## Original Research Article

# Depression and quality of life in family caregivers of individuals with psychiatric illness

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### ABSTRACT

**Background:** Psychiatric illnesses are mushrooming more than any physical illness. Change in health care delivery system emphases the need of family caregivers. Providing care for a psychiatric patient is demanding and challenging task leads psychosocial distress and negative impacts in quality of life. The study aims to determine depression, quality of life and their association with sociodemographic variables of family caregivers.
**Methods:** Sample consisted 150 family caregivers of individual with psychiatric illness seeking psychiatric outpatient department services. Physical health questionnaire (PHQ-9) and World Health Organization quality of life –BREF (WHOQoL-BREF) was used to ascertain information on depression and quality of life. A relevant descriptive and inferential statistics was applied to compute results.
**Results:** Findings exhibit that environmental quality of life domain was severely affected in caregivers. Further, 24% caregivers reported symptoms of moderate-severe depression. Occupation of caregiver found significant association with physical (p=0.001), psychological (p=0.001), social (p=0.016) and environmental (p=0.001) domain of QoL. Support from society also expressed significant association with psychological (p=0.001), social (p=0.007) and environmental (p=0.044) domain of QoL. Further, education of the caregiver shows significant association with physical (p=0.000), psychological (p=0.000), social (p=0.002) and environmental (p=0.000) domain of QoL.
**Conclusions:** Findings of the study sensitize policy makers and administrators to consider the need based psychiatric rehabilitation and implement it to reduce psychological distress and improve the quality of life of caregivers.

**Keywords:** Caregiver, Mental illness, Depression, Quality of life

## INTRODUCTION

Psychiatric disorders became major challenges and public health problem. The prevalence of psychiatric disorders is keep on rising globally. Change in psychiatric care concept such as deinstitutionalization and shifting the community care aspect enforce the need of role of family members to take over the care of a psychiatric patient. In India, psychiatric patient receives transient care at hospital and discharge for community care augments the role of caregivers in patient' care.[1] On the other hand, lack of formal home rehabilitation in India also push the role of active involvement of caregivers in care of patient at home.[2]

However, a significant development in psychiatric care from conventional methods of treatment to larger community involvement indicates growth in one corner of field. A caregiver is the family members who stay with patient and spend much time in different types of care

such as bathing, toileting, bedding, dressing and grooming etc, and helps a patient in social interaction with others.[3] Caregiving is a 24 hours' job with no rewards, sick leave or paychecks.

Caregiving is a demanding and difficult task that may have a negative impact on QoL of a caregiver. It has been reported that chronic caregiving become a burden for caregivers and leads psychosocial distress and compromised QoL in a caregiver.[4] WHO defined quality of life in terms of an individual's own perception of his/her life in his culture and customs. However, this definition gone multiple revision and edition and many changes over a period of time and included concepts of social, clinical and functional life in it. QOL also consist concepts of satisfaction to particular domain of life or to life as unit.[5]

Research evident that the QoL of caregivers of physical or mental illness generally has poor as compared to other family members not involved in patient care.[6] In the same way, caregivers of patient with mental illness shows poor QoL as compared to other family members and caregivers of individual with physical illness.[7] Further, it has been reported that caregivers of patient with mental illness experience more psychosocial distress such as anxiety, depression, insomnia, and poor social interaction and possibly early sickness and death. Similarly, a high level of stress, headache and family conflict, were also common in caregivers of individual with mental illness.[8]

It has been reported that environmental condition, caregivers' factors and caregiving situation had a significant impact on QOL of caregivers. Socio-demographic features of the patient such as age, gender, marital status, education status and patients' diagnosis had a direct link to psychosocial distress and QoL of a caregiver.[9] A better QOL was reported in male, young (<50 years), educated & employed caregivers in compare to their counterparts.[10] However, on the other hand research presented contrary findings indicates no relationship of gender of caregiver, and diagnosis of patient with QoL of caregivers.[11] Similarly, in an Ethiopian study, female caregiver, lack of peer support and psychosis diagnosis found linked with poor QoL in caregivers.[12] Likewise, increase duration of care and treatment, non-compliance with drugs, more frequent hospital admission, poor physical health and dementia as a differential diagnosis reported predictors of compromised QoL in caregivers.[13]

A major part of research in psychiatric field focused on QoL of patient and only a bunch of studies focused on caregivers and psychosocial distress. The aim of the study is to determine QoL, depression and their association with socio-demographic variables of caregivers.

## METHODS

A cross sectional descriptive study was conducted in the month of October 2017 – May 2018 in outpatient services at All India Institute of Medical Sciences (AIIMS), Rishikesh, Uttarakhand, a tertiary care teaching hospital. Sample size was calculated (180) considering the sample studied in previous study.[14] However, constrained data collection period reduced the sample size to 150. Purposive sampling with major subject criteria of 18 years of age, who diagnosed with psychiatric illness (diagnosis was made based on International Classification of Disease-10), and caregivers who are staying for minimum 3 months with patient and actively involved in daily activities of the patient were selected. Physical health questionnaire (PHQ-9) and World Health Organization Quality of Life (WHOQOL-BREF) was used to get information on study variables. The detail of the study instruments are as follows;

### World Health Organization quality of life- BREF (WHOQOL-BREF)

WHO had devised this questionnaire to measure health related quality of life (HRQoL).[15] The questionnaire consisted of 26 items categorized under 4 domains namely 1) Physical (7 items), 2) Psychological (6 items), 3) Social relationship (3 items), and 4) Environment (8 items). Each item rated on a 6-point rating scale from Not at all (1) to Important (5) or very dissatisfied to (1) to Very satisfied (5). WHO provided Hindi version of the questionnaire is used in the study. This questionnaire is cross culturally reliable (Cronbach's alpha=0.82) and valid to use.

### Physical health questionnaire (PHQ-9)

PHQ-9 is 3-point rating scale range; 0 (not at all) to 3 (nearly every day).[16] This instrument shows high criterion, convergent validity and internal consistently (Cronbach's alpha=0.88) in measurement of stress, depression, panic disorder and functional outcomes. A cut off score of more than 10 represent depression in an individual. Ethical permission sought from Institutional Ethical Committee (IEC) (IEC-115/IEC/SRS/2017).

## RESULTS

Appropriate descriptive and inferential statistics was applied to generate the results. Table 1 highlights the socio-demographic details of 150 caregivers and patients. It represents that 54.7% of the patients were females and 54% of the caregivers were male while 46% were female. 30% of caregivers were educated up to secondary school followed by 29.3% of the caregivers educated up to senior secondary school. In terms of occupation of caregivers, 47% were have private job, daily workers and shop owners etc. whereas 34% were homemakers and only 18.7% were in government job.

**Table 1: Socio-demographic variables of caregiver and patients (n=150).**

| Variables | f (%) |
|---|---|
| **Gender of patient** | |
| Male | 68 (45.3) |
| Female | 82 (54.7) |
| **Gender of caregiver** | |
| Male | 81 (54) |
| Female | 69 (46) |
| **Education of caregiver** | |
| Informal | 26 (17.3) |
| Up to secondary | 45 (30.0) |
| Up to senior secondary | 44 (29.3) |
| Graduate and above | 34 (22.7) |
| **Occupation of caregiver** | |
| Government job | 28 (18.7) |
| Home maker | 51 (34.0) |
| Other occupations*** | 71 (47.3) |
| **Habitat** | |
| Urban | 75 (50) |
| Rural | 75 (50) |
| **Entertainment activities** | |
| TV and sports | 74 (49.3) |
| Spiritual** | 37 (24.7) |
| Others | 39 (26.0) |
| **Support from society*** | |
| Yes | 54 (36.0) |
| No | 86 (64.0) |
| **Diagnosis of patient** | |
| Psychosis | 90 (60) |
| Neurosis | 60 (40) |

**Note:** *Financial and emotional support;**Reading religious books, prayer, going religious place etc.;***- private job, daily workers, shop owner etc.

Equally half of the subjects were belongs to urban (50%) and rural (50%) area. Nearly half (49.3%) of the caregivers engage in watching television and sports for entertainment and 24.7% use spiritual measures like prayers, reading religious books and visiting religious places for entertainment purpose. Majority (64%) of the caregivers were having no support from society and providing care to psychosis patients (60%).

**Table 2: Descriptive statistics of WHO QOL-BREF (n=150).**

| QoL domains | Mean±SD |
|---|---|
| **Physical** | 53.44±9.68 |
| **Psychological** | 51.44±11.0 |
| **Social** | 53.48±10.4 |
| **Environmental** | 49.28±9.28 |

Table 2 show descriptive statistics of WHOQOL-BREF revealed that caregivers have poor quality of life in environmental domain (49.28) followed psychological (51.44), physical (53.44) and social (53.48) domain of QOL.

PHQ-9 scoring of the subjects given in Table 3 showing mean score is 5.73 (±5.28). Further, findings revealed that nearly 24% subjects were in moderate to severe depression. However, around 49.3% subjects did not reports any symptoms of depression.

**Table 3: Level of depression in caregivers (as per PHQ-9) (n=150).**

| Level of depression | f (%) |
|---|---|
| **No depression** | 74 (49.3) |
| **Mild depression** | 40 (26.7) |
| **Moderate depression** | 26 (17.3) |
| **Moderately severe depression** | 10 (6.7) |
| **Mean±SD** | 5.73±5.28 |

**Table 4: Association of socio-demographic variables with WHOQOL-BREF (n=150).**

| Variables | QOL domains (Mean±SD) | | | |
|---|---|---|---|---|
| | Physical | Psychological | Social | Environmental |
| **Age of patient (years)** | | | | |
| <35 | 13.05±2.62 | 12.74±2.84 | 13.22±2.88 | 12.01±2.52 |
| >35 | 13.75±2.31 | 13.36±2.57 | 13.55±2.23 | 12.69±2.01 |
| P value | 0.086 | 0.042* | 0.442 | 0.072 |
| **Age of caregiver (years)** | | | | |
| Up to 40 | 13.88±2.62 | 13.31±2.85 | 13.73±2.54 | 12.46±2.40 |
| Above 40 | 12.94±2.32 | 12.49±2.63 | 13.07±2.63 | 12.20±2.26 |
| P value | 0.021* | 0.071 | 0.126 | 0.513 |
| **Gender of patient** | | | | |
| Male | 12.66±2.59 | 11.73±2.64 | 12.84±2.90 | 11.91±2.39 |
| Female | 13.94±2.26 | 13.80±2.48 | 13.80±2.25 | 12.65±2.21 |
| P value | 0.002* | 0.000* | 0.024* | 0.051 |

Continued.

| Variables | QOL domains (Mean±SD) | | | |
|---|---|---|---|---|
| | Physical | Psychological | Social | Environmental |
| **Gender of caregiver** | | | | |
| Male | 13.98±2.25 | 13.64±2.48 | 13.75±2.33 | 12.62±2.25 |
| Female | 12.65±2.59 | 11.95±2.80 | 12.93±2.84 | 11.96±2.36 |
| P value | 0.001* | 0.000* | 0.055 | 0.086 |
| **Occupation of caregiver** | | | | |
| Govt. job | 13.98±2.29 | 13.90±2.65 | 13.86±2.52 | 13.63±1.91 |
| Home maker | 12.30±2.37 | 11.74±2.75 | 12.52±2.88 | 11.70±2.25 |
| Other occupations | 13.88±2.44 | 13.26±2.55 | 13.78±2.29 | 12.25±2.34 |
| P value | 0.001* | 0.001* | 0.016* | 0.001* |
| **Education of caregiver** | | | | |
| Informal | 11.56±1.77 | 11.15±2.44 | 11.79±2.96 | 10.75±1.83 |
| Upto secondary | 13.38±2.52 | 12.65±2.84 | 13.30±2.58 | 11.68±2.18 |
| Upto sr. secondary | 13.79±2.27 | 13.06±2.37 | 13.61±2.10 | 12.88±1.64 |
| Graduate and above | 14.25±2.56 | 14.20±2.70 | 14.35±2.50 | 13.53±2.69 |
| P value | 0.000* | 0.000* | 0.002* | 0.000* |
| **Support from society** | | | | |
| Yes | 13.13±2.19 | 13.86±3.00 | 14.12±2.70 | 12.82±2.34 |
| No | 13.79±2.93 | 12.30±2.44 | 12.94±2.4 | 12.03±2.27 |
| P value | 0.118 | 0.001* | 0.007* | 0.044* |
| **Habitat** | | | | |
| Urban | 13.74±2.28 | 13.24±2.70 | 13.35±2.42 | 12.71±2.46 |
| Rural | 12.99±2.65 | 12.49±2.76 | 13.39±2.79 | 11.93±2.12 |
| P value | 0.066 | 0.097 | 0.934 | 0.039* |

*p value significant as ≤0.01.

**Table 5: Association of depression with demographic variables (n=150).**

| Variable | No depression (f) | Mild depression (f) | Moderate - severe depression (f) | P value |
|---|---|---|---|---|
| **Patient age (years)** | | | | |
| Up to 35 | 35 | 20 | 27 | 0.019* |
| Above 35 | 39 | 20 | 09 | |
| **Caregiver education** | | | | |
| Informal | 06 | 08 | 12 | |
| Up to secondary | 23 | 08 | 14 | 0.010* |
| Up to senior secondary | 25 | 14 | 05 | |
| Graduate and above | 19 | 10 | 05 | |
| **Habitat** | | | | |
| Urban | 39 | 25 | 11 | 0.017* |
| Rural | 35 | 15 | 25 | |
| **Gender of patient** | | | | |
| Male | 28 | 16 | 24 | 0.013* |
| Female | 46 | 24 | 12 | |

Chi square test, *p value significant as ≤0.01.

Table 4 represents findings related to association of socio-demographic variables with domains of WHO QOL-BREF. Findings revealed that physical QOL found significantly associated with occupation of caregiver (p=0.001), gender of caregiver (p=0.001), and gender of patient (p=0.002), education of caregiver (p=0.000) and age of caregiver (p=0.021).

Psychological domain found significantly associated with government job as occupation of caregiver (p=0.001), male as gender of caregiver (p=0.000), presence of some support from society (p=0.001), female as gender of patient (p=0.000), education of caregiver as graduated (p=0.000) and age above 35 years of patient (p=0.042).

Social domain was found to be significantly associated with government job as occupations of caregiver

(p=0.016), presence of support from society (p=0.007), female as gender of patient (p=0.024) and education of caregiver as graduated and above (p=0.002).

Environmental QOL domain found significantly associated with government job of caregiver (p=0.001), urban residency (p=0.39), availability of support from society (p=0.044) and education of caregiver (p=0.000).

Table 5 shows association of depression with socio-demographic variables of the caregivers and patients. Chi-square test was used to produce results. Findings revealed a significant association of depression with age of the patient (p=0.019), education of caregiver (p=0.010), habitat (p=0.017) and gender (p=0.013) of the patient.

## DISCUSSION

The present study aims to determine quality of life (QOL) and depression in 150 family caregivers of individual with psychiatric illness. Although, there is lack of control group and small sample size, the findings are exemplary to sensitize the health care personnel to take necessary and corrective steps to treat early psychosocial problems in this most neglected set of population.

In India, caregiving is an obligation to respect his/her family members when they fall sick or ill. Family members automatically take a role of caregiver and unite to provide best possible care. Still, a transient caregiving assignment may not have any significant impacts on health of caregivers, but chronic and long lasting caregiving charge may have adverse impacts on health of a caregiver.

Study findings represent a poor quality of life in caregivers in all domains and environmental quality of life is severely affected. These study findings are in-line with the work conducted by Neong et al which reported a poor quality of life in environmental domain followed by psychological, social and physical quality of life in caregivers.[7] Further, study findings are in agreement with the results of study conducted on caregivers of obsessive compulsive disorders reported a compromised quality of life.[17] Close related and steady findings also reported in Uganda study for compromised quality of life in caregivers.[18] However, these findings are because of high level of burden perceived and reported by the caregivers in terms of more attention, sparing much time, and energy in patient care. Further, in a Hon Kong study on caregivers reported significantly lower quality of life than other Chinese population.[19] Poor quality of life also reported in an Indian work conducted by Basheer et al on caregivers of mentally ill patients.[9] Similar findings for impaired quality of life in caregivers also reported in caregivers group of Pakistan.[20]

Successively, study findings represent that chronic caregiving task push around 24% caregivers in moderate

to severe depression. The mean PHQ-9 score is 5.73 (±5.28). These findings are in-line with the work of Jeyaguruhathant et al, which represent a mean score 4.73 (±5.26).[13] Further same work revealed that 18.3% caregivers were perceived symptoms of depression while 12.7% were in anxiety (based on general anxiety disorder, GAD). Similarly, a close related findings for depression reported in a work of Liang et al in which 22.4% of caregivers reported depressive symptoms while 26.5% were have cognitive deficit.[21]

We found a statistical significant difference in the mean of physical, psychological, social and environmental domains score according to caregiver education, occupation. Patient's age, gender, support from society, residence status, and gender of caregiver were other factors that affected quality of life.

These results are in agreement with several studies in which it has reported that less educated, unemployed, female and elderly caregiver, patient's gender had statistically significant association with impaired quality of life as compare to their counterparts.[8,9,13,18,22-26]

## CONCLUSION

The study findings reported compromised quality of life in caregivers of individuals with mental illness. Further, a bunch of caregivers found in high level of depression and need immediate intervention to overcome any untoward events. Further, it was reported that younger caregivers found mores psychologically disturbed to manage older patients. Similarly, female caregivers reported more poorer quality of life as compared to their counterparts.

### Recommendations

The study recommends that policy makers should take early and necessary steps to develop a structured home based programme and devise policy to execute at community level for better rehabilitation of individuals with mental illness in order to improve the QOL of caregivers. Furthermore, it gives opportunity to health care personnel to observe caregivers for any psychosocial or emotional problems, and suggest right interventions timely.

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