated with muscle

weakness. Similarly patients who are bed bound are found to be at a considerably higher risk of developing physical impairments which may be avoided if the patient is mobilized early. Ageing and the rapid spread of chronic diseases increase the complications of disability among populations. Exercise and physiotherapy has shown to make a considerable improvement in overall wellbeing generally and the quality of life of patients. It also has a positive effect on fatigability, general patient condition, mood of the patient and coping with chronic illness(s) (Salakari et al. 2015). Subsequently, early detection, prevention and avoidance of potential serious risks factors can significantly improve patients' health outcomes (Hashem et al. 2016).

Rehabilitation services are given by physiotherapists who focus on patient management techniques and self-management

strategies. Self-management programs are defined as a comprehensive systematic provision of patient education and interventions by a healthcare provider to increase the patient's skills and his/her confidence in managing their own health (Dufour et al. 2015). Physical therapists help patients to attain skills and self-assurance to manage their ailment and provide self-management tools (Bodenheimer et al. 2002). These services improve the quality of life and physical performance of the client/patient (Salakari et al. 2015).

Nonetheless, patients with stroke and musculoskeletal disorders are bound to face chronic disability and have functional limitations which requires lifelong assistance from caregivers in order to achieve maximum efficiency. These caregivers are usually the family members or relatives of the patient and provide physical and emotional support to these patients (Pagani et al. 2014). Elderly patients and patients having neurological conditions are generally physically and cognitively impaired and therefore, require assistance in performing daily living activities and care for a longer term from family members, guardians or professionals' caregivers (Bastawrous 2013). Caregivers also assist patients take part in social activities and contribute to improving their overall well-being. Caregivers act as facilitators because they provide informal care and continuous effort to reduce the disability and improve the patient's functioning (Leonardi et al. 2012, Hollander et al. 2009, Wade et al. 1986). They may also assist patients in physiotherapy, but emotional, psychological and physical capacity of every relative does not allow them to participate. Healthcare staff and members of the team must assess this properly and caregivers should be guided a structured plan and proper training before participation (van Delft et al. 2020).

Caregivers often take on this responsibility suddenly and in extreme circumstances, with very less preparation and minimal guidance and support from healthcare systems and are therefore susceptible to compromising their general health and their own quality of life during this process (Hashem et al. 2016). The health of primary caregivers should be of primary focus because they can only provide effective caregiving if they themselves are in optimal health. Perception of being burdened in caregivers is commonly associated with decline in their own health. Research indicates that caregivers are at risk for body fatigue and their sleep pattern is disturbed with low immune

function, increase in insulin levels, high blood pressure, altered lipid profiles and ultimately a very high risk for cardiovascular diseases (Reinhard et al. 2008).

The most common undesirable outcomes are the burden taken up by the caregiver and depressive symptoms of providing care for the elderly and chronically ill patients. 'Family burden' is the commonly used term which describes problems experienced by patient's relatives as a result of their role as a caregiver. Family burden can be differentiated into subjective and objective dimensions. Symptoms of anxiety, depression and loss of hope which can experience by caregivers are categorized as subjective burden. In addition, objective burden includes problems related to disturbance in family affairs and limitations in social activities (Magliano et al. 2005).

Common features of long term stress experience creates an unusually great amount of psychological and physical stress over long periods of time which can accompany higher levels of uncontrollability and unpredictability, simultaneously it has the ability to develop secondary stress in various life domains such as relationships, work and family. The most concerning being the financial difficulties, loss of employment, compromising leisure activities and other lifestyle interferences (Schulz et al. 2008). Limited resources have negative impact on caregivers because it not only leads to an overall lesser health-related quality of life but it also compromises the value of care they provide to their relatives (van Beusekom et al. 2016, Ain et al. 2014).

Caregivers looking after their relatives for a long-term disease have a responsibility to fulfil and for this, they also have to make many sacrifices and alterations in their own lifestyles. While many caregivers adapt to these lifestyle changes, others experience depression and anxiety symptoms (Kruithof et al. 2016). The unwanted effects on caregivers of caregiving for a longer period of time are very diverse and complicated, which can be intensified in return exacerbating. The effects of long-term caregiving on caregivers are diverse and complex, and there are many factors that may aggravate or upgrade how caregivers react and feel as a result of their respective roles (Logiudice et al. 1999). A similar study showed by Van Beusekom in 2016 I et al informed that there is an increased pervasiveness of symptoms of apprehension and depression in informal caregivers. Whereas a study by Ain QU et al in 2014 reported that increased length of

care giving is associated with decreased level of sleep, physical stress and other strains on time probably as caregiving becomes more routine and their knowledge and capability grows over period of time. Correspondingly, a study by Van Wijnen HG et al in 2017 on the effect of cardiac arrest on long term comfort and caregiver load of family caregivers reported that the overall welfare of the carer during the first year improves up to regular levels. However, carers with perceived cognitive and emotional problems at 12 months are at danger for evolving a higher caregiver burden.<sup>19</sup> Moreover, the stigma for caring for patients with stigmatized illnesses such as Alzheimer's disease increases the burden on the caregiver. In cases of psychosocial interferences and in order to reduce carer burden one should target stigmatic beliefs (Werner et al. 2012).

There is a need to increase awareness regarding the importance of the health of caregivers, so that they may provide better care for individuals with chronic disabilities. There is a paucity of literature assessing the level of anxiety, stress and depression in caregivers caring for patients with stroke and musculoskeletal issues undergoing physiotherapy treatment. There is no study on the prevalence of caregiver burden, anxiety and depression in family members of rehabilitation patients undergoing treatment in a tertiary care hospital in Pakistan. Therefore, the aim of this study was to find levels of caregiver burden, anxiety and depression in family members of rehabilitation patients undergoing treatment in a tertiary care hospital in Pakistan. A secondary aim of this study was to assess the association of caregiver burden with anxiety and depression.

## MATERIALS AND METHODS

This observational, cross-sectional survey was conducted at Riphah Rehabilitation and Research Centre (RRRC), Pakistan Railway General Hospital Rawalpindi. The study extended over a period of 6 months from September 2019 to February 2020. The said study was started after the approval by the Riphah Institutional Review Committee.

Sampling was done using non-probability convenience sampling. A total of 200 male and female caregivers were included, who had been involved in caring for patients treated at Railway General Hospital. Those caregivers who were allotted multiple patients or those who were suffering from any diagnosed musculoskeletal, systemic, neurological, mental health issues or

orthopedic disease/condition were excluded from the study. Verbal and written informed consents were taken from all of the participants.

A questionnaire was used for data collection purposes. The questionnaire had three sections. Section A assessed the burden of care using Caregivers burden scale. Section B assessed the depression status of the participants using the Hospital anxiety and depression scale (HADS). Section C contained demographic details of the participants. Printed questionnaires were distributed among the selected participants. Completed questionnaires were collected back from all participants.

Care givers burden and hospital anxiety and depression (HADS) scale was administered to all the participants. Sample size was calculated using Rao Software. The Caregiver burden scale is a twenty two (22) item instrument which asks the participants to rate their feelings on a scale known as the (five-point) likert scale ranging from -never- to -nearly always-. The overall scale score arrays from zero to 88. Scores are further divided into categories, these are four in number: 1. little or no burden 0-20, 2. mild to moderate burden 21- 40, 3. moderate to severe burden 41-60 and . 4severe burden 61-88. The HADS question scale has up to seven items each for anxiety and depression. Scoring for every item is done on a three-point scale, with three representing the highest anxiety or depression level. The total anxiety and/or depression scores range from 0 – 21. The anxiety and/or depression scores are further divided into three categories: normal (0 – 7); borderline abnormal (8-14) and abnormal (15-21).

Data was analyzed using SPSS 21.0. Frequencies and percentages were described for categorical variables, such as age group, gender, employment and educational status, monthly income bands, family system, disease history, travelling distance from hospital, relation to the patient and care burden categories. Standard deviation and mean were described for variables which are quantitative, such as total HADS Anxiety score, total HADS depression score and the Care burden score. Pearson's correlation coefficient was calculated to assess the associations between the Caregiver burden score and HADS anxiety score; and between the Caregiver burden score and the HADS depression score. In order to compare the frequency distribution of the difference Caregiver burden categories between each of the HADS anxiety levels, chi-squared test was applied. Chi-squared test was also applied to do comparison and find

any difference in the distribution of frequency in the Caregiver burden categories among the HADS depression levels. An arbitrary p value of less than 0.05 was considered to be significant.

## RESULTS

A total of 200 caregivers were recruited for this study. Out of these there were 106 (53.0%) males and 94 (47.0%) females. Demographic data has been described in table 1. The frequency of participants in the different caregiver burden, anxiety and depression categories has been illustrated in table 2.

A strong positive Pearson's correlation coefficient was found between anxiety and carer

burden (Pearson's correlation coefficient = 0.682,  $p < 0.001$ ). A moderately positive Pearson's association coefficient was found between depression and care giver burden (Pearson's correlation coefficient = 0.542,  $p < 0.001$ ).

The frequency distribution of caregiver burden status for each anxiety category has been illustrated in table 3. A greater number of caregivers with 'moderate to severe' ( $n = 17$ , 17.5%) and 'severe' burden ( $n = 10$ , 10.3%) had 'abnormal' levels of anxiety, as compared with those with 'little or no' and 'mild to moderate' burden (Chi squared statistic = 87.93,  $p < 0.001$ ).

**Table 1: Demographic Characteristics of Participants**

	Variable	Frequency (%)
<b>Gender</b>	Male	106 (53.0%)
	Female	94 (47.0%)
<b>Age</b>	Less than 20 Years	17 (8.5%)
	21- 40 Years	130 (65.0%)
	Over 40 Years	53 (26.5%)
<b>Education</b>	No formal school education	59 (29.5%)
	SSC/HSSC	120 (60.0%)
	Graduate/Post-graduate	21 (10.5%)
<b>Employment Status</b>	Employed	44 (22.0%)
	Unemployed	156 (78.0%)
<b>Monthly Income</b>	Up to Rs 10000	81 (40.5%)
	Between Rs 11000 – 20000	119 (59.5%)
<b>Family System</b>	Nuclear	38 (19.0%)
	Joint	151 (75.5%)
	Extended	11 (5.5%)
<b>Disease History</b>	Stroke	18 (9.0%)
	Cerebral Palsy	22 (11.0%)
	Knee Osteoarthritis	85 (42.5%)
	Chronic Lower Back Pain	75 (37.5%)
<b>Distance from Hospital</b>	5 km	137 (68.5%)
	6-10 km	48 (24.0%)
	10-20 km	5 (2.5%)
	More than 20 km	10 (5.0%)
<b>Relation with Patient</b>	Siblings	92 (46.0%)
	Parents	40 (40.0%)
	Spouse	5 (2.5%)
	Children	63 (31.5%)

**Table 2: Frequency Distribution of Caregiver Burden, HADS Anxiety and Depression Categories**

	Variable	Frequency (%)
<b>Caregiver Burden</b>	Little or No Burden	63 (31.5%)
	Mild to Moderate Burden	110 (55.0%)
	Moderate to Severe Burden	17 (18.5%)
	Severe Burden	10 (5.0%)
<b>Anxiety</b>	Normal	19 (9.5%)
	Borderline Abnormal	84 (42.0%)
	Abnormal	97 (48.5%)
<b>Depression</b>	Normal	27 (13.5%)
	Borderline Abnormal	74 (37.0%)
	Abnormal	97 (48.5%)

**Table 3: Frequency Distribution of Caregiver Burden for Anxiety Categories (\*Fisher's exact test was applied to calculate the p value, since 4 cells had expected count less than 5)**

		Anxiety Categories			Chi-squared Statistic	P Value*
		Normal	Borderline Abnormal	Abnormal		
<b>Caregiver Burden Categories</b>	Little or no burden	0 (0%)	53 (63.1%)	10 (10.3%)	87.93	< 0.001
	Mild to moderate burden	19 (100%)	31 (36.9%)	60 (61.9%)		
	Moderate to severe burden	0 (0%)	0 (0%)	17 (17.5%)		
	Severe burden	0 (0%)	0 (0%)	10 (10.3%)		
	Total	19 (100%)	84 (100%)	97 (100%)		

**Table 4: Frequency Distribution of Caregiver Burden for Anxiety Categories (\*Fisher's exact test was applied to calculate the p value, since 4 cells had expected count less than 5)**

		Depression Categories			Chi-squared Statistic	P Value*
		Normal	Borderline Abnormal	Abnormal		
<b>Caregiver Burden Categories</b>	Little or no burden	4 (14.8%)	37 (50.0%)	22 (22.2%)	45.85	< 0.001
	Mild to moderate burden	23 (85.2%)	37 (50.0%)	50 (50.5%)		
	Moderate to severe burden	0 (0%)	0 (0%)	17 (17.5%)		
	Severe burden	0 (0%)	0 (0%)	10 (10.1%)		
	Total	27 (100%)	74 (100%)	99 (100%)		

**Table 5: Frequency Distribution of Caregiver Burden for Male and Female Patients (\*Fisher's exact test was applied to calculate the p value, since 1 cell had expected count less than 5)**

		Males	Females	Total	Chi-squared Statistic	P Value*
		<b>Caregiver Burden Categories</b>	Little or no burden	29 (27.4%)		
	Mild to moderate burden	62 (58.5%)	48 (51.1%)	110 (55.0%)		
	Moderate to severe burden	11 (10.4%)	6 (6.4%)	17 (8.5%)		
	Severe burden	4 (3.8%)	6 (6.4%)	10 (5.0%)		
	Total	106(100%)	94 (100%)	200 (100%)		

The frequency distribution of caregiver burden status for each depression category has been illustrated in table 4. A greater number of caregivers with 'moderate to severe' (n = 17, 17.5%) and 'severe' burden (n = 10, 10.1%) had 'abnormal' levels of depression, as compared with those with 'little or no' and 'mild to moderate' burden (Chi squared statistic = 45.85,  $p < 0.001$ ).

On assessing the difference of caregiver burden between males and females, no significant difference was found ( $p = 0.342$ ), as illustrated in table 5.

## DISCUSSION

The results of this study suggested a strong positive correlation between anxiety and caregiver burden (Pearson's correlation coefficient = 0.682). None of the caregivers with "little or no" and "mild to moderate" burden had abnormal levels of anxiety. However, 17.5% (n = 17) of caregivers with 'moderate to severe' burden and 10.3% (n = 10) of caregivers with 'severe' burden had abnormal levels of anxiety ( $p < 0.001$ ). Thus, anxiety and caregiver burden have a strong relationship as reported in similar studies (van Beusekom et al. 2016, Karahan et al. 2014). With increasing burden of care, anxiety levels rose as well.

Moreover, the results of our study also suggested a moderately positive correlation between caregiver burden and depression as well (Pearson's correlation coefficient = 0.542). Similar to trends found for anxiety, none of the caregivers with 'little or no' and 'mild to moderate' burden had abnormal levels of depression. On the other hand, 17.5% (n = 17) of caregivers with 'moderate to severe' and 10.1% (n = 10) of caregivers with 'severe' burden of care had abnormal levels of depression ( $p < 0.001$ ). Therefore, depression and caregiver burden also have a strong relationship. With increasing burden of care, depression levels were found to increase as well. Similarly, a literature review on stated burden on casual caregivers of ICU patients conducted by Van Beusekom et al. in 2016 reported that the prevalence of depression among familiar caregivers of ICU survivors was higher than among informal caregivers of patients with colorectal cancer and following stroke, coronary bypass surgery, congestive heart failure, hip fracture and myocardial infarction indicating an increasing level of burden increases the level of depression among caregivers.

Our study found no difference in the burden of

care between male and female caregivers ( $p = 0.342$ ). While 15 (14.2%) males had 'moderate to severe' or 'severe' burden of care, there were 12 (12.8%) female caregivers had 'moderate to severe' or 'severe' burden. Similarly, in a study conducted by Ali Yavuz Karahan et al. on effects of reintegration services on depression and caregiving burden on stroke patients observed no difference between the levels of anxiety and depression of female and male caregivers (Karahan et al. 2014). However, a study by Smi Choi-Kwon et al. in 2005 on factors affecting the burden on stroke caregivers in South Korea showed care-giver burden to be more common in older adult females with depression and anxiety.

In our study, the majority of the participants were caring for patients with knee osteoarthritis (n = 85, 42.5%) or chronic back pain (n = 75, 37.5%). Only a very small number of participants were caring for patients with stroke (n = 18, 9.0%) and cerebral palsy (n = 22, 11.0%).

Our study showed that most participants experienced mild to moderate caregiver burden (55%, n=110). In a systematic review conducted by Rigby H, the prevalence of caregiver burden was found to be around 25-54% and it persisted elevated for an indeterminate period following stroke and several studies in the systematic review recognized caregiver psychological health and the quantity of time and energy required of the carer as significant determinants of caregiver burden (Rigby et al. 2009). Moreover, the stigma for caring for patients with stigmatized illnesses such as Alzheimer's, increases the burden on the caregiver. In such cases psychosocial involvements should target stigmatic views in order to decrease caregiver burden (Werner et al. 2012).

This study had the limitation of selecting a relatively smaller sample size. Also, only caregivers of patients with only four different conditions were selected. The proportion of caregivers for stroke and cerebral palsy was quite small.

The findings of this study suggest that caregivers responsible for providing care to chronic, debilitated patients suffer from mental health issues, such as anxiety and depression. These factors lead to poor quality of life for these caregivers. There should be recognition of the negative impact on the health of caregivers. Professional mental health services should be made available for caregivers of chronic, debilitated patients. Recommendations should be made on the different strategies to cope with the

health problems faced by caregivers.

## CONCLUSION

There is existence of anxiety and depression among caregiver which has strong positive correlation with caregiver burden.

## CONFLICT OF INTEREST

The authors declared that present study was performed in absence of any conflict of interest.

## AUTHOR CONTRIBUTIONS

MOB refined the idea, designed the methodology and critically reviewed the manuscript. MMK conceived the idea and critically reviewed the manuscript. APQ collected the data and analyzed as well. MM drafted the article and interpretation of data. ZA drafted the article and interpretation of data. MB collected the data and analyzed the data.

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