

## Characterizing the Burden of Care on Families of Children with Pediatric Solid Tumors

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**Background:** New childhood cancer diagnoses require timely, multi-specialty care coordination, imposing considerable burdens for families. To better understand these challenges and optimize care delivery, this study aims to 1) track the trajectory of medical burden over time by quantifying medicalized days and services received by children with solid tumors 2) quantify impactful expenses for families and 3) identify factors impacting medical burden.

**Methods:** A retrospective chart review of pediatric patients with extra-cranial non-osseous solid tumors treated at an academic health center was conducted. We collected data on demographics, treatment plans, and healthcare utilization in the first-year post-diagnosis. Indirect costs, including income loss, parking, and mileage expenses, were calculated. Children were also stratified by tumor stage, and we assessed for significant differences in medicalized days, median household income, and distance travelled between low/intermediate and high-risk tumor patients.

**Results:** One hundred thirty-eight children met the study criteria, with a median age at diagnosis of 2.1 years. The most common diagnoses were neuroblastoma (37%), retinoblastoma (21%), and nephroblastoma (14%). Among the children, 37% received three or more treatment modalities, and 75% underwent surgery. Median medicalized days were 9 in one month, 20 in three months, 33 in six months, and 50 in twelve months. Service utilization at one year included a median of 106 lab draws, 20 imaging studies, 3 surgical procedures, and 10 unique prescriptions. Families came from 107 ZIP codes across four states, with a median one-way distance to the center of 64 miles. Estimated annual travel costs were \$1,561, and lost wages were \$14,813, or about 20% of the median household income. High-risk tumor patients had significantly more medicalized days at 6 and 12 months, greater travel distances, and lower household incomes compared to low/intermediate risk patients.

**Conclusion:** The study highlights the substantial medical and financial burden on families of children with solid tumors, especially those with higher stage tumors. This underscores the need for multidisciplinary clinics and solid tumor programs that address both medical and socioeconomic needs of pediatric oncology patients. Interventions to support families, including utilizing home health or telehealth appointments, and advocating for built-in travel support within insurance policies could alleviate some of the burdens identified.

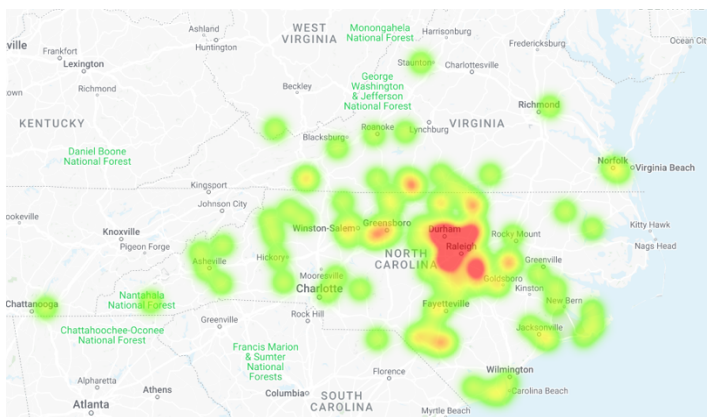


Figure 1: Geographic Distribution of Patient Cohort

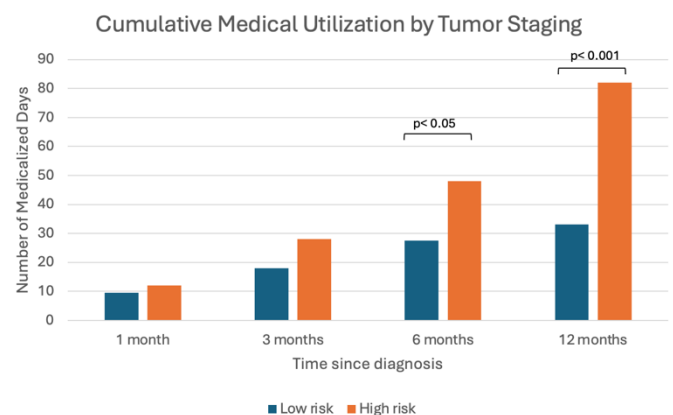


Figure 2: Cumulative Medicalized Days in Low vs High-Risk Tumor Patient Cohorts