

"Oh My Word, So Overwhelmed": Exploring the Patient and Family Experience with Diagnosis and Treatment Decision Making in Pediatric CNS Tumors

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Pediatric central nervous system (CNS) tumors are the leading cause of cancer-related mortality in children, with survival outcomes significantly influenced by racial, ethnic, and socioeconomic disparities. These disparities may arise from delayed diagnosis, unequal access to care, and challenges in navigating complex treatment decisions, including clinical trial enrollment. To better understand the patient and family perspective at the beginning of their journey, we performed a qualitative study to explore their experience from symptom onset through treatment initiation, focusing on diagnosis, treatment discussions, and decision-making processes. We conducted semi-structured interviews with a diverse cohort of 17 families during diagnosis or early treatment; 13 completed a follow-up interview later in treatment. We examined the emotional and logistical challenges encountered during diagnosis and treatment planning. Our findings reveal the profound emotional toll of diagnosis, characterized by uncertainty, shock, and urgency. Families reported difficulties understanding complex medical information and accessing advanced treatment options, including clinical trials. Decisions about treatment were shaped by perceptions of therapeutic efficacy, anticipated side effects, and the resources available to support care. The study underscores differences in families' perceptions of care, with variations in barriers and obstacles influenced by individual circumstances. These disparities shaped the types of support families sought from their care teams, highlighting the necessity of personalized communication and tailored resources to meet diverse needs. By centering patient and family experiences, this study contributes a nuanced understanding of disparities in pediatric CNS tumor care, emphasizing the need for targeted interventions to improve access to innovative treatments, support informed decision making, and enhance communication. Future research should incorporate quantitative methods, including surveys and clinical trial enrollment analysis, to validate findings and guide the development of scalable solutions. Addressing the structural and informational barriers identified can reduce disparities and improve the experiences of families navigating pediatric CNS tumor care.