

## Quality of life and caregiver burden among caregivers of patients with psychiatric disorders

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**Objective:** To explore the relationship between quality of life and caregiver burden among caregivers of patients with psychiatric disorders (schizophrenia and chronic depression) and how caregiver's life is affected by looking after these patients.

**Methodology:** This correlational study included 100 primary caregivers (50 males) and (50 females), from different hospitals of Rawalpindi and Islamabad. Age ranged from 20 to 65 years. Convenient sampling technique was used. Quality of life was assessed through Urdu translated version of WHO Quality of life questionnaire and Caregiver burden was measured with caregiver

burden assessment checklist.

**Results:** Quality of life had strong, significant and negative relationship with caregiver burden ( $r = -.56$ ,  $**p \leq .01$ ). Gradual increase in burden was considerably associated with decline in quality of life of caregivers.

**Conclusion:** A considerable negative correlation among caregiver burden and quality of life was found as with increasing level of burden the quality of life decreases. The finding may be useful in planning services for the caregivers. (Rawal Med J 202;45:565-568).

**Keywords:** Quality of life, caregiver burden, patient with psychiatric disorders.

### INTRODUCTION

Psychiatric disorders include disorders like depression, schizophrenia, addiction and anxiety disorders. There are number of people who are suffering with psychiatric disorders they need proper care. The need of committed caregivers is an important part of life for these patients.<sup>1</sup> Caregivers provide emotional care and help patients during several stages of treatment and play an important part in assisting effective treatment.<sup>2</sup> Caregivers looking after patients with chronic mental health conditions encounter depression and anxiety at double the rate of the overall public and have adverse effect on their quality of life.

Quality of life is the over-all wellbeing of individuals and societies, outlining negative and positive structures of life. It observes life contentment, comprising everything from physical health, education, employment, wealth, family, religious principles, finance and the environment.<sup>3</sup> Caregiver burden implies to the effectual reaction of people to the altering challenges which arise as they provide support and care to the elderly individual.<sup>4</sup>

Care giving is an act of giving free support and care to family members, relatives that have physical, spiritual, or growing needs and generally has three forms of caring i.e. informational, instrumental, and emotional. Caregivers who take care of patients with mental health issues face many problems in their daily life routine.<sup>5</sup> Their social, individual, personal, and environmental relation worsens with the time as illness prolonged. Giving care to individual with psychiatric illness is a long-term stressor and increase one's burden.<sup>6</sup> Caregiver burden, particularly stress and tension is linked with use of maladaptive coping styles, low quality of life and increase level of psychological illness in caregivers.<sup>7</sup> In Pakistan, the incidence of issues regarding mental health is increasing steadily, as 10-16% people are experiencing mild to moderate mental illness and 1% are experiencing severe mental illness.<sup>8</sup> About 11.9% of the worldwide burden comprises of psychiatric disorders<sup>9</sup> and adds to the 1,607 DALYs/100,000 of the population in Pakistan.<sup>10</sup> Caregivers burden increases due to high physical, mental and social stress and caregivers are more

affected than patients and are at risk for developing depression stress and mood disorders, which worsen their health and quality of life.<sup>11</sup> The present study was intended to assess the impact of caregiver burden on quality of life in caregivers of patients with psychiatric disorders.

## METHODOLOGY

This correlational study included 100 patients with psychiatric disorders (schizophrenia and chronic depression) of duration 5 years or more. The sample for study consisted of 100 caregivers who were caring these mentally ill patients. Primary caregivers were the ones who spent most of the time with patient and looking after the patient. The age range of caregiver were 20 to 65. Sample of 100 caregivers of patients with psychiatric disorders were taken from different hospitals of Islamabad and Rawalpindi through convenient sampling technique. Only those participants are included in the study who are looking after of patients since 5 last years. Rest all were excluded. The study was MSc research Thesis, which was approved by the Institutional Review Board of University. Informed Consent was taken from all participants.

Data gathering instruments included Urdu version of WHO Quality of Life Questionnaire (WHOQOL-BREF)<sup>12</sup> which assessed the caregivers quality of life. It consists of 26 items from which the initial item is regarding the overall quality of life; the next item regarding overall bodily health; and other 24 items assess four areas of quality of life containing: bodily health (7 items); mental health (6 items); societal relationships (3 items), and environment (8 items). Higher scores signify higher level of quality of life. Second scale was Caregiver Burden Assessment Checklist. A popular caregiver self-report measure contain 9-item questionnaire consisting of 3-point likert scale. Response options range from 1 (about the same) to 3 (all the time). If answered two or more of these questions with 'All the Time' or if checked five or more with either 'More Frequently' or 'All the Time' it shows high level of burden.

**Statistical Analysis:** To estimate the internal consistency of the scales, Alpha reliability coefficient was computed and for the investigation of variable of present study Pearson Product

Moment Coefficient of Correlation was computed.

## RESULTS

Out of 100 caregivers, 50 were males and 50 female. Age range was 20-65 (Table 1). The  $\alpha$ -reliability of the scales showed that the instruments used are highly significant. WHO quality of life scale has reliability (i.e., .76) and caregivers burden checklist (i.e., .79) for sample of present study (Table 2).

**Table 1. Demographic characteristics of care givers.**

| Variable                      | Frequency | Percentage |
|-------------------------------|-----------|------------|
| <b>Gender</b>                 |           |            |
| Male                          | 50        | 50         |
| Female                        | 50        | 50         |
| <b>Age</b>                    |           |            |
| 20-33                         | 35        | 35.0       |
| 34-47                         | 31        | 31.0       |
| 48-62                         | 34        | 34.0       |
| <b>Social economic status</b> |           |            |
| Lower                         | 36        | 36.0       |
| Middle                        | 64        | 64.0       |
| <b>Occupation</b>             |           |            |
| Teacher                       | 25        | 25.0       |
| Driver                        | 11        | 11.0       |
| Shopkeeper                    | 22        | 22.0       |
| Army                          | 42        | 42.0       |
| <b>Duration</b>               |           |            |
| 5 years                       | 56        | 56.0       |
| 8 years                       | 31        | 31.0       |
| 10 years                      | 13        | 13.0       |
| <b>Family structure</b>       |           |            |
| Joint                         | 25        | 25.0       |
| Nuclear                       | 75        | 75.0       |
| <b>Psychiatric Disorders</b>  |           |            |
| Chronic Depression            | 36        | 36.0       |
| Chronic Schizophrenia         | 64        | 64.0       |

**Table 2. Descriptive and  $\alpha$ -reliability Value for Scales Quality of life and Care Giver Burden (N=100).**

| Scales | Mean  | SD   | $\alpha$ -reliability | Skewness | kurtosis | Range |
|--------|-------|------|-----------------------|----------|----------|-------|
| QOL    | 82.12 | 9.54 | .76                   | 0.19     | 4.07     | 66.0  |
| CGB    | 18.92 | 4.41 | .79                   | 0.56     | .14      | 18.0  |

*Note.* QOL=Quality of life; CGB=care giver burden

**Table 3. Relationship between care giver burden, and quality of life (N=100).**

| Variable | 1 | 2      |
|----------|---|--------|
| QOL      | - | -.56** |
| CGB      | - | -      |

Note QOL=quality of life, CGB=caregiver burden

**Table 4. Relationship of caregiver burden with quality of life subscales (N=100).**

| Variable | 1     | 2     | 3      | 4     | 5      | 6 |
|----------|-------|-------|--------|-------|--------|---|
| GH       | -     |       |        |       |        |   |
| PF       | .29** |       |        |       |        | - |
| IF       | .45   | .67** |        |       |        | - |
| SF       | .75   | .25   | .28**  |       |        | - |
| EF       | .47** | .30** | .57**  | .21*  |        | - |
| CGB      | -.32  | -.17  | -.29** | -.22* | -.34** | - |

Note. CGB= caregivers burden GH=general health, PF=psychological functioning, IF=individual functioning's SF=social functioning, EF=environmental functioning \*p≤.05. \*\*p≤.01\*\*\*p≤.001

Quality of life had strong, significant and negative relationship with care giver burden ( $r=-.56^{**}$ ) (Table 3). Caregiver burden was negatively related with all domain of quality of life and the relationship is highly significant with individual functioning, social functioning and environmental functioning (Table 4).

## DISCUSSION

We found higher level of burden on care giver is associated with disturbed quality of life. Our study findings are in coherence with the preceding literature.<sup>5-7,13</sup> Provision of care to psychologically ailing members of family with prolonged illness results in emotions of burden or pressure on caregivers which can deteriorate their quality of life. Providing care to patients has been described as a stressful experience that may erode psychological well-being, physical health, social and environmental functioning of caregiver. Maintaining patients care needs and sustaining well and fit life style can be challenging for caregivers. Social isolation, stigmatization and marital issues are outcomes which increases the burden. A study by Natasha et al showed that burden scores were

significantly related to caregivers' quality of life.<sup>14</sup> High burden results decrease in quality of life.

All domains of quality of life were badly affected. In physical health domain, caregivers stated that they were not able to move around and they need proper support for daily activities. In the social relationships, they reported that they were not able to satisfy personal relations and have difficulty in getting proper social support from surrounding. In the environment domain, caregivers reported that they needed a strong financial and healthy physical support in term of wealth, as well as time for extra activities, information about problem and good conditions of living.<sup>15</sup>

Further, the study showed that family members of patients with psychiatric disorders mostly face additional stressors directly and implicitly, their health conditions and life quality are lower than the overall people, with greater probability of depression. The caregivers of prolonged psychologically ill patients hold the complete caregiver burden, and consequently, they endure bodily and social health effects and economic difficulties as well as female perceive high burden as compare to males.<sup>16,17</sup>

The present observation on needs, burden and health related quality of life will be useful in planning services for the caregivers in Pakistan and in other countries of similar socio-cultural setting. This study suggests there is an unmet need to address the caregiver burden of caregivers. Taken as whole, these findings provide support for emphasizing early community intervention through redesigning in-home services that better meet the challenged needs of caregivers.

## CONCLUSION

The connection between the quality of life and burden in the research results revealed a negative association among them; increasing level of burden resulted in the poorer quality of life. Gradual increase in burden substantially are associated with deteriorating health related quality of life in caregivers.

**Author Contributions:**

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