Evaluation of Pathway to Diagnosis of Pediatric Brain Tumors in Tamil Nadu, India

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DOI https://doi.org/10.1200/GO.23.00214

ABSTRACT

PURPOSE Delayed diagnosis and poor awareness are significant barriers to the early intervention of pediatric brain tumors. This multicenter observational study aimed to evaluate the baseline routes and time to diagnosis for pediatric brain tumors in Tamil Nadu (TN), with the goal of promoting early diagnosis and timely referrals in the future.

METHODS A standard proforma was used to retrospectively collect information on demographics, diagnosis, referral pathways, and symptoms of incident pediatric brain tumor cases between January 2018 and October 2020 across eight tertiary hospitals in TN. Dates of symptom onset, first presentation of health care, and diagnosis were used to calculate total diagnostic interval (TDI), patient interval (PI), and diagnostic interval (DI).

RESULTS A total of 144 cases (mean age, 6.64 years; range, 0-15.1 years) were included in the analysis. Among those, 94% (135/144) were from city/district areas, 40% (55/144) were self-referred, and 90% (129/144) had one to three health care professional visits before diagnosis. Median TDI, PI, and DI were 3.5 (IQR, 1-9.3), 0.6 (IQR, 0.1-4.6), and 0.6 (IQR, 0-3.3) weeks, respectively. Low-grade gliomas had the longest median TDI (6.6 weeks), followed by medulloblastomas (4.6 weeks) and high-grade gliomas (3.3 weeks). Average number of symptoms recorded was 1.7 at symptom onset and 1.9 at diagnosis.

CONCLUSION Although there are some similarities with data from the United Kingdom, many low-grade and optic pathway tumors were unaccounted for in our study. DIs were relatively short, which suggests that infrastructure may not be a problem in this cohort. Increased training and establishment of proper cancer registries, combined with proper referral pathways, could enhance early diagnosis for these children.

ACCOMPANYING CONTENT

Data Supplement

Accepted December 18, 2023
Published February 22, 2024

JCO Global Oncol 10:e2300214

INTRODUCTION

Brain tumors in India account for 8%-12% of all childhood cancers compared with 21% in the West.[1,2] Despite the rise in incidence over the past few years, reported brain tumor cases in India are still just half of that in the developed world.[3] Many factors contribute to this presumed low incidence of brain tumors. These include incorrect diagnosis, inequity of access to health care services, and voluntary cancer notification. Delayed diagnosis and poor awareness are also massive barriers to the management and treatment of pediatric brain cancers. Delayed diagnosis is associated with a higher risk of life-threatening and disabling neurologic complications at presentation and a poor cognitive outcome among survivors.[4-8] With a 5-year survival rate as low as 26.8% in India, early detection and treatment is crucial for combating childhood brain cancers.[9]

Public awareness campaigns have proven successful in accelerating time to diagnosis. In the United Kingdom, the HeadSmart: Be Brain Tumour Aware campaign was established to raise awareness of symptoms and the importance of timely imaging, and successfully reduced the median total diagnostic interval (TDI) from 14.4 weeks to 6.7 weeks.[10] In India, although several studies highlighted the barriers to the diagnosis of children with cancers across the country,[11-15] there were no national studies that specifically investigated the diagnostic intervals (DIs) or presentation symptoms of pediatric CNS tumors across India.

CONTEXT

Key Objective

In the absence of registry data on childhood cancer in India, our aim was to collect baseline data on routes and time to diagnosis for children and young people with brain tumors in Tamil Nadu (TN), India.

Knowledge Generated

Baseline data for diagnostic intervals (DIs) and tumor types were generated across eight hospitals in TN. This shows that some tumors, particularly low-grade glioma and optic pathway tumors, are underdiagnosed in TN, while access to diagnostic imaging is good.

Relevance

This study provides baseline data on key parameters which we could compare with future data following interventions aimed at reducing DIs or standardizing routes to diagnosis.

To close this gap, we initiated a collaborative project in Tamil Nadu (TN), India, aiming to reduce the diagnostic intervals (DIs) experienced by children and young people with brain tumors by raising symptom awareness. TN is the seventh-largest state by population, with a total of 72 million residents. Among them, 24% were children age 0-14 years and 32% were age 0-19 years. The state boasted an approximate literacy rate of 80%, and 48% of the population resided in urban areas (Census of India, 2011).[16] In terms of health care, the NITI Aayog's SDG India Health Index 2020-21, which assesses progress of achieving health outcomes, ranked TN the second-best state in the country.[17] The state has also pioneered several new approaches to improve access to high-quality health services at an affordable price. Considering these factors, TN was the ideal state to conduct this investigation and to pilot methods for early diagnosis.

This multicenter observational study serves as the first step, aimed to assess time and route to diagnosis for pediatric brain tumors across eight large tertiary hospitals. The purpose was to scope the issue of diagnostic pathways and improve our understanding of service utilization in the region.

METHODS

Study Design and Setting

This is a multicenter observational study involving eight private or nongovernmental organization (NGO)–managed hospitals providing specialist pediatric cancer care, located in large cities in TN. Fifteen centers across sectors—government, charity, and private tertiary oncology centers with the ability to provide comprehensive neuro-oncology care—were approached; eight agreed to take part, all of which were either not-for-profit or private health care providers. All pediatric brain tumor cases diagnosed during the study period (January 2018 and October 2020) at the eight centers were included in the study.

Data Collection

Data were collected retrospectively by the clinical team using a standard proforma (Data Supplement). The primary outcome measure was TDI, and secondary outcome measures were patient interval (PI) and DI, as defined in Figure 1. DIs were calculated on the basis of the dates of symptom onset, first presentation to health care, and diagnosis (clinical imaging or biopsy) collected by the center. Clear instructions were provided on how to establish the approximates if an exact date cannot be determined. Other data items included patient demographics, tumor details (type, location, and stage), the pathway from first consultation with health care professional (HCP) to diagnosis, the distance between home and the hospital, how treatment was funded, as well as symptom(s) at first onset and at the time of diagnosis.

Statistical Analysis

Descriptive statistics, chi-squared tests, *t*-tests, and Kruskal-Wallis tests were used to compare differences between subgroups. The Bonferroni correction was applied for multiple comparisons when necessary. Data were analyzed using SPSS 27.0 (IBM SPSS Statistics for Windows, Version 27.0; IBM Corp, Armonk, NY). $P < .05$ were considered statistically significant in all analyses.

RESULTS

Study Population

A total of 144 brain tumor cases diagnosed between January 2018 and October 2020 were included in the analysis, and their characteristics were summarized in the Data Supplement (Table S1). Mean age of the patients was 6.64 years

(range, 0-15.1 years), with 40% younger than 5 years, 47% between age 5 and 11 years, and 12% aged 12 years or older.

Tumor Type and Location

Approximately 93% (134/144) of the patients underwent biopsy or surgery, except for 10 patients who had tumors located in the brainstem (n = 6), optic pathway (n = 1), pineal gland (n = 1), suprasellar (n = 1), and thalamus (n = 1). Medulloblastomas (28%) and low-grade gliomas (24%) were the two most common tumor types, followed by ependymomas (17%; Fig 2A). Majority of the tumors were localized; only 8% of all cases were metastatic (Data Supplement, Table S1). About a third of the tumors arose from the posterior fossa/cerebellum, and one in five were midline tumors (Fig 2B).

Route to Diagnosis

The pathways to diagnosis are detailed in Table 1. Upon onset of symptoms, 64% of the patients resided in city. Notably, 88% (n = 120) chose to visit private hospitals, with 71% (n = 91) opting for their first consultation with a pediatrician. Most patients (90%; n = 129) had one to three visits to HCP before diagnosis, and only 9% (n = 12) of the scans were requested through emergency department. Regarding the route to diagnosis, 25% of the patients were referred by primary care practitioners, while the remaining patients either self-referred (40%; n = 55) or were referred by another hospital or consultant (36%; n = 49).

For diagnosis and treatment, 35% (n = 50) traveled <20 km, 19% traveled 20-100 km, 27% traveled <500 km, and 19% traveled >500 km. About three fourths of the patients self-financed their treatment costs, whereas the rest received mixed funding (11%), free treatment (9%), or insurance coverage (7%).

Time to Diagnosis

The median TDI was 3.5 (IQR, 1-9.3) weeks, with a mean of 9.3 ± 14.9 weeks. Median PI and DI were both 0.6 weeks, while mean PI was much longer than DI (6.1 ± 13.6 and 3.2 ± 7.2 weeks, respectively) with a maximum of 100.3 weeks (Data Supplement, Table S2).

Tumor Type

The subgroups that had a median longer than the group median were low-grade glioma at 6.6 weeks and medulloblastomas at 4.6 weeks (Fig 3A). Low-grade gliomas also showed an IQR wider than other tumor types. The median PI of the four main tumor types was similar, ranging from 0.4 to 0.6 weeks (Fig 3C). Median DIs were all shorter than 1 week (Fig 3E), with a wider IQR in low-grade glioma and medulloblastoma.

Tumor Location

Tumors located in cerebral hemispheres/overlapping lesions, posterior fossa/cerebellum, and the ventricles showed a median TDI longer than the group median (4.7, 4.1, and

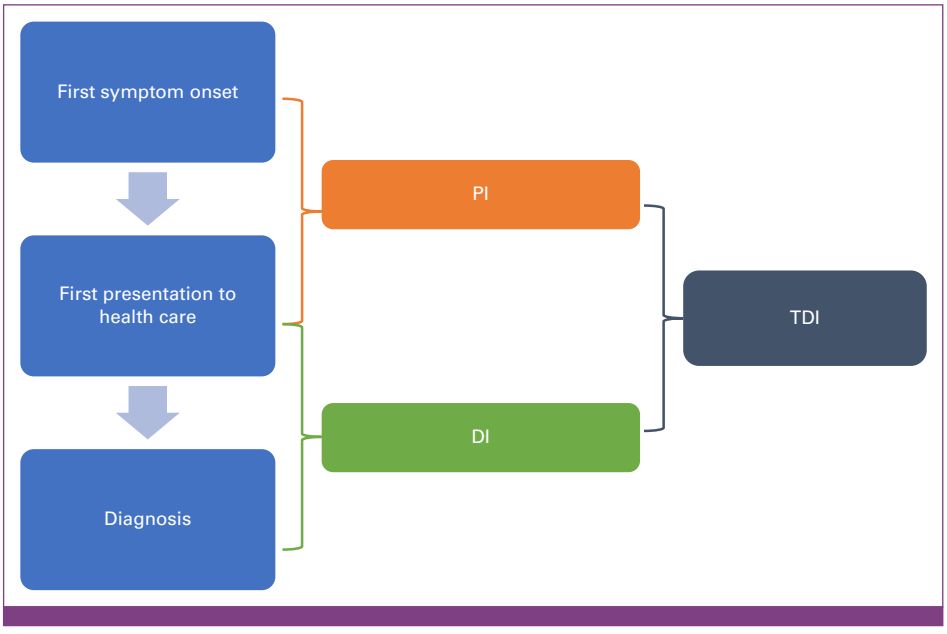

FIG 1. Definition of primary outcome (TDI) and secondary outcomes (PI and DI). TDI: the period between first presentation of symptoms and diagnosis. PI: the period between the first presentation of symptoms and the first notification to any HCP. DI: the period between the patients' first notification to any HCP and diagnosis. DI, diagnostic interval; HCP, health care professional; PI, patient interval; TDI, total diagnostic interval.

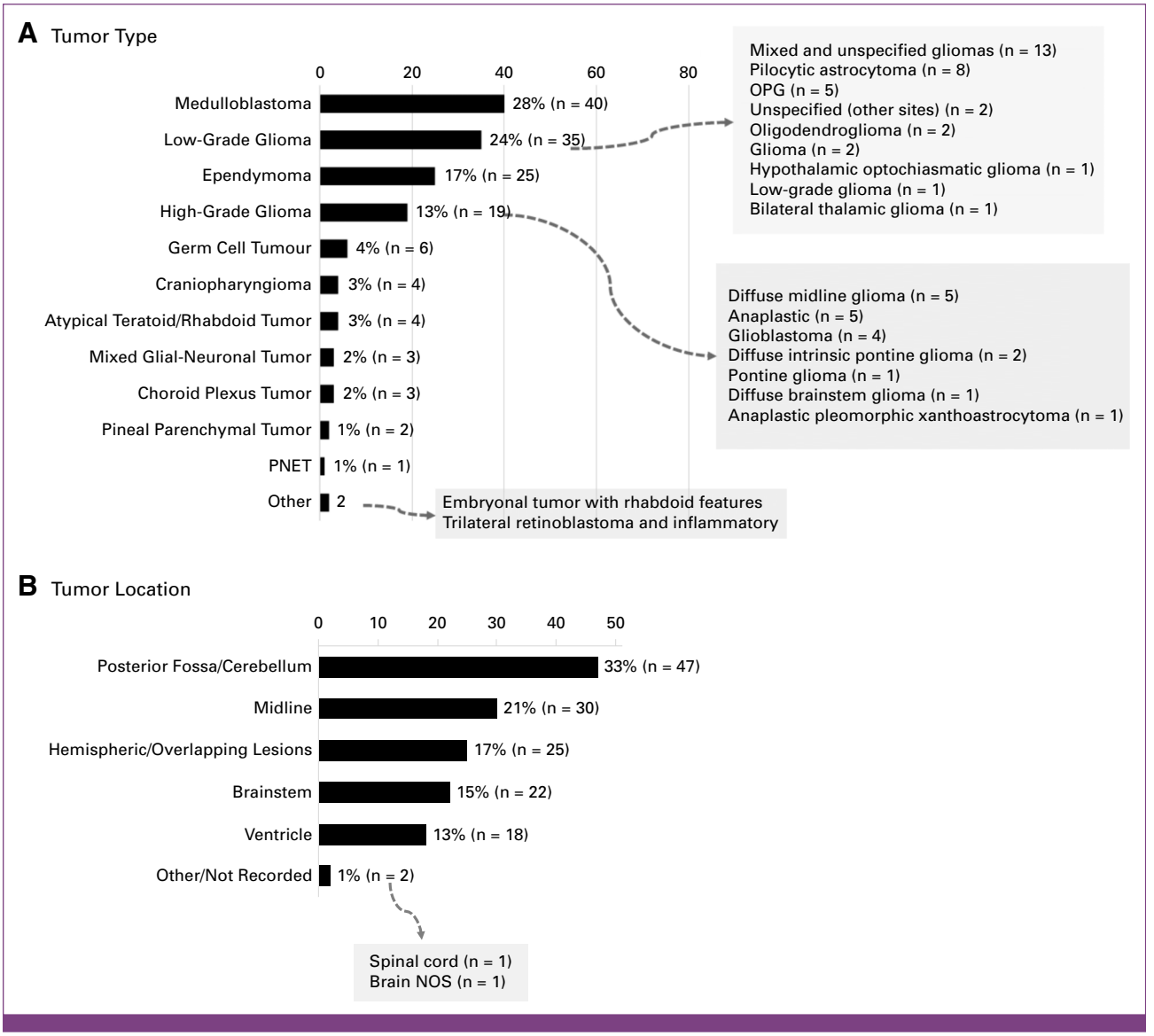

FIG 2. Distribution of (A) tumor type and (B) tumor location (N = 144). NOS, not otherwise specified; OPG, optic pathway glioma; PNET, primitive neuro-ectodermal tumor.

4.1 weeks, respectively; Fig 3B). Hemispheric/overlapping lesions had the longest median PI of 1.6 weeks, and midline tumors showed a wider IQR than other tumor locations (Fig 3D). Furthermore, ventricle, brainstem, and hemispheric tumors had a median DI longer than the group mean of 0.6 weeks (1.2, 1.1, and 0.7 weeks, respectively). It is notable that midline tumors showed a short DI of 0.7 weeks and a much tighter IQR compared with other locations (Fig 3F).

Age Group

The median TDI for children under 5, 5-11, and 12 years or older were 4.9, 4.1, and 5.7 weeks, respectively (Fig 4). The median PIs ranged between 0.4 and 1.6 weeks and there was no significant difference across age groups (P = .784). Furthermore, patients age 12 year or older exhibited a slightly longer DI of 2.2 weeks than the other two age groups, but this difference did not reach a significant level (P = .321).

Patient Location at First Presentation to Health Care

Significant differences in TDI were found on the basis of patients' location at their first health care presentation (P = .028; Fig 5A), with higher medians in villages (7.9 weeks), followed by districts (4.8 weeks) and cities (2.3 weeks). A similar pattern was seen in PI (P = .029; Fig 5C), where medians for villages, districts, and cities were 2.0, 1.8, and 0.3 weeks, respectively. There was no significant difference in DI among the three groups (P = .064; Fig 5E).

Despite the Kruskal-Wallis tests showing significance in TDI and PI, none of the pairwise comparisons reached a significant

TABLE 1. Summary of Patient's Pathways From First Presentation to Diagnosis

First Presentation to Health Care	N = 144, No. (%)
The first HCP patient/family saw about the initial symptom(s)	
Pediatrician	91 (71)
Other HCPs[a]	37 (29)
Type of hospital	
Private	120 (88)
Government hospital/PHC	16 (12)
Patient location	
City	92 (64)
District	43 (30)
Village	9 (6)

Route to Diagnosis	n = 144, No. (%)
No. of HCP visits before diagnosis	
1-3	129 (90)
4-6	15 (10)
Place of care when the scan identified the tumor was requested	
Outpatient	81 (58)
Inpatient	44 (31)
Emergency department	12 (9)
Other[b]	3 (2)
Route to hospital diagnosis	
Self-referral	55 (40)
Consultant/hospital referral	49 (36)
Primary care referral	32 (24)
Distance between home and the hospital where diagnosis made, km	
<20	50 (35)
20-100	28 (19)
100-500	39 (27)
≥500	27 (19)
How was the treatment paid for	
Self-financed	105 (73)
Mixed funding	16 (11)
Free treatment	13 (9)
Insurance	10 (7)

Abbreviations: ENT, ear, nose, throat; HCP, health care professional; ICU, intensive care unit; PHC, primary health care center.
[a]Neurologist (13), adult physician (5), neurosurgeon (11), ophthalmologist (5), ENT (1), general surgeon (1), and neonatologist (1).
[b]Self-referral (2) and neonatal ICU (1).

level, indicating the group differences might be small and not strong enough to survive Bonferroni correction.

Distance Between Home and Hospital (diagnostic center)

The median TDI for patients residing ≥100 km away from the hospital (4.1-4.5 weeks) was longer than the group median. Median PIs for all subgroups were less than a week, with no differences observed among them. Significance was detected in the DI ($P < .001$). The highest median DI was found in patients located 100-500 km away from the hospital (2.0 weeks), while the other groups all had intervals within a week. Pairwise comparisons revealed a significant difference between the 100-500 km and <20 km groups ($P < .001$).

Signs and Symptoms at Initial Onset and at Diagnosis

The average number of symptoms is 1.7 at onset and 1.9 at diagnosis, with the biggest changes observed in motor problems, in particular, abnormal gait (Table 2). Vomiting and headache were the most common symptoms, experienced by 62% and 47% of patients, respectively, at diagnosis. About 44% of patients had motor problems,

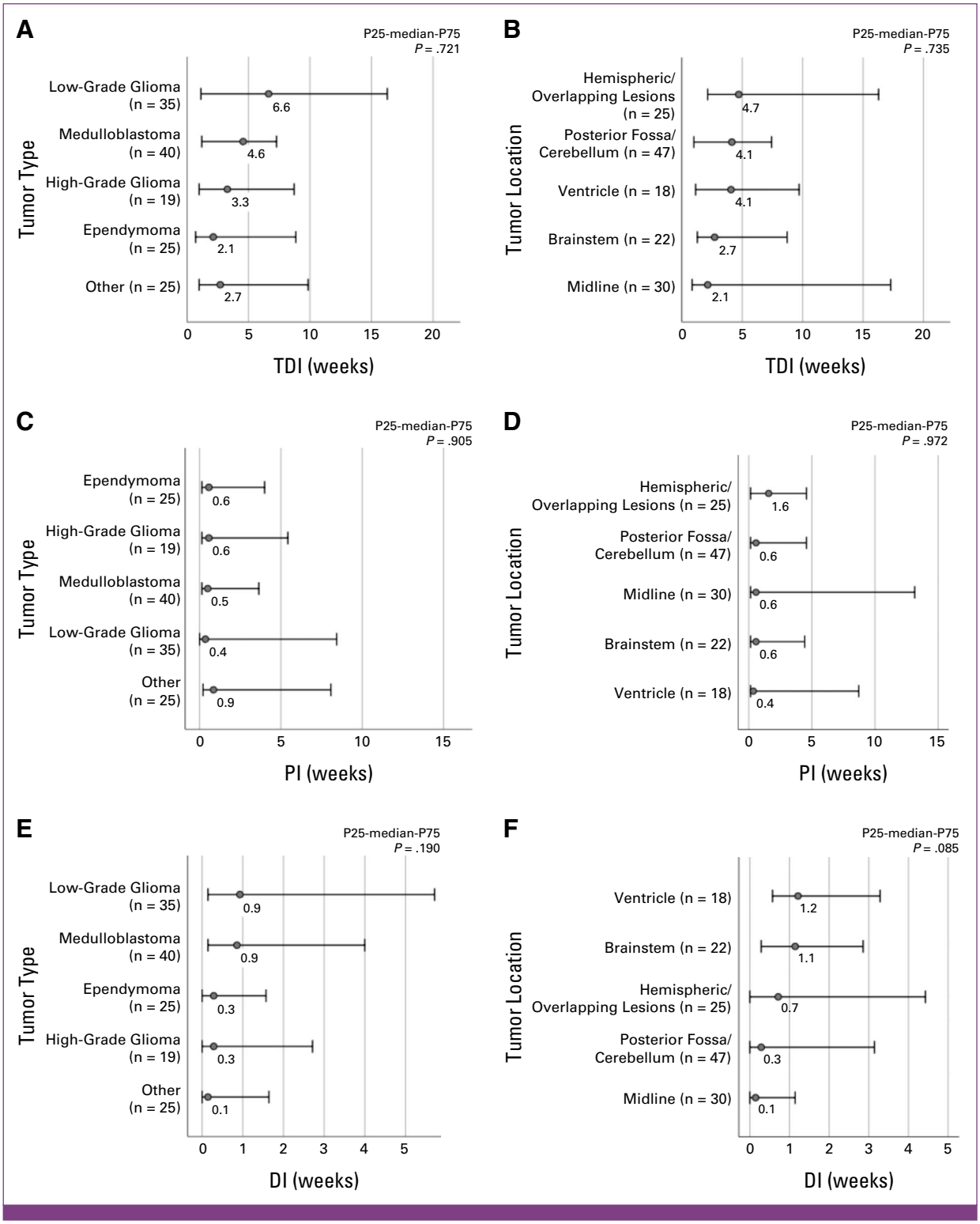

FIG 3. Comparison of TDI, PI, and DI by tumor type (A, C, E) and tumor location (B, D, F). The solid dot represents the median, and the error bars represent the 25th and 75th percentiles. Data were ranked by median. Subgroup(s) with 10 or fewer cases were regrouped and presented as other. DI, diagnostic interval; PI, patient interval; TDI, total diagnostic interval.

with abnormal gait (35%) and focal motor weakness (15%) being the most common. Visual problems were observed in 26% of the patients at diagnosis, with reduced acuity (14%) and abnormal eye movements (7%) being the prevalent symptoms. Only 2% of all patients exhibited weight loss. The most common behavioral problem was lethargy, which was reported in 5% of patients.

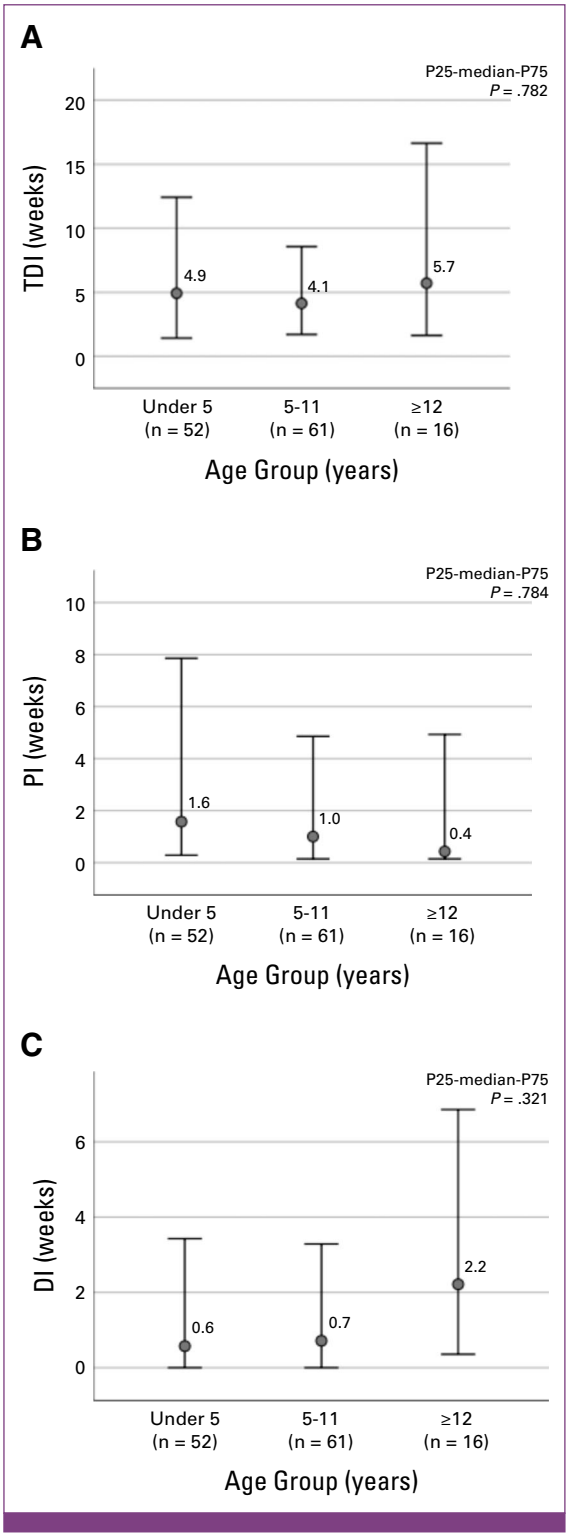

FIG 4. Comparison of (A) TDI, (B) PI, and (C) DI by age at diagnosis. The solid dot represents the median, and the error bars represent the 25th and 75th percentiles. DI, diagnostic interval; PI, patient interval; TDI, total diagnostic interval.

DISCUSSION

This study evaluates time to diagnosis in children with brain tumors across several health care providers in TN. Such retrospective studies are inherently susceptible to bias. However, as tumor registries do not exist in India, and health care systems and infrastructure are not standardized across the country, this study serves to provide a useful baseline to evaluate any future interventions aimed at reducing delays to diagnosis in a similar patient population. Although the total number of cases and distribution of all childhood cancer was not collected as part of the study, every center submitted the percentage rate of CNS tumors as a proportion of all cancers in their center. This figure when averaged was 12%, which is half the rate of cases diagnosed in the developed world. Although this may vary from center to center and from region to region, this estimate is in keeping with the low incidence of CNS tumors in other published studies.

The CNS tumor types in our study aligned with those in India and the West. However, compared with the United Kingdom (UK) HeadSmart data,[18,19] our study had a lower proportion of central tumors (31.7% in HeadSmart and 21% in our study). Additionally, few optic pathway tumors were registered in our study, contrasting with the study conducted in the UK, where optic pathway tumors comprised 5.2% of all cases. Furthermore, a higher proportion of high-grade/metastatic tumors was noted relative to localized tumors. Possible explanations for these findings include the following. First, patients who have had surgery only may have been treated in a smaller surgical center and not been aware of or referred to these tertiary specialist centers. Second, some CNS tumors may have been diagnosed and treated by specialists elsewhere, for example, by ophthalmologists, reflecting the fragmented nature of care in India. Unfortunately, verifying this is challenging because of the lack of registry data.

Our study reported shorter DIs compared with the UK data.[18,19] On the one hand, these may reflect the different diagnostic pathways. The lack of standard pathways in TN and variation in the health service utilization because of the absence of a national or regional governmental comprehensive cancer care system are likely to lead to patients self-referring to private health care providers and the composition of our study population (Data Supplement, Tables S3 and S4). On the other hand, an element of reporting bias cannot be excluded.

Despite these differences, low-grade tumors still showed a longer TDI compared with high-grade tumors, in line with previous research findings that reported the relatively shorter TDIs of aggressive tumors.[20] This can be attributed to the rapid onset of symptoms, facilitating quicker presentation and diagnosis in aggressive tumors. Conversely, slow-growing tumors require an extended period for noticeable symptoms to emerge, leading to delayed identification, sometimes accompanied by subsequent brain damage.

Low-grade gliomas were seen to have one of the longest TDIs and wide IQR in the UK and South India, where the DI was twice as long PI. As a result, we will focus future activities in improving the time to diagnosis in these patients. We have

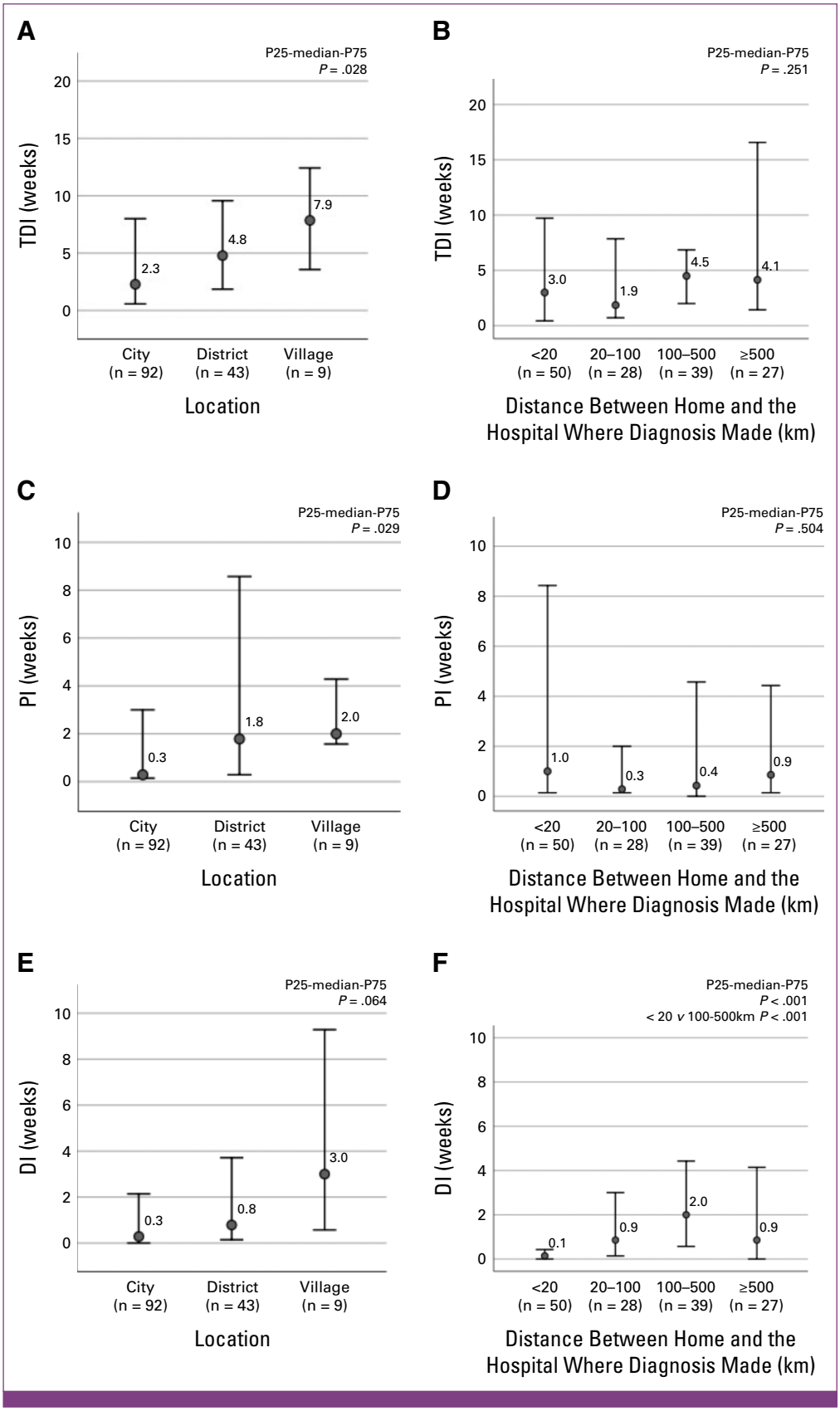

FIG 5. Comparison of TDI, PI, and DI by patient location at first presentation to health care (A, C, E) and distance between home and hospital that made the diagnosis (B, D, F). The solid dot represents the median, and the error bars represent the 25th and 75th percentiles. DI, diagnostic interval; PI, patient interval; TDI, total diagnostic interval.

TABLE 2. Frequency of Signs and Symptoms of Pediatric Brain Tumors at Symptom Onset and Diagnosis (N = 144)

Sign and Symptom	At Symptom Onset, No. (%)	At Diagnosis, No. (%)
Headache	66 (46)	68 (47)
Vomiting	82 (57)	89 (62)
Eye/visual problems (any)	31 (22)	37 (26)
Reduced acuity	17 (12)	20 (14)
Abnormal eye movements	7 (5)	10 (7)
Squint	7 (5)	8 (6)
Papilledema	1 (1)	1 (1)
Proptosis	5 (3)	5 (3)
Reduced visual fields	6 (4)	8 (6)
Motor problems (any)	56 (39)	64 (44)
Abnormal gait	40 (28)	50 (35)
Abnormal coordination	8 (6)	13 (9)
Focal motor weakness	18 (13)	21 (15)
VII palsy	9 (6)	11 (8)
Swallowing difficulties	3 (2)	4 (3)
Regression in motor skills	3 (2)	2 (1)
Abnormal growth or puberty (any)	3 (2)	6 (4)
Growth faltering	1 (1)	1 (1)
Weight loss	2 (1)	3 (2)
Delayed/arrested puberty	1 (1)	1 (1)
Early puberty	0 (0)	0 (0)
Diabetes insipidus	1 (1)	3 (2)
Behavioral problems (any)	11 (8)	10 (7)
Change in behavior	2 (1)	2 (1)
Lethargy	7 (5)	7 (5)
Difficulties with school	3 (2)	3 (2)
Seizures	12 (8)	17 (12)
Reduced consciousness	6 (4)	7 (5)

also developed networks with ophthalmologists and eye hospitals in the region to improve the diagnostic rates for optic pathway glioma. This is also in alignment with the World Health Organization's Global Initiative for Childhood Cancer.[21]

Very short DIs indicate that patients probably received a magnetic resonance imaging (MRI) scan shortly after their first consultation with a HCP, which suggest good imaging infrastructure in these private/NGO specialist cancer centers. However, it was somewhat surprising that midline tumors had a median TDI of 2.1 weeks, with both median PI and DI being approximately 4 days (0.6 weeks). This is strikingly different to the UK data, which concluded that anatomically midline tumors were associated with longer TDIs. Although we cannot ascertain the reason behind this discrepancy, it may be, at least partly, related to the lower proportion of midline/optic pathway glioma in our study population, coupled with the possibility of parents underreporting the PIs. Further exploration is needed in future studies.

Unlike previous studies, there was no significant differences in DIs across age groups. This is likely because of the fact that the overall DI was fairly short.

A study across seven care facilities in India found that the median travel distance between a child's place of residence and treatment was 338 km, with an average travel time of 9 hours.[22] Our study found differences in TDI and PI on the basis of the patient's initial health care presentation location. Patients living in cities had a seemingly shorter DIs compared with patients who lived in villages. But this was not statistically significant, probably because of the small number of children from villages in our study (n = 9). Longer DI was associated with the distance patients had to travel to reach the hospital, although the relationship was not linear. One explanation is that patients who traveled more than 500 km might have different characteristics because of their ability to undertake such lengthy journeys. We further explored the association between DI and number of HCP visits. Compared with those resided within 20 km from the hospital, patients who traveled more than 20 km were 8.6 times more likely (95% CI, 1.1 to 67.3) to have four or more visits to HCPs before diagnosis.

Signs and symptoms are consistent with data from the West, although the changes in the number of symptoms between symptom onset and diagnosis were smaller (1.7-1.9) compared with the UK data (1-6).[18] This is likely because of the rapidity with which MRI scans were performed in our population.

Several studies have highlighted the barriers to childhood cancer diagnosis in India.[11-15] Factors contributing to delays include lack of awareness of symptoms,[15] misdiagnosis,[23] and lack of diagnostic neuroimaging facilities and referral pathways.[24] Health systems also play a role with difficulties for patients navigating complex, fragmented health care provision with poor infrastructure in many places.[11]

The study is subject to several limitations. The retrospective design inherited problems of recall bias and recall errors. Additionally, as data were collected by the clinicians, social factors may have also led to underreporting of the number of HCPs seen by patients. The main limitation is that the participating centers were private and NGO hospitals located in metropolitan areas. Despite approaching multiple tertiary centers in the region, only private and NGO hospitals agreed to participate in the project. Our study population had a high biopsy rate in brainstem and midline tumors and high proportions of self-referred and self-financed patients. Therefore, our findings may not be generalizable, as cases diagnosed at public institutions may exhibit different characteristics and diagnostic pathway. The results should be interpreted with caution.

In conclusion, the size of the burden of pediatric brain tumor in India is still not known. Although the data presented have

many similarities to the data in the UK, more studies need to be conducted to investigate the differences observed. More studies should investigate the effect of tumor location on symptomology of patients to aid in quicker and accurate diagnosis. Increased training and establishment of proper cancer registries, combined with appropriate referral pathways, could lead to early diagnosis and improve outcomes for these children.

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SUPPORT

Supported by the University of Nottingham International Collaboration Fund.

DATA SHARING STATEMENT

Data are available upon reasonable request. Please contact Dr Madhumita Dandapani for access.

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AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

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Open Payments is a public database containing information reported by companies about payments made to US-licensed physicians (Open Payments).

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No other potential conflicts of interest were reported.

ACKNOWLEDGMENT

The authors thank Dr Krishna Kumar Rathnam, Meenakshi Mission Hospital, Madurai, India, and Dr Arun Seshachalam, GVN Multispecialty Hospital, Trichy, for their support for the project.

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