

RESEARCH PROTOCOL

Family Functioning Through a Cardiac Arrhythmia Diagnosis

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Abstract

Inherited arrhythmia syndromes include the risk of sudden cardiac death. This is a serious diagnosis with many implications for life-long management and monitoring. Genetic counselors work with families to understand the diagnosis, risks and management recommendations. While adult patients exhibit a variety of coping styles and resiliency, pediatric patients may be influenced in their resiliency by differing parenting styles they experience. Parenting style can be used as a predictor of many behavioral outcomes for children through development and into adulthood. The goal of this study is to assess if there is a change in parenting style after receiving an inherited arrhythmia diagnosis in a child and how the family dynamic is affected by a new diagnosis.

A. Specific Aims

The purpose of this study is to identify the impact of a family history of sudden arrhythmia death and/or a cardiac arrhythmia diagnosis and treatment decisions on parenting style. Specifically this study aims to:

1. Identify the perceived parenting style change after a diagnosis from the child's perspective compared to before
2. Identify the perceived parenting style change after a diagnosis from the parent/caregiver's perspective compared to before
3. Determine how a family history of sudden arrhythmia death, sudden unexplained death or sudden infant death syndrome (SIDS) impacts the perceived parenting style
4. Identify how treatment decisions impact parenting style

B. Background and Significance

Parenting style has been long described in literature and the influence on outcomes, achievement and mental health of children are well studied. Baumrind along with Maccoby and Martin describe parenting style as measured by demandingness and responsiveness (1983; 1991). Based on this, Baumrind classified four types of styles: authoritative, authoritarian, indulgent and neglectful. Authoritative style consists of high responsiveness and high demandingness with support and warmth, defined rules and consistent discipline. Authoritarian style comprises low responsiveness and high demandingness with hostile control and punishment that is not consistent. Indulgent parenting exhibits high responsiveness to the child but low demandingness with no