Quality of Life in Mucormycosis Patients Post Discharge: A Pilot Study Using a New MQOL-36 Questionnaire

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Abstract To evaluate the Quality of Life in Mucormycosis patients in our hospital using a new MQOL36 questionnaire post discharge. 37 cases between Apr 2021 to July 2021 were included in the study with a minimum follow up period of 4 weeks. They were administered Mucormycosis quality-of-life questionnaire (MQOL-36) either in person or via telephonic interview and answers were recorded into digital questionnaire modulated by us using a digital data recording app—KoBoCollect. Their demographic, clinical, imaging, histopathological and treatment data was retrieved and analysed. Most of the patients reported their health to be good with only 1 patient who had extensive cranial involvement reporting as poor and still undergoing repeated surgeries. 46.67% had no nasal complaints, 20% had nasal obstruction, 13.33% had nasal discharge with 2 patients complaining of crusting and 1 of whistling sound at quiet respiration. Most worrying factor was financial condition with 33.33% patients financially distraught and 43.33% being affected but barely managing at present. Only 2 patients reported no economic impact. Mucormycosis in COVID-19 has changed the face of otorhinolaryngology as we know it—while treating the disease is important, treating the post operative aftermath also becomes equally important. The MQOL-36 produces a quality-of-life profile scoring an individual’s perception of quality of life in the following domains: Physical, Psychological, Level of Independence, Social Relationships and Environment. Monitoring the quality of life in patients post discharge could help us manage the enormous morbidity associated with the disease.

Keywords Mucormycosis · Post COVID · Quality of life · Post operative complaints · Socioeconomic burden · Financial impact

Introduction
The COVID-19 pandemic brought the entire world to a standstill in the first wave in 2020, but the second wave of COVID-19 in 2021 unleashed a deadly havoc in the form of an epidemic within the pandemic with a surge of a once rare invasive fungal infection, that is—Mucormycosis—in devastating numbers. From May 5th July 12, 2021, 41,512 cases and 3,554 deaths were attributed to this rare, but life-threatening fungal infection. The majority of those cases occurred during active SARS-CoV-2 outbreaks in India, prompting the Central Government of India to declare a mucormycosis epidemic on May 10, 2021 [1]. The otorhinolaryngologists rose up to the challenge with treating Mucormycosis cases at an emergency basis with a multidisciplinary involvement. The management protocol was mainly a two-step process of functional endoscopic sinus surgery with repeated surgical debridements and medical management by intravenous Amphotericin, with further surgical management depending on extent of involvement [2, 3]. Following aggressive treatment most of the patients were discharged after improvement in their general condition and 2 negative KOH samples. Although a lot of studies documenting high incidence of mucormycosis in COVID-19 patients have recently emerged in literature, data pertaining to treatment outcomes and the quality of life in post COVID Mucormycosis patients in

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Received: 1 March 2022 / Accepted: 23 September 2022 / Published online: 12 November 2022
such cohorts is lacking [4]. Health-related quality of life is an essential aspect concerned with the treatment outcomes. This article attempts to document and formulate a standard protocol to monitor the quality of life in Mucormycosis patients post discharge by documenting our own experience in managing Mucormycosis patients in our tertiary care centre.

Materials and Methods

Patient Selection and Characteristics

Study Sample Size and Study Period

The sample size was 37 keeping in mind patients who were treated under a uniform protocol under a single surgeon. A total of thirty-seven cases of mucormycosis (HPE proven) who underwent management at our tertiary care centre between Apr 2021 to July 2021 were included in the study. Their demographic, clinical, imaging, histopathological and treatment data was retrieved and analysed.

Inclusion Criteria

All the patients were under a single consultant and managed with a uniform protocol of management to maintain uniformity in results.

Exclusion Criteria

Patients who refused to participate in the questionnaire or had loss to follow up were also excluded from the study.

Treatment Protocol

A strict institutional protocol was followed with a step-by-step approach, aiming towards an early and aggressive management of the condition. An otolaryngologist performed a detailed initial assessment adhering to all COVID-19 precautionary measures. An aseptically collected medial meatal nasal swab or representative tissue were sent for KOH (potassium hydroxide) staining, microscopy using fluorescent brightener, special stains (Periodic acid–Schiff and Grocott-Gomori methenamine silver), fungal culture, gram stain and bacteriological culture. Also, samples for relevant haematological and biochemical investigations including glycosylated haemoglobin (HbA1c) and RT-PCR for COVID-19 were obtained on admission. Imaging (CT or MRI) to confirm or negate the diagnosis and assess the disease extent (nasal cavity, paranasal sinuses, orbit and intracranial structures) was performed. The contrast enhanced CT was employed as the initial imaging modality with evaluation by MRI limited to those with equivocal CT imaging findings, clinico-radiological mismatch and high index of suspicion for intracranial extension.

Mucormycosis Quality of Life Questionnaire

All the patients treated for mucormycosis in the study period were followed up with Mucormycosis quality-of-life questionnaire MQOL-36 (Fig. 1) either in person or via telephonic interviews. The questionnaire was an adaptation of the SF-36 Questionnaire which was tested for the first time in our centre with all patients treated in our study period under a single consultant and single treatment protocol to maintain uniformity in results. A pilot study was done with a test study on five patients following which the current study was instituted for all the patients.

Each patient was asked a set of 36 questions that covered aspects as General Health, Limitation of Activities, Physical Health Problems, Emotional Health Problems, Social Activities, Pain, Energy and emotions and Mucormycosis targeted areas.

Scoring Of The MQOL-36

The MQOL-36 produces a quality-of-life profile. It is possible to derive eight domain scores, 24 specific facet scores, and one general facet score that measures overall quality of life and general health. The six domain scores denote an individual’s perception of quality of life in the following domains: Physical, Psychological, Level of Independence, Social Relationships and Environment. Domain and facet scores are scaled in a positive direction where higher scores denote higher quality of life. Some facets (pain and Discomfort, Negative Feelings, dependence on medication) are not scaled in a positive direction, meaning that for these facets higher scores do not denote higher quality of life.

Statistical Analysis

The data was analysed using Chi Square test and p value was elicited.

Results

Mean age of the subjects was 49.87 ± 8.33 years with a male preponderance of 80% with 24 subjects being males and 6 females. Most of the patients contracted Mucormycosis post COVID, 76.67%, with only 23.33% that is 7 subjects having no prior COVID history. Along with that most of them were unvaccinated or vaccinated with only single dose, with 24 subjects – 80% being unvaccinated and mere 20% having vaccination history that too with single dose. (Fig. 2).
Out of these patients 66.67% had Diabetic Mellitus as a comorbidity with uncontrolled sugars, 16.67% with hypertension and 6.67% with Bronchial Asthma as a complicating factor.

All of the patients were treated with a uniform protocol in our centre under a single surgeon and had course of treatment averaging around 30 days over with depending on the extension of disease FESS/ FESS with multiple debridements/ FESS with hard palate excision/ Orbital decompression/ Craniectomy was planned. Following surgical intervention all patients received a full course of Amphotericin B.

Mucormycosis Targeted Areas

During the study 4 expired to systemic complications and one went against medical advice thereby 5 in the study have had loss to follow up. Among the 25 subjects who
responded to the questionnaire 46.67% had no nasal complaints, 20% had nasal obstruction while 13.33% had nasal discharge with only 2 (6.67%) patients complaining of crusting and 1 of whistling sound at quiet respiration. (Fig. 3, 4).

1 patient complained of pain near the medial canthus site, 1 with watering of eyes, one with uncontrolled diabetes, one with voice change associated with hypoesthesia around nasal dorsum, with patients with palate excision mostly complaining of tooth pain, Oro antral fistula and feeding plate issues.

73.33% (22) were able to take solid feeds, while only one patient was on liquid diet, 3 patients with palate excision complained of oral feeds regurgitating into nasal cavity.

Fig. 2 Bar graph showing comparison between Mucormycosis in patients with COVID and Vaccination history

Fig. 3 Post discharge patient complaints at follow-up (p < 0.0375; significant)

Fig. 4 Nasal crusting observed on Diagnostic Nasal Endoscopy in Post operative period in a follow up patient

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General Health

Most of the patients reported their health to be good with only 1 patient who had extensive cranial involvement reporting as poor and still undergoing repeated surgeries. 10% (3) of the patients reported as fair due to the palatal effect on quality of life. Others were comparatively satisfactory.

70% of the patients reported feeling better as compared to discharge while only 13.33% (4) patients felt about the same. 23.33% patients felt that they seem to get much sicker as compared to normal people and expected their health to get worse, while 56.67% felt they are as healthy as anybody they knew.

Social Problems

When asked about the emotional problems faced by patients post discharge, 26.7% reported normalcy with 23.33% having slight change. Two of the patients however reported severe detachment with one patient being ostracized by distant relatives due to their condition and other maintaining distance from relatives and neighbours post discharge. 63.33% reported no change in their usual activities while 20% having cut down on it—with underlying age being a factor in half of them. Among these 26.67% felt that they have accomplished less than they liked and limited in work or had to put in extra effort to get things done as compared to before contracting Mucormycosis.

Socioeconomic Problems

46.67% patients had resumed going back to work with others not resuming work owing to old age or being housewives.

The most worrying thing observed was the financial condition of the patients with 33.33% patients financially distraught due to the expenses of undergoing repeated debridements and 43.33% being affected but barely managing at present. Only 2 patients reported no economic impact (Fig. 5).

Limitation of Activities

Most of the patients reported no limitation of activities with 50% being able to continue with vigorous activities and 13.33% being limited little. Most of them had resumed work like before being mostly engaged in menial labour or in the teaching profession.

13.33% reported difficulty in climbing stairs or any straining activity with 23.33% having breathlessness with climbing stairs—most of them had previous COVID history with affected lungs as an underlying cause.

76.67% were able to take solid food, while others were on liquid diet. Only 1 patient with extensive cerebral involvement had his vision impaired while others had intact visual function. 73.33% were able to do their day-to-day activities without seeking help from others.

Emotional Problems

46.67% patients felt normal to go on with daily lives while others were nervous about the future due to implications of the disease with and underlying depressive spectrum. One patient refused to mingle with others post discharge while one felt ostracized by his community. 43.33% felt they had energy to do any activity while most others felt tired to do anything.
Discussion

Mucormycosis in the second wave of COVID-19 lead to an unprecedented number of patients being maimed by a once rare disease. Multiple surgical procedures ranging from functional endoscopic sinus surgery with multiple debridements with hard palate excision, orbital decompression and craniectomy depending on the extent of involvement left a huge number of post op patients grappling not only with health impairment, socioeconomic impact of financial drain from prolonged hospital stay with cost of medications [5], psychosocial impact [6] on not only the patients but their family as well. Our study aimed to follow up on these patients and create a better post operative plan of care to manage the morbidity associated with mucormycosis.

The MQOL-36 questionnaire was developed at our centre with a set of 36 questions that had SF-36 questionnaire at its core which was used in the past to evaluate the disease burden of diabetes mellitus and kidney disease [7] and incorporated into a questionnaire for mucormycosis patients taking into consideration their general health, physical health scores, emotional health, socioeconomic impact and mucormycosis targeted areas.

All of the thirty patients operated at our centre in the study period were followed up with the questionnaire either in person or via telephonic interview and their answers were recorded verbatim into digital questionnaire modulated by us using a digital data recording app–KoBoCollect.

The results of the study showed that most of the patients who contracted Mucormycosis had a previous COVID history with an unvaccinated status; the ones with no COVID history had comorbidities like diabetes, hypertension and bronchial asthma. While most of the patients have gone back to life there is a huge economic and emotional drain left behind by Mucormycosis. Most of the patients have been crippled by the financial burden of treatment with some yet to receive monetary compensation. Some of the patients have underlying depressive or anxiety spectrum which could be better addressed by psychological care. There were certain post operative complications which have been unaddressed due to loss to follow up.

Conclusion

Mucormycosis in COVID-19 has changed the face of otorhinolaryngology as we know it—with the once rare aggressive invasive fungal infective rising in incidence to epidemic proportions a multidisciplinary team had to be setup to manage the varied systemic challenges associated with the primary involvement of nasal cavity, sinuses, orbit and hard palate leaving behind in its wake a number of maimed individuals crippling with economic and emotional burden of the disease. While treating the disease is important, treating the post operative aftermath also becomes equally important. Monitoring the quality of life in patients post discharge could help us manage the enormous morbidity associated with the disease.

Authors contribution All authors contributed to the study conception and design. Material preparation, data collection and analysis were performed by PN, PG, ADK and PB. The first draft of manuscript was written by PG, ADK and PB. Review and guidance were provided by SPN and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

Declarations

Conflicts of interest All authors declare that they have no conflict of interest.

Compliance with ethical standards All authors have read and approved the final manuscript.

Ethical approval Institutional ethical committee approval was obtained for the conduction of this study. All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Consent to participate Informed consent was obtained from all individual participants in the study, after explaining the objectives and methodology clearly.

Consent to publish Patients signed informed consent regarding publishing their data as per the guidelines of the institution and the journal prerequisites.

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