

Community Awareness Level Regarding Brain Tumours and Reasons of Delay in Total Diagnostic Interval

BABAR BUTT, ADNAN KHALID, AMANURREHMAN, RIZWAN MASOOD BUTT

Punjab Institute of Neurosciences (PINS), Lahore General Hospital, Lahore

ABSTRACT

Objectives: This study was conducted to determine the awareness in the Pakistani community regarding Brain tumors and exploring the reasons for the delay in Total Diagnostic Interval (TDI).

Material and Methods: The methodology used to determine community level of awareness by anonyms, questionnaire based descriptive study. The duration of the study was 4 months and data was taken from the patients operated in Neurosurgery Unit I of Punjab Institute of Neuroscience (PINS).

Results: A total of 102 patients were recorded, of which sixty five (63.7%) were male patients and thirty seven (36.2%) female patients. Immense delay was noted in getting the first basic radiological investigation, i.e., more than one year in 33 cases (32.35%) after the appearance of their first symptom. The study revealed that 46 cases (45.00%) got treatment from Quack, 38 cases (37.00%) from spiritual healer/Hakeems and 8 cases (07.00%) had homeopathic treatment. It was noted that 35 (34.30%) of the patients were unaware of their disease, and 67 patients (65.00%) were aware of their disease. The awareness group revealed that 28 cases (27.45%) know about their disease, but reluctant to get surgery, while 30 cases (29.00%) were considered quacks treatment. Seventy five cases (73.52%) presented after 12 weeks of their initial symptom in our series.

Conclusion: Awareness regarding brain tumors is insufficient that is resulting in delay of Total Diagnostic Interval, moreover the scenario was further complicated by adopting alternative methods of treatment like Hakeems/quacks/homeopathic and spiritual healers.

Keywords: Brain tumors, community awareness, Total Diagnostic Interval, Tertiary Care Center.

INTRODUCTION

This study was conducted in the department of Neurosurgery of Punjab Institute of Neuroscience. This department was established in 1966. Now PINS is a 500 bedded hospital in a catchment area comprising of mainly Punjab. Referred cases from KPK, Azad Kashmir, FATA and even Afghanistan are managed in this institution. It has the most well equipped Operation Rooms and State of the art diagnostic facilities for neurosurgical patients. We have a variety of gadgets including Endoscopes, Microscopes, CUSA, Neuronavigation system, Stereotactic system, Microelectrode recording, Spinal cord evoked potentials and facial monitoring along with one of the best neuro-radiology department with 3 CT scans (latest is 128 slice), 2 MRI (1.5 & 3Tesla) and Digital

Subtraction Angiography (DSA).¹ In OPD, 200-250 patients are examined and in emergency nearly 80 patients are seen on an average/day. In one year about 900-1000 elective and 800-900 emergency Neurosurgical operations are done.¹ This study was undertaken to determine the level of awareness in the Pakistani community regarding brain tumors and to explore the reasons for the delay in Total Diagnostic Interval in our health care systems. This study reflects the level of awareness in the Pakistani community in general and among the admitted patients of brain tumor in a tertiary care hospital in particular. Although, statistical information on brain tumors is poor, since the registration is not mandatory in many countries worldwide.² Pakistan is among the densely populated country in South Asia with an estimated

population of 190 million, but with no national cancer registry setup.³ Various studies published on brain tumors revealed an incidence or prevalence and provide regional data, thus the awareness of the tumor among the general population is difficult to predict. Our study only depicts trend of the society. The low literacy rate, lack of awareness, the socioeconomic status and quackery had complicated the health care system of our society. The patient usually presents late to the hospital when their symptoms got worse. This result in delay of TDI and its impact is increasing in morbidity and mortality among the cases treated in our tertiary care hospitals.

MATERIAL AND METHODS

This descriptive study was conducted in the Punjab Institute of Neuroscience for the period of four months.

Inclusion Criteria

All newly admitted patients with brain tumors.

Exclusion Criteria

1. Previously operated cases.
2. Who refused to give consent for this study.

Data Collection Procedure

The study was supervised by the head of Department of Neurosurgery Unit 1, with the consent of patients. In case of a minor, the consent was taken from the attendants. The research was based on anonymous questionnaire, which include the personal detail of the patient, clinical symptoms, the time when patient have first symptom, the time gap for the radiological investigation, the alternative treatment before the surgery and the informed patient had regarding his/her disease. Later, the mode of treatment was also analyzed.

Data Analysis

Data analysis was formulated in tables and percentages were calculated.

RESULTS

Sex Incidence

The result of the study showed that a total of 102 patients were included and admitted with the diagnosis

of Brain tumor in Neurosurgical Unit I of PINS in the period of four months. Sixty five cases (63.70%) were male and thirty seven (36.30%) cases were female. as shown in Table 1.

Table 1: Gender Distribution.

Sex	No.	Percentage
Male	65	63.7%
Female	37	36.3%
Total	102	100%

Age Incidence

The age of the patient was categorized into age groups, with a mean age of 35.5 years. Maximum patients were found in their fourth decay of life, i.e., 29 cases (28.40%). The least number of the patients was recorded in the sixth decay of life; 2 cases (01.96%), followed by first decay; 6 cases (05.90%). The age distribution of cases can be seen in detail in Table 2.

Table 2: Age Distribution.

Age Group of Patient	Frequency	%
1 – 10 year	6	5.9%
11 – 20 year	10	15%
21 – 30 year	23	22.5%
31 – 40 year	29	28.4%
41 – 50 year	14	13.7%
51 – 60 year	18	17.6%
61 – 70 year	2	2%
71 – 80 year	0	0

Clinical Presentations

The Clinical symptoms are shown in (Table 3) where most the patients presented with headache 72 patients (70.58%) followed by loss of vision in 26 cases (25.49%), vomiting in 23 cases (22.54%), neurological deficiencies in 20 cases (19.60%) and fits in 19 cases (18.62%), gait disturbance in 17 cases (16.66%), vertigo in 8 cases (07.84%), alter the level of consciousness 7 cases (06.86%), behavior changes seen in 7 cases (06.86%). Altered state of

consciousness: 5 cases (04.90%), hearing deficit: 4 cases (03.92%) loss of balance in 1 case (0.98%) while, fecal and urinary incontinence were recorded in 1 case (0.98%).

Time Gap

The **time gap since to the appearance of the first symptom and admission of the patient** in the hospital was inquired (Fig. 1) which showed that most of the patients neglected their initial symptoms and presented late in a tertiary care center. Twenty seven cases (26.47%) presented after 2 years of the appearance of their first symptom and collectively 75 cases (73.52%) presented after 3 months of the initial symptom. This immense delay is totally against the international reports where the max. The average delay in presentation of brain tumor cases to the tertiary care centers varies from 8 to 12 weeks of their initial symptoms. In our study, 98% of patient’s symptoms were already deteriorated when they admitted in a tertiary care center. This shows the reason of delay in Total Diagnostic Internal (TDI) of brain tumors in Pakistani community.

Investigations Gap

The investigation done initially was either CT scan brain or MRI brain. Our study evaluated the **time gap between the appearance of initial symptoms and**

the time of first basic radiological investigation (Table 4). Most of the patient had either radiological investigation in the first week 26 cases (25.49%) or

Table 3: Clinical Symptoms.

S. No.	Symptoms	No.	Percentage
1..	Headache	72	70.58
2.	Loss of Vision	26	25.49
3.	Vomiting	23	22.54
4.	Neurological Deficit	20	19.6
5.	Fits	19	18.62
6.	Gait Disturbance	17	16.68
7.	Vertigo	8	7.84
8.	After Level of Consciousness	7	6.86
9.	Behavior Changes	7	6.86
10.	After State of Consciousness	5	4.9
11.	Hearing Deficit	4	3.92
12.	Loss Balance	1	0.98
13.	Fecal and Urinary Incontinence	1	0.98

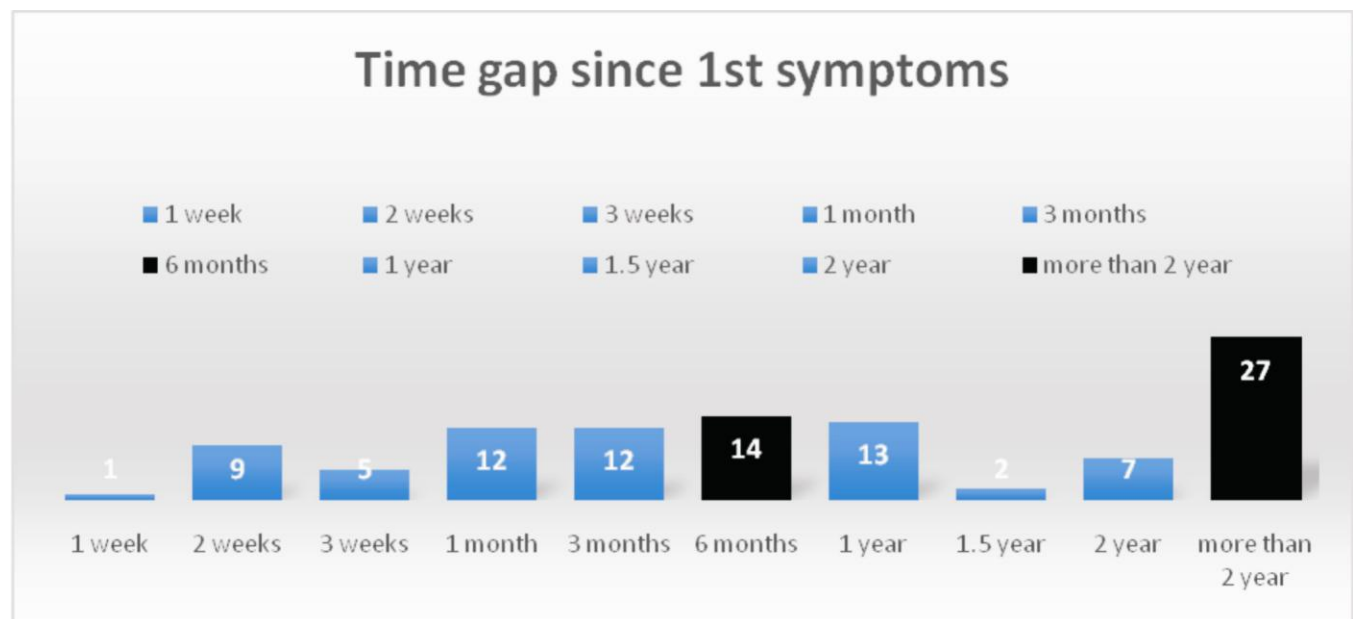


Fig. 1: Time gap from hospitalization to initial symptoms.

Table 4: Time gap between the investigation and initial symptoms.

S. No.	Time Gap	No.	Percentage
1.	1 Week	26	25.49
2.	2 Week	10	9.80
3.	3 Week	1	0.98
4.	1 Month	16	15.69
5.	3 Month	8	7.84
6.	6 Month	7	6.86
7.	1 Year	3	2.94
8.	1 st Year	6	5.88
9.	2 nd Year	3	2.94
10.	More than 2 Years	20	19.68

within 1 month 53 cases (51.96%), while 40 cases (39.21%) patients have their investigation after 6 months of the appearance of their 1st symptoms. This alarming delay in getting the basic investigation again explains the increase of TDI in our community.

Alternative Modalities of Treatment

The patient who was reluctant to get surgical treatment, had mostly adopted the **alternative methods of treatment before hospitalization**. The alternative methods include medication from Hakeem, Quack or Homeopathic doctor, as shown in Table 5. Eighty four (82.35%) got treatment from Hakeem and Quacks collectively.

Table 5: Alternative Modalities of Treatment.

Alternative Medication	No. of Patients	Percentage %
Hakeem	38	37%
Quack	46	45%
Homeopathic	8	7%
None	10	9%

Level of Awareness and Response of the Patient towards Disease

The level of awareness was then evaluated by asking

the patient about their illness (Table 6). It was observed that 35 cases (34.3%) were unaware of their disease while 67 cases (63.72%) were aware of their disease. Twenty eight patients (27.45%) were aware of their disease, but reluctant to get surgical treatment, thirty others (29.41%) were getting treatment from quacks while 5 patients (04.90%) want to get only conservative treatment with medicine. While 4 cases (03.92%) were not getting any sort of treatment.

Table 6: Showing the Awareness of patient and the response of the patient toward disease..

S. No.	Level of Awareness Disease	Number	Percentage	Accumulative Percentage
1.	Not aware of disease	35	34.31%	34.31%
2.	Aware but reluctant to get surgery	28	27.45%	61.75%
3.	Aware but getting conservative management	5	4.90%	66.65%
4.	Aware but getting quack treatment	30	29.41%	96.06%
5.	Aware but not getting treatment	4	3.93%	100%
Total		102	100%	100%

The **volume of the lesion** when the patient was admitted in a tertiary care center had a mean value of $27.74 \pm 2.0 \text{ cm}^3$, with maximum volume reaching 91.9 cm^3 and minimum around 3.60 cm^3 . The Table 6 shows the volume of space occupying lesion of patients that we had to manage in our case series.

Table 7: Volume of Lesion.

Volume in cm^3	No. of Patients	Percentage %
1 – 10	20	19.4
11 – 20	27	26.2
21 – 30	23	22.3
31 – 40	12	11.7

41 – 50	6	5.8
51 – 60	6	5.8
61 – 70	2	1.9
71 – 80	4	3.9
81 – 90	2	1.9
Total	102	99.97

Treatment in the Hospital

The Surgical management done in our case series was in the form of craniotomy and removal of lesions in 91 cases (88.30%) while in 7 cases (06.86%) only biopsy was taken and remaining 4 cases (03.92%) were managed conservatively (Table 8).

Fig. 8: Treatment Modalities in the Hospital.

Treatment	Number	Percentage	Accumulative Percentage
Gross total and removal	91	88.30%	88.30%
Biopsy	7	6.86%	95.86%
Conservative	5	3.93%	100%
Total		100%	100%

DISCUSSION

It is a known fact that presentation of brain tumors is usually not different from the presentation of other common diseases. There is no exclusive sign or symptom at initial phase that can distinguish the disease right from the beginning. This has become even more difficult in younger age group, especially when we move towards first decay of life down to infants and neonates. Common modes of presentation are headache, vomiting, vertigo, visual symptoms, cognitive disorders, behavior abnormalities and so on, but none of these are specifically indicated towards the possibility of having brain tumors⁴. This leads to difficulty in diagnosis of this entity. End result is delay of Total Diagnostic Interval (TDI) and late diagnosis that leads to late treatment and worse prognosis. Different factors in general resulting in prolongation of the total diagnostic interval (TDI) are underprivileged community, illiteracy, lack of medical facilities, cultural and religious taboos.

The only symptom that is found a little bit helpful in early diagnosis of brain related diseases is seizure⁵⁻⁶

or adult onset of epilepsy which is specifically indicated towards some new development in the brain and hopefully if patients get an earlier CT/MRI done may result in diagnosis of the lethal disease well in time.

It is also observed that presentation with migraine in the diagnosed cases of the brain tumors is another possible alarming situation. Migraine is present,⁷ 2.5 fold more in patients with brain tumors and especially the odd are worse for the male population. Therefore aggressive investigations for non-settling migraine may result in early diagnosis of any offender lesion hidden within the Brain. Most of other symptoms and sign being nonspecific usually lead to misdiagnosis.

The total diagnosis interval is equal to: Patient Interval + Doctor Interval + System Interval. Using this equation, NHS Published the referral guidelines in 2008 by the Royal College of Pediatrics and child health. Due to this extensive study a campaign was raised with the name “Head Smart- Be Brain Tumor Aware” for early features of CNS tumors and need for timely imaging.⁸⁻⁹

A study was carried out in East and North West of England in which it was evaluated that why the brain tumors were missed in their primary care system. It was found that the reason of missed opportunities was the lack of awareness of the population regarding subtle changes rather than the symptoms that remained un-noticed by the patient, attendants or physician. Quality of Communication in GP consultations was found another major culprit.

In our system where the patient is most of the time illiterate, there is no proper referral system, no GP available in all primary health centers and numerous cultural and religious taboos result in increase of missed diagnosis many folds. In another study⁴ it was mentioned that due to lack of recognition of the subtle presentation of the brain tumors by the patients and their attendants leads to delay in coming to the primary care level. This is further enhanced when the GPs could not find the gravity of situation urgent enough to be referred to a tertiary care center. The reason is either the symptoms are not explained to him properly or unfortunately he is not familiar with the presentation of neurological disease. Therefore, a complex interplay of patient attendants and GPs may result in either early detection or rapid referral to the next health care level or if any of the links is loose or broken may result in prolongation of TDI.

Early diagnosis is paradoxically associated with worse overall survival, because aggressive phenotypes

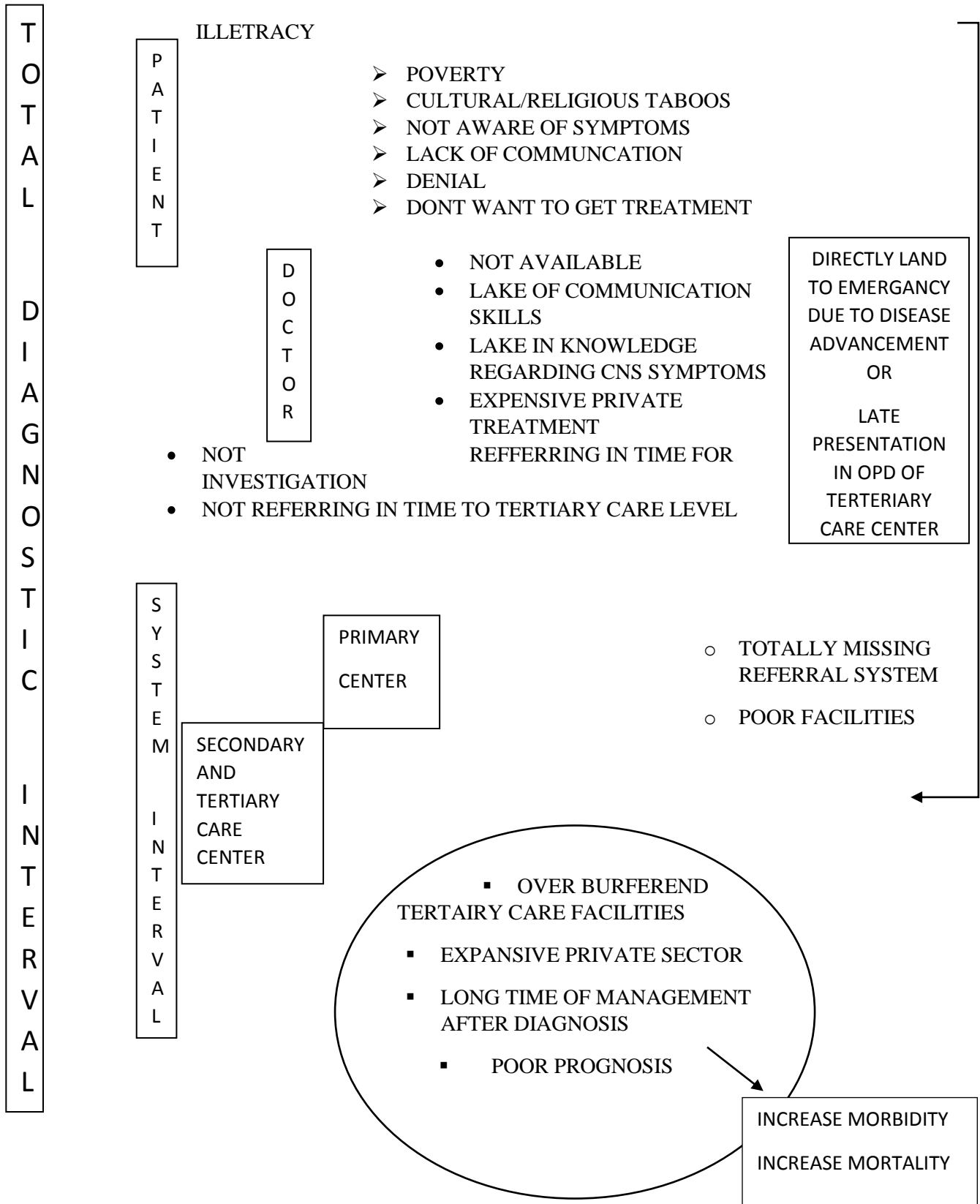


Fig. 2: Factors Causing Disturbed Algorithm and Prolonging Total Diagnostic interval in our health care system.

in a relatively younger age group of high grade Glioma present with rapidly deteriorating picture in an emergency, hence even earlier diagnosis cannot help in increase of overall survival.¹²

Since there is no elaborated chain of referral for patients from the Primary care center to a tertiary care center in our country. People are not educated therefore delay starts right from the beginning in the Algorithm of the total Diagnostic interval. A total interval which is actually comprised of patient interval, doctor interval and system interval increased in all three parts in case of our community. Patient are not able to recognize the disease or they recognized the changes, but may not elaborate it properly, immediate helping attendants are not available in cases of female, old age or pediatric age group. Denial of disease, socioeconomic status, use of alternative ways like Hakeem/Quacks/spiritual healers and avoidance of treatment due to phobia of getting a dangerous disease all leads to delay in TDI on the part of patients in our study.

Delay in Doctor related Interval is due to non-availability of qualified doctors. Private treatment is expensive, non-familiarity of doctor with the presentation of CNS tumors, missed diagnosis due lack of appropriate knowledge, communication gap between patient and GPs.¹⁵ Minimal referral to higher center by the primary physician. Delay in carrying out the basic relevant investigation like imaging in the symptomatic patients.¹⁴

System interval starts with referral of patient from primary care level to Secondary center and then to tertiary care level since there is no existence of such referral system in Pakistan therefore patient is either stuck at primary care level too long or come directly in the emergency of a tertiary care center with profound advancement and deterioration of disease. This can be noticed in our study, where in 40 cases 1st basic investigation was delayed for 6 months to 2 years. Since there is no proper system of managing such cases at primary and secondary level, therefore always tertiary care levels are overburdened. This lead to delay in final diagnosis; prolonging the system interval many folds. The net result is late diagnosis and late management, leading more prolonged morbidity, and increase mortality, poor prognosis and decrease overall survival in most of the CNS tumors.

Complex interplay of all three segments contributing in an overall delay in TDI in our health care system can be recognized in Fig. 2.

In primary brain tumors ,Gliomas account for

more than 70%, and of these, Glioblastoma is the most frequent and malignant histologic type (World Health Organization [WHO] grade IV).¹⁰ In our study Gliomas are on the top of the list as well. Some reports indicate that Caucasians have a higher incidence than African or Asian populations¹¹. Many environmental factors and lifestyle variations are responsible for these trends.

Brain cancer is responsible for only 2% of all cancer deaths in Pakistan. Brain cancer is mostly reported in women at an average of 4.8%. In 2016, a total of 7,046 neoplasms was registered, of which 459 were having benign and 6,587 having malignant cancer. Reflecting an increase of about 19% of new cancer registrations from previous year 2015. Unfortunately, in Pakistan, central registration system for cancer patients is missing. There is a dire need for public awareness as well. As Pakistan is the 5th largest population; and cancer patients are increasing, the need of a more modern research Centre is increasing.¹³

RECOMMENDATIONS

1. **Pre-Surgeons Availability** Target populations must be addressed by the neurosurgeons about signs and symptoms that are early indicators of having CNS tumors so that General Practitioners and health care providers at primary care level can identify the disease and refer the case in time to higher centers.
2. **Diagnostic facilities** must be available at primary care centers level to exclude these conditions in case of suspicion at an early stage. Therefore, we suggest the availability of CT scan and MRI at district level.
3. **Public awareness seminars**, effective use of communication services like TV, radio, cable and social media, awareness at the level of school and colleges, awareness regarding disease to the religious leaders in rural areas may help in early diagnosis of these lesions and reduce the Diagnostic time interval.
4. **Brain Tumour Registry** by starting a Brain tumor awareness campaign in our community at the basic level and maintaining the brain tumor registry at national level may be the two best things that can lead to a reduction in sufferings from these harmful conditions.

CONCLUSION

With the help of this study it was concluded that:

1. We are far behind from the point of early detection of the brain tumors in our adult population. The condition is even worse among the pediatric age group and female population.
2. Main reasons are well defined, patient's are illiteracy, ignorance, religious and cultural taboos, poverty, denial from disease and adaptation of alternative methods even after becoming aware of the condition.
3. People are afraid of brain and spine surgery and it is a common belief that surgery of these regions always carries poor prognosis and even the picture is made further horrible due to false explanations given by the so called spiritual/ healers/ hakeems/ homeopathic and quacks. They don't know about the pathophysiology of the disease and just to make money and keep their client satisfied they play with the poor patients and keep them away from the actual treatment and diagnostic facilities.
4. Late diagnosis leads to late treatment in tertiary care level and results in larger and aggressive size of lesions to deal with that finally leads to poor outcome and bad prognosis. This can be reduced significantly if the community awareness is raised regarding brain tumors.

ROLE OF AUTHORS

Babar Butt: Paper Writing and Study Design.

Adnan Khalid: Results Writing.

Aman-ur-Rehman: Data Collection.

Rizwan Masood Butt: Paper Editing.

Additional Information

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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.

Address for Correspondence:

*Dr. Babar Butt, Assistant Prof. Neurosurgery
Department of Neurosurgery Unit I*

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