

ABSTRACT 1 - SCIENTIFIC

For children who have been diagnosed and treated for a central nervous system (CNS) tumor and their families, life is drastically changed, as family life is forced into patterns of attempted adjustment to uncertainties about health outcomes and the changes necessitated by treatment requirements. Although scientific strides have been made in the treatment of childhood CNS tumors, survival rates remain variable and are related to age, tumor location, pathologic characteristics, surgical interventions, radiation and chemotherapy treatment protocols. The effects of treatment on quality of life are complex, involving issues of the nature as well as the length of future survival, and a host of emotional as well as practical problems. Consequently, the goal of treatment must be not only progression free survival, with minimal physiologic and neuropsychologic sequelae, but also to identify, build upon and nurture strengths of the family in order to promote an optimal quality of life. Unfortunately, to date little is known about the specific aspects of living through the treatments and sequelae from the perspectives of child and family. The overall objective of this proposed research is to generate a comprehensive and in-depth understanding of childrens' and parents' emotional responses to their experiences as well as the coping strategies that they find helpful as they reorganize their lives. Specifically, this study will investigate quality of life from both child and parent perspectives, as well as examine the relations among parenting styles, parent coping styles, parents' perceptions of child well-being and the child survivors' self concepts, resiliency and self-reported quality of life. To accomplish the goals of this project, one hundred and twenty school age children from six through twelve years of age who have completed treatment for a brain or spinal cord tumor at the Institute of Neurology and Neurosurgery at Beth Israel Medical Center Singer Division along with their parents will be enrolled in the study. Both traditional psychometric measures as well as open-ended and qualitative interviews will be conducted, using both telephone and in-person methods. In addition, a minimum of ten families will be selected to participate in an in-depth qualitative component of this project, which will target all immediate family members including siblings, and use narrative analysis of content to give "voice" to their experiences. It is anticipated that results of this project will : 1. Generate a beginning understanding of how school age survivors of CNS tumors and their families experience the impact of serious childhood disease, with special attention to the dimensions they identify as important for positive psychosocial and developmental outcomes; 2. Suggest a model of the ways in which parent variables contribute to the child's resiliency, self concepts and overall quality of life, as well as maintaining a cohesive and positively functioning family environment; and 3. Provide directions for tertiary interventions aimed across health professions in a joint effort to arrive at well-integrated and scientifically founded approaches to interventions which will address multidimensional needs articulated by children and their families. To address the complexity of factors contributing to child and family outcomes, pattern recognition techniques and artificial intelligence approach to modelling will be applied for the first time to this research area. This will be the first study of its kind to address multidimensional life quality outcomes in school age children treated for spinal cord and brain tumors.