DEMOGRAPHIC DIFFERENCES ON CAREGIVER BURDEN, PSYCHOLOGICAL DISTRESS AND HOPELESSNESS AMONG CAREGIVERS OF PSYCHIATRIC PATIENTS

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ABSTRACT

OBJECTIVE: To explore the demographic differences on caregiver burden, hopelessness, and psychological distress among caregivers of psychiatric patients.

METHODS: This descriptive cross-sectional study was conducted in Pakistan Institute of Medical Sciences Islamabad and Nishtar Hospital Multan, Pakistan in eight months from 10th April 2019 to 20th November 2019. Purposive sampling technique was used to include 240 caregivers of different age of psychiatric patients (with different duration of illness and type of illness) which were assessed on Burden Scale for Family Caregivers, Kessler Psychological Distress Scale and Beck Hopelessness Scale.

RESULTS: Out of 240 participants, 124 (51.6%) were females and 116 (48.3%) were males, ranging in age from 18 to 45 years. Results disclosed that age group 36-45 years showed significant mean difference on psychological distress and age group 18-35 years showed significant difference on Hopelessness at p < 0.01. While, caregivers dealing with patients who have illness for more than 20 years have significant mean difference on psychological distress and hopelessness at p < 0.05. Caregivers dealing with patients who have less than 5 years of illness have significant mean difference on caregiver burden at p < 0.001, and caregivers of patients with schizophrenia have significant mean difference with substance abuse, mood disorder and mental retardation on psychological distress and hopelessness at p < 0.05.

CONCLUSION: Older adults have higher psychological distress while, young adults have higher level of hopelessness. Caregivers of prolonged mental illness have higher psychological distress and caregiver burden. Caregivers of schizophrenic patients have higher level of psychological distress and hopelessness.

KEY WORDS: Care giver burden (Non-MeSH); Hopelessness (Non-MeSH); Psychological Distress (MeSH); Psychiatric patients (Non-MeSH).

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INTRODUCTION

aregiver burden is usually the outcome from providing care to the patients with chronic illness. It can occur in any of the 43.5 million individuals providing support to patients with different psychiatric illnesses. Explicitly they announced serious dimensions of depression, anxiety and emotional distress while dealing with the patients having long course of illness.¹

Previously it was reported that caregiver burden of the caregivers of psychiatric patients is assessed only 14% around the globe.² Psychiatric disorders have significant negative outcomes on the personal satisfaction of patients and their caregivers or companions, especially in low-and middle-income individuals. Caregiver burden has been portrayed as the general physical, emotional, and economic expenses of thinking about a relative.³ During illness, caregivers encounter stress, guilt, sleeplessness, and anxiety. In the previous decades, most scientists and psychological wellbeing experts have focused a lot of their time and endeavors on individuals living with psychiatric disorders with specific symptomatology. There is presently the

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need to concentrate on caregivers of patients with psychiatric patients too, particularly in wellbeing frameworks for overseeing emotional wellness of patients and their caregivers who are facing inadequate environment.⁴ Inaccessibility of wellbeing frameworks influences personal satisfaction. In this way, the psychological well-being of caregivers tends to reduce among individuals with psychiatric problems and worsening caregiver burden.⁵

Psychological distress is a general term that is utilized to portray unpleasant sentiments or feelings that affect your degree of work.6 The administration of psychological distress is a significant thing to measure concerning psychological issues that may intensify the indications of the illness and increment of social insurance costs.⁷ In any case, psychiatric patients habitually report significant levels of distress and selfdestructive thoughts (evaluated rate: 7%25%), and they demonstrate a higher risk of suicidal ideation than the overall public. Second, anxiety and depression influence the personal satisfaction of oncologic psychiatric patients in a few spaces.⁸ Elevated levels of depression and anxiety during the psychiatric procedure detrimentally affect prevalence rates of caregiver burden.⁹

A feeling of hopelessness appears to prompt progressively negative assessments of new circumstances and less viable adapting new techniques; in this manner, the recognition is that one won't achieve anything meaningful. To date, very few examinations have

| Variables | Sources of variation | SS | DF | MS | F | Sig |
|------------------------|-------------------------|----------|-----|--------|-------|---------|
| | Between Groups | 760.45 | 2 | 380.22 | 3.53 | .031* |
| Psychological distress | Within Groups | 25487.34 | 237 | 107.54 | 3.33 | .031* |
| | Total | 26247.79 | 239 | | | |
| | Between Groups | 828.34 | 2 | 414.17 | 11.96 | .000*** |
| Hopelessness | Within Groups | 8204.30 | 237 | 34.61 | 11.90 | .000 |
| | Total | 9032.65 | 239 | | | |

TABLE I: ONE WAY ANOVA FOR DIFFERENCES OF CAREGIVERS WITH DIFFERENT AGE GROUPS ON PSYCHOLOGICAL DISTRESS AND HOPELESSNESS (N=240)

researched the connection between caregiver burden and hopelessness." An enormous group of research substantiates the impacts that psychological problems can have on the emotional, social, and physical wellbeing of the family such as parents. Researches have uncovered the fact that parents of cancer patients report negative impacts on their wellbeing, for example, anxiety, depression, exhaustion, hopelessness, guilt, fear, restlessness, social disengagement, and burnout. It has been expressed that patients with disorders and their family guardians experience comparable degrees of hopelessness.¹¹⁻¹³

The purpose of the current study was to explore the caregiver burden with psychological distress and the mediating role of hopelessness for different demographic properties (age, duration of illness, and type of illness) among caregivers of psychiatric patients. It was aimed to explore the demographic differences (age, duration of illness, type of illness) on care giver burden, hopelessness and psychological distress among caregivers of psychiatric patients.

METHODS

This descriptive cross-sectional study was done at Pakistan Institute of Medical Sciences (PIMS) Islamabad and Nishtar Hospital Multan, Pakistan. There were 240 participants, selected through purposive sampling technique which comprises of caregivers of psychiatric patients including Schizophrenia, mood disorder, substance abuse and mental retardation. Both male and female caregivers participated in this research which were 124 female (51.6%) and 116 male (48.3%) age ranging between 18 to 45 years only caregivers of psychiatric patients were included and caregivers related to some other kind of illness we excluded from the study. Data was collected from PIMS Islamabad and Nishtar Hospital Multan Pakistan in eight months from 10th April 2019 to 20th November 2019. Permission of data collection was granted from both hospitals prior to conducting the study. The data was gathered from the caregivers of psychiatric patients who bring them for follow up sessions in Out Patient Department. Informed consent was given to the participants and get that signed. Demographic variables were asked such as age, gender, duration of illness of the patients and type of illness of the patients. Questionnaire were filled to measure care giver burden, hopelessness and psychological distress among caregivers of psychiatric patients.

Burden Scale for Family Caregivers was used to measure care giver burden comprising of 28 statements for assessment of caregivers perceived subjective burden for looking after of persistently-ill family member with strong reliability (.80). Four response categories ranging from strongly agree =0 to strongly disagree =3 are used for each statement. Higher score on this tool indicates the higher degree of burden.¹⁴

Kessler psychological distress scale was used to assess psychological distress. It

| CAREGIVERS ON PSYCHOLOGICAL DISTRESS AND HOPELESSNESS (N=240) | | | | | | | | | | |
|---|--|--|--|--|---|--|--|--|--|--|
| Age groups | | Mean difference | 6 | Sig | 95%CI | | | | | |
| | | | 31 | Sig | LL | UL | | | | |
| 18-35 | 36-45 | 2.207 | 1.62 | .363 | -1.6171 | 6.0315 | | | | |
| 18-35 | 46-55 | -2.237 | 1.63 | .358 | -6.0881 | 1.6132 | | | | |
| 36-45 | 46-55 | -4.444* | 1.67 | .023 | -8.3869 | 5025 | | | | |
| 18-35 | 36-45 | 3.181* | .919 | .002 | 1.0115 | 5.3510 | | | | |
| 18-35 | 46-55 | 4.337* | .926 | .000 | 2.1531 | 6.5225 | | | | |
| 36-45 | 46-55 | 1.156 | .948 | .443 | -1.0801 | 3.3932 | | | | |
| | Age g 18-35 18-35 36-45 18-35 18-35 | Age groups 18-35 36-45 18-35 46-55 36-45 46-55 18-35 36-45 18-35 36-45 18-35 36-45 18-35 36-45 | Age groups Mean difference 18-35 36-45 2.207 18-35 46-55 -2.237 36-45 46-55 -4.444* 18-35 36-45 3.181* 18-35 46-55 4.337* | Age groups Mean difference St 18-35 36-45 2.207 1.62 18-35 46-55 -2.237 1.63 36-45 46-55 -4.444* 1.67 18-35 36-45 3.181* .919 18-35 46-55 4.337* .926 | Age groups Mean difference St Sig 18-35 36-45 2.207 1.62 .363 18-35 46-55 -2.237 1.63 .358 36-45 46-55 -4.444* 1.67 .023 18-35 36-45 3.181* .919 .002 18-35 46-55 4.337* .926 .000 | Mean difference St Sig 959 18-35 36-45 2.207 1.62 .363 -1.6171 18-35 46-55 -2.237 1.63 .358 -6.0881 36-45 46-55 -4.444* 1.67 .023 -8.3869 18-35 36-45 3.181* .919 .002 1.0115 18-35 46-55 4.337* .926 .000 2.1531 | | | | |

TABLE II: POST HOC ANALYSIS FOR DIFFERENCES IN AGE GROUPS OF CAREGIVERS ON PSYCHOLOGICAL DISTRESS AND HOPELESSNESS (N=240)

*p<.05, **p<.01, ***p<.001; LL=Lower Limit; UL=Upper Limit

is a five-point Likert scale ranging from I = none of the time through to 5 = all of the time score 10-19 depicts the wellness, while 30-50 indicate severe disorder and has good reliability i.e., 0.89.¹⁵

Beck Hopelessness Scale was used to analyze hopelessness. Reliability of the scale was good i.e., 0.81 and its asses the answer through true and false for each statement score of this scale range from 0 to 20 and higher score indicate higher level of hopelessness.¹⁶

RESULTS

This study was conducted on 240 caregivers of psychiatric patients, which included 116 (48.3%) males and 124 (51.6%) female age ranging between 18 to 45 years, were included as the sample of the study. Differential statistical Analyses Version 18 were applied by SPSS to investigate the results of Oneway analysis of variance (ANOVA) and multiple analysis of variance (post hoc).

Table I showed One way ANOVA for differences in age groups of caregivers on psychological distress and hopelessness. Results revealed that there is significant mean difference among different age groups of caregivers on psychological distress at p < .05 and hopelessness at p < .000.

Table II shows Post hoc Analysis for differences in age groups of caregivers on psychological distress and hopelessness. Results indicated that age group 36-45 years showed significant mean difference with age group 46-55 years on psychological distress and age group 18-35 showed significant mean difference with age groups 36-45 years and 46-55 years on hopelessness at p<0.01.

Table III shows One way ANOVA for duration of illness on psychological distress, hopelessness and care giver burden. Results indicated that there were significant differences between duration of illness on psychological distress at p<.001, hopelessness at p<.001 and care giver burden at p<.001.

Table IV shows post hoc analysis for differences among caregivers in duration of illness on psychological distress, hopelessness, and care giver burden. Results of post hoc analysis revealed that caregivers dealing with individuals who have illness above 20 years have

| Variables | SS | DF | MS | F | Sig | |
|------------------------|----------------|----------|-----|---------|-------|------|
| | Between Groups | 3648.95 | 3 | 1216.31 | 12.70 | .000 |
| Psychological distress | Within Groups | 22598.84 | 236 | 95.75 | 12.70 | |
| | Total | 26247.79 | 239 | | | |
| | Between Groups | 820.04 | 3 | 273.34 | 7.85 | .000 |
| Hopelessness | Within Groups | 8212.60 | 236 | 34.79 | 7.05 | |
| | Total | 9032.65 | 239 | | | |
| | Between Groups | 7421.15 | 3 | 2473.71 | 34.24 | .000 |
| Caregiver burden | Within Groups | 17047.73 | 236 | 72.23 | 34.24 | .000 |
| | Total | 24468.89 | 239 | | | |

| TABLE III: ONE WAY ANOVA FOR DURATION OF ILLNESS ON PSYCHOLOGICAL |
|---|
| DISTRESS, HOPELESSNESS AND CARE GIVER BURDEN (N=240) |

significant mean difference with the course of illness of less than 5 years, 5-10 years and 11-20 years on psychological distress and hopelessness at p < 0.05 and on the other hand caregivers dealing with less than 5 years of illness have significant mean difference with 11-20 years and above 20 years while 5-10 years have significant mean difference with above 20 years on caregiver burden at p < 0.001.

Table V shows One way ANOVA for types of patients on psychological distress and hopelessness. Results indicated that there were significant differences between groups of caregivers of patients with schizophrenia, mood disorders, substance abuse and mental retardation on psychological distress at p<.001 and hopelessness at p<.001.

Table VI shows post hoc analysis for differences in types of patients with schizophrenia, mood disorders, substance abuse and mental retardation on psychological distress, hopelessness, and care giver burden. Results of post hoc analysis revealed that caregivers of patients with schizophrenia have significant mean difference with substance abuse, mood disorder and mental retardation with psychological distress at p < 0.05. On the other hand, mood disorder has significant mean difference with schizophrenia, substance abuse and mental retardation at p < 0.05.

DISCUSSION

Present study was meant to explore the demographic differences for caregiver burden, psychological distress, and hopelessness among caregivers of psychiatric patients. Which concluded that elderly people have higher level of psychological distress while, younger have higher level of hopelessness. And those who are dealing with patients of prolonged illness have higher psychological distress and caregiver burden. On the other hand, caregivers of schizophrenic patients have higher level of psychological distress and hopelessness.

It was hypothesized that there will be significant mean differences among

caregivers of different age groups on psychological distress and hopelessness thus current hypothesis of the present study was also accepted. Results of post hoc analysis revealed that caregivers of age group 36-45 years showed significant difference with age group 46-55 years on psychological distress and age group 18-35 years showed significant difference with age groups 36-45 years & 46-55 years on hopelessness at p < 0.001. The results were in conformity with other studies that were conducted in Indonesia and Bali, which found that there was positive relationship of psychological distress with age of caregivers of schizophrenic patients.17

Another assumption of the study was meant to measure the differences on care giver burden, psychological distress and hopelessness or duration of illness of patients. Results of post hoc analysis revealed that caregivers dealing with individuals who have prolonged illness more than 20 years, have significant difference with the course of illness of less than 5 years, 5-10 years and 11-20 years on psychological distress and hopelessness at p<0.05 and on the other hand caregivers dealing with less than 5 years of illness have significant difference with 11-20 years and above 20 years while 5-10 years have significant difference with above 20 years on caregiver burden at p<0.001. These findings are parallel to the outcomes of a previous studies.¹⁸⁻¹⁹

TABLE IV: POST HOC ANALYSIS FOR DIFFERENCES AMONG CAREGIVERS IN DURATION OF ILLNESS ON PSYCHOLOGICAL DISTRESS, HOPELESSNESS AND CARE GIVER BURDEN (N=240)

| Duration | ofillnoss | | Age group Mean | | | 95% CI | | |
|--------------------------------|-------------|----------|----------------|-------|------|--------|--------|--|
| Duration of illness (years) | | (years) | 8.8.4 | | Sig | LL | UL | |
| | | 5-10 | .760 | 1.825 | .976 | -3.96 | 5.482 | |
| | Less than 5 | 11-20 | -1.594 | 1.769 | .804 | -6.17 | 2.984 | |
| Psychological | | above 20 | -9.166* | 1.817 | .000 | -13.86 | -4.464 | |
| distress | F 10 | 11-20 | -2.354 | 1.761 | .540 | -6.91 | 2.202 | |
| | 5-10 | above 20 | -9.926* | 1.809 | .000 | -14.60 | -5.244 | |
| | 11-20 | above 20 | -7.572* | 1.753 | .000 | -12.10 | -3.036 | |
| | Less than 5 | 5-10 | 1.930 | 1.100 | .298 | 916 | 4.777 | |
| | | 11-20 | 1.495 | 1.066 | .499 | -1.26 | 4.255 | |
| | | above 20 | 5.134* | 1.095 | .000 | 2.29 | 7.969 | |
| Hopelessness | 5-10 | 11-20 | 435 | 1.061 | .977 | -3.18 | 2.311 | |
| | | above 20 | 3.203* | 1.090 | .019 | .38 | 6.026 | |
| | 11-20 | above 20 | 3.639* | 1.056 | .004 | .90 | 6.373 | |
| | Less than 5 | 5-10 | -3.805 | 1.585 | .080 | -7.90 | .295 | |
| | | 11-20 | -7.418* | 1.536 | .000 | -11.39 | -3.44 | |
| Course in the second of the | | above 20 | -15.279* | 1.578 | .000 | -19.36 | -11.19 | |
| Caregiver burden | E 10 | 11-20 | -3.612 | 1.529 | .087 | -7.57 | .345 | |
| | 5-10 | above 20 | -11.473* | 1.571 | .000 | -15.53 | -7.407 | |
| | 11-20 | above 20 | -7.860* | 1.522 | .000 | -11.80 | -3.920 | |

| | | · · | | | |
|----------------|---|---|--|--|--|
| Variables | | | MS | F | Sig |
| Between Groups | 2445.71 | 3 | 815.23 | 8.08 | .000 |
| Within Groups | 23802.08 | 236 | 100.85 | | |
| Total | 26247.79 | 239 | | | |
| Between Groups | 881.48 | 3 | 293.82 | 8.50 | .000 |
| Within Groups | 8151.16 | 236 | 34.53 | | |
| Total | 9032.65 | 239 | | | |
| | Within Groups Total Between Groups Within Groups | Within Groups 23802.08 Total 26247.79 Between Groups 881.48 Within Groups 8151.16 | Between Groups 2445.71 3 Within Groups 23802.08 236 Total 26247.79 239 Between Groups 881.48 3 Within Groups 8151.16 236 | Between Groups 2445.71 3 815.23 Within Groups 23802.08 236 100.85 Total 26247.79 239 Between Groups 881.48 3 293.82 Within Groups 8151.16 236 34.53 | Between Groups 2445.71 3 815.23 8.08 Within Groups 23802.08 236 100.85 100.85 Total 26247.79 239 - - Between Groups 881.48 3 293.82 8.50 Within Groups 8151.16 236 34.53 - |

TABLE V: ONE WAY ANOVA FOR TYPES OF PATIENTS ON PSYCHOLOGICAL DISTRESS AND HOPELESSNESS (N=240)

It was hypothesized that there will be differences among caregivers of patients with schizophrenia, substance users, mood disorder and mental retardation on hopelessness and psychological distress. Results of post hoc analysis revealed that caregivers of patients with schizophrenia have significant difference with substance abuse, mood disorder and mental retardation with psychological distress at p < 0.05. On the other hand, mood disorder has significant difference with schizophrenia, substance abuse and mental retardation at p < 0.05. Other study discovered the similar findings for instance in a study outcome revealed that being a caregivers of a critically psychologically ailing family member, (schizophrenic sufferer) caregivers had to face both types of difficulties in the form of an emotional impact such as feelings of sadness, hopelessness, nervousness, and discomfort in addition to burden related to helping in the daily activities of dependent patient.20

Limitations and Suggestions

The study has been done with the sample of caregivers of only four types of psychiatric patients suffering from Schizophrenia, mood disorder, substance abuse and mental retardation, a further study should be conducted on family caregivers of other types of psychiatric patients so that the findings can be more generalized. The sample for this study was selected only from government Institute of mental health and caregivers from semi -government and private mental health institutions were overlooked. This study should be done with the sample draw from semi government and private mental health hospitals from different cities of Pakistan. Moreover, in relation to present study further study should include more variables such as caregivers' perceived help and hours of care providing per day as well as care provider's economic status should be added and a comparison among caregivers should be done on the basis of newly added variables. The results of the study were perhaps more related to Pakistani population and due to the culture related deviations there is limited scope for generalization the results in other countries.

CONCLUSION

Older adults have higher psychological distress while, young adults have higher level of hopelessness. Caregivers of individuals having prolonged mental illness have higher psychological distress and caregiver burden. Caregivers of schizophrenic patients have higher level of psychological distress and hopelessness.

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TABLE VI: POST HOC ANALYSIS FOR DIFFERENCES IN TYPES OF PATIENTS WITH SCHIZOPHRENIA, MOOD DISORDERS, SUBSTANCE ABUSE AND MENTAL RETARDATION ON PSYCHOLOGICAL DISTRESS, HOPELESSNESS AND CARE GIVER BURDEN (N=240)

| Patients' groups | | | Mean difference | St | Sia | 95%CI | |
|------------------|-----------------|--------------------|-----------------|-------|-------|---------|---------|
| Fatients grou | 5 | | Mean difference | 51 | Sig | LL | UL |
| | | Substance Abuse | 6.850* | 1.833 | .001 | 2.1058 | 11.5942 |
| | Schizophrenia | Mood Disorder | 7.650* | 1.833 | .000 | 2.9058 | 12.3942 |
| Psychological | | Mental Retardation | 7.516* | 1.833 | .000 | 2.7725 | 12.2608 |
| Distress | Substance abuse | Mood Disorder | .800 | 1.833 | .972 | -3.9442 | 5.5442 |
| | | Mental Retardation | .666 | 1.833 | .984 | -4.0775 | 5.4108 |
| | Mood Disorder | Mental Retardation | 133 | 1.833 | 1.000 | -4.8775 | 4.6108 |
| | Schizophrenia | Substance Abuse | .666 | 1.072 | .925 | -2.1096 | 3.4429 |
| | | Mood Disorder | -4.11667* | 1.072 | .001 | -6.8929 | -1.3404 |
| | | Mental Retardation | .15000 | 1.072 | .999 | -2.6263 | 2.9263 |
| Hopelessness | Substance abuse | Mood Disorder | -4.78333* | 1.072 | .000 | -7.5596 | -2.0071 |
| | | Mental Retardation | 51667 | 1.072 | .963 | -3.2929 | 2.2596 |
| | Mood Disorder | Mental Retardation | 4.26667* | 1.072 | .001 | I.4904 | 7.0429 |

*p<.05, **p<.01, ***p<.001; LL=Lower Limit; UL=Upper Limit

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AUTHOR'S CONTRIBUTION

Following authors have made substantial contributions to the manuscript as under:

IB: Conception and design, acquisition, analysis and interpretation of data, drafting the manuscript, critical review, approval of the final version to be published

GM: Analysis and interpretation of data, drafting the manuscript, approval of the final version to be published

IM: Acquisition of data, drafting the manuscript, approval of the final version to be published

Authors agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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DATA SHARING STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.



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