JPPS 2010; 7(1): 23-28 **ORIGINAL ARTICLE**

CARING FOR THE CAREGIVERS: MENTAL HEALTH, FAMILY BURDEN AND QUALITY OF LIFE OF CAREGIVERS OF PATIENTS WITH MENTAL ILLNESS

Nazish Imran, Muhammad Riaz Bhatti, Imran Ijaz Haider,
Lubna Azhar, Amna Omar, Ahsan Sattar

ABSTRACT

Objective: To examine anxiety, depression, family burden and quality of life in Primary caregivers of patients with mental illness.

Design: Cross Sectional Study

Place & Duration of study: The study was carried out in Mayo Hospital Lahore from January to June 2009.

Subjects & Methods: One hundred Primary Caregivers of Psychiatric patients were interviewed and administered Hospital Anxiety & Depression Scale (HADS), Family Burden Interview Schedule and WHO- QOL Bref.

Results: Majority of Primary caregivers of Psychiatric patients were females (74%) and spending more than 32 hours/week with the patient (56%). High proportion of caregivers scored above the cutoff of HADS for Anxiety & Depression respectively (86% and 85% respectively). We did not found any significant association between anxiety and depression with various patient and caregiver related factors in our sample. Financial constraints and effect on family routine were found to be significant sources of family burden. Caregivers of patients with Mental Illness had impaired Quality of life(QOL).

Conclusion: Primary Caregivers of Patients with Mental Illness have high rates of Mental Health Difficulties, family Burden and impaired Quality of Life. Healthcare Personnel in contact with Caregivers should consider screening them for psychiatric symptoms and QOL and if necessary, recommend evaluation by their doctors.

Key words: Caregivers, Anxiety, Depression, Quality of life, Family burden

INTRODUCTION

During the last few decades, there has been an increase focus all over the world towards community care of psychiatric patients thus leading to an increase in care giving responsibility on family and friends. It is a demanding and challenging task and places great demands on the caregivers. Study to understand Prognosis and Preferences for outcomes and Risks of Treatment reported that one fifth of all family members of severely ill patients had to quit work or make another major life change in order to care for their family members. Almost one third reported the loss of all their family savings and 29% reported loss of major source of family income[1].

In Pakistani setup, family caregivers are regarded as the backbone of the healthcare system. Mostly the primary caregivers are patient spouses, parents or closest relatives and are responsible for providing physical and emotional support for the mentally ill patients for long periods ranging from months to years. This responsibility in turn can affect primary caregiver's own mental and physical health and quality of life. It can also lead to subjective as well as objective burden on the whole family like emotional (shame, embarrassment, feelings of guilt, and self blame), psychological, physical and economic impact. Burden can also result from stigmatising attitudes of society towards psychiatric patients and their families.

Nazish Imran, MBBS; MRCPsych (London), Assistant Professor, Child & Family Psychiatry Department, King Edward Medical University, Lahore, Pakistan.
E-mail nazishimran@hotmail.com

Muhammad Riaz Bhatti, MRCPsych, FRCPsych, DPM, Professor, Department of Psychiatry& Behavioural Sciences, King Edward Medical University, Lahore.

Imran Ijaz Haider, MBBS; MRCPsych (London); DPM (England), Associate Professor, Department of Psychiatry& Behavioural Sciences, Fatima Memorial College of Medicine and Dentistry, Lahore, Pakistan.

Lubna Azhar, MSc; ADCP, Clinical Psychologist, Mayo Hospital, Lahore.

Amna Omar, MBBS, House Officer, Department of Psychiatry, Mayo Hospital, Lahore.

Ahsan Sattar, MSc., Psychologist. Department of Psychiatry, Mayo Hospital, Lahore.

Correrspondence:

Dr. Nazish Imran

A survey of mental health of informal caregivers in Ontario, found higher rates of affective (6.3%vs 4.2%) and anxiety(17.5%vs 10.9%)disorders in caregivers compared with non caregivers and use of mental health services for caregivers was nearly twice the rate as well[2]. A study conducted in Pakistan also found significantly high levels of depression and anxiety in caregivers of patients with Psychiatric illnesses and gender differences were also observed[3]. High frequency of depression in caregivers of schizophrenia is also reported in another small scale sudy[4]. Emotional and behavioural symptoms of illness, drug abuse, suicide threats and violent behaviour are considered as constant source of anxiety and stress for caregivers.

Compared to west, very few studies have looked at the impact of a psychiatrically ill member on the rest of the family in Pakistani settings. The aims of our study was to explore as to who are the primary caregivers of psychiatrically unwell patients in Pakistan, to determine the psychological and emotional stress associated with the caregiving role, family burden and caregivers quality of life.

SUBJECTS AND METHODS

Primary caregivers of patients with mental illness (both inpatients as well as outpatients) in Mayo Hospital, Lahore were consecutively invited to participate in this study. Informed consent was sought and willing participants were requested to complete the study questionnaire. The eligibility criteria for the patients were age between 16-65 years, ability to speak Urdu/ Punjabi language, mental illness of at least six month's duration and patient not acutely unwell. Primary caregiver included in the study was identified by the patient and his/ her consent was also sought to contact the caregiver for inclusion in the study. Caregiver had to be more than 16 years of age, fluent in Urdu language and giving informed consent.

The initial section collected demographic information about the patient and the caregiver as well as information about patient illness and severity.

Assessment of Anxiety and Depression:

Anxiety and depression were self rated by Hospital Anxiety and Depression Scale (Urdu version) [5, 6]. HADS consists of 14 items, seven on depression subscale (HADS-D) and seven on anxiety subscale (HADS-A). Each item is scored on a four point scale from 0(not present) to 3(considerable) and the items are added giving HADS-D & HADS-A score from 0(minimal symptom load) to 21(maximum symptom load). Based on literature, cases of anxiety or depression were defined by a score of 7 or more on HADS-A or HADS-D respectively. However, caseness defined by HADS does not correspond exactly with definite mental illness as assessed by ICD-10 OR DSM-IV which remains the gold standard for the diagnosis of depression and anxiety.

Family Burden Assessment:

Family Burden Interview Schedule was used to assess the burden on the family of a psychiatric patient[7]. It assess burden in various categories which include financial burden, disruption of various family activities, disruption of family leisure, disruption of family interaction, effect on physical health of others and effect on mental health of others. Each category as well as each item is scored on a three point scale 0(No Burden), 1(moderate burden) and 2(severe burden).

Quality of Life:

WHO QoL-Bref was used to assess the quality of life of caregivers[8, 9]. It is a 26 item self administered questionnaire and a shorter version of WHO QoL-100 scale. This scale assesses the subjective responses of life conditions with assessment made over the preceding 2 weeks. It covers four domains: physical health, Psychological health, social relationships and environment in addition to general well being. Each item is scored between 1-5. Higher scores indicate better quality of life. Scoring of three negatively scale items was reversed to match the pattern of other items as indicated in the Questionnaire manual. The mean score of each domain, calculated by dividing the total score by the number of items in the domains, ranges between 1 and 5 and the total scale score ranges between 5 and 25.

Both the family burden interview schedule and WHO-QoL Bref were translated in Urdu language by multiple forward translation method. One of the authors (NI) and a senior psychologist translated the scales and the most suitable and culturally appropriate translation for each item was compiled. It was forwarded to one consultant and two senior psychologists in the department to rate appropriateness of the translation on two basic guidelines. Firstly does this translation represent the idea that is conveyed by the original instrument in English and does it reflect the cultural equivalence? Consensus was achieved by incorporating suggestions of reviewers in the final translated version which was piloted on 5 caregivers and any ambiguity removed before the scales were used in the study.

Data was analyzed by using Statistical Package for Social Sciences 17.0 (SPSS17.0). Descriptive statistics of socio-demographic information were determined. Chi square test was used to examine associations between patient and caregivers characteristics and various variables. For all purposes, a p- value of <.05 was considered as a criteria of significance.

RESULTS

Patients:

Of the 100 patients (69 females), the mean age was 28.3(SD 10.12), 56 were inpatients and 32 were married. The diagnosis were Schizophrenia(20), Depression(32), Bipolar affective disorder(11),Generalized anxiety disorders/Panic attacks(8), Dissociative disorder(11), Obsessive compulsive disorders(8), Substance Abuse(7) and 3 patients had comorbid disorders (Schizophrenia with depression one, depression with substance abuse two). Duration of illness was more than 2 years in 44 patients, more than a year in 17 patients and in 39 patients duration of illness was between 6 months -1 year. 37 patients had history of at least 1 admission in Psychiatric units, with 45 patients reported to be violent in past and 23 had history of self harm.

Caregivers:

Demographic details about caregivers are given in Table 1. 90% of caregivers reported their relationship with the patient as good. Five caregivers were under psychiatric care at the time of the study. Majority of caregivers denied that their Physical and Psychological health is affected adversely due to care giving (58% and 62% respectively). 65 caregivers mentioned that they are able to cope with patient behaviour to some extent with 11 feeling completely unable to cope and 24 mentioning complete satisfaction with their ability to manage patient difficulties. Table 2 describes the frequency of depression and anxiety in the caregivers samples on basis of Scores of HADS. No statistical differences were observed on comparison of caregivers groups scoring above the cut-offs for anxiety and depression on various patient and caregiver related factors. (Table 3)

Table 1

Primary Caregivers Demographic Details. (n=100)

Caregiver Factors	Frequency
Age of Primary caregiver	Mean 40.3 years (SD 13.2)
Gender:	
Male	26
Female	74
Relationship with the patient:	
Parent	44
Spouse	14
Sibling	21
Child	15
Others	6
Monthly Income:	
< 5000	37
Between 5-10,000	39
>10,000	15 (data missing in 9)
Education:	
No formal education	48
0-10 years	16
10-14 years	19
>14 years.	17
Carer resides with the patient	
Yes	64
No	36
Time spent with the patient	
<9 hrs/week	19
9-32 hrs/week	25
>32 hrs/week	56

Table 2

Frequency of Depression & Anxiety In Caregivers according to HADS.

Rating Scale	Mean Score (Standard Deviation) (Total n=100)	Number of Caregivers above the Cuttoff Score
Hamilton Depression Rating Scale	9.69 (3.26)	86
Hamilton Anxiety Rating Scale	10.27 (3.7)	85

Family burden Interview mean score along with subcategories scores are given in Table 4. Non-depressed caregivers reported significantly more financial burden than the depressed caregivers (P-value <0.05) There was no significant difference noted between anxious and nonanxious caregivers in family burden interview mean scores.

WHO QoL score profiles of caregivers shows a total mean score of 15.46(SD 3.28) (Table 5). On comparison, depressed caregivers reported poor overall quality of life as well as significant impact on psychological domain.(both P values <0.05). No statistically significant difference was observed in anxious and nonanxious caregiver's quality of life.

DISCUSSION

Although the sample size was small and there was no control group, the study has demonstrated findings which are of interest to professionals working with mentally ill patients. There are many reasons why health professionals need to focus on caregivers. Patients themselves are more likely to have unmet needs if their caregiver has depression and high level of burden[10]. Furthermore as caregivers Psychological needs increase, patients activities may decrease[11].

Care giving for mentally ill patients impacts on various aspects of a caregiver's life, including his or her physical, emotional and psychological health. In Pakistan, Informal caregivers without any state help are solely responsible for looking after the needs of patients with Psychiatric illness. Nearly half of caregivers in our sample were parents or spouses. The main finding was an alarmingly high level of HADS-defined depression

Table 3

Comparison of Caregiver and Patient factors Among Caregiver groups according to Hospital anxiety and depression Scale scores.

FACTORS STUDIED	Hamilton Depression Rating Scale			Hamilton Anxiety Rating Scale		
	>7	<7	P value	>7	<7	P value
Gender of caregiver						
Male	22	4		21	5	.340
Female	64	10	.521	64	10	
Patient Gender						
Male	26	5		24	7	132
Female	60	9	.449	61	8	.
Carer resides with patient						
Yes	46	11		50	30	.844
No	32	2	.172	8	5	
Duration of patient illness						
6months-1 year	31	8		33	6	
1-2 years	14	2		13	3	.886
>2 years	41	3	.182	38	6	
H/O self harm in Patient						
Yes	19	4		19	4	.508
No	64	9	.378	62	11	

Table 4

Scores of Caregivers on Family Burden Interview Schedule (Total n=100. Minimum score in subcategories =0, Maximum score in subcategories=2)

Family Burden Interview Schedule	Mean	Standard Deviation (SD)
Total Score	2.75	1.87
Financial Burden	.85	.635
Effect on Family routine	.82	.647
Effect on Family leisure Activities	.75	1.35
Effect on Family Interaction	.75	.56
Effect on Physical Health of Family Members	.49	.62
Effect on Mental Health of Family Members	.43	.63

Table 5

Score Profiles on WHO Qol In Caregivers (Total Score Range between 5-25, Domain Score Range between 1-5)

Domain	Mean	Standard Deviation
General	2.98	0.66
Physical Health	3.00	.732
Psychological Health	3.02	.726
Social Relations	3.22	1.08
Environment	2.85	.87
Total Score	15.46	3.28

(86%) and anxiety symptoms(85%) in primary caregivers of both genders, but in the absence of control group the results need to be interpreted with caution as high rates of psychiatric morbidity is reported in studies of community samples in Pakistan. These results are in line with previous studies in west as well as in subcontinent including Pakistan that caregivers of patients with mental illness are at higher risk of psychopathology[2-4,12]. Concerns related to future, fear of being alone with sole responsibility of coping with difficult behaviors, stigma associated with mental illness in our society and social isolation are some of the factors which may contribute to increase level of affective disorders in caregivers. We have not found an association between caregiver depression and anxiety with gender of patient or caregivers, with duration of patient illness and history of self harm or violence indicating increase psychopathology risk among the caregivers of Patients with various psychiatric diagnoses independent of gender or severity of illness. Our Results highlight the need for attention to the mental health needs of this vulnerable group.

The burdens of caring for someone with mental illness at home are considerable[13, 14]. Burden may be 'subjective' (the extent to which relatives felt they carried a burden) and 'objective' (e.g., effects on health, financial loss). Financial problems are very significant in Pakistani setting as well as restrictions on social and leisure activities. We found financial burden to be greatest in our caregivers group. Of concern is the fact that majority of caregivers reported less impact on their mental health. Although HADS scores indicated that they were experiencing significant levels of depression and anxiety, these caregivers appear to be either unaware or unwilling to admit to their mental health needs. We did not found any difference in burden of care of male or female patients, which differs from previous studies noticing more subjective and objective burden in caregivers of male patients[3].

All the above findings need to be seen in context of Pakistani culture. Majority of our caregivers were parents, and majority of parents in our society continue to look after their adult children with no complaints. Element of denial, shame and guilt among caregivers if they admit to not being able to cope along side perception of being expected to handle the situation by themselves may contribute to increase rates of psychopathology and burden in caregivers . Previous studies have also reported discrepancy between subjective and objective burden. Hoeing and Hamilton found that almost a quarter of the households carrying a lot of objective burden made no complaints of subjective burden, reflecting the tolerance of families towards the patient with mental illness[15]. Professionals in Pakistan need to recognize the problems faced by relatives who are "on duty" all the time and whose emotional involvement with the patient makes it difficult for them to remain neutral in their interaction with the patients. Information, help and support to families needs to be made available by the professionals.

Reports on the quality of life of family caregivers of psychiatric patients are uncommon in Pakistan. WHO defines Quality of Life as individual's perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns[8, 9]. All experiences, physical, emotional, spiritual or financial are assessed through subjective perception of caregiver or patient in terms of how they affect a person quality of life. Our result of mean total score of 15.46 on WHOQol is comparable with other studies done in subcontinent with mean total score of 16.60[16]. Previous research in India has also showed agreement in Qol assessment between patient and relatives of schizophrenia with suggestion that relatives can be used as a form of proxy rating in studying QoL in severe mental illnesses.. However these results must again be seen in the context of family setup in subcontinent. Compared to West, traditional joint family system is still a norm. Considerable amount of social support is provided by families and there is much better knowledge of patient's difficulties than might exists in western settings.

Various limitations of the study need to be considered. Patients who were acutely unwell and not able to identify a primary carer as well as those who did not speak Urdu or Punjabi were excluded and this may have introduced bias. Secondly anxiety and depression were assessed by a screening tool (HADS), which although has shown to perform well in detecting these states in general population, primary care as well as hospital cohorts, still is not a diagnostic tool based on Gold standard criteria[17]. In the absence of control group, it is not possible to determine if the increase psychopathology is a direct result of care giving responsibility.

Despite these limitations we feel that the results of our study have important implications for service delivery and clinical practice. We found high rates of mental health difficulties, burden of care and impaired quality of life in Primary caregivers of mentally ill patients. Previous studies done in Pakistan on the same topic had smaller sample size and assessed only the presence of anxiety and depression in caregivers with no exploration of burden of care as well as impact on their quality of life which gives a more comprehensive view of impact of a psychiatrically unwell patient on a family functioning. Health care personnel should be observant of emotional problems of caregivers and if subjective complaints or functional impairment are present, evaluation and therapeutic interventions should be suggested. Information regarding support and practical assistance should also be offered to families of Psychiatric patients. Further research should study larger samples, and effectiveness of various mental health interventions on the long term psychological adjustment and quality of life of caregivers. This will help to determine how best to meet the caregiver's mental health needs in our Society setup.

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