

Assessing Parenting Capacities and Stress in Neurofibromatosis 1

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ABSTRACT

This study will identify caregiver needs and concerns about parenting children with Neurofibromatosis Type 1 (NF1). Specifically, we seek to identify parenting styles, types of parenting stress, levels of over-protectiveness, perceptions of their child's vulnerability, and how these variables influence the emotional, behavioral, and psychosocial adjustment in children with NF1. To achieve these objectives, focus groups will be conducted with caregivers of children diagnosed with NF1 at the University of Oklahoma Health Sciences Center, and the M.D. Anderson Hospital in Houston, Texas. Qualitative analysis of the data collected in the focus groups will then be used to assemble a battery of standardized assessment tools for parenting capacities, and to generate further hypotheses. Participants will also be asked to join a prospective cohort for further follow up in later parts of the study. Our long term objective is to develop a disease-relevant and clinically meaningful intervention for caregivers of children with NF1.

INTRODUCTION

- NF1 is an autosomal dominant genetic disorder affecting about 1 in every 3,000 newborns.
- Parents face substantial difficulties not only in adjusting to their child's diagnosis, but also in negotiating the demands of parenthood under considerable uncertainty about their child's health outcomes.
- To date, no studies have sought to evaluate the specific demands and needs of parents of children with NF1.
- Literature supports the significance of the parent-child adjustment outcome relationship in childhood chronic illness and indicates parental adjustment as one of the single best predictors of child adjustment.

SPECIFIC AIMS

- Identify parenting styles, parenting stress, parental overprotection, perceived child vulnerability in parents of children with NF1.
- Identify the possible relationship of parenting style, parenting stress, parental overprotection, and perceived child vulnerability to psychosocial adjustment and quality of life in children diagnosed with NF1.

METHODS

- Parents of children with NF1 will be recruited from outpatient clinics at each of the data collection sites; approximately 8 focus groups will occur at the two study sites, with total subject recruitment of up to 80 caregivers.
- Focus group leader will ask a series of open-ended questions designed to identify how parenting capacity potentially influences child adjustment.
- Investigators will analyze the recorded notes from focus group discussion using a thematic analysis.
- Information gathered will also be used to develop an assessment battery measuring various aspects of parent capacity, to provide the basis for a larger empirical assessment.

PROGRESS TO DATE

- Established collaboration between the two study sites, University of Oklahoma Health Sciences Center and M.D. Anderson
- IRB in place at both Oklahoma and Texas sites
- Clinical population surveyed and potential subjects identified