Title:
Diffuse Intrinsic Pontine Glioma (DIPG): A Qualitative Study

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Session Title:
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Keywords:
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Abstract Summary:
Diffuse Intrinsic Pontine Glioma (DIPG); A Qualitative Study: The purpose of this study is to better understand potential warning signs of DIPG in early child development, bring public awareness of this lethal cancer, and support for ongoing research to develop a cure.

Learning Activity:

<table>
<thead>
<tr>
<th>LEARNING OBJECTIVES</th>
<th>EXPANDED CONTENT OUTLINE</th>
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<tr>
<td>Learner will understand that this pediatric cancer exists and that there has been no advancement in cure rates since its discovery.</td>
<td>Statistical data related to DIPG mortality compared to all other pediatric cancers.</td>
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<td>Learner will gain perspective into the overwhelming emotional, physical, and financial toll a DIPG diagnosis has on a family.</td>
<td>In depth interviews with parents of children who have passed away as a result of DIPG.</td>
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Abstract Text:
Parent's lived experience caring for their child with DIPG. Identifying abnormal growth and development prior to diagnosis. An overwhelming experience for parents is the diagnosis of cancer for their child, especially a type that is rare, and offers few treatment options. The leading cause of cancer related deaths in children is brain cancer. While treatment and survival rates for pediatric cancer have improved over the past 30 to 40 years, there remain few effective treatments and no advancement in survival rates for children diagnosed with Diffuse Intrinsic Pontine Glioma (DIPG). DIPG comprises 10 to 15 percent of all pediatric brain tumors, effecting 200 to 400 children with a median age of six years, are stricken every year in the United States alone. Likewise the median survival rate is only nine months. There is a scarcity of research to indicate a genetic or environmental cause. Consequently recent research suggests that DIPG tumor formation may be linked to brain development. The purpose of this study is to better understand potential warning signs of DIPG in early child development, bring public awareness of this lethal cancer, and support for ongoing research to develop a cure. The research methodology is
qualitative phenomenology and a purposive sample of parents who have lost a child from DIPG will be recruited to participate in the study. In depth interviews with participants will provide information on their lived experience and what it is like to have a child diagnosed with DIPG. Detailed analysis of data will help gain insight into parent’s experience and discovery of any pre-existing health issues for children diagnosed with DIPG. Implications for practice include providing support for parents and development of educational programs on DIPG. Further research will help to determine a correlation between health markers for DIPG and treatment methods to improve prognosis.