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Original Article

Quality of Life of Family Caregivers of Patients with Mental Illness in a Hospital

Anjani Karna[1*], Rajdevi Adhikari[2], Tilarupa Bhattarai[3]

[1]Assistant Professor, Birarngar Nursing Campus, TU, IOM,
[2]Associate Professor, Adult Health Nursing Department, Maharajgunj Nursing Campus, TU, IOM
[3]Lecturer, Psychiatric Nursing Department, Maharajgunj Nursing Campus, TU, IOM
***Corresponding Author**: Anjani Karna, njnkarna@gmail.com

ABSTRACT

Background: Quality of Life (QOL) is a measure of a person's functional capacity and overall health. Those who provide care for people with mental illnesses have reported a lower quality of life. Caregivers of mentally ill patients often experience higher levels of stress, psychological problems, social isolation, and family conflict. This study aimed to evaluate QOL for individuals caring for people with mental illness.

Method: A descriptive cross-sectional study design was used. A total of 264 caregivers from the Mental Hospital's Psychiatric Outpatient Department in Lagankhel were selected using a non-probability purposive sampling technique. Data were collected from BS 2079/04/22 to 2079/05/18 using a structured questionnaire. The WHOQOL BREF Questionnaire and questions about sociodemographic and mental health factors were included in the interview questionnaire. Data were analyzed using descriptive and inferential statistics version 16.

Results: findings of the study showed that 44.3% of respondents had poor QOL, while 55.7% had good QOL. QOL was associated with several demographic factors, including patient age group ($p = 0.035$), sex ($p = 0.030$), and disease type ($p = 0.038$). Additional associations were observed with caregiver age group ($p = 0.017$), sex ($p = 0.018$), education ($p = 0.043$), and relationship with patients ($p = 0.0009$).

Conclusion: Caregivers' QOL was lower in the social domain and higher in the physical domain. health care practitioners should pay attention to caregivers' social needs to improve their overall quality of life.

Keywords: Caregiver, Hospital, Mental illness, Quality of Life

INTRODUCTION

According to the World Health Organization (WHO), approximately 970 million people globally[1] (1 in every 8) are affected by mental illnesses, including schizophrenia, bipolar disorder, and depression. The population living with disabilities is increasing, and mental illness constitutes a significant portion of this burden. In the context of Nepal, the prevalence and disease burden of mental disorders are high. Mental illnesses account for approximately 18% of the non-communicable disease (NCD) burden[2]. Among these, it is estimated that about 1% of the Nepalese population is affected by severe mental disorders.[3]

People who provide care for patients are known as caregivers, and most of them are the patients' family members.[4] Their patients' families are the main sources of support in their lives. They offer patients emotional support, personal attention, and practical help.[5] The caregiver role is an unpredictable experience that requires continuous hard work and effort. Some of these tasks include providing care measures for the patient's personal hygiene and providing emotional support, such as listening, counselling, and company, as well as informational care, such as how to change the patient's living environment. [6] evidence indicates that they have a high prevalence of various problems in their personal lives.[7] Mental illnesses in a family may affect other members, resulting in a lack of leisure activities, alteration in domestic routine, social isolation, financial difficulties, and employment difficulties, which disrupt caregivers' lives. Emotional strain might include feelings of fear, despair, wrath, guilt, loss, rejection, and stigma.[8]

Due to the substantial disability brought on by their sickness, patients with severe mental illness become highly dependent on caretakers. Their health, employment, relationships, and social interactions are all impacted by this reliance and caregiving duty, which also adds to their distress.[9] caregiving is a very challenging task, caregiving not only determines care but also the well-being of individuals with disabilities or illnesses and that of caregivers.[10] Family members' mental illnesses have an impact on the caregivers' financial situation, causing or exacerbating poverty.[11]

A study from Hong Kong states that 57.3% had poor QOL.[12] A similar study conducted in Europe found that caregivers' QOL is lower than that of the general population.[13] studies conducted among caregivers at the outpatient of psychiatric hospital show that 53.2% of caregivers had a low QOL.[14]

A similar study in Nigeria found that the physical domain score was 14.2 ± 2 2.47, the psychological domain was 17.19 ± 1.71, the social domain was 16.64 ± 3.50, and the environment domain was 15.78± 2.82.[15]

A study was carried out at the Hospital of Uganda, environmental domain 50.49 ± 17.35.12, social domain 51 ±.64 21.08, psychological domain 55.97 ± 15.94, and physical domain 55.20 ± 15.90.[12]

The overall mean QOL scores for each domain were as follows: social domain 55.97 ± 15.94 and physical domain 55.20 ± 15.90. A study conducted in Penang, Malaysia, reported these values, with the physical domain receiving the highest mean score among respondents.

The main goal of this study is to evaluate the quality of life of family caregivers of patients. Another objective is to measure certain characteristics of the caregivers that may influence their quality of life.

METHOD

A cross-sectional, descriptive research design was used. The Lagankhel Mental Hospital's outpatient department (OPD) served as the study's site. Ethical approval was taken from Maharajgunj, Kathmandu. Permission was obtained from the hospital by submitting a written request Letter. Family caregivers of patients were selected as participants, ensuring the dignity and consent of both the caregivers and the patients. Data were collected through structured interviews. The interview was conducted in a separate corner in the outpatient department. The requirements for caregiver inclusion are: relatives of those suffering from mental illness, especially schizophrenia, mood disorder, anxiety disorders, and depression, who have been under treatment for more than three months, should be of the age 18 years or above. Those family members who are the most responsible persons for taking care of patients and providing necessary daily care for at least 3 months. Caregivers were selected from those accompanying patients attending the psychiatric outpatient department (OPD) of the Mental Hospital, Lagankhel. Selection was based on OPD tickets of patients visiting the psychiatric OPD.

After screening the OPD tickets of patients attending the psychiatric OPD, family members of patients with specific mental illnesses were identified and contacted. The instrument used for data collection was a standardized tool, the WHOQOL-BREF, comprising 26 items rated on a 5-point Likert scale (1–5).

This instrument was divided into five sections: part one included the sociodemographic data of family caregivers, part two covered the sociodemographic data of patients suffering from mental illness, part 3 consisted of disease related variables, part 4 consisted of care provision related factors and part 5 consisted of WHO QOL- BREF Questions. 27 family caregivers of patients with mental diseases who were enrolled at Tribhuvan University's Teaching Hospital, Mahrajgunj psychiatric outpatient department. participated in a pre-test of the instrument. Before data collection, each family caregiver provided written informed consent. The dignity of the family caregiver and the patient was preserved by giving them the option to leave this study at any moment without incurring any fees. Data was collected from

2079/04/22 to 2079/05/18. The average time taken to complete the interview for one participant was approximately 25-30 minutes. Data was coded, organised, and entered into SPSS 16.0. Frequency, percentage, mean, median, and inferential statistics were computed from the data using descriptive statistics. The association between QOL and different covariates was evaluated using the chi-square test.

RESULT

The study was carried out with 264 family caregivers of mentally ill patient Most respondents were aged 40–50 years (31.8%), with a mean age of 38.69 ± 11.86 years. Males (61.0%) predominated. The largest ethnic group was Brahmin/Kshetri (37.1%), and most respondents were Hindu (72.3%). More than half lived in joint families (55.3%), and the majority were married (76.5%).

The majority of respondents were literate (86.0%), with secondary education being the most common level (31.2%). Business was the most frequent occupation (31.8%). More than half of the respondents' families had sufficient income for more than 12 months (52.3%). Spouses constituted the largest group of caregivers (37.9%).

Most patients were aged 18–28 years (29.9%), with a mean age of 37.9 ± 13.44 years. Females comprised the majority (59.5%). Most patients were married (61.0%) and literate (88.6%). Business was the most common occupation (34.8%), while 12.1% of patients were unable to work.

Most of the patients diagnosis was Schizophrenia (41.7%). Most patients had no history of hospitalization (69.3%). Over half of the patients had an illness duration of less than two years (55.3%). The majority were receiving medication only (81.4%). Most patients did not require caregiver support (67.4%). The highest mean QOL score was observed in the physical domain (22.14 ± 2.1), followed by the environmental, psychological, and social domains. The social domain showed the lowest mean score (8.7 ± 2.8). More than half of the respondents (55.7%) had a good quality of life, while 44.3% had a poor quality of life. Respondents' quality of life showed a statistically significant association with age, sex, education status, and relationship with the patient ($p < 0.05$).

Respondent's patient quality of life was significantly associated with patients' age, gender, and type of mental illness ($p < 0.05$).

TABLE 1

Socio-demographic Characteristics of the Respondents n = 264

Variables	Frequency	Percent
Age in completed years	60	22.7
18 – 28	79	29.9
29 - 39	84	31.8
40 – 50	31	11.7
51 – 61	10	3.9
≥ 61		
(Mean 38.69, SD ± 11.86)		
Sex		
Male		
Female	161	61.0
	103	39.0
Ethnicity		
Brahmin/Kshetri		
Janjati	100	37.1
Dalit	66	24.1
Muslim	56	21.1
Madheshi	17	10.0
	25	8.0
Religion		
Hinduism		
Buddhism	191	72.3
Christianity	35	13.5
Islam	20	7.6
	18	6.6
Type of family		
Joint family		
Nuclear	146	55.3
Extended family	114	43.2
	4	1.5
Marital status		
Married		
unmarried	202	76.5
Singlehood	47	17.8
	15	5.7

Table 1 presents the sociodemographic characteristics of the respondents. The largest age group of respondents was 40–50 years (31.8%). The majority of respondents were male (61.0%). Nearly one-third of the respondents (37.1%) belonged to the Brahmin/Kshetri ethnic group, and most respondents (72.3%) were Hindu. More than half of the respondents (55.3%) lived in joint families, and the majority (76.5%) were married.

TABLE 2

Socio-demographic Characteristics of the Respondents n= 264

Variables	Frequency	Percent
Education status		
Can read and write	227	86.0
Cannot read and write	37	14.0
Educational Level (n=227)		
Primary	37	16.2
Basic	65	28.6
Secondary	71	31.2
Bachelor and above	54	23.7
Occupation		
Business	84	31.8
Service	69	26.2
Homemaker	36	13.6
Labor	35	13.5
Farmer	25	9.5
Student	15	5.7
Family Income		
Enough for 6- 12 month	138	52.3
Enough for more than 12 month	95	36.0
Enough for 6 month only	31	11.7
Relationship with patient		
Spouse	100	37.9
Children	67	25.4
Parent	65	24.6
Sibling	32	12.1

Table 2 shows that most of respondents (86.0%) could read and write. Among them nearly one third of the respondents (31.27%) had obtained secondary level education. Similarly, nearly one third of the respondents (31.8%) were engaged in business. Regarding the monthly family income, more than half of the respondents (52.3%) family earns enough money sufficient for a year. More than one third (37.9%) of the respondents were spouse of their patients.

TABLE 3

Socio-demographic Characteristics of the Patients, n = 264

Variables	Number	Percentage
Age group in completed years		
18 – 28	79	29.9
29 – 39	65	24.6
40 – 50	72	27.3
51 - 60	33	12.5
>61	15	5.7
Mean 37.9, SD ± 13.44		
Sex		
Male	107	40.5
Female	157	59.5
Marital status		
Married	161	61.0
Unmarried	62	23.5
Separated	24	9.1
Window	17	6.4
Literacy status		
can read /write	234	88.6
Cannot read/write	30	11.4
Educational level (n=234)		
Primary	33	14.10
Basic	67	28.6
Secondary	93	39.7
Bachelor and above	41	17.6
Occupation level		
Business	92	34.8
Service	42	15.9
Homemaker	35	13.3
Labor	25	9.5
Farmer	21	8.0
Student	17	6.4
Unable to work	32	12.1

Table 3 shows that more than one-third of the patients (29.9%) were between the ages of 18 and 28 yrs. Similarly, 59.5% of the patients were female. The majority of patients (61.0%) were married, and the majority of patients (88.6%) could read and write. Similarly, one-third of patients' (34.8%) occupations were business, and 12.1% of respondents' patients were unable to work.

TABLE 4

Illness related Characteristics of Patients, n= 264

Variables	Number	Percentage
Types of mental illness		
Schizophrenia	110	41.7
Anxiety Disorder	59	22.3
Bipolar Affective disorder	61	23.1
Depressive disorder	34	12.9
History of hospitalization		
Yes	81	30.7
No	183	69.3
Frequency of hospitalization (n= 81)		
One time	32	12.1
Two time	15	5.7
Three time	18	6.8
More than four times	16	6.1
Duration of illness	146	55.3
< 2 year	22	8.3
2- 4 year	18	6.8
4- 6 year	78	29.6
≥7		
Current treatment		
Medicine	215	81.4
Medicine and	19	7.2
Psychotherapy	30	11.4
Medicine, Psychotherapy		
and Traditional		
Support from caregiver		
No need for caregiver	178	67.4
support	39	14.8
Continuous support from	47	17.8
caregiver only		
Continue support from		
caregiver and other family		
member		

Table 4 shows that more than one third of the respondent's patient were (41.7%) diagnosis with Schizophrenia. Likewise, Majority of the patient (69.3%) had not history of Hospitalization of hospital. Regarding hospitalization, 12.1% patients were hospitalized for one time. Similarly more than half (55.3%) of patient had less than 2 years as their duration of illness. Regarding the current treatment most of the patient (81.4%) used medicine. Regarding the support from caregiver majority of the patient (67.4%) take care of own self and 17.8% required continue support from caregiver only.

TABLE 5

Domain wise and Overall Level of QOL Scores of the Respondents, n = 264

Domain	Minimum	Maximum	Raw Mean score± SD	Transformed Mean Score ± SD
Physical	14	30	22.14 ± 2.1	50.87 ± 13.57
Environmental	13	27	20.65 ± 1.9	54.64 ± 13.12
Psychological	12	23	17.19 ± 1.7	47.18 ± 8.75
Social	4	13	8.7 ± 2.8	30.83 ± 15.13
Overall	5	10	5.7 ± 1.1	42.25 ± 13.75

Table 5 portrays that the minimum score and maximum scores for physical domain. The mean scores± SD were 22.14 ± 2.1, 20.65 ± 1.9, 17.19 ± 1.7 and 8.7 ± 2.8 for Physical, environmental, psychological and social domains respectively. Whereas, overall mean score of all domains was 5.7 ± 1.1 SD. The mean score of Physical domain appears to be highest with comparison to other three domain.

TABLE 6

Level of QOL of the Respondents, n = 264

Level of QOL	Number	Percentage
Poor (< 45)	117	44.3
Good (≥45)	147	55.7
Mean 45 , SD ± 8.064		

Table 6 shows that more than half of respondents (55.7%) had good QOL and 44.3% of respondents had poor QOL.

TABLE 7

Association between QOL of the Respondents and Socio-demographic Characteristic, n = 264

Variables	QOL Poor No. (%)	QOL Good No. (%)	χ2	p-Value
Age groups (in years)				
18 – 39	52 (40.0)	87 (60.0)	5.677	0.017
40 – 68	65 (52.0)	60 (48.0)		
Sex				
Male	62 (53.0)	99 (47.0)	5.643	0.018
Female	55 (67.3)	48 (32.7)		
Education status				
Literate	99 (44.6)	123(55.4)	0.835	0.043
Illiterate	18 (42.9)	24 (57.1)		
Relationship with				
patient	40 (61.5)	25 (38.5)	11.507	0.009
Parents	35 (35.0)	65 (65.0)		
Spouse	28 (41.8)	39 (58.2)		
Children	14 (43.8)	18 (56.3)		
Sibling				

Table 7 shows that the QOL of respondents was significantly associated with their age, sex, education and relationship with patient. Level of significance: < 0.05

TABLE 8

Association between QOL and Socio-demographic Characteristic of the Respondents' Patients, n = 264

Variable	Poor QOL No. (%)	Good QOL No. (%)	χ2	p- value
Age group in year				
18 – 39	64 (43.0)	86 (57.0)	4.462	0.035
40 – 65	53(46.5)	61 (53.5)		
Patient gender				
Male	56 (52.3)	51 (47.7)	4.612	0.030
female	61 (38.9)	96 (61.1)		
Types of mental illness				
Schizophrenia	57 (51.5)	53 (48.5)	4.298	0.038
Others*	60 (33.1)	94 (66.9		

Table 8 shows that QOL of respondents' patients was significantly associated with their patients' age, sex and types of mental illness. Level of significance: < 0.05

DISCUSSION

In this study, the QOL was assessed in four distinct domains: environmental, social, psychological, and physical. The QOL mean and standard deviation for the physical, psychological, social, and environmental categories were 54.64±13.57, 46.62±8.75, 30.83±15.13, and 50.87±13.12, respectively. The study from Nigeria showed that the QOL of the social domain was comparatively higher than other domain with the mean scores: Physical domain 14.22 ± 2.47, psychological domain 17.19 ± 1.71, social domain 16.64 ±3.50, environment domain 15.78± 2.82.[16]

A study was carried out in a tertiary care facility's outpatient department in an urban Indian hospital. The physical domain had the highest score (15.15), followed by the social (12.75), environmental (12.96), and psychological (12.52) domains. These results were less than those of the current investigation.

In terms of respondents' QOL, less than half (44.3%) reported having a poor QOL. A similar study in Pekanbari, Indonesia, found that 53.2% of respondents had a low QOL.[14] A similar type of study conducted in the Hospital of Uganda has found that 57.30% had poor QOL.[12] QOL in the present study seems a bit higher than in previous studies. The difference in findings might be because of different cutoffs taken by each study, as the obtained mean Scores were different in different studies.

In contrast, a study conducted in Indonesia reported a statistically significant correlation between respondents' age and their quality of life (*p* = 0.017). [20] Similarly, a related study carried out in a metropolitan area found that the age of the caregiver significantly affected most WHOQOL dimensions. [19]

Regarding the association between QOL and sex of respondents (p- 0.018), the present study showed a significant association of QOL with respondents' sex, which is support in study conducted in Indonesia that showed consistent findings with the present study. [14]

Regarding the association between QOL and sex of respondents (p- 0.018), the present study showed a significant association of QOL with respondents' sex, which is support in study conducted in Indonesia that showed consistent findings with the present study. [14]The finding of present study showed significant association between QOL and relationship of respondents with their patients, (p-0.0009) which is Supporting the present study, A study carried out in Indonesia found a strong correlation between patients' relationships with their caregivers and their quality of life.[14]The current study finds a significant relationship between QOL and respondents' educational status (p- 0.043), which contrasts with the findings of an Indonesian study. [13] Similar study conducted in Korea revealed a significant association between QOL and caregiver's education status.[16]The current study found a significant association between caregiver QOL and patient age (p - 0.035), which is similar to the results of a study conducted in Ghana. [21] Patient sex and caregiver QOL were significantly correlated (p = 0.03). which contrasts with the findings of an Indonesian study, which found no significant association between the given variables.[6] The current study found a significant relationship between caregiver QOL and type of mental illness, (p=0.038) which is supported by a Ghanaian study.[17]

CONCLUSION

Based on the results of the study, caregivers of individuals with mental illness have a lower quality of life (QOL). The QOL of caregivers was found to be associated with their age, gender, education, and relationship with the patient, as well as the age and gender of the patient. Additionally, caregivers' QOL was lower in the social domain and higher in the physical domain.

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