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

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Background

- Pediatric central nervous system (CNS) tumors are the leading cause of related mortality in children, with survival outcomes significantly influenced by racial, ethnic, and socioeconomic disparities.
- Disparities may arise from delayed diagnosis, unequal access to care, and challenges in navigating complex treatment decisions, including clinical trial enrollment.

Aims: This study explored the experiences of a diverse cohort of families from symptom onset through treatment initiation, focusing on their perspectives on diagnosis, treatment discussions, and decision-making processes.

Methods

- Qualitative study utilizing semi-structured interviews with families of children diagnosed with pediatric CNS tumors

Interview 1 → (3 Months) → Interview 2

- Around the time of treatment discussion for new or relapsed CNS tumor
- A few months into treatment

- Transcripts were analyzed by two separate coders using thematic analysis

Results

Experience of Diagnosis

- Symptoms leading to diagnosis
  - 17 Families (100%)
- Delay in Diagnosis
  - 5 Families (29%)
- Efficiency in Diagnosis
  - 8 Families (47%)
- Lack of Transparency
  - 2 Families (12%)

"I would have to say, knowing that it's a lot to take in, just even the diagnosis, right? That is a huge pill to swallow. Then being told what the care plan is, shortly after, when you don't even understand how or why, or all the questions you ask yourself. How could this happen? Did I do something? It would have been good to know, like, 'Here's the plan of care. We're going to start with carboplatin and vinblastine, and then we're going to—you know, it's going to be hard.'"

Treatment Discussion

- Confidence in their care team
  - 6 Families (35%)
- Difference in opinion among healthcare providers
  - 2 Families (12%)
- Overwhelming or confusing discussion
  - 3 Families (18%)
- Positives in treatment discussion
  - 6 Families (35%)
- Families' recommendations
  - 2 Families (11%)

"He came in, I remember, on a Monday and talked to us for two hours about traditional and conventional chemo versus this clinical trial and all the intricacies. Oh my word, so overwhelmed. When they left, we were just shot, mentally. Still, throughout the week, they would pop in... we spent probably 6 hours discussing and trying to find more information to help us make a decision."

Treatment Decision

- Single Option
  - 10 Families (59%)
- Confidence in their care team
  - 3 Families (18%)
- Long-term effects
  - 7 Families (41%)
- Support Network
  - 4 Families (24%)
- Logistical factors
  - 2 Families (12%)
- Financial
  - 1 Families (6%)

"I don't want to tell you what my opinion is because my opinion doesn't matter in this world. So yeah, we just wanted [the doctor] to drive [the treatment decision] and tell us."

Communication

- Positive Experience
  - 7 Families (41%)
- Negative Experience
  - 9 Families (53%)
    - Lack of communication and expectations
    - Lack of knowledge or clarity
    - Language barrier
    - Delayed responses
    - Terminology
- Social challenges
  - 7 Families (41%)

"I wish I would have known more, so I could ask more questions. Knowing more, like if the infusions didn't work, what our next steps would be. What are the long-term side effects? Just more detailed information. We got hit with so much information in such a short period of time. We couldn't even wrap our heads around the diagnosis, let alone his treatment"

Conclusions

- Emphasizes the need for targeted interventions to improve access to innovative treatments, support informed decision making, and enhance communication
- Lays the groundwork for future quantitative studies to validate findings and develop scalable solutions to address structural and informational barriers, aiming to reduce disparities

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