

# Pediatric Ependymoma Outcomes Study

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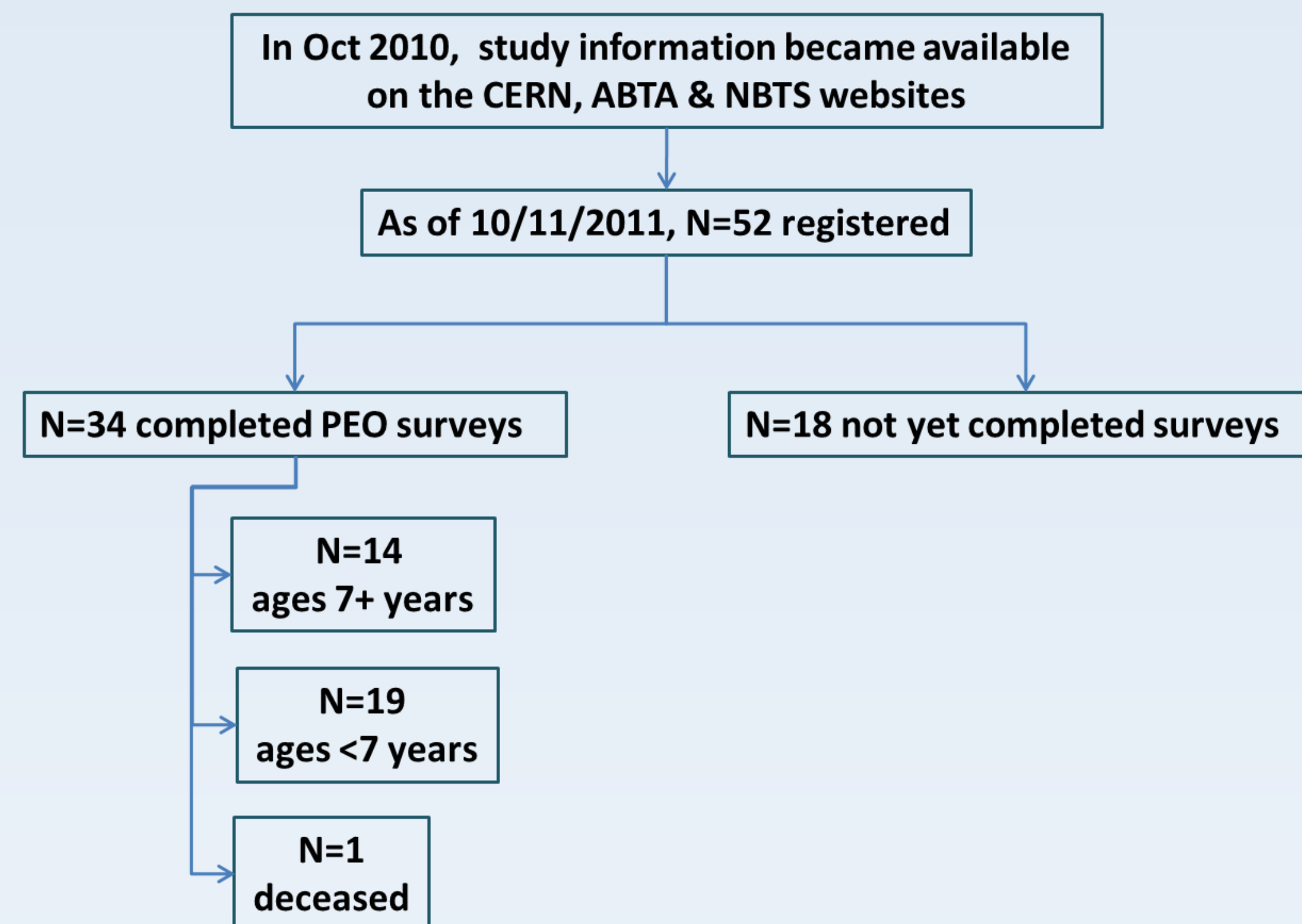
## Abstract

Ependymomas are rare CNS tumors in children, and as a consequence, few reports are available regarding the clinical course, symptomatology at presentation, and impact to patients and families. The Collaborative Ependymoma Research Network (CERN) is a multi-institutional effort that is focused on better define the disease and improving treatment for all patients with ependymoma, with the mission to improve health-related quality of life (HRQOL) for patients and families. The Pediatric Ependymoma Outcomes (PEO) study is an online survey designed as one of the first steps to reach this goal. The primary objectives are to obtain treatment, symptoms, functional status, and quality of life reported by patients and their parents; and to evaluate the relationship between health status and disease and treatment characteristics. Broad inclusion criteria are used with an attempt to draw a more through picture of children with ependymoma and include children ages 7-17 parents of children ages 0-17; and parents of deceased children. In addition to demographic, disease and treatment information, both parents and patients ages 7-17 are asked to complete the pediatric Functional Assessment of Chronic Therapy – Fatigue (pedsFACIT-F), pedsFACIT-Childhood Brain Tumor Survivors (pedsFACIT-BrS), Perceived Cognitive Function Item Bank – Short-Form, and pediatric Functional Assessment of Anorexia/Cachexia Therapy. Parents of patients with ages 0-6 will complete symptom severity scale and Impact of Event Scale. To date, 14 parents and 13 children have been recruited. Recruitment is still on-going and expected to be completed by the end of 2011. Upon completion, we will have a better understanding of how ependymoma and its treatment may impact patients and their families, and appropriate interventions can then be implemented in a timely manner.

## Objectives

To explore health-related quality of life for children with ependymoma and their families by using survey methodology

## Methods



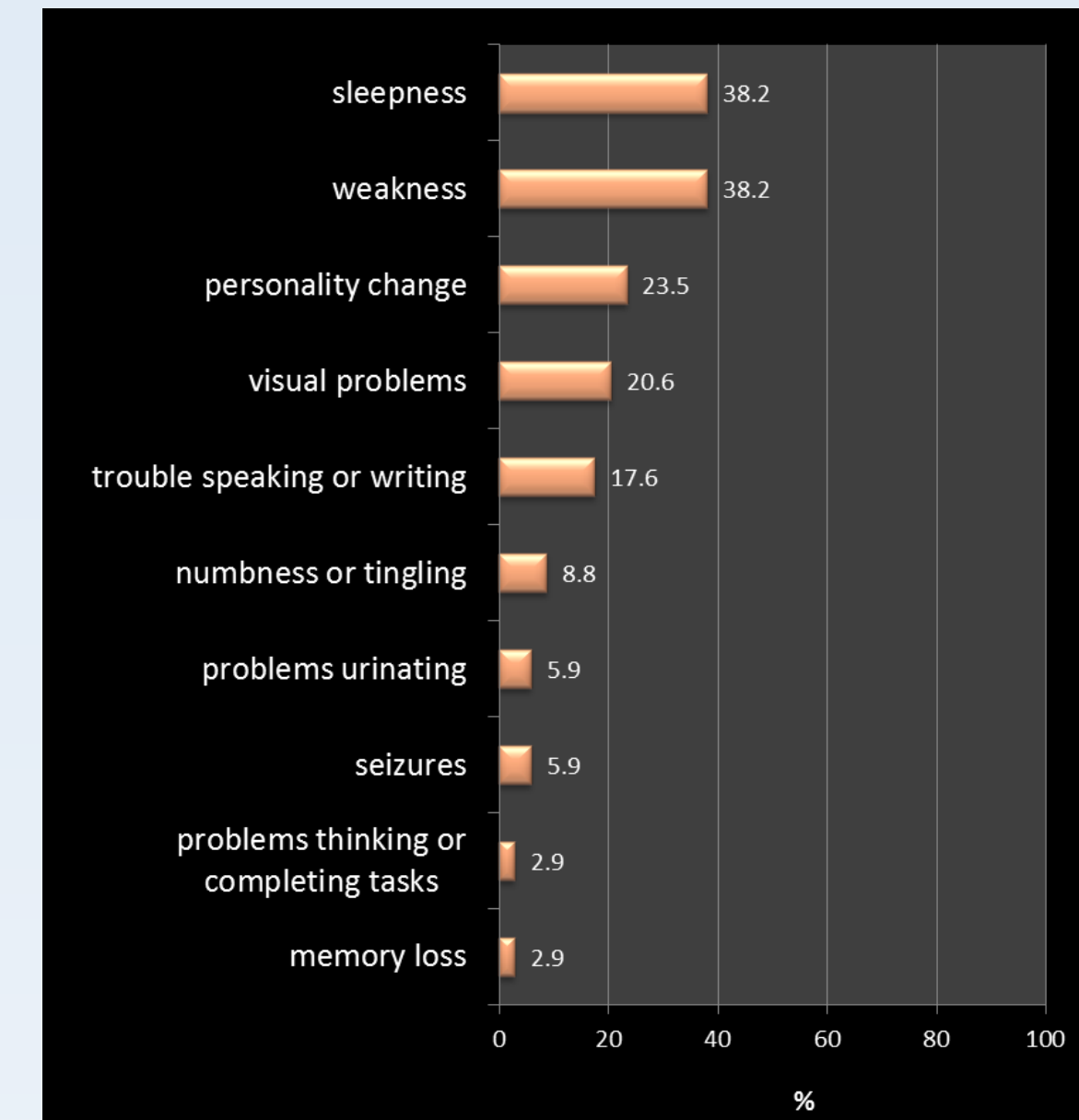
### Sample:

- Age: 83.3±53.5 months (range: 12-240)
- 71% boys; 94% White
- Most parents rated their child's QOL either good/very good (64.7%) or excellent (26.5%)
- 29% reported a family income of \$100,000 or more
- 64.7% agreed that they had all the healthcare they need for their child.
- 94% felt they were either somewhat (55.9%) or very (38.2%) knowledgeable about their child's ependymoma
- 52.9% parents were very satisfied and 44.1% were somewhat satisfied with the medical care that they child received
- Name of the 1st tumor: 55.9% Anaplastic ependymoma; 44.1% ependymoma
- 97.1 % in the brain
  - 47% - brainstem, 38.2%- cerebellum
  - 58.8% grade III; 35.3% grade II Treatment
  - 47% had 1, 26.5 had 2 and 26.5 had ≥ 3 surgeries
- Type of the first surgery: 67.6% craniotomy with all of tumor removed & 29.4% with part of tumor removed
- 47.1% received chemotherapy; 94.1% received radiation therapy
- 32.4% had tumor recurred

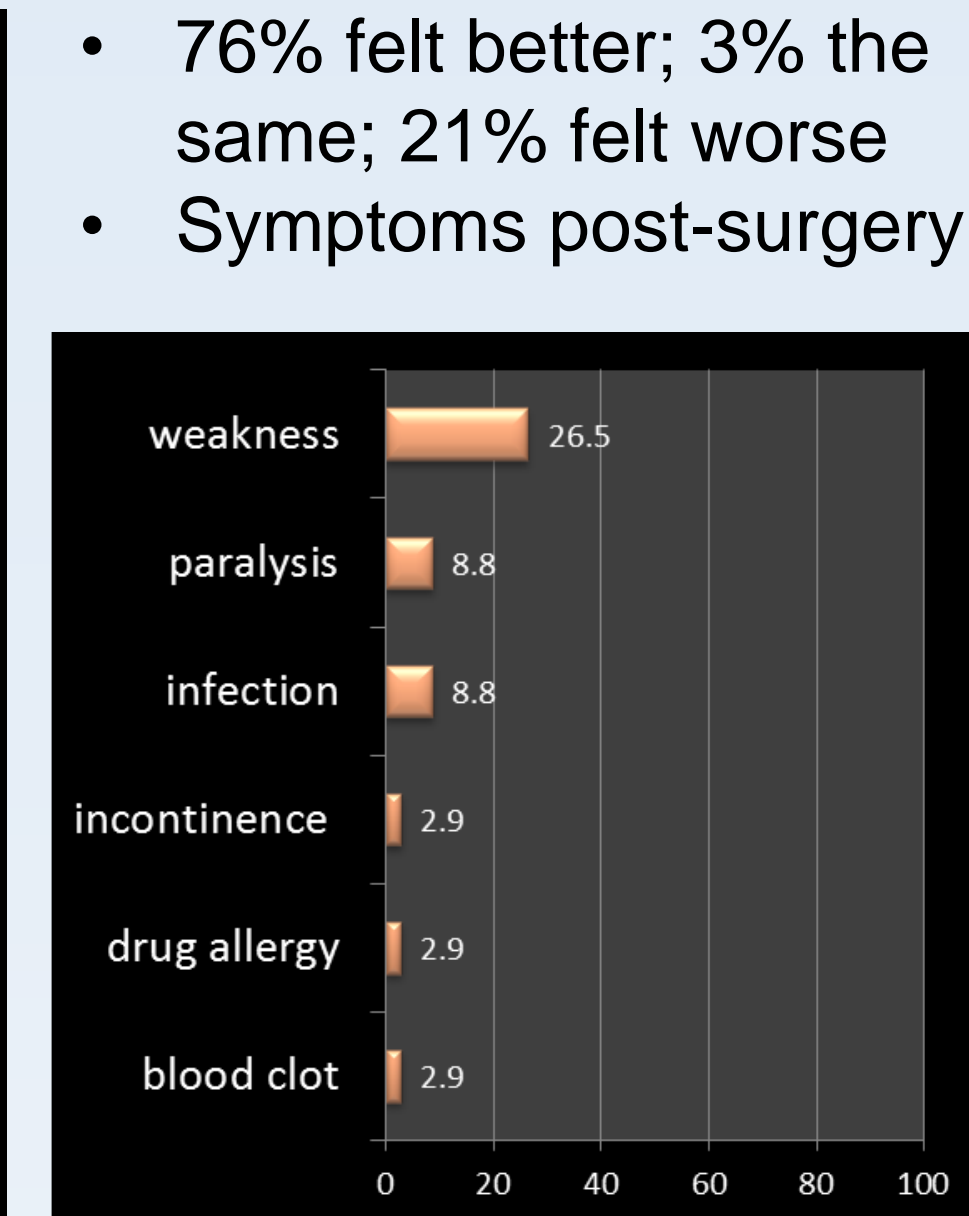
## Results

### All Patients

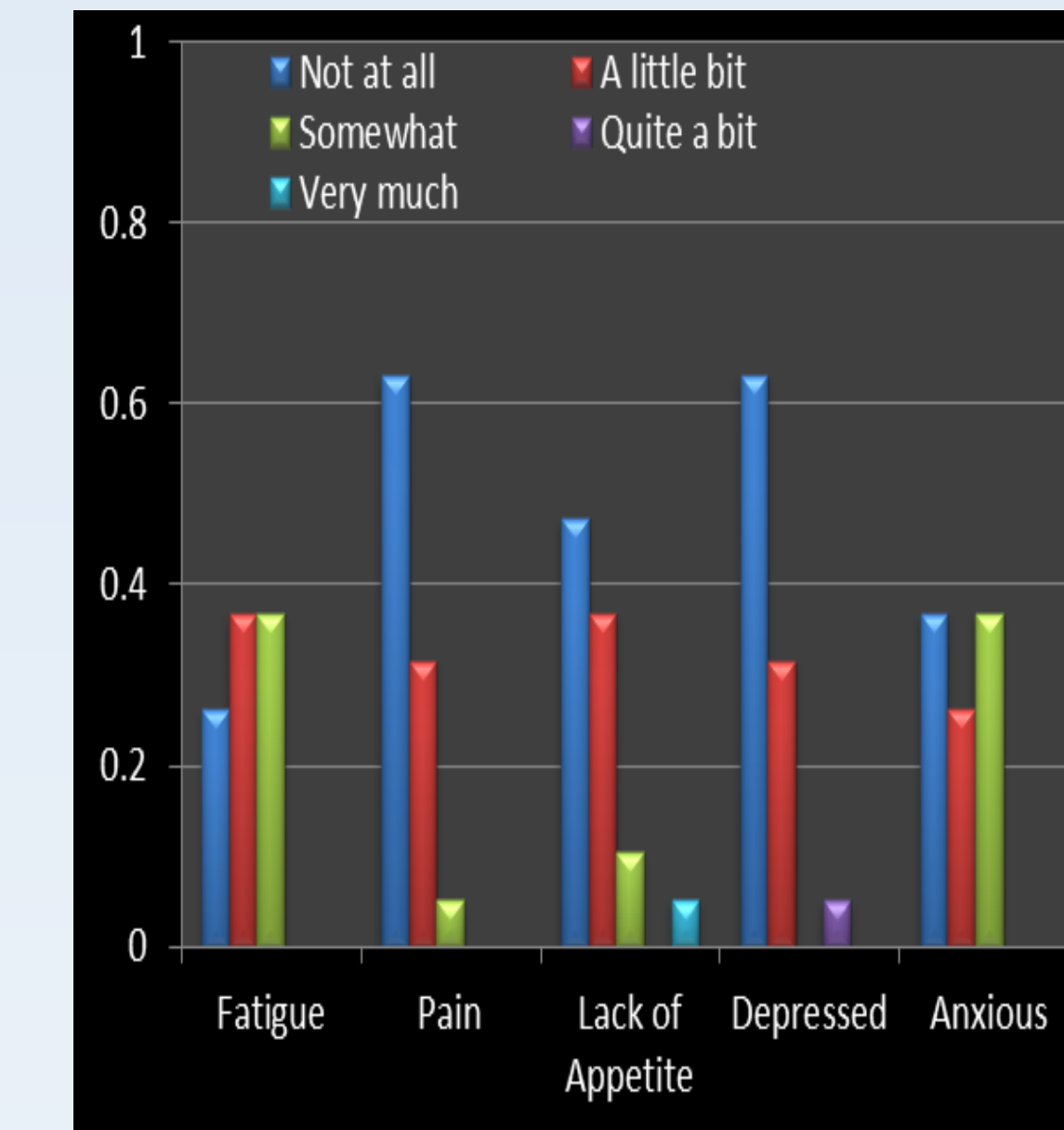
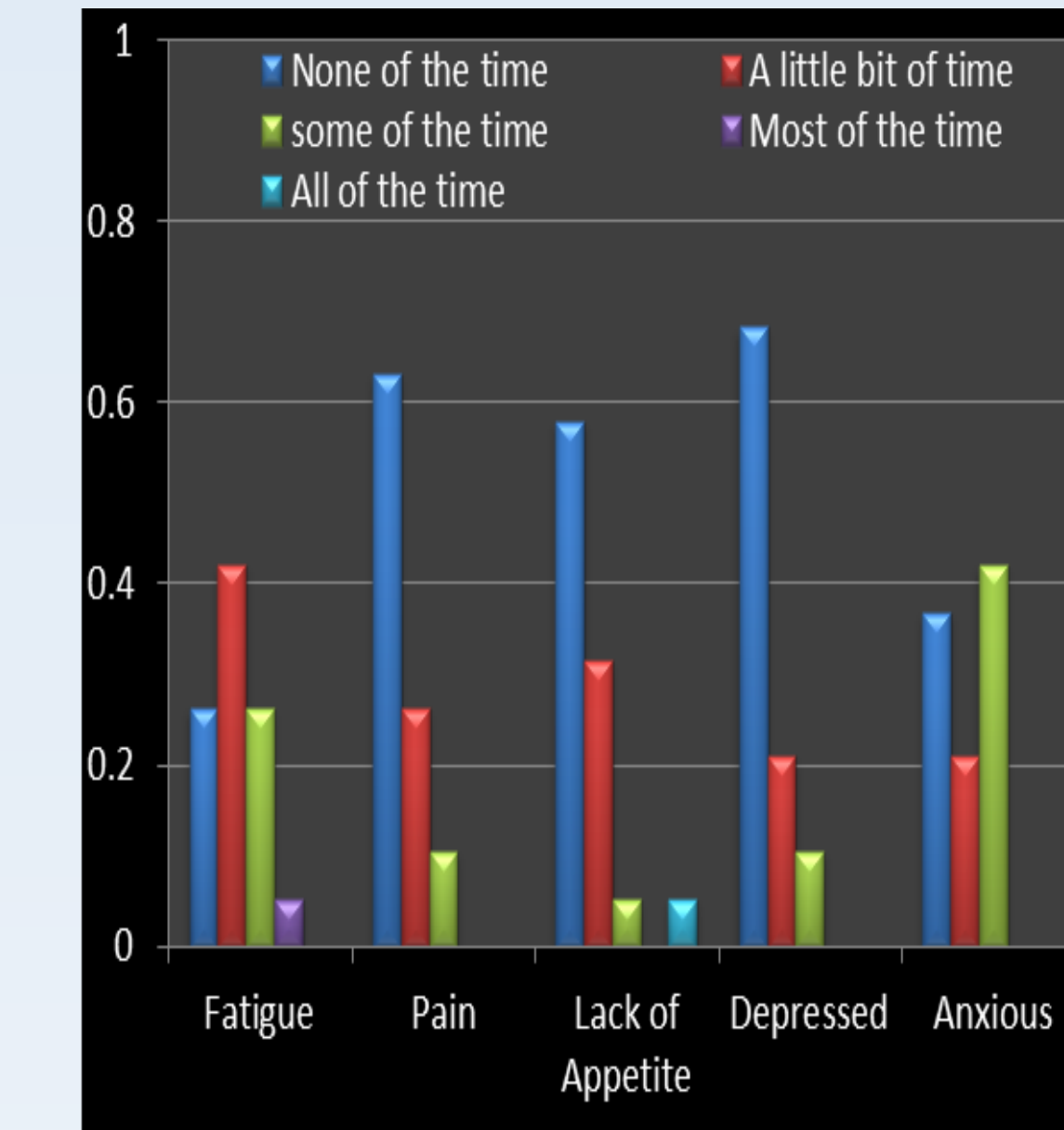
#### Symptoms prior to surgery



#### Post surgery

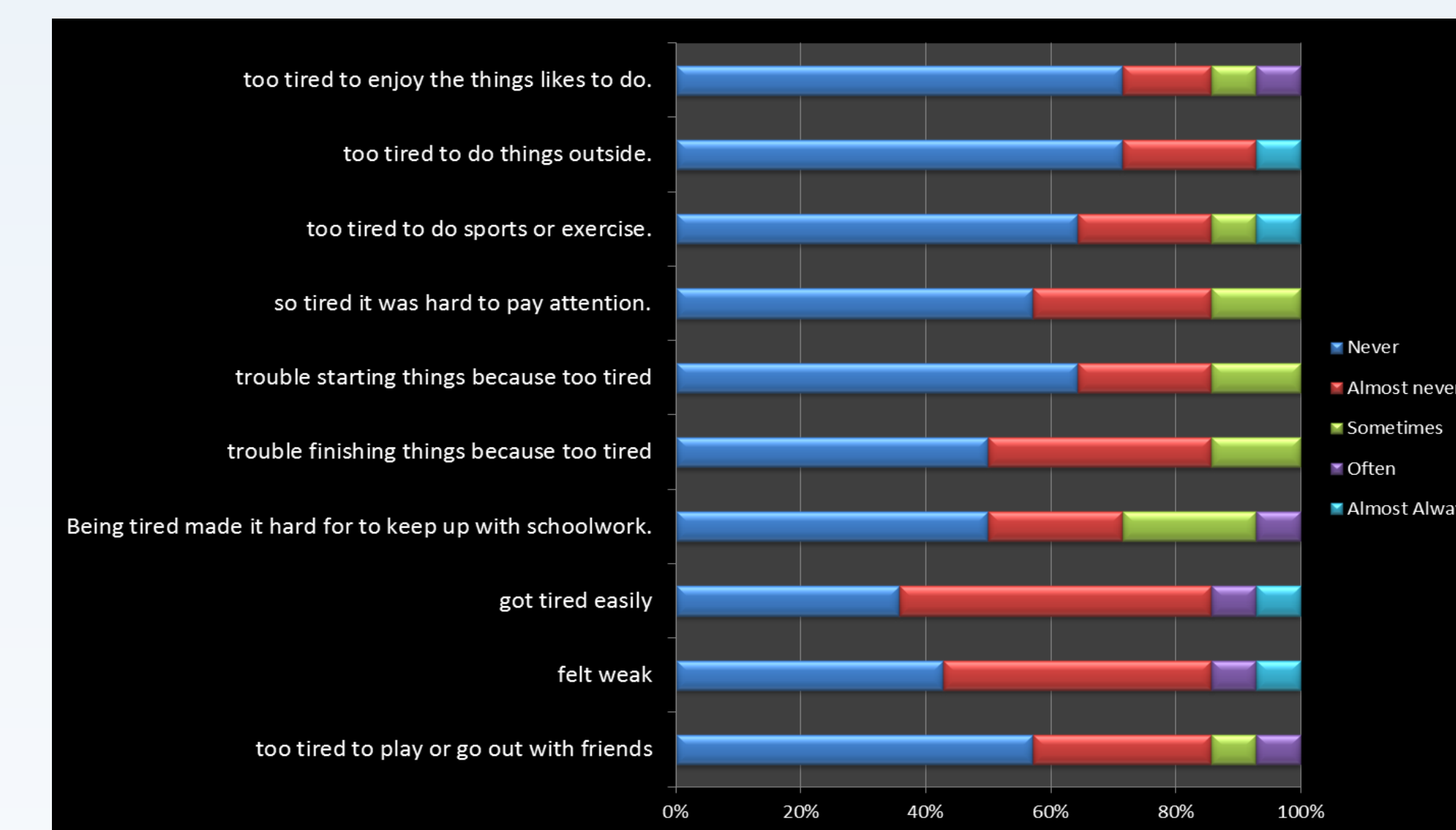


### Patients aged 0-6 years old

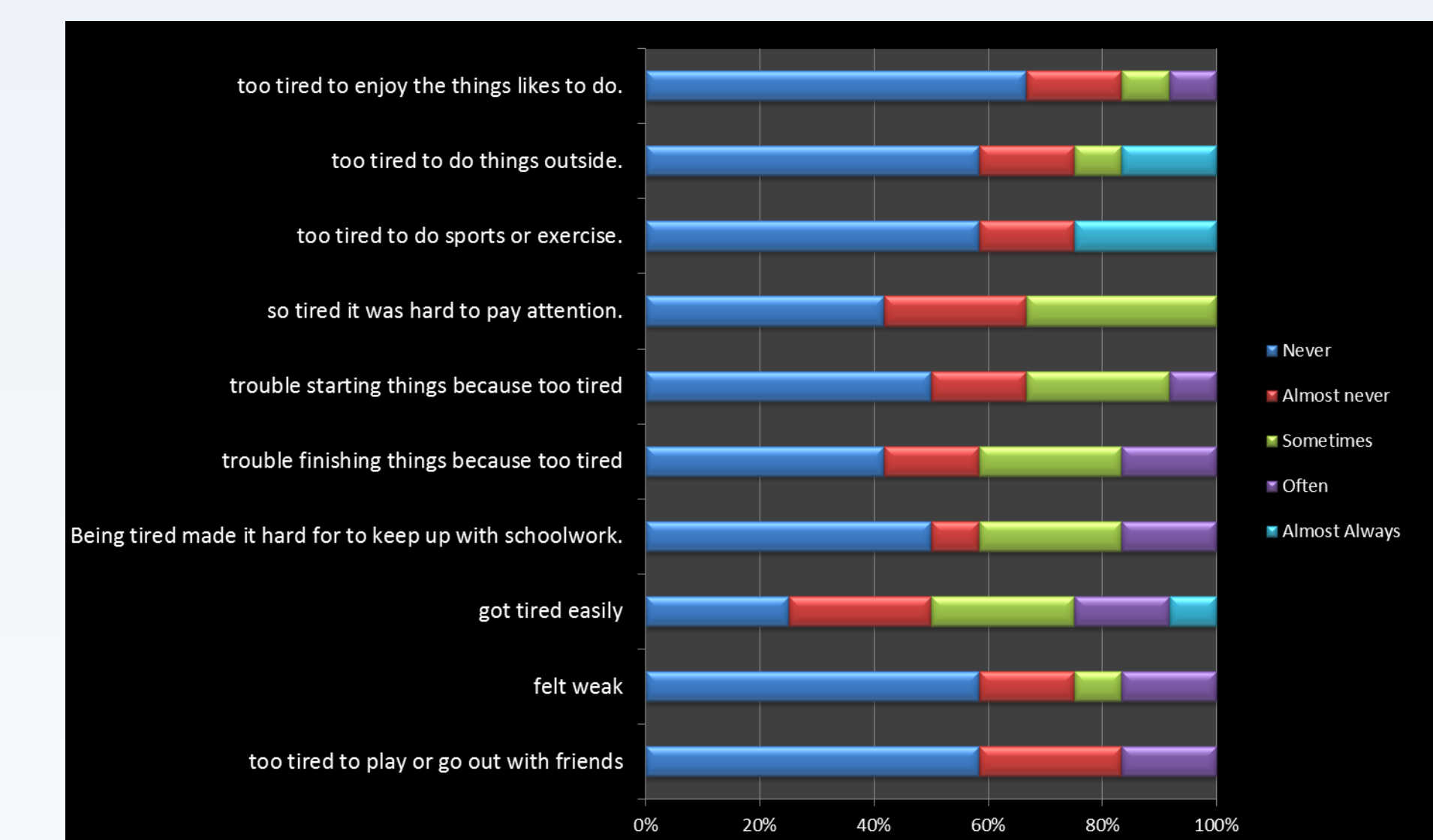


### Patients aged 7 years old and older (examples)

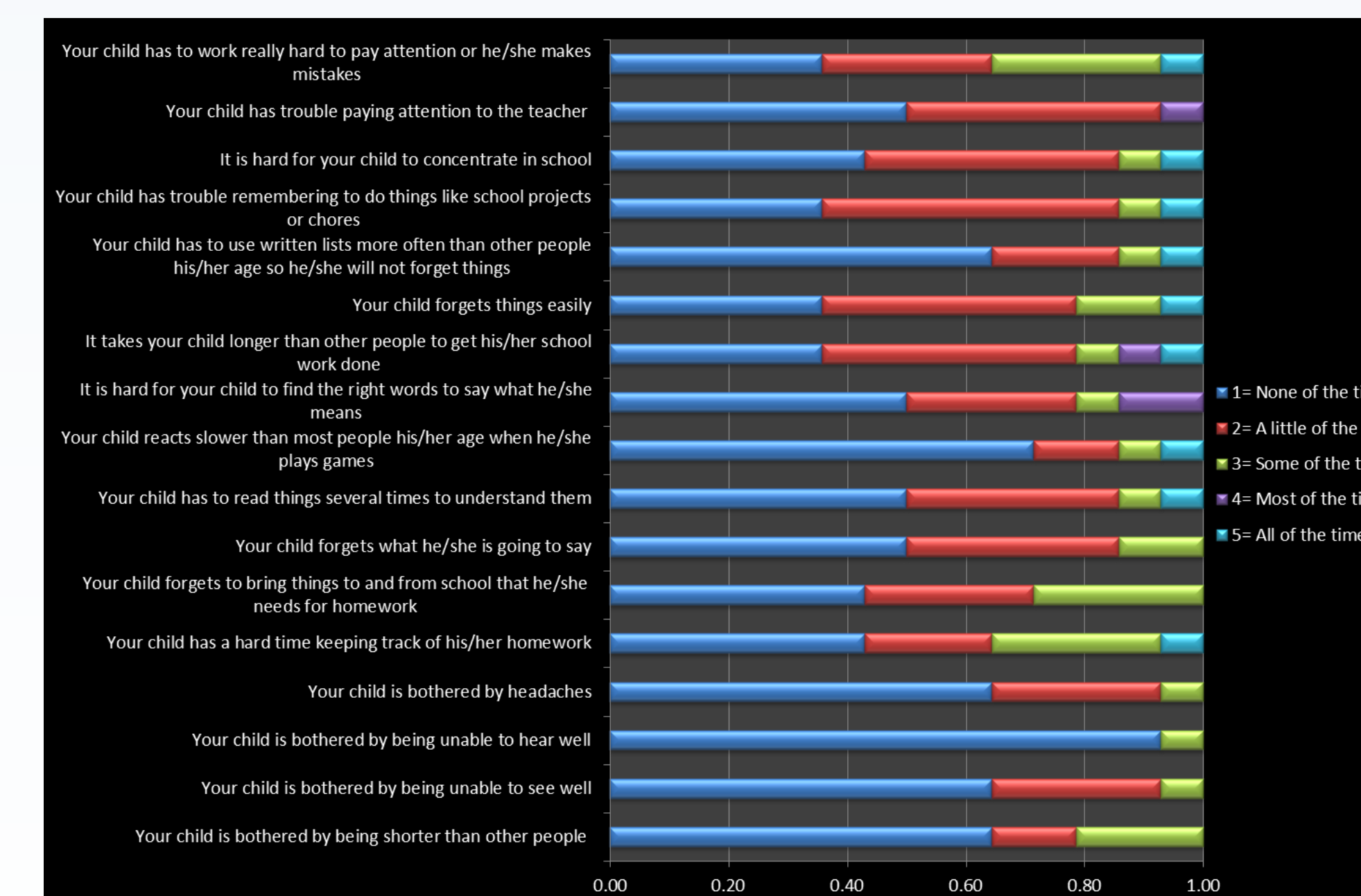
#### Parent-reported Fatigue



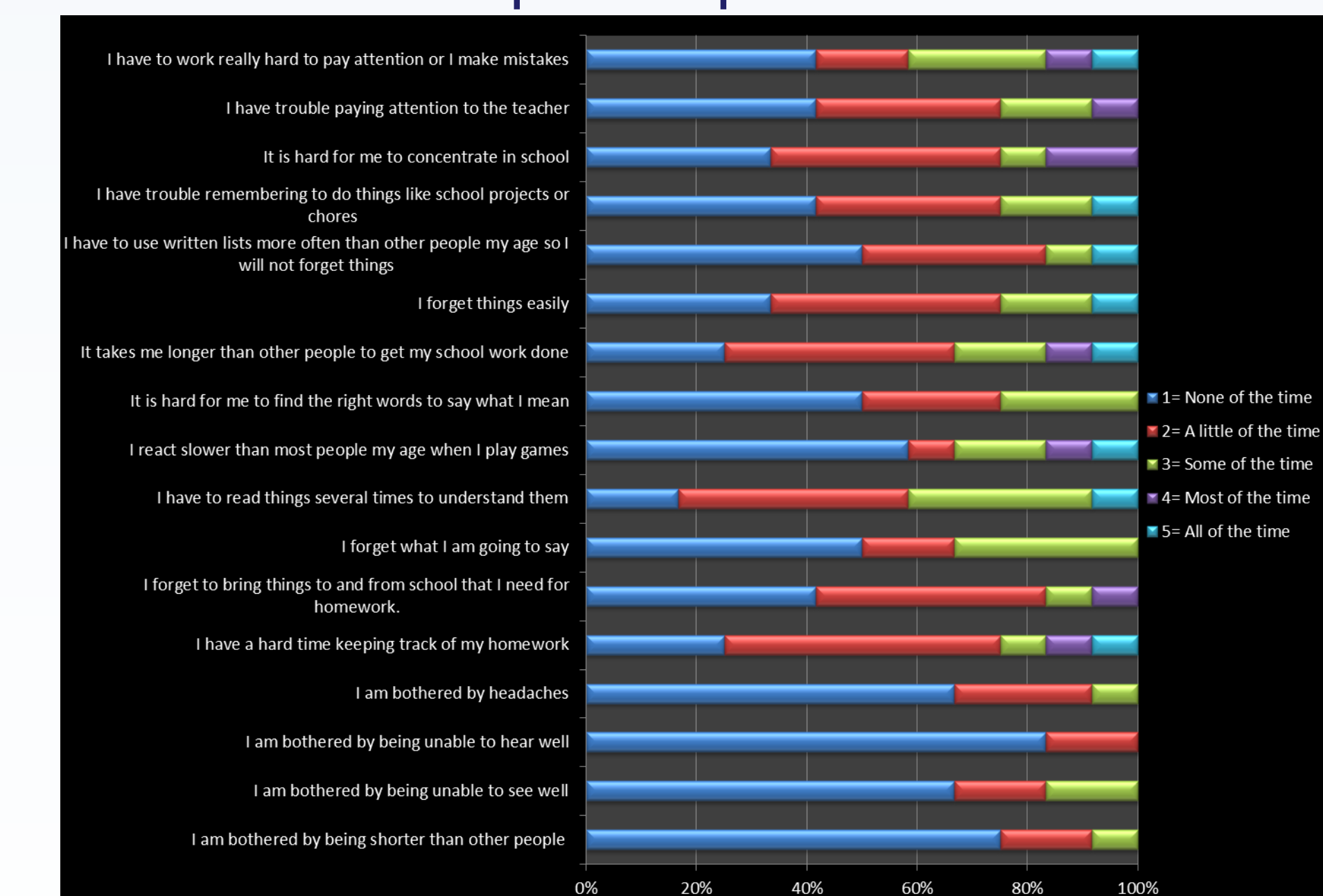
#### Child-reported Fatigue



#### Parent-reported pedsFACIT-BrS



#### Child-reported pedsFACIT-BrS



## Conclusion

- In general, both parent and child reported moderate or good quality of life, expect some specific concerns within each domain.
- Fatigue related symptoms were the primary concerns both prior to and post surgeries.
- A larger sample size is needed to make more robust conclusions. Recruitment is still on-going