

## **Empowering Help seeking Behavior in Caregiver during Hospitalization: A Social Case Work Approach**

**Dr. Birudu Raju**, *Assistant Professor, Department of Psychiatric Social Work, National Institute of Mental Health and Neurosciences, Bengaluru, Karnataka.*

**Ms. Manaswita Kalita**, *Psychiatric Social Work, Department of Psychiatric Social Work, National Institute of Mental Health and Neurosciences, Bengaluru, Karnataka.*

### **Abstract**

Hemangioblastoma is a rare benign vascular tumor of the central nervous system, which causes significant physical, emotional, and financial burden on patients and their caregivers. The financial burden is quite high in families hailing from lower socio-economic status especially with no coverage of health insurance. Further, the psychosocial issues associated with brain tumors are commonly studied but very rarely intensive efforts are made from health care teams to reduce the psychosocial burden. The present case illustration will highlight the role of community support and need for psychoeducation, empowering caregivers, importance of community linkage with hospitals, developing help seeking behavior and reducing caregiver burden in easing psychosocial burden in families with brain tumor patients. Integrating community resources and addressing systemic barriers to provide holistic care to support vulnerable families by Medical and Psychiatric Social Workers are recommended.

### **Background**

Hemangioblastoma is a rare, benign vascular tumor of the central nervous system which predominantly affects the brain stem, cerebellum or spinal cord.<sup>[1]</sup> These tumors can result in significant neurological impairments, including headaches, lack of coordination, and difficulties in balance. While these tumors are non-cancerous, asymptomatic and resolve over a period of time, some can lead to complications that affect quality of life and cause disabilities.<sup>[2]</sup> Patients undergoing Hemangioblastoma can have deficits that require considerable support from caregivers. The caregivers are usually family members who take the caregiving responsibility. While fulfilling the

caregiving role, the caregivers can go through significant physical, emotional and financial burden. In addition to this, caregivers face complex and diverse caregiving needs, including balancing employment with caregiving responsibilities and making efforts to cope with their own emotional problems. <sup>[3]</sup>Adding to this, poor understanding about illness, difficulty in accessing health care services, lack of social support and respite care, psychological distress and financial constraints also increase the caregivers burden and these caregivers needs are unmet.<sup>[4],[5]</sup> The unmet psychosocial needs are one of the reason for social exclusion among families with brain tumor due to limited resources.<sup>[6]</sup> Further, research showed that increased cost of treatment is associated with potential loss of income<sup>[7]</sup> and high economic burden on patients, their caregivers and healthcare systems worldwide.<sup>[8]</sup>Thus, meeting treatment cost by families with brain tumor hailing from low socio-economic status is always challenging due to poverty, low income levels, lack of knowledge on health insurance and livelihood. Therefore, social support and community support becomes essential in alleviating these financial strains and is crucial for patients with hemangioblastomas, as it provides essential resources and assistance that substantially improves their recovery and quality of life.<sup>[9]</sup> However, there are barriers in help seeking especially asking for financial support due to cultural values thinking how others will perceive if asked for financial help, self-dignity and lack of help seeking behavior. There is substantial need to develop help seeking behavior and providing psychosocial support to caregivers to ensure the best treatment provided as a collective responsibility from holistic care perspective. Thus, the present case study aimed to highlight the role of community support to ease the psychosocial burden of hemangioblastoma survivor and his caregiver hailing from below poverty line.

**Clinical details of the TBI survivor:** A 40-year-old married, male patient hailing from low socio-economic status was admitted in our hospital due to sudden onset of severe headache followed by vomiting. Patient was later diagnosed with hemangioblastoma and subsequently undergone surgery. Post operatively His hospitalization was continued for more than 7 months and need for intensive care and posed significant psychosocial challenges for his wife, who is the only primary caregiver. The family faced severe financial constraints, compounded by the lack of valid income certificate or below poverty line card to access welfare benefits and to get the treatment concession at the treating hospital. The patient's medical expenses were substantially high due to Intensive Care, and the caregiver's income as a private school teacher was insufficient to meet the costs. Thus, the treatment team referred the case to Medical and Psychiatric Social Workers (MPSWs) to render professional

help and mobilize the financial resources to continue the treatment and provide the supportive care to the primary caregiver. In regard to this case, the psychosocial interventions that MPSWs had provided as a part of the multidisciplinary team were elaborated in detail here.

**Psychosocial Assessment & Immediate Actions:** Soon after the referral, MPSWs had conducted the detailed psychosocial assessment with primary caregiver as the part of routine clinical care using social case work method. This method allows MPSWs to assess the psychosocial needs of brain tumor survivors and the caregiver in a systematic way. In this case, the psychosocial assessment conducted with only primary caregiver since brain tumor survivor was in tractotomy care and not amenable to converse. The following steps were followed while conducting the psychosocial assessment such as study, social diagnosis, intervention/treatment and management.<sup>[10]</sup> The psychosocial assessment results revealed that the caregiver was highly distressed due to increased financial burden, poor understanding about illness, low motivation, lack of health seeking behavior, lack of social support, lack of health insurance and psychological distress have increased the caregiver burden during hospitalization. Figure 1 showed various psychosocial problems faced the caregiver. Following which the MPSW Team had provided the psychosocial interventions;

**Psychoeducation on illness and need for homecare:** A session was focused to educate the primary care was his wife. His wife was educated about the patient's condition in consultation and day to day discussions with the treating team. The patient's poor prognosis was explained and that helped her set realistic expectations. She was provided with guidance on home care for the patient, caregivers roles and responsibilities, importance of long-term nursing care, informed about the necessary support and resources she could access in her caregiving to assist him to get possible recovery. Also educated on the various options available to get the treatment concession at treating hospital and its eligibility, importance of health insurance and guided her to get enrolled in Ayushman Bharat Scheme to meet future financial needs.

**Providing Emotional Support and reducing Psychological Distress:** Another session focused to provide emotional support and engaged her in peer counselling. The MPSW team provided consistent emotional support to the caregiver since she was emotionally distressed, filled with thoughts of helplessness and hesitant to seek help from friends and coworkers. Further, the Zarit

Caregiver Burden Scale was administered, a score of 59 revealing a severe level of caregiver burden since she had been a primary caregiver since the onset of illness. In response, the team created a safe and supportive environment for her to express her emotions and explored her coping strategies. MPSWs offered guidance on effective stress management techniques, assisted in setting realistic goals aligned with the patient's prognosis, facilitated decision-making processes regarding seeking financial help, and provided ongoing supportive counseling to address her emotional and psychological needs by involving her weekly in peer led caregiver support groups.

**Community Support in Action:**The other intervention done by MPSW team was mobilizing community support. The financial assessment showed that the patient and his family belong to low socio-economic status and no health insurance policy was available to meet the treatment expenses. Following which the MPSWs did a detailed file review and psychosocial assessment as the routine care to identify various supportive care needs. It was found that the patient's wife was the primary caregiver and she was taking care of all the financial needs. The patient, formerly a businessman, faced severe financial losses, leaving his wife as the sole breadwinner. Patient's wife worked in a private school as a teacher and due to patient's medical condition she had exhausted the amount of savings she previously had. The patient and his wife had a love marriage against their families' wishes, leading to 25 years of estrangement from the both families. Patient's wife was the only single child in her family. Her father had died and she had no relatives to support her emotionally or financially. This lack of support made her face more challenges in managing daily medications and treatment cost. Considering the financial need as high priority, MPSWs initiated in negotiating with Resident Medical Officer (RMO) and Chief Medical Superintendent (MS) for free medication and diet. The treating hospital administration such as RMO and MS were kind enough to sanction the free medication, necessary diet for patient including caregiver. Despite efforts made by the MPSWs team to secure financial assistance for day today medications, procedural barriers made it difficult to access treatment concession under below poverty line category or poorest of the poor category due to insufficient valid documents and lack of insurance. This accelerated the caregiver to experience high stress highlighting the need for a broader support network.

Other hand, patients' stay in the hospital extended for more than 7 months and treatment expenses also proportionately increased. In the meantime, MPSWs encouraged the caregiver to participate in

the caregiver support group meetings which were especially designed for brain tumor caregivers in the hospital premises by the MPSW team. The caregiver support group meetings aimed at providing peer support, learning best caregiving practices, providing emotional support, and improving coping abilities. Caregiver involvement in the supportive group work and interaction with peers inspired her to develop help seeking behavior. She had raised several questions on how to seek financial help from friends, coworkers, colleagues and community. Assurance was given to the caregiver that possible support would be provided. The MPSW's team along with peer caregivers helped her on how to get financial help from various resources from friends, known people, colleagues, and spiritual leaders in the community. Her interaction with MPSW's team and peer caregivers had helped her to get rid of self-hesitation to seek help from her friends, coworkers, school management, and spiritual leaders in the community. Slowly she developed courage and explained her husband's health condition over phone and personal interactions within her supportive network such as neighbors, from her friends, coworkers, school management, and spiritual leaders in the community who rendered financial help as soon as she approached them facilitated by MSW's team with necessary documents and clarifications. Almost 9-10 lakh Indian Rupees were mobilized to cover the patient's hospital treatment expenses. This collaborative support eased her immediate financial burden, emotional distress and enabling her to continue caring for her husband.

**Outcome:** As an outcome of the case, the primary caregiver successfully managed to pay the hospital bills with support from community resources, including friends, colleagues, her school management, spiritual leaders and treating hospital. Further, tailored made psychosocial interventions had enhanced her disease knowledge, deal with emotional distress, improve coping abilities, develop help seeking behavior, mobilize financial resources and reduce caregiving burden. With consistent support and guidance from MPSW team, she was able to process the challenges that she faced, sought necessary assistance, and gained a comprehensive understanding of the patient's condition. This enabled her to develop realistic plans for the future and focus on positive coping strategies. At the time of discharge, she had paid the outstanding bills and was mentally prepared to take on the caregiving responsibilities at home and expressed her immense gratitude to all the stakeholders who supported her husband and her.

## Discussion

The present case study aimed at highlight the developing help seeking behavior in caregiver and role of community support to the brain tumor survivor hailing from low socio-economic status and subsequently addressed various psychosocial problems by providing intensive psychosocial interventions to the caregiver. Brain tumor survivors depend on caregivers for their daily needs during hospitalization and at home especially brain tumor survivors who are in disabled and vegetative state. In this connection, caregivers' roles are not only demanding but also profoundly affect the mental health of caregivers. Caregivers' mental health needs are highly sensitive and delicate, often requiring professional support to address the day-to-day psychosocial challenges associated with the patient's condition and caregiving responsibilities.<sup>[6]</sup> MPSWs are trained in dealing with mental health issues and have the essential medical knowledge in health care setting. They play a crucial role in crisis and emergency situations by creating safety environment for patients and their caregivers. Thus, MPSWs are now considered as essential part of health care along with doctors and allied health care professionals. Adding to this, MPSWs are relied upon for supplying information that is of fundamental importance in reaching the correct diagnosis and management of the patient's health. Social case work method which assesses the social background of a disease and underlying causative factors can directly help to assist the treating physician by arriving at a holistic diagnosis and estimating the prognosis of the disease.<sup>[11]</sup>

In the present case MPSWs used social case work method using interview as a main tool to conduct the psychosocial assessment and found that brain tumor survivor was in need of financial support for treatment, which in turn increased financial burden, reduced social support, increased emotional distress, poor understanding and help seeking behavior in primary caregiver. This finding goes line with the previous studies report that financial constraints, physical exhaustion, psychological distress, prolonged nature of caregiving and lack of community support force caregivers into more vulnerability.<sup>[3]</sup> Considering the substantial needs derived from the assessment, the tailored made psychosocial interventions were provided. Objective focused counselling services and tailor made systematic psychosocial interventions would enhance illness knowledge, reduce psychological distress along with caregiver burden, and enhance family support.<sup>[6]</sup> There is a growing concern that strong linkage between the institution and the community for resource mobilization are needed to reduce financial burden needsof families.<sup>[7]</sup> Previous studies showed that major focus is given to

address the educational and emotional distress but not on mobilizing financial resources with the help of community support.<sup>[12]</sup> In order to this, the present case study contributes highlighting how communities help in all means when caregivers seek help. Seeking help during crisis times is always challenging for family members due to family reputation, lack of help seeking attitude and pre-conceived notion on how others think and treat in the community when asking for help. MPSWs in this case study understood the concerns of caregivers and made intensive efforts to empower her to develop help seeking behavior in the view of brain tumor survivors' treatment, recovery and pave the way to ensure caregivers emotional wellbeing. To achieve this objective MPSWs provided psychoeducation for caregiver, motivated and involved her in weekly peer supportive groups, provided emotional support, clarified day to day concerns and enhanced social support not just in the hospital but also in the work place, and community. These interventions helped her to develop help seeking behavior being a primary caregiver. Soon after, she approached friends, co-workers, colleagues, spiritual leaders in the community and school management all stakeholders supported financially voluntary within their capacity to continue the treatment. A total of 9 lakhs rupees financial resources were mobilized and monitored by MPSWs. The community support not only reduced financial burden in caregiver but also enhanced her social support, eased emotional burden and developed sense of hope on patient's recovery. Previous studies report that addressing caregiver needs is a major component of comprehensive patient care. The dynamic nature of brain tumor progression requires caregivers to continually adapt to new roles and responsibilities, often without adequate support systems. This ongoing adjustment can lead to chronic stress and diminished quality of life. Effective support systems can reduce caregiver burden, improve patient outcomes, and create a safety net during emergencies. Previous studies have highlighted that community resources such as support from non-governmental organizations, work place environment, local organizations play a crucial role in providing financial aid. These resources can be very beneficial in providing tangible and emotional support for families facing difficult challenges.<sup>[13]</sup> In order for patients to be able to utilize these resources, collaboration with community resources, systematic guidance and involvement by MPSWs is necessary. Mobilizing these resources for brain tumor survivor's family and social integration requires systematic interventions and prolonged collaboration with community resources. The findings of this case study underscore the multidimensional challenges faced by patients with brain tumor patients and their caregivers, reaffirming existing research on the subject. This case study and its success in utilizing resources strengthens the ties between medical and

psychiatric social workers, treating team and community resources to provide holistic care to address the caregiver burden. The proactive role of the social work team in this case including advocacy, counseling, and resource mobilization is consistent with the best practices outlined by previous studies.<sup>[3], [14]</sup> The caregiver's reliance on community resources, including support from friends and support from her workplace, illustrates the significant role of secondary and tertiary support systems. This finding aligns with previous studies which underscore the importance of secondary support systems in mitigating the impact of financial and emotional distress.<sup>[15]</sup> The success of such resources in this case reinforces the argument for strengthening ties between medical social work and community-based organizations to provide holistic care and multi-component psychosocial interventions are recommended.<sup>[12]</sup> The interventions highlight the need for MPSWs to adopt a multi-dimensional approach to address both immediate and long-term needs of patient and caregivers. Figure 2 showed the various steps taken to empower the caregivers help seeking behavior.

### **Limitations**

One of the primary limitations of the MPSWs intervention was the inability to facilitate treatment cost concession to patient due to insufficient documentation despite the patients' low socio-economic background status. Patient and the caregiver also had lack of awareness on the importance of health insurance. Despite extensive efforts and advocacy by the MPSW team, these systemic barriers hindered the provision of direct financial support, ultimately requiring the caregiver to rely on personal and community resources to address the financial burden. This highlights the need for more flexible institutional policies and efficient processes to facilitate timely financial assistance in similar cases especially for people under vulnerability and below poverty line.

### **Conclusion**

In conclusion, it highlights the need for integrated, multi-level support systems that combine the efforts of medical social workers, healthcare providers, and community resources to ensure comprehensive care to address the various psychosocial problems of patients and their caregivers.

## References

1. Cleveland Clinic. Hemangioblastoma [Internet]. [cited 2025 Jan 17]; Available from: <https://my.clevelandclinic.org/health/diseases/22738-hemangioblastoma>
2. Chamli A, Aggarwal P, Jamil RT, Litaem N. Hemangioma [Internet]. In: StatPearls. Treasure Island (FL): StatPearls Publishing; 2025 [cited 2025 Jan 17]. Available from: <http://www.ncbi.nlm.nih.gov/books/NBK538232/>
3. Schubart JR, Kinzie MB, Farace E. Caring for the brain tumor patient: family caregiver burden and unmet needs. *Neuro-oncology* [Internet] 2008 [cited 2025 Jan 17];10:61–72. Available from: <https://academic.oup.com/neuro-oncology/article-abstract/10/1/61/1226781>
4. Raju B, Bora D. Letter to the Editor Regarding " Health Literacy in Neurosurgery: A Scoping Review". *World neurosurgery* [Internet] 2024 [cited 2025 Jan 17];189:496–7. Available from: <https://pubmed.ncbi.nlm.nih.gov/39252339/>
5. Birudu R, Kanmani TR. Are Psychosocial Problems Adequately Investigated in Pediatric Glioma? *Oncology Journal of India* [Internet] 2018 [cited 2025 Jan 17];2:65. Available from: [https://journals.lww.com/ojji/fulltext/2018/02030/are\\_psychosocial\\_problems\\_adequately\\_investigated.7.aspx](https://journals.lww.com/ojji/fulltext/2018/02030/are_psychosocial_problems_adequately_investigated.7.aspx)
6. Raju B, Lukose S, Reddy NK. Does lack of resources within the family starting point to social exclusion for persons with brain cancer. *J Neurosci Rural Pract* [Internet] 2016 [cited 2025 Jan 17];7:125. Available from: [https://www.researchgate.net/profile/Suresh-Lukose/publication/312247745\\_Does\\_Lack\\_of\\_Resources\\_within\\_the\\_Family\\_Starting\\_Point\\_to\\_Social\\_Exclusion\\_for\\_Persons\\_with\\_Brain\\_Cancer/links/59fab56a458515d20c7d8582/Does-Lack-of-Resources-within-the-Family-Starting-Point-to-Social-Exclusion-for-Persons-with-Brain-Cancer.pdf](https://www.researchgate.net/profile/Suresh-Lukose/publication/312247745_Does_Lack_of_Resources_within_the_Family_Starting_Point_to_Social_Exclusion_for_Persons_with_Brain_Cancer/links/59fab56a458515d20c7d8582/Does-Lack-of-Resources-within-the-Family-Starting-Point-to-Social-Exclusion-for-Persons-with-Brain-Cancer.pdf)
7. National Brain Tumour Society. Katie & Pete's Story: Navigating Financial Challenges Following a Glioblastoma Diagnosis [Internet]. Available from: <https://braintumor.org/news/katie-petes-story-navigating-financial-challenges-following-a-glioblastoma-diagnosis/>
8. Khanmohammadi S, Mobarakabadi M, Mohebi F. The Economic Burden of Malignant Brain Tumors [Internet]. In: Rezaei N, Hanaei S, editors. *Human Brain and Spinal Cord Tumors: From Bench to Bedside*. Volume 1. Cham: Springer International Publishing; 2023 [cited 2025 Jan 17]. page 209–21. Available from: [https://link.springer.com/10.1007/978-3-031-14732-6\\_13](https://link.springer.com/10.1007/978-3-031-14732-6_13)
9. Genetic and Rare Diseases Information Center. Hemangioblastoma [Internet]. Available from: <https://rarediseases.info.nih.gov/diseases/8232/hemangioblastoma>
10. Fjeldheim S, Levin I, Engebretsen E. The theoretical foundation of social case work. *Nordic Social Work Research* [Internet] 2015 [cited 2025 Jan 17];5:42–55. Available from: <http://www.tandfonline.com/doi/full/10.1080/2156857X.2015.1067900>
11. Shrivastava SR, Shrivastava PS, Ramasamy J. Medical social worker: Strengthening linkages between the hospital and the community. *Int J Health Syst Disaster Manag* [Internet] 2014 [cited 2025 Jan 17];2:130. Available from: [https://www.researchgate.net/profile/Saurabh-Shrivastava-17/publication/273813139\\_Medical\\_social\\_worker\\_Strengthening\\_linkages\\_between\\_the\\_hospital\\_and\\_the\\_community/links/648878fd79a72237652c3be6/Medical-social-worker-Strengthening-linkages-between-the-hospital-and-the-community.pdf](https://www.researchgate.net/profile/Saurabh-Shrivastava-17/publication/273813139_Medical_social_worker_Strengthening_linkages_between_the_hospital_and_the_community/links/648878fd79a72237652c3be6/Medical-social-worker-Strengthening-linkages-between-the-hospital-and-the-community.pdf)

12. Reinhard SC, Given B, Petlick NH, Bemis A. Supporting family caregivers in providing care. Patient safety and quality: An evidence-based handbook for nurses [Internet] 2008 [cited 2025 Jan 17]; Available from: <https://www.ncbi.nlm.nih.gov/books/NBK2665/>
13. Reblin M, Small B, Jim H, Weimer J, Sherwood P. Mediating burden and stress over time: Caregivers of patients with primary brain tumor. *Psycho-Oncology* [Internet] 2018 [cited 2025 Jan 17];27:607–12. Available from: <https://onlinelibrary.wiley.com/doi/10.1002/pon.4527>
14. Desai A, Jella TK, Cwalina TB, Wright CH, Wright J. Demographic analysis of financial hardships faced by brain tumor survivors. *World Neurosurgery* [Internet] 2022 [cited 2025 Jan 17];158:e111–21. Available from: <https://www.sciencedirect.com/science/article/pii/S1878875021016211>
15. Aoun SM, Deas K, Howting D, Lee G. Correction: Exploring the Support Needs of Family Caregivers of Patients with Brain Cancer Using the CSNAT: A Comparative Study with Other Cancer Groups. *Plos one* [Internet] 2016 [cited 2025 Jan 17];11:e0148074. Available from: <https://journals.plos.org/plosone/article/file?id=10.1371/journal.pone.0148074&type=printable>