Beyond Survival: Quality of Life at 18-Month Follow-Up among Patients with COVID-19-Associated Rhinoorbitocerebral Mucormycosis

Shubashree Karat, Aaron Charles Lobo, Nivedhitha Nikhil, Anita Ross, Anna Philip, Sanjana Thomas, Suneetha Nithyanandam

Department of Ophthalmology, St John's Medical College

DOI: https://doi.org/10.51244/IJRSI.2025.1215000160P

Received: 26 September 2025; Revised: 07 October 2025; Accepted: 10 October 2025; Published: 24 October 2025

ABSTRACT

The COVID-19-associated Rhinoorbitocerebral Mucormycosis (ROCM) epidemic in India was a daunting challenge, marked by high morbidity and mortality. While aggressive treatment strategies saved lives, many survivors endured prolonged hospitalisations, multiple surgeries, and significant psychosocial burden. Long-term impacts on their quality of life remain poorly documented. This study evaluated the quality of life of COVID-19 ROCM survivors at 18months follow-up.

Method: This ambispective cohort study included 69 COVID-19-associated ROCM patients treated from May to July 2021. Of the 56 patients discharged after the first admission, 37 were available for follow-up at 18 months. The quality of life in these 37 patients was assessed using the SF-12 questionnaire. A value <50 was considered to indicate poor QOL.

Results: Of the 69 patients included, 23/69(33·33%) had sinonasal disease, 27/69(39·13%) rhinoorbital disease, 15/69(21·73%) rhinoorbitocerebral disease and 4/69(5·79%) rhinocerebral disease. After primary admission, 56/69(81.1%) were discharged and 13/69(18.8%) had died.

At 18 months follow-up, 37/56 were alive and completed the questionnaire. The median physical component (PCS) score was 50.96(IQR 42.18-56.07) and the median mental component (MCS) score was 47.14(IQR 35.49-53.95). The PCS in 16/37(43%) patients and MCS in 23/37(62%) were less than the national average of 50. The financial burden of treatment, COVID-19 death in the family, disfigurement, and loss of vision were cited for poor mental health.

Conclusion: The impact of COVID-19-associated ROCM extends far beyond survival, leaving patients with lasting physical disability and psychosocial distress. Long-term and comprehensive rehabilitation is not optional, but it is imperative.

INTRODUCTION

Mucormycosis is a rapidly progressive fungal infection associated with high morbidity and mortality. Historically, it is a rare clinical entity. An unprecedented surge of Rhinoorbitocerebralmucormycosis (ROCM) was noted in patients during the COVID-19 pandemic.[2,3] India was particularly affected, with 45,274 reported cases of invasive fungal infections in COVID-19(including 4332 deaths) as of July 20, 2021, with ROCM being the commonest presentation.[4] While the prevalence of mucormycosis has always been higher in India than in developed nations [1] , this surge challenged an already overwhelmed healthcare system.

Patients were treated amidst a severe shortage of antifungal agents, including amphotericin B and posaconazole[5,6]. Sinus debridement, in all cases with orbital and neurosurgical debridement when indicated, was performed in all patients, despite the overwhelming surgical load. However, post-operative rehabilitation was not addressed in many patients. Prolonged and expensive treatment, pandemic-mandated

ISSN No. 2321-2705 | DOI: 10.51244/IJRSI | Volume XII Issue XV September 2025 | Special Issue on Public Health

lockdowns, and loss of employment imposed a severe socio-economic burden on the patients and their families.[6]

Although multiple studies have described the short-term outcomes of COVID-19-associated ROCM, [7-11], its impact on the quality of life has been reported to a lesser extent. [12-17] This study evaluated the overall Quality of life (QOL) among these patients at 18-month follow-up.

METHOD

This ambispective cohort study (retrospective study with a prospective arm), was conducted in a tertiary care hospital in South India. The study design and participants' flow chart are shown in Figure 1. Institutional ethics review board approval for the study was obtained prior to its initiation (IEC Study No 181/2021), and the study was conducted in accordance with institutional ethical guidelines.

The cases included all patients diagnosed and treated for COVID-19-associated Rhinoorbitocerebral mucormycosis (ROCM) in our hospital between 1st May 2021 to 30th July 2021. Waiver of consent was obtained for the retrospective arm of the study, while consent was obtained for the prospective arm of the study. The risk factor for this cohort of COVID-19-associated ROCM patients, the treatment protocol for COVID-19 and ROCM, and long-term outcomes for life and vision, have been described in detail in a prior publications[18,19]

At 18 months follow-up, we contacted all 56 patients who discharged following the primary admission. Some patients were on regular follow-up at our institution for further treatment of mucor or its sequelae. Those patients who did not return for follow-up were contacted telephonically or through letters, to the telephone number or address provided during registration. At 18 months following discharge, 37 of 56 patients were available for follow-up for QOL assessment; 6/56 patients had died, and 13/56patients were lost to follow-up despite our best efforts to contact them.

To evaluate QoL, we employed the Short Form-12 Health Survey (SF-12), a validated instrument that measures physical and mental health across eight domains, yielding two composite scores: the Physical Component Summary (PCS) and the Mental Component Summary (MCS). The SF-12 questionnaire was administered either in person during outpatient visits or telephonically for patients unable to attend in person, ensuring accessibility and minimizing loss to follow-up.

Data collection was carried out by trained clinical staff familiar with the SF-12 protocol. Responses were recorded, scored, and analyzed according to standard guidelines.

The Physical Component Score (PCS) and Mental Component Score (MCS) were calculated for each patient, and the median scores for the cohort were determined. Patients were also asked questions specific to mucormycosis.

For statistical analysis, the national average of PCS and MCS was taken as 50.[20,21] Only Descriptive statistics was computed, including frequency counts with percentages for categorical variables and mean(+SD)/ median (IQR) for continuous variables. No inferential statistics was undertaken as the sample size was small.

RESULTS

The 37 patients who were available for follow-up were assessed for quality of life using the SF-12 questionnaire. The median PCS was 50.96334 (IQR 42.18202 to 56.06965) and the median MSC was 47.14346 (IQR 35.48879 to 53.94707). The PCS was less than the national average in 16/37 (43%) patients and MCS less than the national average in 23/37 (62%).

Over 37% of patients experienced both physical and emotional challenges due to ROCM affecting their work capacity and ability to perform tasks carefully (Figure 2). About 30% reported difficulties in climbing stairs and other moderate physical activity due to ROCM (Figure 3). The pain and subsequent mental distress experienced by patients also affected their social activities (5/37), and physical activities (11/37) and contributed to a low mood (7/37) (Figure 4).

ISSN No. 2321-2705 | DOI: 10.51244/IJRSI | Volume XII Issue XV September 2025 | Special Issue on Public Health

In feedback obtained using open-ended questions, patients consistently highlighted the financial burden of treatment, the grief of losing a family member to COVID-19, disfigurement, and the loss of vision as key contributors to poor mental well-being.

DISCUSSION

The COVID-19-associated ROCM epidemic left a trail of significant mortality and morbidity. The mortality rate at the time of discharge in most studies was 35%, with a range of 15% to 53%.[2,7-11] The mortality rate in our study at the time of discharge was 19% (13/63), with another 6 having died at 18months follow-up, making it a cumulative mortality rate of 27%. This study provides a sobering look at the long-term journey of survivors, revealing that the battle often continues well beyond discharge.

In the current study, we evaluated the quality of life of patients in addition to the health status of COVID-19-associated ROCM survivors nearly 18 months after diagnosis. The PCS and MCS scores were reduced considerably (MCS>PCS). In a large multicentric study reported by Abdulkhader et al, emotional, social, and functional impairment occurred in 30% of patients, with one out of every two CAM patients showing poor QOL, similar to QOL findings in our patients. [12]

Disfigurement and loss of vision is an important cause of poor QOL in ROCM patients.[15] Disfigurement is a common sequela of ROCM, due to both the fulminant invasive nature of the disease and the consequent aggressiveness of treatment, particularly in patients who have undergone exenteration. In a report by Ahuja A, et al, patients who had undergone exenteration had severely affected self-esteem, with severe depression, anxiety, and suicidal ideas. Exenteration leads to the formation of an orbito-antro-oral fistula, which leads to distressing symptoms. Rehabilitation measures in exenterated patients resulted in improved QOL scores. [22,23] Persisting symptoms like headache, facial puffiness and discoloration, and loose teeth also contributed to poor QOL scores. [14]

In addition, the expensive and prolonged treatment had an enormous economic impact as reported by patients and their families. Other studies also found that the economic burden of the disease affected QOL.[13,17] In our cohort, some patients required repeat surgeries as part of ongoing treatments or as part of treatment for the disfigurement. The loss of a family member to COVID-19 also contributed to poor mental well-being in patients, and these factors had an impact on the QOL of the patients.

One of the limitations of the study is the lack of information on the 13/69 patients who were lost to follow-up, despite our best efforts to trace them. This reduced our sample size and caused a selection bias, as those who were lost to follow-up could potentially have had a more severe form of disease and poorer outcomes. However, in a larger study reported by Abdulkader et al, on sensitivity analysis found that the lost to follow-up did not have an impact on survivorship status. The second limitation was that during the 18-month follow-up, the SF-12 questionnaire was applied telephonically in some patients, with a potential for recall bias. Despite these limitations, this cohort study fills the gap in knowledge on long-term QOL of patients with COVID-19-associated ROCM.

In conclusion, the COVID-19-associated ROCM epidemic was associated with high mortality and morbidity not only during the initial hospital admission but also continued to affect individuals well after discharge. The QOL of these patients was affected, with a large number being unable to accomplish their desired level of work, which affects long-term mental well-being. Their journey highlights an urgent and unmet need for structured, long-term, multidisciplinary support systems that address not only surgical and medical rehabilitation but also the profound psychological and socioeconomic consequences of this life-altering illness.

REFERENCES

1. Skiada A, Pavleas I, Drogaria-Apiranthos M (2020) Epidemiology and diagnosis of mucormycosis: an Update. J Fungi. 6(4):265
2. Sen M, Honavar SG, Bansal R, Sengupta S, Rao R, Kim U, et al. Epidemiology, clinical profile, management, and outcome of COVID-19-associated rhino-orbital-cerebral mucormycosis in 2826

patients in India – Collaborative OPAI-IJO Study on Mucormycosis in COVID-19 (COSMIC), Report 1. Ind J Ophthalmol 2021; 69:1670-92.

3. World Health Organization. WHO Coronavirus (COVID-19) Dashboard: India, https://covid19.who.int/region/searo/country/in; 2023. [accessed 6 February 2023].
4. Pasquier G. COVID-19-associated mucormycosis in India: Why such an outbreak? J Mycol Med. 2023;33:101393. doi: 10.1016/j.mycmed.2023.101393. Epub 2023 May 9. PMID: 37182234
5. Ghazi BK, Zahid U, Usman MA, Kazmi Z, Hunain R, Riaz MM, et al. Antifungal drugs shortage in India amidst looming increase in invasive fungal infections among COVID-19 patients: An impending crisis. Innov Pharm 2022;13.
6. 10. Prakash H, Chakrabarti A. Epidemiology of Mucormycosis in India. Microorganisms. 2021;9 doi: 10.3390/microorganisms9030523
7. Choksi T, Agrawal A, Date P, Rathod D, Gharat A, Ingole A, et al. Cumulative Mortality and Factors Associated with Outcomes of Mucormycosis After COVID-19 at a Multispecialty Tertiary Care Center in India. JAMA Ophthalmol. 2022; 140:66–72. doi:10.1001/jamaophthalmol.2021.5201
8. Dave TV, Nair GA, Hegde R, Vithalani N, Desai S, Adulkar N, et.al. Clinical Presentations, Management and Outcomes of Rhino-Orbital-Cerebral Mucormycosis (ROCM) Following COVID-19: A Multi-Centric Study. Ophthalmic Plast Reconstr Surg. 2021;37:488-495. doi: 10.1097/IOP.0000000000002030.
9. Patel A, Agarwal R, Rudramurthy SM, Shevkani M, Xess I, Sharma R, et al. Multicenter Epidemiologic Study of Coronavirus Disease–Associated Mucormycosis, India. Emerg Infect Dis. 2021; 27:2349–2359. doi: 10.3201/eid2709.210934
10. Vare AA, Yellambkar S, Farheen A, Nandedkar V, Bhombe SS, Shah R Incidence, cumulative mortality and factors affecting the outcome of COVID-19-associated mucormycosis from Western India. Indian J Ophthalmol 2021; 69:3678–3.
11. Moorthy A, Nayak T, Bachalli PS, Tripathi KK, Dutt SK, Kale P, et.al. COVID-associated rhinocerebral mucormycosis: a retrospective analysis of presentation and outcomes. Eur Arch Otorhinolaryngol 2023; 280: 713–721 https://doi.org/10.1007/s00405-022-07544-y.
12. Abdulkader RS, Mohan M, Saravanakumar D, Ponnaiah M, BhatnagarT, Devika S, et al. Survival and quality-of-life in mucormycosis: a multicentric ambispective cohort study, Clinical Microbiology and Infection, doi.org/10.1016/j.cmi.2025.06.001
13. Nayak PS, Goswami P, Kumar AD, Bhaskar P. Quality of Life in Mucormycosis Patients Post Discharge: A Pilot Study Using a New MQOL-36 Questionnaire. Indian J Otolaryngol Head Neck Surg 2023; 75:397–403 https://doi.org/10.1007/s12070-022-03196-w
14. Kumar P, Rao UR, Roy N, Agrawal D, Ahmad S, Bhavana K. Quality of life in patients treated for COVID-19–associated mucormycosis at a tertiary care hospital. Osong Public Health Res Perspect. 2023; 14:119-128.
15. Ahuja A, Samudra M,Prasad SP, Chaudhury S, Bora S, Singh V, et al. Correlates of depression, anxiety, self-esteem, and suicidal ideas in COVID-associated mucormycosis patients and the effects of treatment. Ind Psychiatry J 2021;30 (Suppl 1):S75—82. https://doi.org/10.4103/0972-6748.328863.
16. Anwar A, Menacherry JJ, Joy L, Ashok V. Impact of Covid 19 associated mucormycosis on quality of life at a tertiary care centre. Int J Acad Med Pharm 2024;6:1085—9. https://doi.org/10.47009/jamp.2024.6.1.215.
17. Pappu LM, Sadanandam S, Munigala A, et al Evaluation of quality of life in post-covid mucormycosis cases: An original research Journal of Cardiovascular Disease Research 2023;13. DOI https//doi.org/10.48047 Srivastava S, Beri N, Das GK, Sahu PK, Singh A, Sharma I. The Psychological Impact of Rhino-Orbital Mucormycosis During the Second Wave of COVID-19 Pandemic from South East Asian Country. Cureus. 2023 Feb 23;15(2).
18. Karat S, Lobo AC, Satish D, Devaraj R, Manjooran RR, Nithyanandam S. Uncontrolled diabetes mellitus exacerbated by COVID-19-induced inflammation is the risk factor for COVID-19-associated rhino-orbito-cerebral mucormycosis: A matched pair case-control study. Indian J Ophthalmol. 2022 Aug;70(8):3096-3101. doi: 10.4103/ijo.IJO_448_22.
19. Orbit management sans exenteration with retrobulbar injection of amphotericin-B in Rhinoorbitocerebral mucormycosis: Impact on survival European Journal of Ophthalmology DOI 10.1177/11206721251361276

20. Pati S, Swain S, Knottnerus JA, Metsemakers JFM, van den Akker M. Health-related quality of life in multimorbidity: a primary-care based study from Odisha, India. Health Qual Life Outcomes. 2019;17:116-19. doi: 10.1186/s12955-019-1180-3. PMID: 31277648; PMCID: PMC6612103.
21. Sinha R, van den Heuvel WJA, Arokiasamy P. Validity and reliability of MOS short-form health survey (SF-36) for use in India. Indian J Community Med Off Publ Indian Assoc Prev Soc Med. 2013; 38:22–26.
22. Rao N, Agrawal A, Kapoor A, Mago V, Vathulya M, Chattopadhyay D Restoring Quality of Life: Assessing the Impact of Free Flap Reconstruction in Coronavirus Disease 2019-Associated Rhino-Orbital Mucormycosis Patients. Indian J Plast Surg. 2023 Oct 16;56(6):507-513. doi: 10.1055/s-0043-1776011.24
23. Chouksey G, Gupta V, Goel P, et al. Maxillary Defects Due to COVID-19 Associated Mucormycosis: Impact on Quality of Life After Rehabilitation With an Obturator. The Journal of Prosthetic Dentistry. 2025;133:1374-1379. doi:10.1016/j.prosdent.2023.07.005.

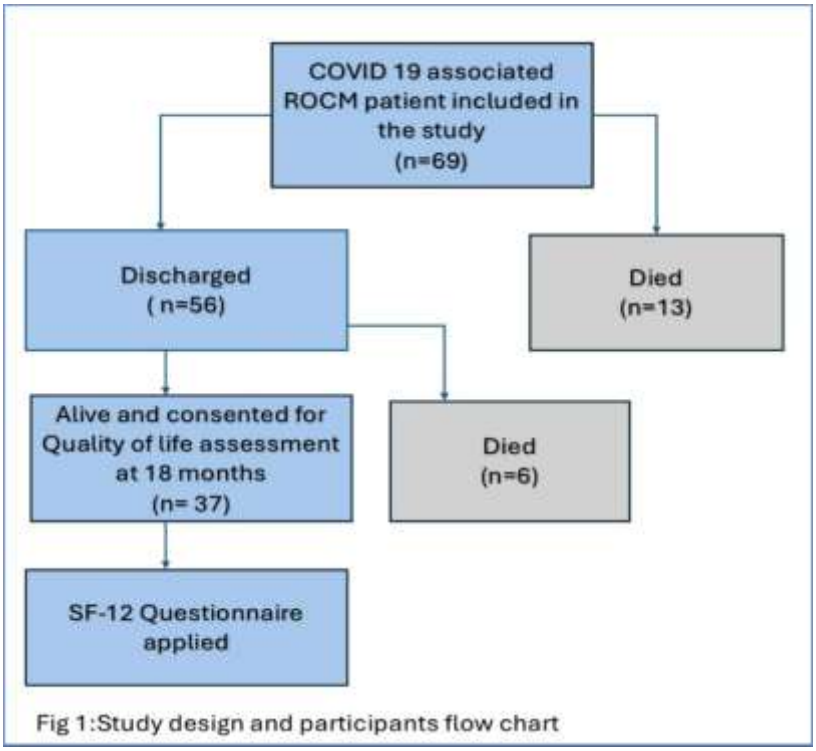

Figure 1: Study design and participants flow chart

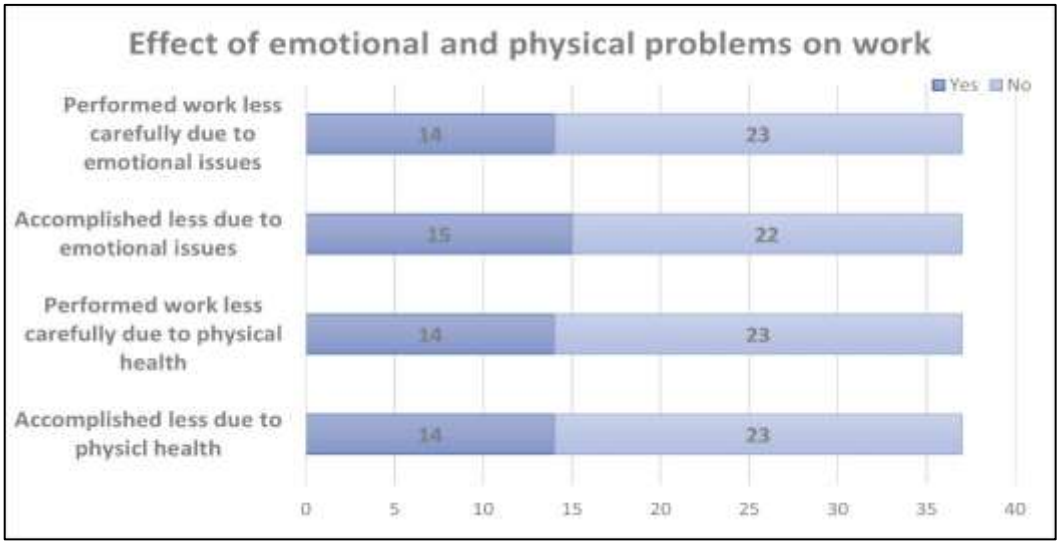

Figure 2: Effect of emotional and physical problems on work

ISSN No. 2321-2705 | DOI: 10.51244/IJRSI | Volume XII Issue XV September 2025 | Special Issue on Public Health

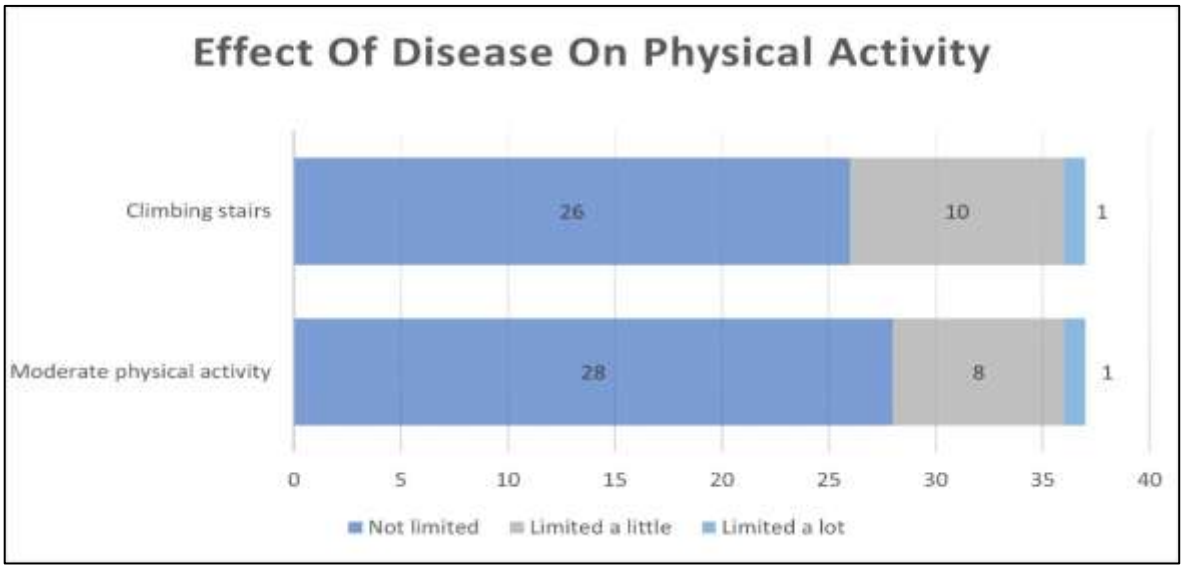

Figure 3: Effect of diseases on Physical activity

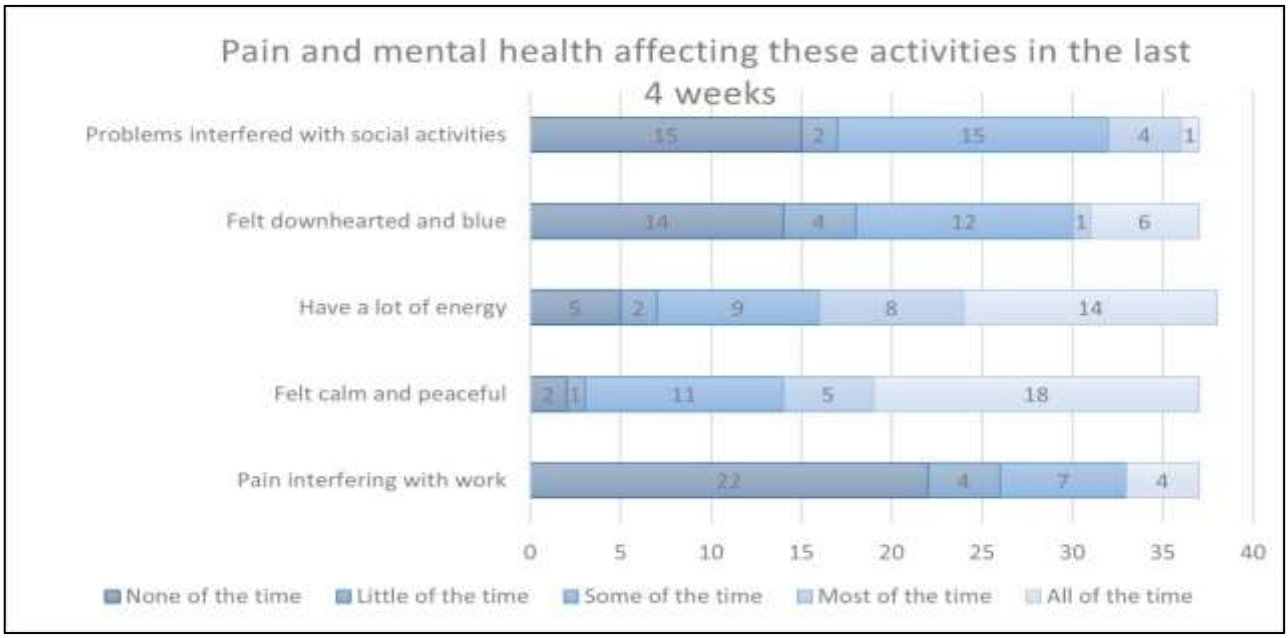

Figure 4: Effect of pain and mental health on social and physical activities