



Original Article

Delay in Diagnosis of Brain Tumors: A Dilemma For Neurosurgical Community Due To Spirituality and Quackery In A Developing Country

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ABSTRACT

Objectives: Primary and metastatic brain tumors are a significant cause of mortality and morbidity. The complex pathway to a cancer diagnosis is not human error and the achievements of better outcomes solely depend on the early diagnosis and management of symptomatic tumors. The estimated time between the first presentation to any health care professional and diagnosis is approximately 3 times longer in the UK as compared to other developed countries.

Material and Methods: It was a descriptive study and included 52 patients who were admitted to the Neurosurgery department at Jinnah hospital Lahore. The required data were collected either directly from the patients or from the hospital record of discharged patients. Our study compares the time interval difference of presentation of a patient to a local care provider (Quacks, Hakeem, and spiritual healers) and Neurosurgeon as well as delay in surgical intervention even after diagnosis and radiological investigations.

Results: 54% of patients presented with supratentorial lesions and out of these, parietal lobe lesions were more common (39%) while 29% of lesions were infratentorial. Around 50% of patients presented to a Local Care Provider within 20 days. However, only 42% of patients presented to a neurosurgeon after 6-9 months of the onset of symptoms.

Conclusion: Public awareness is the key to timely diagnosis, proper management, and better outcomes. The availability of specialists in peripheral hospitals can bring a change in this regard.

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INTRODUCTION

Primary and metastatic brain tumors are a significant cause of mortality and morbidity. According to studies worldwide, the incidence of brain tumors ranges from 17.6/100,000 to 22.0/100,000.¹ The outcome of brain tumors depends on the early diagnosis and proper management of symptomatic tumors.² Non-specific symptomatology, patient appraisal and self-management, delay in help-seeking and follow-ups, GP's inaccessibility to diagnostics, and referral system loopholes are major causes of diagnostic delay.^{2,3} Literature shows the diagnostic interval, i.e., the estimated time between the first presentation to any health care professional and diagnosis is approximately 3 times longer in the UK as compared to other developed countries.⁴

According to the National Health Interview Survey, 69% of cancer patients pray for their health and this ratio is only 45% in the general healthy population in the US.⁵ Patients' perception regarding the spiritual aspect of their disease is linked to their doctor as well. Patients desire holistic care from their doctors and also strong doctor-patient relationships.^{5,6} Most cancer patients involve their healthcare professionals in their queries and consider their spiritual guide as a part of their healthcare team.^{6,7} The contributing factors that delay surgical management including patients' fear of brain and spinal surgeries and false hopes by spiritual healers and quacks lead to delays in diagnosis with poor outcomes.^{8,9}

Our study explored the time interval of presentation of a patient to a local care provider (Quacks, Hakeem, and spiritual healers) and Neurosurgeon as well as delay in surgical intervention even after diagnosis and radiological investigations.

MATERIAL AND METHODS

Study Design & Setting

A descriptive study was conducted at the

Department of Neurosurgery, Jinnah Hospital Lahore for one year (February 2021 to February 2022).

Sample Size

52 patients, directly from the patients admitted in the ward or from hospital records of previously admitted patients.

Questionnaire

It was based on the bio-data of the patient, level of education, symptoms at the time of presentation, and the interval between the onset of symptoms and presentation to the local care provider and neurosurgeon. Moreover, the time duration from the onset of symptoms and the radiological diagnosis was also assessed.

Operational Definition

A local care provider is defined as a Spiritual healer, Hakeem, and Quack.

RESULTS

Gender & Age Information

Out of 52 patients, 27 were male while 25 were female. The age of the patients included in the study ranged from 6 years to 74 years while the majority of patients (44) were between 30-50 years.

Location of the Lesion

Data regarding the anatomical location of the lesion was collected (Table 1) and it shows that 54% of patients presented with supratentorial lesions and out of these, parietal lobe lesions were more common (39%) while 29% lesions were infratentorial (Table 1a and 1b).

Table 1: Location of the lesion (n = 52).

Location of Lesion	No.	%Age
Supratentorial	28	54
Infratentorial	15	29
Brainstem lesion	2	4
Sellar lesion	7	13
Total	52	100

Table 1a: Lobar location of the supratentorial lesion (n = 28).

Location of the Lesion	No.	%Age
Parietal	11	39
Frontal	9	32
Temporal	6	21
Occipital	2	7
Total	28	100

Table 1b: Location of infratentorial lesion (n = 15).

Location of the Lesion	No.	%Age
CP angle	9	60
Midline	5	33
Paramedian	1	7
Total	15	100

Time Interval

The time interval between the onset of symptoms and first presentation to the local care provider i.e., Quack, Hakeem, or spiritual healer (Table 2) showed that a maximum number of patients presented within weeks of the onset of symptoms while only 2% presented after 6 months and 2 patients presented directly to neurosurgeons.

The maximum number of patients presented after 6 – 9 months of the onset of their symptoms

Table 2: Visit to local care provider (n = 50).

Visit Local Care Provider	No.	%Age
0 – 7 days	16	32
8 – 21 days	25	50
3 – 6 weeks	5	10
3 – 6 months	3	6
> 6 months	1	2
Grand Total	50	100

to a neurosurgeon (Table 3) and only 2 individuals (4%) presented directly to the specialist.

Table 3: Duration of the visit to the neurosurgeon (n = 52).

Visit to Neurosurgeon	No.	%Age
0 – 3 months	2	4
3 – 6 months	9	17
6 – 9 months	22	42
9 – 12 months	16	31
1 – 2 years	2	4
> 2 years	1	2
Grand Total	52	100

Symptoms at Presentation

Patients presented with various symptoms of raised intracranial pressure. The most common symptoms were headache and vomiting. Other symptoms included vertigo and deterioration of vision and fits (Table 4).

Table 4: Symptoms at presentation.

Symptoms	No. of Patients	Percentage
Headache	15	29
Vomiting	15	29
Vertigo	10	19
Focal deficits	9	17
Blurred vision	7	13
Fits	7	13
Ataxia	4	8
Behavioral changes	2	4
Weight loss	1	2

Radiological Investigation

There was a wide range of intervals related to investigations done, from 5 days to years. Patients were reluctant to surgery even after diagnosis and even presented to the specialist to repeat investigation after treatment from spiritual healers (Table 5).

Table 5: Delay in radiology (n = 52).

Radiology	No.	%Age
5 days	1	2
1 week	9	17
2 weeks	6	12
1 month	8	15
2 months	3	6
3 months	1	2
4 months	1	2
5 months	1	2
6 months	7	13
9 months	1	2
1 year	8	15
2 years	3	6
> 2 years	3	6
Grand Total	52	100

Local Care Provider

The majority of patients relied on quacks for their disease while others visited Hakeem and spiritual healers (Table 6).

Table 6: Local care providers (n = 52).

Local Care Provider	No. of Patients	Percentage
Quacks	29	58
Hakeems	13	26
Spiritual healers	8	16
Total	50	100

Management in Tertiary Care Hospital

Data regarding the management of the disease were collected and 83% of people had to undergo surgery as a part of their treatment and only 29% of cases were discussed with a multidisciplinary team (MDT – oncologist, radiologist, etc.), whereas 88% patients showed up in our special follow up a clinic that we

Table 7: Management in tertiary care hospital.

Disease Management	No.	%Age
Surgery	43	83
Follow up	46	88
MDT management	15	29

managed every Saturday in our department for enrolled patients (Table 7).

DISCUSSION

The data regarding brain tumors is not precise as the registration process is not accurate and recording is limited only to malignant tumors, the benign and borderlines are often excluded.¹⁰ In the United States, approximately 18,500 cases/year of primary malignant brain tumors are diagnosed with 3% of 5 – year survival.¹¹ About 81% of malignant brain tumors are gliomas but because of a high number of histologic subtypes, each type is considered rare. In the pediatric population, CNS tumors are the second most commonly diagnosed cancer after Acute Leukemia but are the leading cause of cancer-related death in children.¹²

Diagnosis of brain tumors is always a challenge especially in the primary health care system due to non-specific symptoms. These symptoms can be broadly classified as physical (headache, fatigue, focal deficits) and behavioral changes (memory loss, hallucinations, depression, anxiety, and anger).¹³ The classification of symptoms can also be site specific i.e., (1) Supratentorial lesions present with focal deficits, visual field defects, language deficits, and fits (2) Infratentorial lesions produce cerebellar dysfunction (3) Brain stem tumors result in cranial nerve deficits (4) Sellar lesions produce a wide variety of symptoms including endocrine abnormalities. Our results show that parietal lobe lesions were more common (Table 1a) and 60% of lesions were at CP angle in infratentorial variety (Table 1b).

Presenting symptoms like headache, vomiting, blurring of vision, etc. are nonspecific and do not show the specificity of having a brain tumor.¹⁴ Similarly, subtle changes such as cognition and personality, are ignored by patients themselves and their relatives.¹⁵ Seizures or adult-onset epilepsy are somewhat specific to brain-related

diseases.^{16,17} The incidence of association of non-settling migraine to brain tumors cannot be ignored.¹⁸

Another major cause of delay in diagnosis is the late presentation of patients to a specialist. Data showed that about 50% of patients presented to a Local Care Provider within 20 days. However, only 42% of patients presented to a neurosurgeon after 6 – 9 months of the onset of symptoms (Table 2, 3). The local care provider was either Quack, Hakeem, or a spiritual healer not even related to the medical profession, and hence no referral system. Patients stuck at this level don't receive adequate medical attention resulting in unacceptable delay and presenting to tertiary care with profound advancement of the disease. In this part of the world, spirituality is dominant and there are various cultural and religious taboos resulting in self-reassurance and delaying of the diagnosis. Table 7 shows that about 15% of the total 52 cases have been to a spiritual healer for their symptoms and thus not consulting a health care professional in the first place.

Literature suggests that cancer patients consider spirituality as a coping mechanism for their illness, particularly in patients with brain tumors due to the high risk of morbidity and mortality.¹⁹ In developed countries, efforts are being made to consider the spiritual needs of patients by the healthcare professionals and to address these needs of patients but in our society, the patient is stuck at this level, not seeking medical help from any medical professional.²⁰

In peripheral and remote areas, the quacks are considered general physicians. Other alternate medicines like homeopathy, Ayurveda, and Unani are also considered as an alternative. One major reason to opt for these treatment modalities in remote/rural areas is the low cost of these treatments. Unfortunately, in many areas, quacks are the first source of medical care due to inefficient health care provided by the state.

Moreover, ignorant and innocent patients are counseled against the adverse effects of surgery, delaying the reaching of these patients to adequate medical services.

In the radiological assessment of a brain tumor, MRI is preferred over CT as it guides more accurately and provides better resolution (however CT remains superior in a few cases). As compared to the study done by Babar Butt, et al, which showed that in a maximum number of cases, 1st basic investigation was delayed for 6 months to 2 years. However, in our study, results suggest that investigations of 30 patients out of a total of 52 were done before 6 months. But besides advancement in diagnostics, the specialist opinion and surgical intervention are delayed on the patient's behalf, opinions from alternative care providers and surgery phobias.

The management of brain tumors is not always surgery alone. Chemotherapy and radiotherapy are two important components in treatment and outcome. Multidisciplinary team discussions and an oncologist on board favor better prognosis. Hence, most CNS tumors require complex hand-in-hand efforts of neurosurgery, radiation oncology, and medical oncology as well as a pathologist.

RECOMMENDATIONS/CONCLUSIONS

- Public awareness is the key to timely diagnosis, management, and hence better outcomes.
- National-level education addresses the main causes of delay in the diagnosis which mainly include false hopes by spiritual healers, Hakeem and quacks, illiteracy, denial, unrealistic fear of surgery, and cultural norms. This education can be delivered by print, electronic and social media. Banners and posters in basic and rural health centers, small public service messages on electronic media, and simplified versions on social media can play a role.

- The availability of specialists in peripheral hospitals can bring change to the presentation of patients in a tertiary care hospital.

LIMITATIONS OF STUDY

These include;

- A small sample size.
- Lesser duration of the study.
- A single-center study and a multicenter study would have given more elaborate information.

The study can be expanded further, increasing the sample size and duration of the study, and the study was conducted in more than one center.

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Additional Information

Disclosures: Authors report no conflict of interest.

Ethical Review Board Approval: The study conformed to the ethical review board requirements.

Human Subjects: Consent was obtained by all patients/participants in this study.

Conflicts 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 relationships at present or within the previous three years with any organizations that might have an interest in the submitted work.

Other Relationships: All authors have declared that there are no other relationships or activities that could appear to have influenced the submitted work.

AUTHORS CONTRIBUTIONS

Sr.#	Author's Full Name	Intellectual Contribution to Paper in Terms of:
1.	Usman Ahmad Kamboh	1. Study design and methodology.
2.	Mehreen Mehboob	2. Paper writing.
3.	Sidra Abid, Sana Jamal	3. Data collection and calculations.
4.	Ghulam Naseer u Din, Mohammad Ashraf	4. Analysis of data and interpretation of results.
5.	Mehwish Manzoor	5. Literature review and referencing.
6.	Manzoor Ahmad	6. Editing and quality insurer.