

## Study of Quality of life of family caregivers of hospitalized COVID-19 patients

Dr. Gunjan Solanki<sup>1</sup>, Dr. Chitra Singh<sup>2</sup>, Dr. Siddharth sharma<sup>2</sup>, Dr. Neeraj Gadwal<sup>3\*</sup>, Dr. Richa Jain<sup>4</sup>

<sup>1</sup>Associate Professor, Department of Psychiatry, <sup>2</sup>Associate Professor, Department of Anesthesia, <sup>3</sup>Senior resident, Department of Psychiatry, <sup>4</sup>Junior resident, Department of Psychiatry, SMS Medical College, Jaipur

\*Corresponding Author: Dr. Neeraj Gadwal

Email: [dr.neerajgadwal@gmail.com](mailto:dr.neerajgadwal@gmail.com)



### Abstract

**Background:** High morbidity and mortality due to this virus led to an international health crisis. Whereas frontline health workers, face problems due to increased work load, intense working schedule and increased chance of getting exposed to positive cases, the primary caregivers who are mostly family members and are indispensable in providing support to their member with illness in acute care settings, are also affected in various domains of their functioning. This affects their overall quality of life. **Materials and Methods:** This cross-sectional observational study was done at Sawai Man Singh and attached hospital, Jaipur. It included 45 caregivers of hospitalized COVID-19 patients. All subjects were evaluated by a general information sheet. WHOQOL-BREF was applied and statistical analysis done by SPSS 23. **Results & Conclusion:** Factors which were significantly associated with QOL and its domains were duration of illness, duration of hospitalization, severity of COVID-19 illness, occupation and marital status. Duration of illness and hospitalization can be reduced with early identification of illness and effective management which may improve QoL of caregivers. Also, there is need to rotate caregivers among family members and incorporating recreational activities for informal caregivers of Covid-19 patients to improve their QoL

**Keywords:** QoL, COVID-19, caregiver

### Introduction

World Health Organization identified COVID-19(Coronavirus disease of 2019)as Public Health Emergency of International Concern (PHEIC)<sup>1</sup> on 30 January 2020 and as being a pandemic on the 11th of March 2020.The spread of this new virus, moreover its increasing incidence, rapidly forced a large part of the world's countries to take drastic health measures to safeguard populations.<sup>2,3</sup> High morbidity and mortality due to this virus led to aninternational health crisis.<sup>4</sup> The present circumstances owing topandemic of this deadly virus have generated increased worry, stress and fear among population subgroups across the countries. Among general population, there'swidespread panic due to lack of substantial data regarding the matter resulting in misconception, misinterpretation, stigma and rumors.<sup>5</sup> Whereas frontline health workers who are pillars of caregiving at hospital settings, face problems due to increased work load, intense working schedule and increased chance of getting exposed to positive cases,<sup>6</sup> the primary caregivers who are mostly family members and are indispensable in providing support to their member with disability or illness in acute care settings,<sup>7</sup> are also affected in various domains of their functioning. This caregiving stress affects their overall quality of life.

A caregiver is an unpaid individual (a spouse, partner, family member, friend, or neighbor) involved in assisting others with activities of daily living and/or medical tasks.Caregivers provide all kinds of support to the care receivers ranging from assistance with daily activities to running errands and providing company/emotional support. Providing care to someone whether full time or part-time, formal or informal takes a huge toll, both physically and emotionally. Allowing the family members to take care of the critically ill patients brings them together emotionally and helps the patients feel comfortable in

unaccustomed setting of a hospital emergency.<sup>4</sup> Just as every pandemic, Covid-19 could lead to emotional and psychological disturbances among caregivers particularly those of hospitalized patients. Dependency on family members for caregiving in acute care setting in hospitalized patients in India is because of lack of adequate trained manpower in hospitals.<sup>8</sup> This may affect Quality of life of caregivers. Several studies have documented the considerable impact that caregiving has on caregiver quality of life (QOL).<sup>9</sup> In the study on survivors of ARDS patients, they have found clinically significant reduction in quality of life of caregivers.<sup>10</sup> Family caregiver QOL is an important issue which influences the quality of care of the patient as well as contributes to psychological morbidity of caregiver, therefore it is important to address the needs and gaps in mental and psychological aspect of health in this subgroup of population. This study is planned in order to elucidate Quality of life of family caregivers during Covid – 19 pandemic.

### **Aim and Objective**

To study quality of life of caregivers (family members) of hospitalized COVID 19 patients.

### **Materials and Methods**

This cross sectional, descriptive, hospital based study was conducted in the Dept. Of Psychiatry, SMS Medical College, Jaipur. After approval from institutional review board and ethical committee, 45 caregivers of hospitalised COVID-19 patients who were willing to participate in study were recruited after taking proper consent. Subjects of both sex and age more than 18 years were included and those with history of taking psychiatric treatment in last 1 month or significant substance use including heavy smoking (more than 15 cigarettes per day) or Clinical evidence of active infection were excluded. This was followed by detail history and clinical examination by using a specially designed General Information Sheet. World Health Organization Quality of Life Instrument, Short Form (WHOQOL-BREF)<sup>11</sup> Hindi version was applied. The WHOQOL-BREF consists of 26 items. Each item uses a Likert-type five-point scale. These items are distributed in four domains i.e. physical health, psychological wellbeing, social relationships and environment. There are also two items that were examined separately: one which asked about the individual's overall perception of QOL and the other which asked about the individual's overall perception of his or her health. Domain scores are scaled in a positive direction (Higher scores denote better quality of life). Data analysis was conducted using frequency distribution for categorical variables and summary statistics for continuous variables using spss version 23. P value less than 0.05 was taken as significant. To find difference between two groups independent sample t-test was applied and for comparing multiple groups one way ANOVA was applied. For comparing continuous variables, Pearson's correlation was applied.

### **Results**

Most of the subjects of our study were young adult (18 to 45 years) married males with educational status graduate and above and skilled and professionals by occupation living in urban area (Table 1). Most of the patients were suffering from acute phase illness of severe COVID- 9 infection (Table 2). Factors which were significantly associated with QOL and all domains were duration of illness and duration of hospitalization. Severity of COVID-19 illness was found to be associated with Psychological domain of QOL. Only sociodemographic factors associated with QOL were occupation and marital status (Table 3).

Table 1. Sociodemographic Profile of caregivers (N=45)

Sr No.	Variable	Number	Percentage	
1	Age (years)	18 - 20	1	2.2
		21 - 30	22	48.9
		31 - 40	10	22.2
		>40	12	26.7
2	Gender	Male	35	77.8
		Female	10	22.2
3	Locality	Rural	17	37.8
		Urban	28	62.2
4	Education	<10 <sup>th</sup> standard	2	4.4
		Secondary to Sr. Secondary	12	26.7
		Graduate and more	31	68.9
5	Occupation	Unemployed	3	6.7
		Semi Skilled	1	2.2
		Skilled	9	20
		Professional	17	37.8
		Student	12	26.7
		Housewife	3	6.7
6	Marital Status	Married	29	64.4
		Unmarried	16	35.6
7	Family Type	Nuclear	7	15.6
		Joint	30	66.7
		Extended	8	17.8
8	Family Income (In Rupees)	25000 to 50000	36	80
		20000 to 25000	7	15.6
		<20000	2	4.4
9	Relation with Patient	Parent	15	33.3
		Sibling	7	15.6
		Spouse	3	6.7
		2 <sup>nd</sup> degree Relative	7	15.6
		Friend	2	4.4
		Others	11	24.4

Table 2. Clinical profile of patients (N=45)

S. No.	Variable	Mean	SD
1	Duration of illness (days)	13.78	11.9
2	Duration of hospitalization (days)	10.78	11.8
3	Severity of Covid infection (CT score on HRCT)	17.9	2.3

**Table 3. Quality of Life (QOL) of Caregiver and it's relationship with sociodemographic and clinical variable (N=45)**

QOL Domains	Domain 1 (Physical)		Domain 2 (Psychological)		Domain 3 (Social)		Domain 4 (Environmental)		QOL total	
Mean(SD)	67.02 (16.9)		70.09 (17.9)		59.77 (18.61)		59.73 (15.9)		99.91 (16.67)	
	Coef	P-value	Coef	P-value	Coef	P-value	Coef	P-value	Coef	P-value
Age	.761	.522	.864	.467	.052	.984	.981	.411	.875	.462
Gender	0.975	0.335	.097	.923	-1.13	.267	1.303	.200	.675	.496
Locality	-0.654	.517	-1.09	.281	.340	.736	.586	.561	-.064	.950
Education	2.251	.118	2.507	.094	.189	.829	.710	.497	1.009	.373
Occupation	.776	.573	2.710	<b>.034</b>	2.408	.054	1.671	.165	1.986	.102
Marital status	.927	.359	-.213	.832	-2.17	<b>.036</b>	.276	.784	.100	.921
Family Type	1.534	.227	.320	.728	1.420	.253	.330	.721	.783	.464
Family income	1.583	.217	1.705	.194	.306	.738	.498	.611	.784	.463
Relation with patient	.808	.551	1.408	.243	1.324	.274	1.619	.178	1.538	.201
Duration of illness	<b>-.376</b>	<b>.011</b>	<b>-.408</b>	<b>.005</b>	<b>-.451</b>	<b>.005</b>	<b>-.441</b>	<b>.002</b>	<b>-.487</b>	<b>.001</b>
Duration of hospitalization	<b>-.410</b>	<b>.005</b>	<b>-.477</b>	<b>.001</b>	<b>-.458</b>	<b>.002</b>	<b>-.463</b>	<b>.001</b>	<b>-.538</b>	<b>.000</b>
Severity of covid infection	-.125	.413	<b>-.386</b>	<b>.009</b>	-.074	.631	-.286	.057	-.200	.187
H/O Covid infection	<b>3.477</b>	<b>.040</b>	<b>3.244</b>	<b>.049</b>	.386	.682	3.036	.059	2.153	.129

### Discussion

It is a well-known fact that family caregivers are pillars of caregiving in most parts of world including India. This improves the quality of care after patients are discharged and sent home.<sup>12</sup> Despite widespread awareness of this fact there is little insight into the effect of this caregiving on their Quality of life. Caregiving may affect physical, psychological, social or financial activities of the caregivers. Since they are involved in all aspects including critical decision-making for the patient, psychological distress is inevitable. The quality of life may be influenced due to multitude of factors. Our study is an attempt to understand factors which may be associated with QOL of caregivers in acute settings.

Most of the subjects of our study were young adult (18 to 45 years) married males with educational status graduate and above, and skilled and professionals by occupation living in urban area. Other studies have also found that caregivers are mostly young adult.<sup>8,13</sup> Although study done in India have found that most of the caregivers were not well-educated, we found that most of cases were fairly educated.<sup>8</sup>

Mean CT score on HRCT of 17.9 suggests severe COVID-19 illness.<sup>14</sup> Mean days of COVID-19 illness and hospitalization (13.78, 10.78 respectively), suggests acute phase of illness. It is known that the need of social support is most felt during acute care settings.<sup>8</sup> This support is mostly in form of caregiving during illness i.e. providing assistance in day to day activities, providing emotional support, as well as critical decision-making. Since COVID-19 illness was a pandemic, and associated with immense fear, this added to emotional burden on caregivers affecting their Quality of Life

Several Studies have reported impact of caregiving on caregivers' quality of life in different illnesses which are mostly chronic in nature.<sup>15,16,17</sup> In our study, we found that although none of sociodemographic factors was found to significantly associated with overall quality of life score but occupational status was

positively associated with quality of life score in psychological domain which includes positive and negative feelings, body image, self-esteem etc. A study by Baumann et al. has also found that psychological domain of QoL was positively linked with academic skills and employment skills.<sup>18</sup> Also Marital status was negatively associated with social domain of QoL which includes personal relationships, social support and sexual activity. This is understandable as residing in hospital along with the patient significantly hinders social activities and pandemic situation which mandates social isolation as a preventive measure significantly reduces possibility of fulfilling marital responsibilities like child rearing, taking care of elderly etc at home along with the hospital. The distress is multiplied due to reduced social support owing to fearful pandemic situation.

While studying clinical variable associated with QoL, It was found that duration of illness and hospitalization were negatively correlated with total QoL score as well as all four domains of QoL. A study done on stroke patients by Umaru M. Badarueta also found significant association between duration of caregiving and QoL.<sup>19</sup> They also reported that caregivers who spend more than twelve hours a day have deteriorating quality of life, while in our study caregivers were attending their patients almost twenty four hours a day. Previous other study done by Yu H et al also supports this finding. Severity of covid infection was negatively correlated with psychological domain of QoL because of multitude of factors; those more particular to COVID-19 are the pandemic situation, high infectivity of covid illness and fear of loss of loved ones, low social support, less opportunities of recreational activities and emotional vulnerabilities, poor sleep and less chances to take rest.

### **Limitation**

The main limitations of this study are small sample size and cross sectional nature of study design. Also, the study is limited to hospital setting and in acute phase of illness. All of these factors may affect generalization of results to general population

### **Conclusion**

Family caregivers are primary pillars of support for hospitalized COVID-19 patients but pandemic situation and demands of caregiving significantly affects their quality of life in all domains. Demographic factors which are significantly associated with quality of life are occupation and marital status which are unmodifiable factors. Clinical variables affecting overall quality of life of caregivers are duration of illness and hospitalization which can be reduced with early identification of illness and management. Also there is need to rotate caregivers among family members and incorporating recreational activities for informal caregivers of COVID-19 patients to improve their QoL.

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