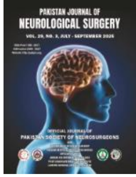

PAKISTAN JOURNAL OF NEUROLOGICAL SURGERY (QUARTERLY) – OFFICIAL JOURNAL OF PAKISTAN SOCIETY OF NEUROSURGEONS

Original Research

Silent Struggles, Resilient Spirits: A Study of Psychosocial Challenges and Quality of Life in Female Brain Tumor Patients at a High-Volume Neuroscience Institute in Pakistan

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ABSTRACT

Objectives: To determine the psychosocial impact of brain tumours in the female population of Pakistan using the FACT-Br Questionnaire.

Materials and Methods: 108 female patients with diagnosed brain tumours between the ages of 13-75 years were enrolled after informed consent from Punjab Institute of Neurosciences, Lahore. After admission, patients were asked to fill out the FACT-Br questionnaire. Demographic data and symptoms were also recorded.

Results: Out of a total of 108 patients, the mean FACT-Br total score was 96.7 (out of 200). This indicated a significant deterioration in the quality of life and psychosocial well-being.

Conclusion: Our results showed that brain tumours had caused major psychosocial and quality of life impairment in our sample. It is advised, based on our findings, that recognition by physicians of these problems is essential, and effort towards a better QOL outcome is required.

Keywords: Brain tumor, Quality of life, Functional assessment of cancer therapy brain (FACT-Br), Female, social wellbeing.

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Date of Submission: 01-04-2025
Date of Revision: 08-08-2025
Date of Acceptance: 25-08-2025
Date of Online Publishing: 01-9-2025
Date of Print: 30-9-2025

DOI: 10.36552/pjns.v29i3.1128

INTRODUCTION

Brain tumours are one of the most catastrophic conditions that can be diagnosed in a human being. The annual global age-standardized incidence of brain tumours is about 4.25 per 100000 person-years. Its clinical presentations, which range from minor headaches to potentially life-threatening conditions, are usually devastating for the patient. Furthermore, the management of these conditions can be prolonged and arduous,

including surgeries, chemotherapy and radiotherapy, lifelong medicines and physical therapies, which also add to the burden that these patients must face.

The social stigma of brain disease is widespread in Pakistan. Patients with brain tumor manifestations such as cognitive impairment, seizures, and neurological deficit in the form of weakness of the body are commonly diagnosed by the illiterate population as having been possessed by demons and evil spirits. As such, they are taken to shamans and spiritual healers for treatment. A study conducted at Jinnah Hospital, Lahore, found that around 50% of patients with symptoms of brain tumours presented to their local healthcare provider, be it a quack or a shaman, within 20 days. However, only 42% of the patients presented to a neurosurgeon even after 6-9 months of the onset of symptoms.[1]

The female population, unfortunately, is especially prone to these hardships. Usually having more delayed presentations and a decreased level of care than their male counterparts.

Those who present to medical professionals (if at all) are mostly with delayed presentations because of people seeking alternative treatments, and the fact that neurosurgery in Pakistan is available in metropolitan cities only. Few centers nationwide are catering to the massive population of brain tumor patients, and patients must be referred to these handful of institutions from far-flung areas.

Punjab Institute of Neurosciences, Lahore, is one of these institutions. Being one of the largest neurological healthcare facilities in the world, serving a population of over 250 million and performing over 1400 brain tumor surgeries per annum[2]. It is the leading centre from which brain tumours are present and are managed from all over the country.

Although the management of brain tumours is a challenging task, neurosurgeons in Pakistan have too long concentrated only on managing the pathology, and we must move beyond assessing successful management by radiological or clinical criteria alone and pay heed to the underappreciated metric that is quality of life (QOL) in these patients. Since the seventies, QOL has gained increasing relevance in the evaluation of brain tumor patients across the Western world.[3,4,5,6,7,8,9]

According to the World Health Organization, QoL is the subjective perception of one's position in life, in the context of the culture and values where you live, and in relation to own objectives, hopes, habits, and matters.[10] The goal of a practitioner should not only be to manage the pathology but also to do the utmost in improving the patient's quality of life. Quality of life is a dynamic and subjective perception, and it may vary significantly in response to several factors.

There are several validated instruments for QOL assessment, such as the functional living index cancer (FLIC),[11] European Organization for Research and Treatment of Cancer Brain Cancer Module (EORTC),[12,13,] and the functional assessment of cancer therapy – brain (FACT-Br).[14]

The Fact-Br is a validated instrument that has been proven to be a valid and reliable scale for evaluating important concerns of patients with brain tumors.[15] It has 5 subscales: Physical Wellbeing, Social/Family Wellbeing, Emotional Wellbeing, Functional Wellbeing, and lastly Brain Cancer subscale. Patients can be evaluated across a variety of different domains to assess their psychosocial status and quality of life, with the last subscale specifically assessing potential detriments to QOL by brain cancer.

Using this questionnaire, a study at the University of Alabama, Birmingham, AL, USA, evaluated 50 patients who presented to the neuro-oncology clinic with GBM. The mean Fact-Br total score was 127.34 out of a total of 200 (63%),[16] indicating significant quality of life deterioration.

A study on brain cancer patients' quality of life using the FACT-Br questionnaire has not yet been done in Pakistan; however, a similar study on the quality of life of brain cancer patients was

conducted in Agha Khan Hospital using the EORTC questionnaire. Their results revealed a mean global QOL of 75.73, which was higher than data from Austria, Germany, France, Turkey, Canada, the Netherlands, Iran, and India.[16]

Thus, we devised this study to assess the quality of life in brain tumor patients of the Pakistani population using the FACT-Br questionnaire, as it may yield valuable insights about the psychological and social condition of these patients. Further improving neurosurgical care and helping us move beyond just the radiological and clinical aspects of disease and onto more patient-centric treatments. The current study focused on evaluating the quality of life and psychosocial status of female brain tumor patients presenting to the Punjab Institute of Neurosciences, Lahore.

MATERIALS AND METHODS

Study Design and Setting

This is a cross-sectional study conducted in the neurosurgery unit II, Punjab Institute of Neurosciences (PINS). The protocol of this study has been approved by the institutional review board at Punjab Institute of Neurosciences. This paper is reported following the STROBE (Strengthening the reporting of observational studies in epidemiology) checklist. A total of 108 female patients with brain tumours who met the inclusion criteria were included in the study after acquiring informed consent.

Inclusion Criteria

Participants included individuals older than 13 years of age who were female and had a confirmed diagnosis of a brain tumor. The study encompassed cases involving both supratentorial and infratentorial brain tumors and included patients with either primary or metastatic tumors.

Exclusion Criteria

The exclusion criteria included patients from the pediatric population, individuals who had previously received treatment for intracranial diseases, those with a known psychiatric illness, and patients presenting with an altered state of consciousness.

Ethical Approval

The institutional review board of Punjab Institute of Neurosciences approved this research on the 11th of March 2025 (reference no. 2096).

Variables

The following variables were recorded:

- Demographic details (name, age, MR number, education, marital status, and address)
- The time lapse between the manifestation of the first symptom of disease and presentation to the hospital for management.
- Symptoms; classified into domains
- The FACT-Br questionnaire: it is composed of 5 categories
  - Physical Wellbeing (PWB) – 7 questions.
  - Social/Family Wellbeing (SWB) – 7 questions.
  - Emotional Wellbeing (EWB) – 6 questions.
  - Functional Wellbeing (FWB) – 7 questions.
  - Brain cancer subscale score (BrCs) – 23 questions.

Each question has scoring on a Likert scale of 0: not at all to 4: very much, with reversals being applied to certain questions with 0: very much and 4: not at all. With 0 being uniformly the worst score and 4 being uniformly the best score. For example, in the question “Do you feel Ill?” 0=Very much and 4=not at all.

Each category yields its separate score, which is the sum of all the individual scores in the category. The FACT-Br total score will be recorded during stay in the ward before surgery.

FACT-Br total score is calculated by summing

the scores of all the categories.
{PWB score} + {SWB score} + {EWB score} + {FWB score} + {BrC score} = {FACT-Br total score}

(The questionnaire, which is copyrighted by Dr. David Cella, Ph.D., was acquired from FACIT.org, to whom Dr. Cella has granted the right to license the use to other parties. After agreeing to the terms and conditions and signing, FACIT.org has granted author Hamza Noman the licence to use this questionnaire).

Study Size

Sample size is calculated as follows:

As per the reference study on the incidence of brain tumors in Pakistan,[17] population proportion = 41.5% (female patients per total number of brain tumor patients).

Population size (approximate no. of brain tumors admitted to NS-2 ward in 6 months) = 150.

Confidence level = 95% Margin of error = 5% Sample size (as calculated by WHO calculator) = 108.

Data Collection

108 patients fulfilling the selection criteria were enrolled from the ward of the neurosurgery unit 2 at PINS. A nonprobability consecutive sampling technique was employed for recruitment. The above-mentioned variables were recorded by a proforma after Informed consent was obtained from the participants regarding participation in the research.

Data Analysis

The data was analyzed using SPSS 27. Quantitative variables are reported as a range. Qualitative variables are expressed as frequencies and percentages.

RESULTS

Participants

108 patients were included in the study after informed consent.

Descriptive Data

Age

Age was stratified into 4 groups: 16-25, 26-40, 41-60, 61-75.

Ages ranged from a minimum of 16 to a maximum of 75 years old.

Education

Education level was divided into the following categories: Uneducated, primary, middle, matric, inter, graduate, and postgraduate.
The most common education level was uneducated.

Marital Status

Marital status was divided into: Married, unmarried, divorced, or widowed, with most of the participants being married. (72%).

Address

The address was recorded as being either rural or urban. 52% of the population was from rural areas, while 48% were from urban areas.

Time Lapse Before Presentation

One of the concerning factors we noticed is that brain tumor patients in our country, especially the female population, usually have delayed presentations to the hospital. This parameter was also recorded as the time interval between the appearance of the first symptom in the patient and her first visit to the hospital for the said symptom of brain tumor.
32% of the patients presented within 3 months of the onset of first symptoms.

36% of patients presented between 3 and 6 months

16% presented between 6 months and 1 year.

While 16% presented later than 1 year.

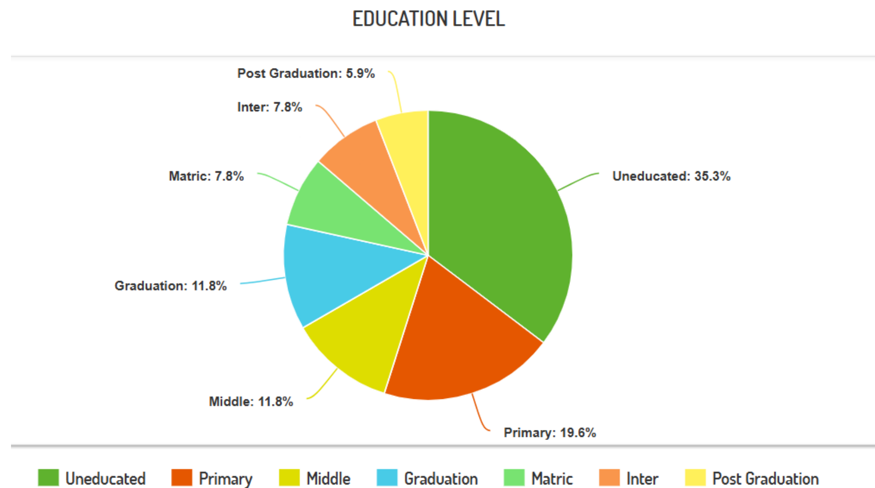

Figure 1: *Education level distribution pie chart.*

Primary Symptom Domain

The presenting symptoms of the disease were classified into 8 categories:

- Motor weakness.
- Seizures.
- Endocrine.
- Cognitive.
- Vision.
- Hearing.
- Altered consciousness.
- None of the above included headache and incidental presentations.

FACT-Br

As stated earlier, it has 5 categories of questions for assessment:

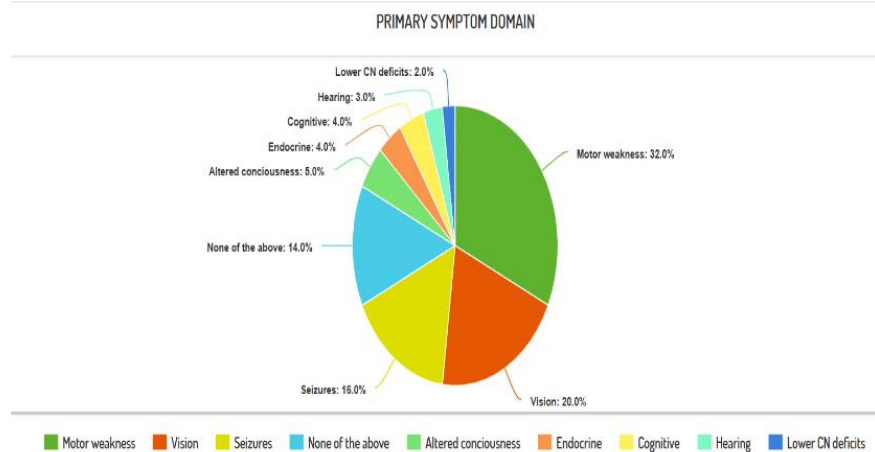

Figure 2: *Primary symptom Domain distribution pie chart.*

Physical Wellbeing – PWB Score

The physical well-being section contains 7 questions, and the final PWB score is calculated by the summation of all the scores.

Our results showed a mean PWB score of 13.7

Social/Family Wellbeing – SWB Score

The social/family wellbeing section consists of 7 questions, and the final SWB score is the sum of all. Our results showed a mean SWB score of 7.75

Emotional Wellbeing – EWB Score

This section contains 6 questions, and the EWB score is their sum. The mean EWB score in our population was: 15.4.

Functional Wellbeing – FWB Score

The FWB score is the sum of 7 questions in this section. The mean FWB score recorded: 11.4

Brain Cancer Subscale Score – BrC Score

The BrC score is the sum of the scores for 23 questions in this section. The mean BrC score in our study was 49.4.

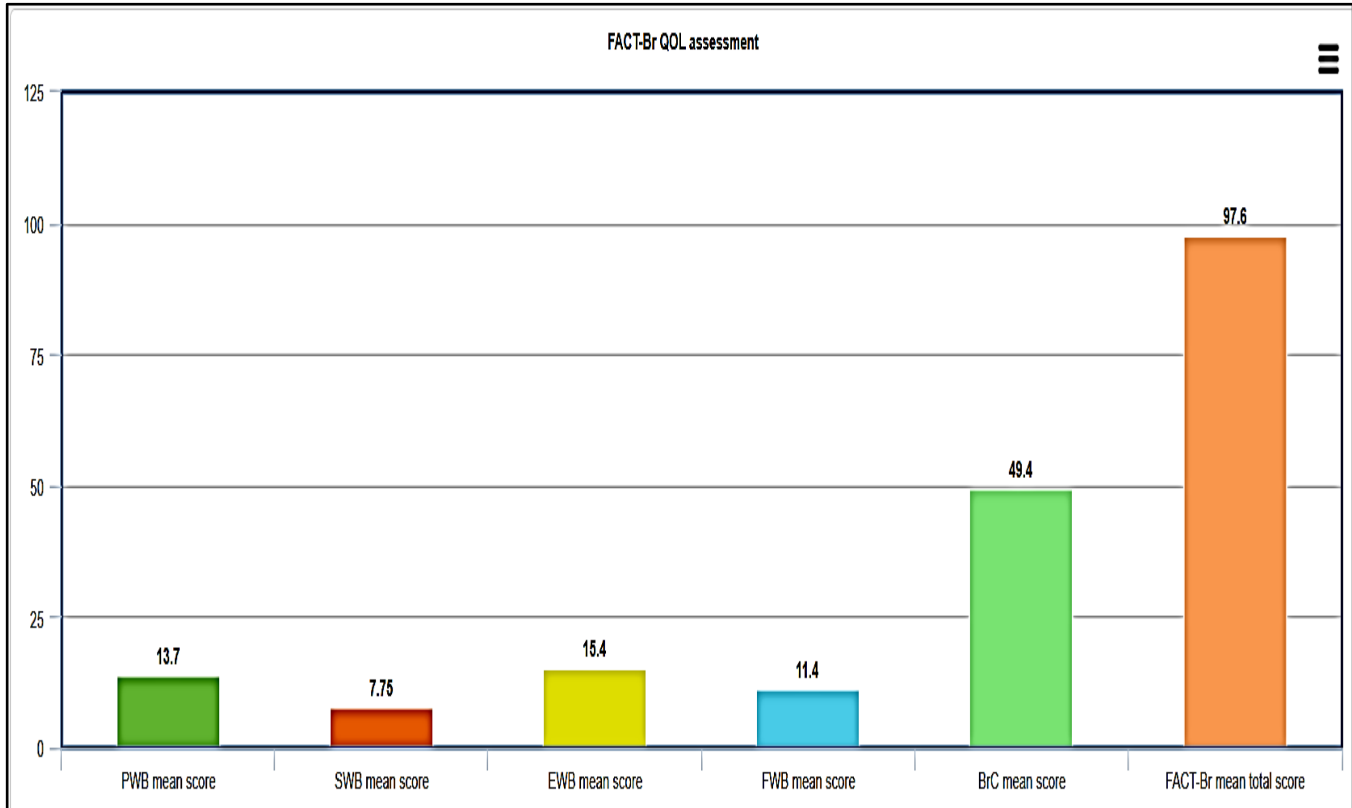

Figure 3: *Bar chart of FACT-Br scores.*

The FACT-Br Total Score

It is the sum of all the individual category scores. In our study, the mean FACT-Br total score turned out to be: 97.6.

DISCUSSION

Brain tumours are devastating, and while survival rates have improved with better therapies, patients face significant psychosocial challenges. These include cognitive, emotional, and social disturbances, along with stigma, especially in developing countries like Pakistan. Patients experience loss of independence, social isolation, and personality changes, which impact their relationships and roles. These Quality-of-life impairments are of utmost importance and must be evaluated and recorded for better management in the future.

The mean FACT-Br total score in our study was 97.6 out of 200, which displays a significant deterioration in the quality of life. Comparing this to studies done in other countries utilizing the same questionnaire (for example, the one done at the University of Alabama, which had a mean score of 127.34[16]), the score in our population was considerably lower.

This could be due to several factors including (but not limited to) the lower education level in the population (only 33% of the participants in our study had education level matric or above), leading to superstitious beliefs and inability to understand the nature of their disease or the stigma that comes with brain tumours causing lower level of self-confidence and decreased perception of well-being.

Another factor could be the underdevelopment of treatment facilities. The small number of neurosurgical centres in the country is overburdened and not accessible to all.

This is causing delayed presentations to the hospital and long waiting times to definitive management, resulting in prolonged ill health and further progression of the disease.

Furthermore, rehabilitation facilities are very limited, resulting in poor post-discharge care. An alarmingly small number of rehabilitation facilities are dealing with a huge population, and even those facilities are not well equipped or specialized to manage neurosurgical patients appropriately. This leads to a worse overall outcome as rehabilitation and post-discharge care are paramount to achieving good outcomes in brain tumor patients.

In addition, the female population of Pakistan generally has a poor quality of life and mental health, even if not considering brain tumours. According to the Health Indicators of Pakistan, Gateway paper – II, the incidence of anxiety/ depressive disorders in Pakistan was 10-33% for males, while 29-66% for females.[18] This highlights the prominent gender discrepancy in mental health. Factors that contribute to this include societal attitudes and norms, as well as cultural practices, dehumanizing attitudes towards women, the extended family system, and domestic violence against women. Especially, in the rural population, where practices such as honour killings, exchange marriages, child marriages, and wife battering are still commonplace. These are all independent factors that lead to a decreased quality of life in the female population of Pakistan.

Adding to it, when these females are diagnosed with brain tumours, this situation further deteriorates. With a significant number presenting late for management or even not at all. The disability and dependency that come with brain tumours cause their quality of life to drop severely.

Females in the country have a pivotal role in the family system and many responsibilities to cater to. When they are subject to brain tumours, their ability to fulfill these responsibilities and roles is adversely affected, as was reflected in our study, with the majority of the participants expressing frustration at not being able to meet their family's needs.

Although not included in this study, another issue is readily apparent at the follow-up of patients. Many female brain tumor patients are noncompliant with treatment regimens and with adjuvant therapies. This leads to further deterioration in these patients and possibly an adverse effect on quality of life.

The need of the hour is for physicians to pay heed to the quality of life of brain tumor patients, as it is perhaps more consequential to the patient's betterment than just pathological cure. Although it is far beyond the physician to improve the quality of life of these patients in all aspects, as this is a multidimensional dilemma with a gamut of facets, they should at least recognize the issues faced by the community to work towards their eradication.

RECOMMENDATIONS

We recommend paying attention to the factors adversely affecting the quality of life in female brain tumor patients and working towards the eradication of these problems.

LIMITATIONS

The limitations of this study include the absence of categorization of tumours (for example, into supratentorial vs infratentorial or primary vs metastatic), which could yield valuable insights into how different tumor categories influence QOL. Another limitation is the lack of follow up which could yield information about the changes in QOL with progression or regression of disease and the impact that different treatment modalities, such as surgery or radio/chemotherapy, have on QOL.

CONCLUSION

In conclusion, the quality of life as assessed by the FACT-Br questionnaire in 108 female brain tumor patients yielded a mean score of 97.6 out of 200,

which indicates a significant deterioration and is worse than similar studies done in other countries. The female brain tumor population of Pakistan faces substantial challenges, and the need of the hour is to pay heed to these challenges and move beyond treating only the pathological aspect of brain tumors. It is advised, based on our findings, that recognition by physicians of these problems is essential, and effort towards a better QOL outcome is required.

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Additional Information

Disclosures: No conflict of interest.
Institutional Ethical Review Board Approval: The study complies with the ethical review board requirements.
Human subject: Consent was obtained from all patients/participants in this study.
Conflict of interest: In compliance with the ICMJE uniform disclosure form, all authors declare the following:
Financial relationships: All authors have declared that they have no financial relationship at present or within the previous three years with any organization that might have an interest in the submitted work.
Other relationships: All authors have declared that no other relationships or activities could have appeared to have influenced the submitted work.
Data Sharing Statement: For data sharing, interested researchers can contact the corresponding authors.

AUTHOR'S CONTRIBUTION

Sr.	Author Name	Author Contribution
1.	Hamza Noman	Paper writing, Literature review and referencing.
2.	Usman Ahmad	Study Design, methodology and discussion.
3.	Raana Shahid	Data collection and analysis.
4.	Arooj Kiran	Data analysis and interpretation of results.
5.	Tehreem Asif	Data collection.
6.	Shahzad Hussain Shah	Quality insurer.