Original Article

Quality of Life of Informal Caregivers of a Person with Mental Illness during COVID-19 Pandemic

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Abstract

Background and Objectives: The COVID-19 pandemic has affected not only people with mental health disorders, but also their family and caregivers. The aim of this study was to assess the quality of life of informal caregivers during the COVID-19 pandemic.

Materials and Methods: Sample consisted of 45 informal caregivers of mentally ill patients attending outpatient service in tertiary care hospital during COVID-19 pandemic. Data was collected using WHOQOL-BREF questionnaire along with additional data including caregiver profile and covid-19 related concern. The higher score meant a better QOL.

Results: Out of 45 informal caregivers, 64 % were female, mean age of participants was 40.47, 67 % were married and 56% were unemployed. Majority (89%) of caregiver expressed increased concern about health during covid-19 pandemic and 82 % of caregiver responded that they were anxious due to covid-19 pandemic. The mean total score of QOL of the study population was 14.9 with the highest mean score 15.21 in the physical domain, followed by 15.11 in psychological, 14.91 in social, and 14.37 in environmental domain. Sociodemographic variables like marital and employment status were found to be significantly associated with QOL of caregivers (0.05).

Conclusions: Informal caregivers of mentally ill patients are experiencing negative physical, psychological as well as social health outcomes during the COVID-19 pandemic. Vulnerable caregivers' quality of life can be improved with the help of health careworkers through early identification of at risk caregiver and psychoeducation.

Keywords: Informal caregivers; quality of life; COVID-19; person with mental illness

Background

"Good mental health improves the overall quality of life"-WHO

The COVID-19 epidemic has placed pressure on various national healthcare systems worldwide. It has disrupted society on a global scale and exacerbated feelings of fear, anxiety, and isolation. The COVID-19 pandemic has had an unprecedented reliance on informal caregivers as one of the pillars of healthcare systems. In such pandemic emergencies, homecare is the only option for people without

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healthcare facility access, with financial issues, and for people living in resource-constrained and low-income settings. The role of the caregiver has become more important in today's society, shouldering a significant responsibility in healthcare delivery, local communities' decision making, care for families and individuals, but also in delivering social protection and care on a long-term basis.[1]

In India one among all four patients who attend the primary care clinics are suffering from mental illness. These people are normally cared by those staying with them in their houses, either professional or non – professional. Caring mentally ill patients affects the mental and physical health of those common people which in turn leading in creation of lots of burden. This eventually makes the caregiver in search for resilience to cope with the stress and for regaining the quality of life.[2]

Informal caregivers are individuals who deliver care to children and adults with disabilities, mental disorders, those who are chronically ill, as well as older family members and friends with specific needs, who may live within or outside the caregiver's home. Most caregivers perform a wide spectrum of activities, such as personal hygiene, assuring patient compliance, and/or supply. The delivery of these forms of care and personal assistance can be both demanding and time-consuming and can often lead to physical and psychological burdens for the caregiver. The COVID-19 pandemic has dealt a heavy blow to the caregivers in regards to the circumstances they face daily. In a short time, informal caregivers became aware of the increased risk of COVID-19 for those they care for, as well as for themselves. In the pandemic, informal caregivers have been working without proper training, protocols, adequate medical equipment, organizational support, and other resources that are to some extent available to formally paid caregivers working within institutionalized programs. Informal caregivers who deliver home care during public health emergencies, such as COVID-19, are a valuable human resource that increases the healthcare capacities of society in general, but also more specifically in aging populations and regions with suboptimal healthcare systems. However, informal caregivers are facing significant challenges during the COVID-19 pandemic, and yet, our knowledge about the impact of healthcare delivery on their physical and mental well-being is limited.[1]

The Quality of life (QoL) of caregivers experience a decline in physical health over the course of healthcare delivery. Caregivers have been known to develop chronic diseases, such as cardiovascular disease, diabetes, arthritis, and malignancies, at almost double the rate compared to those who are not a caregiver. Multiple studies have shown that poor mental health is widespread in caregivers, with depression and anxiety being the most common symptoms. Extended periods of physical and psychological efforts, associated with high-level uncertainty and inability to adequately balance between work, private life, and providing care, have a negative impact on the emotional and psychological well-being of the informal caregivers [3]

Need of the Study: Since the first confirmed case of covid-19 was announced at the end of 2019, the coronavirus disease has been a global health emergency. A mixed method study on caregivers of people with dementia conducted by NIMHANS during Covid pandemic where the result highlighted that the proportion of caregivers experienced moderate to extremely severe depression (11.5%), anxiety (11.6%) and stress (12.5%). Caregivers expressed many negative emotions associated with care provision. One caregiver stated that *'I feel a sense of isolation and lack of support and honestly, I think I am out of words to even explain my situation'*. The lack of socialization during lockdown further heightened feelings of loneliness and isolation. Few caregivers also reported feelings of stress caused by loss of employment or consistent income due to the lockdown.[4] Unfortunately, the circumstances of caregivers are not always a focus of attention of mental health services worldwide. There is limited research on the effect of COVID-19 on caregivers' quality of life during this pandemic. This study is essential to highlight the unique challenges faced by informal caregivers during the COVID-19 pandemic, particularly their mental well-being, social support systems, and coping mechanisms

Research Gap: While several studies have explored the general impact of COVID-19 on mental health, there is limited research focusing specifically on the quality of life of informal caregivers of patients with mental illness. Most existing studies concentrate on formal caregivers or frontline healthcare workers, often overlooking the psychological, emotional, and socio-economic burden borne by informal caregivers. Furthermore, the intersection of caregiving stress and pandemic-related challenges remains under-investigated, particularly in low- and middle-income countries

Objectives

- To assess the Quality of Life among informal caregivers of patient with mental illness.
- To find the association between informal caregivers' QOL and selected socio-demographic variables.
- To find the association between informal caregivers' QOL and COVID-19 pandemic concern.

Material and Method

The study included a sample of 45 informal caregivers of mentally ill patients attending outpatient psychiatric services at a tertiary care hospital during the COVID-19 pandemic. Participants were selected using convenience sampling, considering the limitations in access and contact during the pandemic period.

The sample size was not calculated through formal power analysis due to the exploratory nature of the study and pandemic-related constraints. However, similar studies with comparable sample sizes have been effective in identifying patterns in caregiver quality of life, making this number appropriate for preliminary analysis.

Data was collected using the WHOQOL-BREF questionnaire, a validated tool for assessing quality of life across four domains: physical, psychological, social, and environmental. In addition, a self-structured proforma was used to gather sociodemographic information and concerns related to the COVID-19 pandemic. Higher scores in the WHOQOL-BREF indicated a better quality of life.

Inclusion Criteria

- Care givers of patients diagnosed with mental disorders as per ICD.
- Caregivers of patients over 18 years of age receiving outpatient services at a tertiary care hospital.
- Caregiver who are actively participating in the patient's daily activities and living with them at least three days a week for at least six months in the previous year.

Exclusion Criteria

- Caregivers with a diagnosed psychiatric illness or cognitive impairment
- Caregivers who were not available or unable to complete the data collection tools due to language or comprehension difficulties

The purpose and nature of the study was explained and informed consent was obtained from each participant. During the data collection, privacy was provided to each participant & assuring confidentiality. A self-administered questionnaire on socio demographic profile, Covid-19 related concern and WHOQOL-BREF questionnaire was administered to the participants of the study. The WHOQOL-BREF is a self-administered questionnaire comprising 26 questions on the individual's perceptions of their health and well-being over the previous two weeks. The WHOQOL-BREF covers four domains i.e. physical domain, psychological domain, social domain and environmental domain. Responses to questions are on a 1-5 Likert scale where 1 represents "disagree" or "not at all" and 5 represents "completely agree" or "extremely".

It has shown high internal consistency (Cronbach's alpha > 0.70) and has been validated across multiple populations, including caregivers and clinical groups, confirming its reliability and effectiveness in diverse settings[5]

Statistical Analysis

Statistical analysis was performed using IBM SPSS statistical software (SPSS for Windows, version 20.0).Numerical data were presented as mean with standard deviation. Categorical variables were summarized by absolute numbers with percentages. All the independent variables having 2 categories other than marital status were compared using Mann-Whitney U test. Marital status was compared using Independent Student's t test since it followed normal distribution. All the independent variables having more than 2 categories were compared using Kruskal Wallis test according to normality of the variables. All the statistical tests are done at 5% significance level.

Section-A

This figure depicts that majority of subjects (84%) were female.

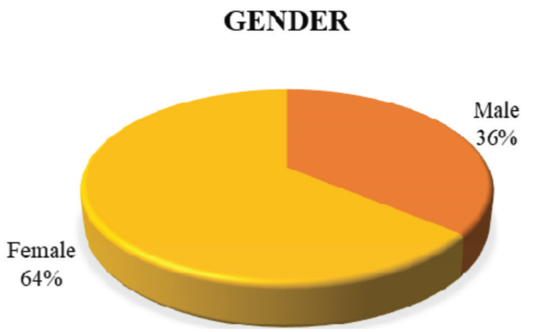


Figure 1: Percentage distribution of respondents by Gender & Age

This figure decipts that majority (38%) belonged to the age group of 29-38 years and 39-48 years (27%).

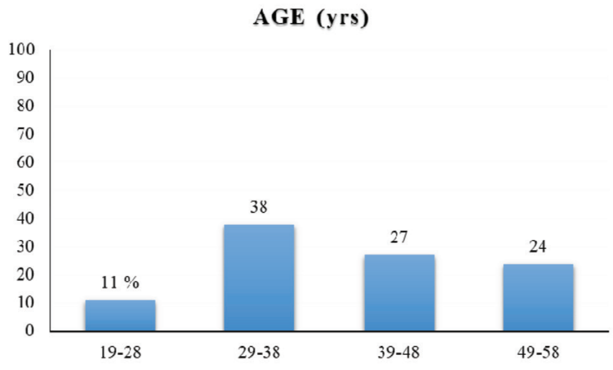


Figure 2: Percentage distribution of respondents by Age

This figure depicts that majority of subjects (56%) had completed their Secondary education.

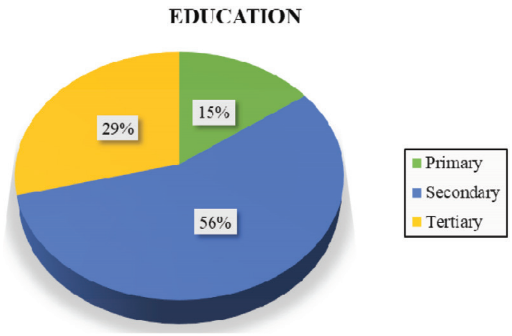


Figure 3: Percentage distribution of respondents by Education

This figure depicts that majority (67%) were married.

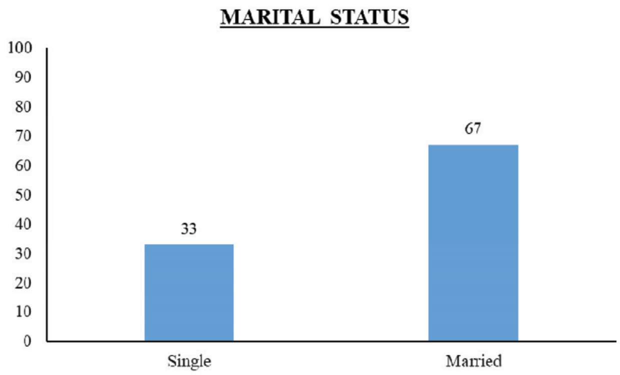


Figure 4: Percentage distribution of respondents by Marital status

This figure depicts that majority (80%) of participants responded that they did not have any major medical condition.

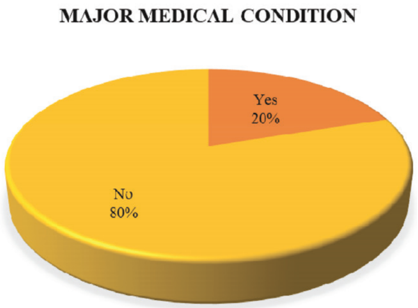


Figure 5: Percentage distribution of respondents by Major medical condition

This figure depicts that 56 % were unemployed at the time of data collection.

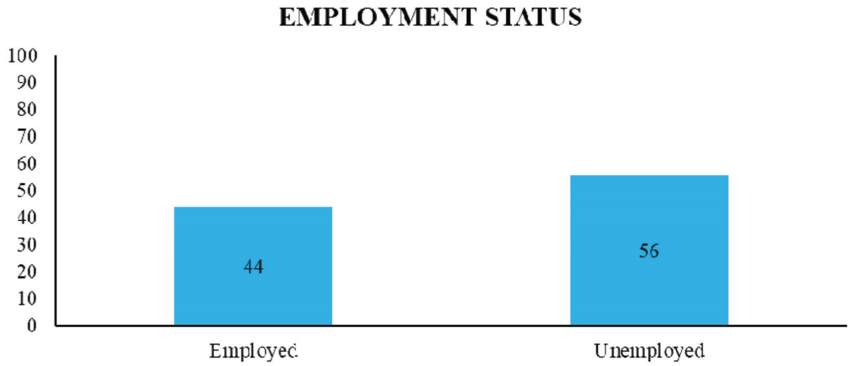


Figure 6: Percentage distribution of respondents by Employment status

Table 1. Frequency and percentage distribution of respondents' Covid-19 related concern

n=45

Questions related to covid-19 pandemic concern	Category	Frequency	Percentage (%)
Do you think your health related concern during covid-19 pandemic has increased?	Yes	40	**89**
	No	5	11
Do you feel more anxious due to covid-19 pandemic?	Yes	37	**82**
	No	8	18

Majority of participants (89%) expressed increased concern towards their health during covid-19 pandemic and 82% felt more anxious due to covid-19 pandemic.

Section-B

Table 2. Domain wise mean and standard deviation of QOL

n=45

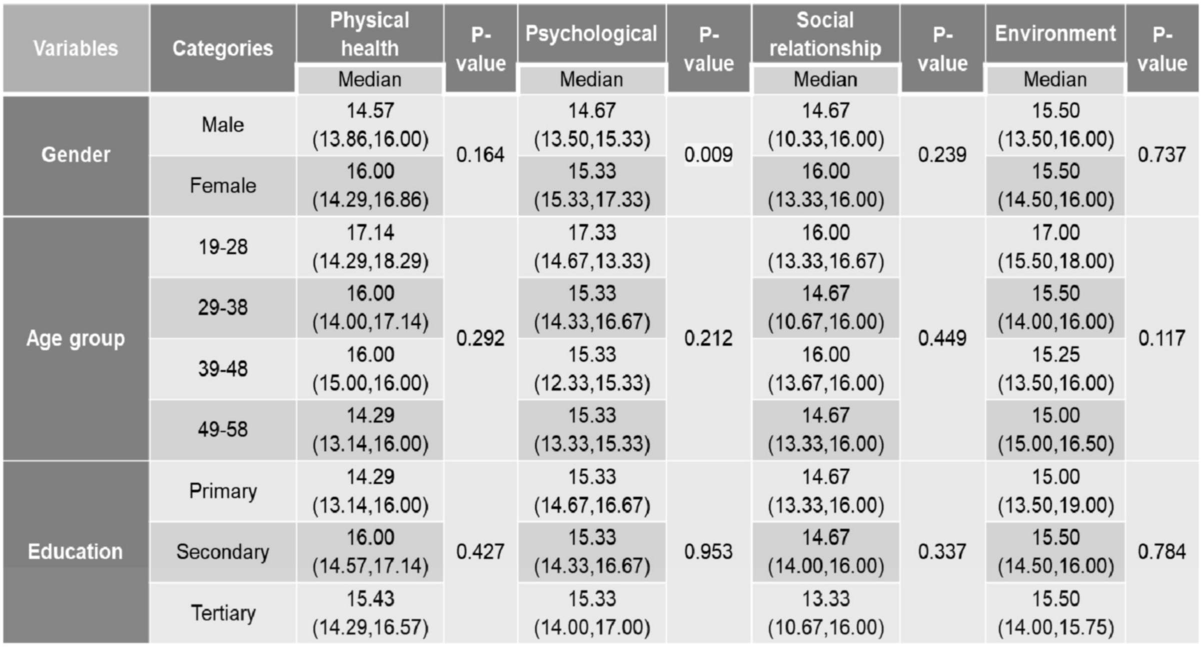
Sl. No	Domain	Mean	SD
1.	Physical Health	15.21	2.251
2.	Psychological	15.11	2.327
3.	Social relationship	14.37	2.444
4.	Environment	14.91	2.322

Table above shows domain wise mean and SD of quality of life of informal caregivers of mentally ill patients. The mean score of physical domain 15.21 with the standard deviation of 2.251 which shows the highest quality of life where as the mean score of social relationship 14.37 with the standard deviation of 2.444 which shows the lowest quality of life.

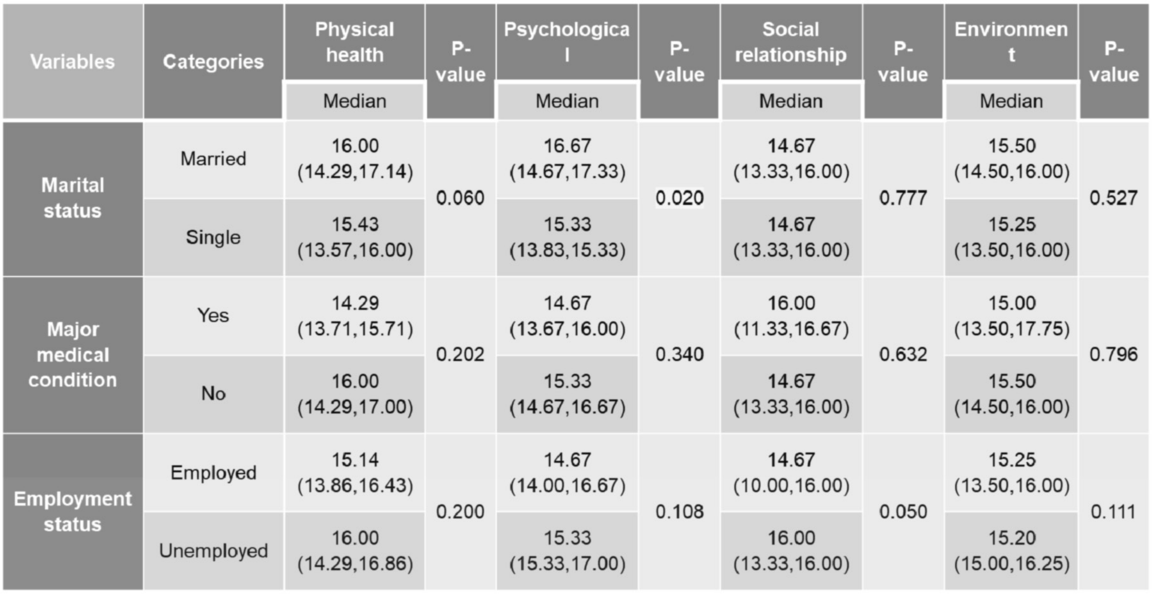
Section-C

Table 3. Quality of life of informal caregivers according to sociodemographic characteristics

n=45



Variables	Categories	Physical health	P-value	Psychological	P-value	Social relationship	P-value	Environment	P-value
		Median		Median		Median		Median	
Gender	Male	14.57 (13.86,16.00)	0.164	14.67 (13.50,15.33)	0.009	14.67 (10.33,16.00)	0.239	15.50 (13.50,16.00)	0.737
	Female	16.00 (14.29,16.86)		15.33 (15.33,17.33)		16.00 (13.33,16.00)		15.50 (14.50,16.00)	
Age group	19-28	17.14 (14.29,18.29)	0.292	17.33 (14.67,13.33)	0.212	16.00 (13.33,16.67)	0.449	17.00 (15.50,18.00)	0.117
	29-38	16.00 (14.00,17.14)		15.33 (14.33,16.67)		14.67 (10.67,16.00)		15.50 (14.00,16.00)	
	39-48	16.00 (15.00,16.00)		15.33 (12.33,15.33)		16.00 (13.67,16.00)		15.25 (13.50,16.00)	
	49-58	14.29 (13.14,16.00)		15.33 (13.33,15.33)		14.67 (13.33,16.00)		15.00 (15.00,16.50)	
Education	Primary	14.29 (13.14,16.00)	0.427	15.33 (14.67,16.67)	0.953	14.67 (13.33,16.00)	0.337	15.00 (13.50,19.00)	0.784
	Secondary	16.00 (14.57,17.14)		15.33 (14.33,16.67)		14.67 (14.00,16.00)		15.50 (14.50,16.00)	
	Tertiary	15.43 (14.29,16.57)		15.33 (14.00,17.00)		13.33 (10.67,16.00)		15.50 (14.00,15.75)	



Variables	Categories	Physical health	P-value	Psychological	P-value	Social relationship	P-value	Environment	P-value
		Median		Median		Median		Median	
Marital status	Married	16.00 (14.29,17.14)	0.060	16.67 (14.67,17.33)	0.020	14.67 (13.33,16.00)	0.777	15.50 (14.50,16.00)	0.527
	Single	15.43 (13.57,16.00)		15.33 (13.83,15.33)		14.67 (13.33,16.00)		15.25 (13.50,16.00)	
Major medical condition	Yes	14.29 (13.71,15.71)	0.202	14.67 (13.67,16.00)	0.340	16.00 (11.33,16.67)	0.632	15.00 (13.50,17.75)	0.796
	No	16.00 (14.29,17.00)		15.33 (14.67,16.67)		14.67 (13.33,16.00)		15.50 (14.50,16.00)	
Employment status	Employed	15.14 (13.86,16.43)	0.200	14.67 (14.00,16.67)	0.108	14.67 (10.00,16.00)	0.050	15.25 (13.50,16.00)	0.111
	Unemployed	16.00 (14.29,16.86)		15.33 (15.33,17.00)		16.00 (13.33,16.00)		15.20 (15.00,16.25)	

P<0.05

Table above shows the associations between four domains of Quality of Life (QoL) of informal caregivers and their sociodemographic characteristics,where only the psychological domain shows a significant association with gender (p = 0.009), indicating that female informal caregivers had better psychological quality of life than males and Marital status (p = 0.020), with married caregivers reporting better psychological well-being. No other significant associations found with age, education, major medical condition or employment status across all domains.

Table 4. Quality of life of informal caregivers according to COVID-19 related variable

n= 45

Variables	Categories	Physical health	P-value	Psychological	P-value	Social relationship	P-value	Environment	P-value
		Median		Median		Median		Median	
Covid-19 (health concern)	Yes	15.71 (14.29,16.43)	0.273	15.33 (14.17,16.67)	0.294	14.67 (13.33,16.00)	0.926	15.50 (14.50,16.00)	0.251
	No	17.14 (14.00,18.29)		16.67 (14.33,18.33)		14.67 (11.33,16.67)		16.00 (13.00,18.00)	
Covid-19 (anxiety)	Yes	16.00 (14.29,16.57)	0.822	15.33 (14.33,16.67)	0.832	14.67 (13.33,16.00)	0.149	15.50 (14.50,16.00)	0.653
	No	14.29 (13.86,17.14)		15.00 (14.17,17.17)		13.33 (10.00,15.67)		15.50 (11.75,16.75)	

P<0.05

Table above shows that there is no statistically significant association of COVID-19-related health concerns or anxiety among informal caregivers with their quality of life across four domains.

Discussion

The following conclusions were drawn on the basis of the findings of the study which revealed that, most caregivers were females (64%) and the average age was 40.47, majority belonged to the age group of 29-38 years (38%) followed by 39-48 years (27%), most caregivers had completed their Secondary school (56%), majority were married (67%), and majority had no major medical condition (80%).89% of caregiver expressed their concern about health during COVID-19 pandemic and 82% said that they were anxious due to COVID-19 pandemic.

In the current study, the mean score of the physical domain (15.21) was the highest among the four domains of quality of life, indicating that caregivers experienced relatively better physical health, whereas the social relationship domain had the lowest mean score (14.37), reflecting poorer perceived social support and interpersonal interaction. This pattern is supported by previous literature. For instance, Basheer S et al. (2015) also reported that caregivers of patients with mental illness had better physical health but compromised social well-being, possibly due to social withdrawal, stigma, and reduced time for social engagement.[6] Moreover, Chadda et al. (2007) emphasized that Indian caregivers often prioritize caregiving responsibilities over personal relationships, leading to diminished social interaction and support.[7] These findings suggest that while caregivers may maintain their physical health to sustain caregiving duties, their social lives are often neglected, underscoring the need for targeted psychosocial interventions that strengthen social networks and community support for informal caregivers.

The variable gender and marital status was found be significantly associated with psychological domain of Quality of life of informal caregivers of mentally ill patients (p=0.009 and p=0.020, respectively). Female caregivers reported better psychological well-being compared to males, and married caregivers demonstrated higher psychological QoL than their single counterparts. These findings are consistent with existing literature. For instance, a study by Kate et al. (2013) in India reported that female caregivers had better coping mechanisms and perceived higher social support, which contributed to improved psychological well-being.[8] Similarly, Chadda et al. (2007) found that caregivers living in joint families or those who were married experienced lower psychological stress, emphasizing the buffering effect of marital and familial support systems in caregiving.[7] Contrarily, some studies, such as Zahid & Ohaeri (2010), observed higher caregiver burden and poorer psychological outcomes among female caregivers, highlighting the influence of cultural and familial expectations.[9] These variations suggest that contextual and sociocultural factors play a vital role in shaping caregiver experiences and their psychological resilience. Therefore, tailored interventions addressing gender- and family-related dynamics may enhance caregiver support programs and promote psychological well-being among this vulnerable group.

Conclusions

Informal caregivers of person with mental illness have experienced negative physical, psychological as well as social health outcomes during the COVID-19 pandemic. Vulnerable caregivers' quality of life can be improved with the help of health care workers through early identification of at risk caregiver and psychoeducation. In the psychosocial management of patients with mental illnesses, careers play a crucial role. Early intervention among vulnerable careers can be facilitated by studies that assess careers' quality of life. Additionally, this might assist mental health practitioners in identifying careers who are particularly vulnerable to emotional and physical issues.

Conflict of Interest: Nil

Source of Funding: Self

Reference

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