Parent's and Children's Perceptions of Type 1 Diabetes: Health-Related Quality of Life and Impact on Family  
Co-Principal Investigators: Hope Cooper-Oliver and Sandra Sinclair

ABSTRACT

**Purpose Statement:** The primary goal of this research is to measure and describe perceptions of health-related quality of life for children with type 1 diabetes and the impact that the disease has on the family.

**Background:** Type 1 diabetes is the most common metabolic disorder affecting children with an incidence of approximately 1 in 400 individuals under the age of 20 (ADA, 2003). The disease occurs when the body’s immune system destroys pancreatic beta cells resulting in the inability to produce insulin to regulate blood glucose (CDC, 2011). Type 1 diabetes is a chronic illness that requires complex management including glucose monitoring, insulin administration, meal planning, and being able to respond to medical emergencies as they occur. Type 1 diabetes affects a child’s physical and psychosocial functioning which impacts their health-related quality of life. In addition, the disease impacts the family unit as a whole. The research that has focused on physical and psychosocial variables related to type 1 diabetes has been conducted primarily with Caucasian children which would be expected since the incidence is highest among the Caucasian population; however, cultural variations exist with regard to perception and attitudes toward chronic illness. The impact that the disease has on family structure related to nontraditional families such as single and military families has not been reported in the literature. Scant literature could be found related to qualitative designs that focused on health-related quality of life and impact on families related to type 1 diabetes.

**Theoretical Framework:** The conceptual framework for this study is Barnard’s Child Health Assessment Model (Barnard & Eyres, 1979). The model is depicted as three overlapping circles to include the caregiver, the child, and the environment. It is proposed that the characteristics and the interactions of the child, caregiver, and environment influence the child’s health-related quality of life and the impact that type 1 diabetes has on the child and family.

**Research aims:** The aims for this research are: 1) to measure and enhance an understanding of health-related quality of life for children with type 1 diabetes and how the disease impacts the family, and 2) to describe the parent and child’s perceptions of how type 1 diabetes affects the child’s physical and psychosocial functioning as well as the impact that the disease has on the family.

**Methods:** **Design:** A mixed-methods research design will be used for this study. **Sample:** A convenience sample of children from 2 to 18 years of age who have been diagnosed with type 1 diabetes and their parents will be recruited. **Selection criteria:** 1) children with type 1 diabetes and their parents who attend the annual family conference or who receive/have received care at TMC and 2) participants who can speak and write in English (when applicable for developmental level). **Measurement:** 1) generic health-related quality of life will be measured using the PedsQL instrument 2) condition-specific health-related quality of life will be measured with the PedsQL Diabetes Module Version 3.2, 3) impact that the disease has on the family will be measured with the PedsQL Family Impact Module Version 2.0, 4) demographics will be obtained from the demographic form, and 5) qualitative data related to health-related quality of life and impact that the disease has on the family will be obtained from focus groups. **Data collection:** Most of the questionnaires will be administered by the nurse researchers during the annual type 1 diabetes family conference in Honolulu. Focus groups will be conducted on dates following the conference. **Data analysis:** Data will be analyzed utilizing SPSS 19.0 and will
include frequency distributions, univariate descriptive statistics, Pearson’s correlations, ANOVA, and regression.

**Protection of Human Subjects:** An institutional review board (IRB) application will be submitted to TAMC IRB and UH IRB. All data will remain confidential. Study numbers will be used for each subject.

**Significance to Nursing:** The results of this study will lay the groundwork for appropriate interventions to improve health outcomes of children with type 1 diabetes and their families. It will also generate new knowledge related to various physical and psychosocial variables with families in the state of Hawaii to further the goal of reducing health disparities and shed light on how type 1 diabetes affects military families.