



## PSYCHOSOCIAL IMPACT OF MUCORMYCOSIS ON CARE-GIVERS DURING COVID 19 PANDEMIC

### Otorhinolaryngology

**Dr. Annapurna S  
Mushannavar**

Assistant Professor, Department Of Ent, Kims Hubli.

**Dr. Megha  
Annigeri\***

Assistant Professor, Department Of Ent, Kims Hubli. \*Corresponding Author

**Dr. Bindya Nayak**

Senior Resident, Department Of Ent, Kims Hubli.

### ABSTRACT

**Introduction:** Mucormycosis is one among the emerging healthcare problem in the Indian population in the present era. The epidemiology of this disease is different from other mycotic diseases because of its high incidence among the patients with uncontrolled diabetes. Treating these cases required a combined approach consisting of surgical debridement and medical management with injection amphotericin B and long hospital stay. Patients need constant supervision, frequent monitoring and rehabilitation. This adds to the psychosocial and emotional burden on the caregivers as well. Hence, we studied the psychosocial impact and the characteristics of the caregivers of the patients with post covid 19 associated rhino-orbital mucormycosis. **Aims and objectives:** The aim of our study was to know the psychosocial impact of mucormycosis on the caregivers of the patients who were diagnosed with mucormycosis. To know the characteristics of these caregivers. **Materials and methods:** This was an observational descriptive study which was conducted in a tertiary health care center where in we included care givers of the first 100 patients diagnosed with mucormycosis who fulfilled the inclusion and exclusion criteria. We have used this zarit score to assess the psychosocial impact of mucormycosis among the care givers of the patients diagnosed with post covid 19 mucormycosis. **Results:** In our study on caregivers of first 100 patients diagnosed with mucormycosis 68 (68%) participants were male and 32 (32%) participants were females belonging to the age group ranging from 18 to 64 years. Sociodemographic features were studied and we noted that 70% of the study participants were married and 64 participants (64%) were employed, 30 (30%) were unemployed and 6(6%) were students. The total disease burden on the caregivers was calculated using the zarit score which had 22 questions and the total score was calculated. 48% caregivers felt none to mild burden, 43% participants felt mild to moderate burden, 7% felt it moderate to severe burden and 2% felt it severe burden. **Conclusion:** There are many studies evaluating the emotional, psychological and quality of life of the patients affected with mucormycosis but none on the caregivers of these patients. Hence we have made an attempt to know the psychosocial impact of mucormycosis on the caregivers.

### KEYWORDS

covid 19; mucormycosis; zarit burden score; psychosocial impact; caregivers;

### INTRODUCTION:

Mucormycosis, is a ubiquitous fungus which belongs to the taxonomic order of Mucorales. It is known for its angio-invasive nature of fungal infection which is commonly seen in immunocompromised hosts like patients of uncontrolled diabetes, leukemia, lymphopenia, and organ transplantation<sup>1</sup>. Mucormycosis is an emerging healthcare problem in the Indian population. The epidemiology of this disease is different from other mycotic diseases because of its high incidence among the patients with uncontrolled diabetes. The patients present commonly as rhino-orbito-cerebral mucormycosis, which is easy to diagnose. But, the mortality rate remains high (nearly 50%), as the patients attend the healthcare facility late in the course of the disease after extensive spread of infection<sup>2</sup>. The year 2021-2022 can be always remembered in the history of mankind as the year of "Black fungus" or Mucormycosis due to the impact of the disease in the general population. Desai et al. found the following treatment measures, such as control of diabetes mellitus, intravenous infusion of intravenous amphotericin B, and surgical debridement of sinuses, useful for rhino-orbital mucormycosis (ROM) seen in post-COVID-19.

### AIM:

The aim of our study was to know the psychosocial impact of mucormycosis on the caregivers of the patients who were diagnosed with mucormycosis. To know the characteristics of these caregivers.

### MATERIALS AND METHODS:

This was an observational descriptive study which was conducted in a tertiary health care center where in we included care givers of the first 100 patients diagnosed with mucormycosis.

### Inclusion criteria:

1. Caregivers of first 100 patients who were diagnosed with mucormycosis and were willing to participate in the study were included in the study.

### Exclusion criteria:

1. Caregivers of patients who were not willing to participate in the study.
2. Caregivers of patients Mini-Mental State Examination score <24,

prior psychiatric illness.

A detailed personal history, family history, socio-demographic history obtained from all the study participants. Gerontologic health scientific literature identifies a number of scales to measure caregiver burden. The Zarit Scale of Caregiver Burden or the Zarit Burden Interview is the most widely used instrument. Originally designed and tested in 1980 containing 29 items, it was reduced to 22 questions (annexure 1). We have used this zarit score to assess the psychosocial impact of mucormycosis among the care givers of the patients diagnosed with post covid 19 mucormycosis.

### RESULTS:

In our study on caregivers of first 100 patients diagnosed with mucormycosis 68 (68%) participants were male and 32 (32%) participants were females belonging to the age group ranging from 18 to 64 years. (figure 1) Most of the caregivers belonged to the age group of 20-40 years (78%), followed by 40-60 years (20%). We had one participant each below the age of 20 and above the age of 60 years. (table 1)

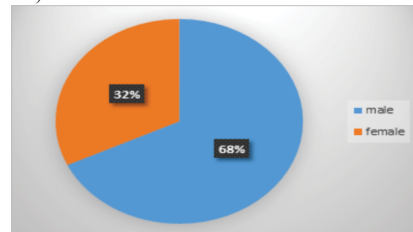


Figure 1 : Sex distribution of caregivers

Table 1 : Age distribution of care givers

Age	Count
<20 years	1
20-40 years	78
41-60 years	20
>60 years	1

We studied the occupational status of these care givers among whom 64 participants (64%) were employed, 30 (30%) were unemployed and 6(6%) were students.

We studied the relationship of the caregivers with patients , wherein 64 participants were the immediate family of the patient ,36 participants were either their distant family member or a friend and 70% caregivers were married. (table 2).

**Table 2: relationship status of caregivers with the patients**

RELATIONSHIP	
son	32
daughter	6
spouse	26
others	36

We observed for commonly occurring comorbidities among the caregivers in which 5 had diabetes, 3 had hypertension and one had both.

The total disease burden on the caregivers was calculated using the zarit score which had 22 questions and the total score was calculated. 48% caregivers felt none to mild burden, 43% participants felt mild to moderate burden, 7% felt it moderate to severe burden and 2% felt it severe burden.

#### DISCUSSION:

Mucormycosis is an epidemic in the pandemic which is a challenge faced by all the doctors, patients as well as the caregivers all around the world. Mucormycosis can affect any age group from premature neonates to elderly people with varying types of underlying conditions, but the current data demonstrates increased incidence in a wide range of specific immunocompromised patient groups.<sup>3,4,5</sup>. Treating these cases required a combined approach consisting of surgical debridement and medical management with injection amphotericin B and long hospital stay. Patients need constant supervision, frequent monitoring and rehabilitation. This adds to the psychosocial and emotional burden on the caregivers as well. Hence , we studied the psychosocial impact and the characteristics of the caregivers of patients with post covid 19 associated rhino-orbital mucormycosis.

We studied the sociodemographic features of the caregivers 68 (68%) participants were male and 32 (32%) participants were females belonging to the age group ranging from 18 to 64 years. Most of the caregivers belonged to the age group of 20-40 years (78%), followed by 40-60 years (20%). We had one participant each below the age of 20 and above the age of 60 years. Coming to occupational status of these caregivers, we found that 64% were employed, 30% were unemployed and 6 were students. This was important because it mandated the care givers to spend a lot of time with the patients and regular follow ups, which made it difficult to manage their occupation since some had to take leave from their respective jobs . This would affect their job as they were the sole breadwinner of the family. This would affect them physically ,mentally and financially too. We also studied the relationship of the caregivers with the patients and found out that 38 participants were their own children and 26 participants were the spouse of the patient and the rest were either a close family member or friends. Among the study subjects 70% were married and 30 % were unmarried. Thus we can say that most of the caregivers had to take care of rest of the family apart from the patient ,so this would challenge them for not giving time to the others in the family . But in turn they also received support from the other family members.

One of the most important pathogenic event occurring in mucormycosis is extensive angioinvasion leading to vessel thrombosis and tissue necrosis<sup>5</sup>. These characteristics will lead to a very aggressive outcome of the disease because the angiinvasive nature of the organism will lead to hematogenous spread of the disease where as the ischaemic necrosis will lead to further prevention of leucocyte and antifungal agents penetration into the tissues.<sup>6,7</sup> Even with the invention of newer antifungal agents the invasive nature of mucormycosis leads to an overall mortality exceeding 50%, but in case of disseminated disease the mortality is almost 100%. Amphotericin B is considered the first line therapy for mucormycosis because of its own Risk-Benefit Ratio. The adverse effects range from simple electrolyte imbalance, impairment of kidney function , blood sugar derangements to severe anaphylactic reactions.<sup>8,9</sup> Since this was a

epidemic and amphotericin injection supply was not adequate as well as if available it was too expensive and difficult for the attenders to arrange the same for the patients and this would put the caregivers under the stress mentally and financially.

We studied the co morbidities of the caregivers and out of 100 caregivers 5 had diabetes, 3 had hypertension and 1 had both diabetes and hypertension. In order to study the impact of the disease on the caregivers we used The Zarit Scale of Caregiver Burden or the Zarit Burden Interview. Originally designed and tested in 1980 contained 29 items, which was then modified and reduced to 22 questions. Each question had scores to be given from 0-4 , and the total score for each care giver was calculated and analysed<sup>10</sup>. The scoring system and the burden of the disease is given in the annexure 1. Zarit Burden Interview: Revised (22-items)  
Total score range: 0 to 88  
0.21: no to mild burden  
21.40: mild to moderate burden  
41.60: moderate to severe burden  
≥ 61: severe burden

The ZBI was developed as a unidimensional measure of burden.<sup>11,12</sup> However, two to four dimensions have been reported in the literature. Dimensions reported include consequences of caregiving, patient's dependence, exhaustion and uncertainty, guilt or self-criticism, embarrassment/ anger or frustration, psychological burden and emotional reactions, personal strain, and role

There are studies done on the psychological effects of the mucormycosis on the patients but there are no studies to evaluate the burden or the psychosocial effect of the disease on the caregivers of these patients. In our study we noticed that 48 % caregivers found it no to mild burdensome, 43% found it mild to moderate burdensome, 7% felt it moderate to severe burdensome and 2 % caregivers felt severely burdened by taking care of the patients. So we can tell that over all mucormycosis did not just effect the patients diagnosed by the disease but the also the caregivers also drastically.

In a study by Sami.Y et al., where in they evaluated the disease burden on caregivers of heart failure patients showed that caregivers with higher score had higher depressive symptoms that those with lower score. Similarly there are various studies where in the zarit score was used to evaluate the disease burden on the caregivers of patients with dementia.<sup>13</sup>

It was the moment where we would all concentrate more on the patient diagnosed with the disease but not much importance was given to the psychosocial effect on the caregivers. The caregivers were burdened both physically, mentally as well and financially due to the disease as we can see from our study. Most of them even had to quit their jobs in order to take care of the patients admitted to the hospital.

#### CONCLUSION:

Mucormycosis, which was very rare in the past had become quite usual in the wake of the COVID-19 pandemic which itself burdened the community. Taking care of patient with the long term disease can have a large impact on the caregivers. Emotional and vitality aspects of caregivers as well as disability of persons with covid associated mucormycosis are important predictors of burden. There are many studies evaluating the emotional, psychological aspects and quality of life of patients with mucormycosis but none on the caregivers of mucormycosis patients. Hence we have made an attempt to know the psychosocial impact of mucormycosis on the caregivers.

**Institution Where The Study Was Performed:** KIMS hospital hubballi

#### Compliance With Ethical Standard :

there was no potential conflicts of interest

The research did not involve any human participants and/ or animals were harmed.

Written informed consent was taken from all the subjects participating in the study.

**Financial Support/funding:** NONE

**Conflict of interest:** There are no conflict of interest.

## Annexure 1 :

	Never	Rarely	Sometimes	Frequently	Nearly Always
1) Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	0	1	2	3	4
2) Do you feel embarrassed you're your relative's behavior?	0	1	2	3	4
3) Do you feel angry when you are around your relative?	0	1	2	3	4
4) Do you feel that your relative currently affects your relationship with other family members or friends in a negative way?	0	1	2	3	4
5) Are you afraid what the future holds for your relative?	0	1	2	3	4
6) Do you feel strained when you are around your relative?	0	1	2	3	4
7) Do you feel that you do not have as much privacy as you would like because of your relative?	0	1	2	3	4
8) Do you feel that your social life has suffered because you are caring for your relative?	0	1	2	3	4
9) Do you feel uncomfortable about having friends over because of your relative?	0	1	2	3	4
10) Do you feel that you have lost control of your life since your relative's illness?	0	1	2	3	4
11) Do you wish you could just leave the care of your relative to someone else?	0	1	2	3	4
12) Do you feel uncertain about what to do about your relative?	0	1	2	3	4

## REFERENCES:

1. JA, Vanover-Sams CL, Baker DJ. Zygomycetes in human disease. *Clin Microbiol Rev* 2000; 13: 236–301.
2. Roden MM, Zaoutis TE, Buchanan WL et al. Epidemiology and outcome of zygomycosis: a review of 929 reported cases. *Clin Infect Dis* 2005; 41: 634–653.
3. Steenblock C, Schwarz PE, Perakakis N, Brajshori N, Beqiri P, Bornstein SR: The interface of COVID-19, diabetes, and depression. *Discov Ment Health*. 2022, 2:5. 10.1007/s44192-022-00007-0
4. Kumar K, Srivastava S, Sharma B, Avasthi RK, Kotru M: Comparison between inflammatory biomarkers (high-sensitivity C-reactive protein and neutrophil-lymphocyte ratio) and psychological morbidity in suicide attempt survivors brought to medicine emergency. *Cureus*. 2021, 13:e17459. 10.7759/cureus.17459
5. Ben-Ami R, Luna M, Lewis RE, Walsh TJ, Kontoyiannis DP. A clinicopathological study of pulmonary mucormycosis in cancer patients: extensive angioinvasion but limited inflammatory response. *J Infect* 2009; 59: 134–138.
6. Skiada A, Pagano L, Groll A et al. Zygomycosis in Europe: analysis of 230 cases accrued by the registry of the European Confederation of Medical Mycology (ECMM) working group on zygomycosis between 2005 and 2007. *Clin Microbiol Infect* 2011; 17: 1859–1867.
7. Lanternier F, Dannaoui E, Morizot G et al. A global analysis of mucormycosis in france: the retrozygo study (2005–2007). *Clin Infect Dis* 2012; 54 (suppl 1): S35–S43.
8. Lewis RE, Liao G, Hou J, Chamilos G, Prince RA, Kontoyiannis DP. Comparative analysis of amphotericin B lipid complex and liposomal amphotericin B kinetics of lung accumulation and fungal clearance in a murine model of acute invasive pulmonary aspergillosis. *Antimicrob Agents Chemother* 2007; 51: 1253–1258.
9. Lewis RE, Albert ND, Liao G, Hou J, Prince RA, Kontoyiannis DP. Comparative pharmacodynamics of amphotericin B lipid complex and liposomal amphotericin B in a murine model of pulmonary mucormycosis. *Antimicrob Agents Chemother* 2010; 54: 1298–1304.
10. Bédard M, Molloy DW, Squire L, Dubois S, Lever JA, O'Donnell M. The Zarit Burden Interview A New Short Version and Screening Version. *The Gerontologist*. 2001;41(5):652–657. [PubMed] [Google Scholar]
11. Chung ML, Lennie TA, Mudd-Martin G, Dunbar SB, Pressler SJ, Moser DK. Depressive symptoms in patients with heart failure negatively affect family caregiver outcomes and quality of life. *European Journal of Cardiovascular Nursing*. 2014;1–9. published online 14 May 2014. [PubMed] [Google Scholar].
12. Springate B, Tremont G. Caregiver Burden and Depression in Mild Cognitive Impairment. *Journal of Applied Gerontology*. 2012 [PubMed] [Google Scholar]
13. Al-Rawashdeh SY, Lennie TA, Chung ML. Psychometrics of the Zarit Burden Interview in Caregivers of Patients With Heart Failure. *J Cardiovasc Nurs*. 2016 Nov/Dec;31(6):E21–E28. doi: 10.1097/JCN.0000000000000348. PMID: 27617563; PMCID: PMC5069100.