



Assessing the Diagnostic Pathway in Pediatric Brain Tumors: Factors Associated with Longer Diagnostic Latency

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BACKGROUND

Pediatric brain tumors are a diagnostic challenge given the variability in their presentation and their tendency to mimic more common diagnoses such as migraine or feeding intolerance. Because of this, there is significant literature on diagnostic delay in pediatric brain tumors, but no clear consensus on factors associated with these “delays”.

Our objective was to map the diagnostic pathway of pediatric patients diagnosed with brain tumors at the University of Wisconsin and assess for factors related to a longer period between presentation and definitive diagnosis.

METHODS

- Reviewed 203 charts of children diagnosed with CNS tumors from December 2007 - December 2017. After inclusion and exclusion criteria applied, 80 charts were included in the analysis.
- Variables: Age at 1st contact, time from 1st contact to diagnosis, gender, race, tumor location, tumor type, symptoms at initial presentation, symptoms at diagnosis, number of imaging studies between first contact and diagnosis, number of health care contacts between 1st contact and definitive diagnosis, number of referrals between 1st contact and diagnosis, location of 1st contact, initial referral type, initial diagnosis.
- Inclusion criteria: Children birth – 18yo treated for primary CNS tumors at UW Health.
- Exclusion criteria: Diagnosis based on incidental imaging finding (eg. study sub, head injury at presentation), previously diagnosed malignancy, genetic syndrome predisposing patient to tumor, incomplete records of diagnostic pathway, pre-existing conditions rendering it difficult to differentiate symptoms associated with preexisting condition from tumor-related symptoms.
- All cases given “Efficiency Grade”

| Efficiency Grade | = | Time (months) | + | Number of Healthcare Contacts | + | Number of Referrals | + | Number of Imaging Studies |
|------------------|---|---------------|---|-------------------------------|---|---------------------|---|---------------------------|
|------------------|---|---------------|---|-------------------------------|---|---------------------|---|---------------------------|

Figure 1: Efficiency Grade Calculation
Time interval for all measures is defined as date of first healthcare contact to date of definitive diagnosis. A lower efficiency grade is associated with a more efficient diagnostic work up.

- On average, definitive diagnosis of pediatric brain tumor required:
 - 2.7 contacts with the healthcare system
 - 0.7 specialist referrals
 - 2.7 months from first healthcare contact
- Only 15% of cases were diagnosed at first healthcare contact
- Factors such as tumor location, presenting symptom and location of first contact contributed to varied efficiency in diagnostic work up

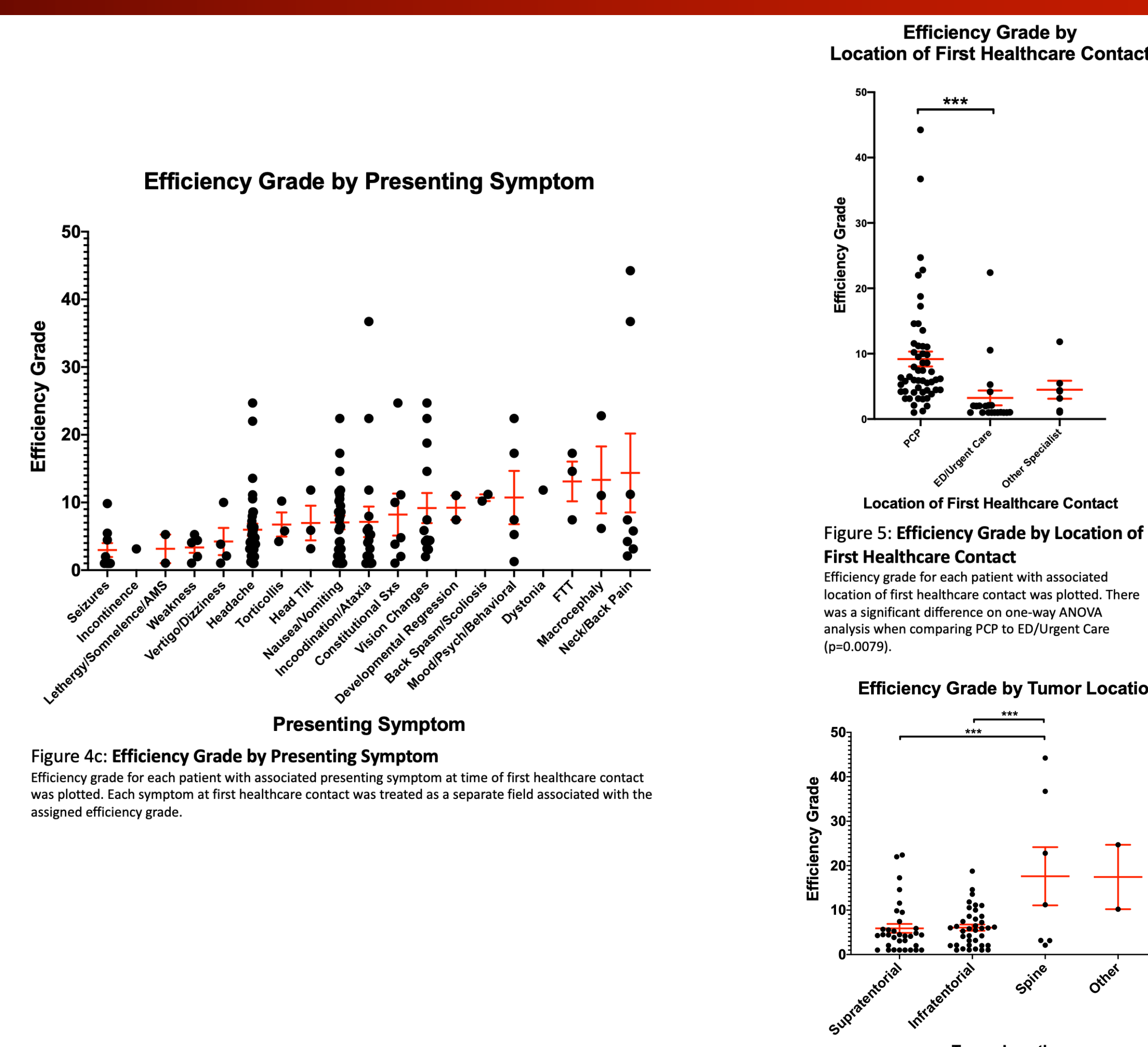
RESULTS

| Symptom | % of Cases with Symptom at First Healthcare Contact | % of Cases with Symptom at Diagnosis |
|-----------------------|---|--------------------------------------|
| Headache | 43.75% | 50.00% |
| Nausea/Vomiting | 35.00% | 42.50% |
| Incoordination/Ataxia | 21.25% | 28.75% |
| Vision Changes | 16.25% | 23.75% |
| Seizures | 11.25% | 15.00% |

Figure 4a: Most Common Presenting Symptoms
Patient charts reviewed for symptoms at both time of first contact as well as at time of diagnosis. The 5 most common symptoms were determined at both time points and are shown as percentage of total cases (n=80).

| Symptom | Efficiency Grade | Efficiency |
|--------------------------|------------------|-----------------|
| Seizures | 2.974 | Most Efficient |
| Incontinence | 3.133 | |
| Lethargy/Somnolence/AMS | 3.150 | |
| Weakness | 3.353 | |
| Vertigo/Dizziness | 4.242 | |
| Headache | 5.977 | |
| Torticollis | 6.744 | |
| Head Tilt | 6.967 | |
| Nausea/Vomiting | 7.046 | |
| Incoordination/Ataxia | 7.137 | |
| Constitutional Sxs | 8.219 | |
| Vision Changes | 9.182 | |
| Developmental Regression | 9.233 | |
| Back Spasm/Scoliosis | 10.700 | |
| Mood/Psych/Behavioral | 10.727 | |
| Dystonia | 11.833 | |
| FTT | 13.100 | |
| Macrocephaly | 13.333 | |
| Neck/Back Pain | 14.358 | Least Efficient |

Figure 4b: Average Efficiency Grade According to Presenting Symptom
The average efficiency grade was determined for each presenting symptom at time of first healthcare contact and subsequently charted from high efficiency (low grade, green) to low efficiency (high grade, red).



LIMITATIONS/FUTURE DIRECTIONS

Limitations:

- Fairly homogenous study population
- Heterogenous group of tumors
- Small sample size, significant amount of excluded cases due to incomplete records

Future Directions:

- Subgroup analysis (based on tumor location, type, appropriate vs inappropriate latency period, removal of cases with diagnosis on day of presentation)
- Addition of phone contacts with healthcare system
- Further analysis of referrals and testing prior to diagnosis
- Case series with selected cases with longest latency periods and most complex diagnostic pathways

CONCLUSIONS

- No correlation between age and efficiency grade (R = 0.0016)
- Spine location was significantly associated with a less efficient diagnostic pathway when compared to both supratentorial and infratentorial location (Figure 3)
- 5 most common symptoms at first healthcare contact were: Headache (35), Nausea/Vomiting (28), Incoordination/Ataxia (17), Vision Changes (13) and Seizures (9)
- 5 most common symptoms at diagnosis were: Headache (40), Nausea/Vomiting (34), Incoordination/Ataxia (23), Vision Changes (19), Seizures (12)
- Most commonly, no referrals were made prior to diagnosis (40), followed by neuro (24), ophthalmology/optometry (11), and GI (6).
- Seizures were associated with the most efficient diagnostic work up. Neck/Back Pain was associated with least efficient diagnostic work up.
- Initial presentation to PCP was associated with a significantly less efficient diagnostic workup when compared to initial presentation to the ED/Urgent care (p=0.0079).