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## YOUTH AND PATERNAL INVOLVEMENT PATTERNS IN INFLAMMATORY BOWEL DISEASE CARE: A LONGITUDINAL INVESTIGATION

Authors: Samina Ahmed, BA; Rachel Neff Greenley, PhD; Jennifer Hauser Kunz PhD; and Michael Stephens MD

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**B. Purpose:** To examine changes in patterns of youth and father involvement in Inflammatory Bowel Disease (IBD) care over a 6 month time period.

**C. Background and Significance:** High youth and parent involvement is thought to be important in promoting adaptive disease management, especially during adolescence; however, little is known about how involvement patterns change over time. Moreover, most research has focused on maternal involvement rather than paternal involvement. Since low paternal involvement is associated with poorer treatment adherence, psychosocial adjustment, and health status, it is important to understand the role of paternal involvement and how it may change over time. Understanding changes in youth and father involvement patterns may assist in addressing illness management problems.

**D. Method/Design:** This is a prospective longitudinal design.

**E. Sample:** Fifty four youth, ages 11-18 ( $M = 14.56$ ,  $SD = 1.90$ ) participated. 59% were male, 93% were Caucasian, and 86% had Crohn's disease.

**F. Setting and Procedure:** Youth completed the IBD Family Responsibility Questionnaire (IBD-FRQ) at baseline (T1) and 6-month follow up (T2). Youths rated each family member's involvement in the medical regimen from 0 (not involved at all) to 3 (involved almost all of the time). A total score and four subscale scores (general health maintenance, condition management, social aspects, and nutrition) were generated. On the basis of these scores, families were placed into one of the following categories: low father/low youth; high father/low youth; low father/ high youth; high father/high youth for total and subscale domains. Low involvement groups consisted of scores  $\leq 2.5$  and high involvement groups had scores  $> 2.5$ . Changes in involvement groups were assessed from T1 to T2.

**G. Results:** Level of involvement changed over time in 19 of 53 cases (36%), of which 12 of 19 (63%) families changed in optimal ways (i.e., either increased involvement of both father and child or increased involvement of child only with father involvement unchanged). No differences in age or gender were documented between the optimal change group and the no change group. Additional analyses will assess for predictors of optimal change, including time since diagnosis.

**H. Conclusion:** Although stability of involvement patterns was present in the majority of the sample, some changes do occur. Suboptimal changes may be risk factors for poorer adherence and disease outcomes; however, more research is needed in this area.

**I. Description of Team:** Clinical counseling psychology graduate student, psychologists, and a pediatric gastroenterologist.

## THE ASSOCIATION BETWEEN PAIN AND SCHOOL FUNCTIONING AMONG ADOLESCENTS WITH INFLAMMATORY BOWEL DISEASE

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Poster Submission, Relevant Topic: Pain

B. Purpose: To evaluate the association between abdominal pain and school functioning of youth with IBD.

C. Framework: A biopsychosocial framework was used.

D. Background and Significance: Among youth with Inflammatory Bowel Disease (IBD), lower school functioning is found when compared to healthy youth. Pain, a primary effect of many chronic illnesses, has been specifically linked to poorer school functioning in other chronic illness groups; however, these relationships have not been examined in pediatric IBD. IBD is characterized by chronic inflammation of the GI tract, and abdominal pain is a primary and recurrent aspect of IBD. Thus, it is necessary to examine how pain contributes to impaired school functioning and the aspects of school functioning that are most impacted.

E. Method: Frequency of abdominal pain, usual pain, and worst pain were measured via youth report of the Abdominal Pain Index during baseline assessment. School functioning data was obtained via youth and maternal report of the school functioning subscale of the PedsQL 4.0 during the baseline assessment

F. Sample: 33 youth participated (ages 12 -17 years; M = 14.75 years). The sample was 58% female and 91% Caucasian.

G. Setting/procedure: Recruitment occurred in the GI Clinic at Children's Hospital of Wisconsin. After providing consent/assent, youth completed the Abdominal Pain Index and youths and mothers completed the PedsQL 4.0 Generic Core Scales. This data is part of a larger clinical trial evaluating an adherence intervention.

H. Results: Correlations suggest that greater abdominal pain is associated with poorer school functioning. Participant's rating of "worst pain" is most detrimental to total school functioning for both youth and female caregiver report, compared to "frequency of pain in the last 2 weeks" and "usual pain in the last 2 weeks." Additionally, "worst pain" impacts the school functioning domains of forgetfulness and missing school because of not feeling well according to youth report and trouble keeping up with school, missing school because of not feeling well, and missing school for medical appointments according to the female caregiver report.

I. Conclusions: Effective abdominal pain management in youth with IBD may be important in optimizing school functioning.

J. Description of Team: Undergraduate psychology student, psychologists, and pediatric gastroenterologist.

**Title:** IMPACT OF PSYCHIATRIC DISORDERS ON INPATIENT HEALTHCARE UTILIZATION IN SICKLE CELL DISEASE

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**Purpose/Background:** Patients with sickle cell disease (SCD) experience a broad range of psychiatric disorders placing them at risk for poor coping with vaso-occlusive pain episodes. Previous research has found a significant relationship between psychiatric disorders (i.e., mood and anxiety disorders) and increased length of stay for hospitalizations among children with SCD experiencing vaso-occlusive pain (Myrvik, Campbell, Davis, & Butcher, 2011). The current study expanded upon these findings by examining the impact of psychiatric disorders on the frequency of hospital admissions for vaso-occlusive pain in a representative sample of patients (ages birth to 18) with SCD.

**Methods:** Patients with a primary diagnosis of SCD with crisis identified through the national representative Pediatric Health Information System (PHIS) from June 2006 to June 2011 were included for analysis. Patients with psychiatric disorders listed as secondary diagnoses were categorized under specific psychiatric disorders (mood disorder, anxiety disorder, disruptive behavior disorder, substance use disorder). Non-parametric and regression analyses were used to determine the effect of psychiatric disorders on hospital length of stay and frequency of hospitalizations for vaso-occlusive pain in SCD while controlling for significant covariates. **Results:** Preliminary analysis reveals that 7,295 patients resulted in 27,275 hospital admissions for vaso-occlusive pain. The average hospital length of stay was 3.83 days. Secondary diagnoses of psychiatric disorders were found in approximately 4% of the patients (n=306 patients). Analyses examined the impact of psychiatric disorders on hospital length of stay and frequency of hospitalizations for vaso-occlusive pain in SCD.

**Conclusion:** This study aims to assess the impact of psychiatric disorders on hospital length of stay and the frequency of inpatient utilization. It is hypothesized that patients with SCD and psychiatric diagnoses will demonstrate longer hospital admissions and more frequent hospital admissions for vaso-occlusive pain than patients without a comorbid psychiatric disorder. The length of hospital stays can affect a child's overall daily functioning. Given that, further support and knowledge of the impact of psychiatric diagnoses in SCD can contribute to the effective interventions related to pain management during VOC hospitalizations, which can potentially reduce future length and frequency of VOC hospitalizations among children with SCD.

## **IMPULSIVITY IN CHILDREN WITH NF-1: COMPARISON TO TYPICALLY DEVELOPING CHILDREN**

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Poster submission, Intersection of Mental & Physical Health or Other Pediatric Behavioral Research

**Purpose:** The purpose of this study was to find out if children with Neurofibromatosis-1 (NF1) have more difficulty with tasks involving impulsivity and patience more so than typically developing (TD) children.

**Background and significance:** Neurofibromatosis-1 (NF1) is a genetic disorder that affects 1 in 3,000 people. Those who have been diagnosed with NF1 usually display café-au-lait spots (spots of darker skin) at an early age and typically develop noncancerous tumors on or under the skin later in life.

**Method & Design:** Snack Delay and Tower of Patience are lab-based play-like tasks designed to show patience and impulsivity in the participant. These tasks were recorded and later coded for specific behaviors (i.e. ringing the bell, eating the m&m, adding a block, saying "its your turn" or "ring the bell" etc) using Noldus Observer.

**Sample Description:** Snack Delay and Tower of Patience was administered to 39 children with NF1. The comparison group consisted of 16 children with siblings that have NF1 and 19 typically developing children. All of the participants were between the ages 3 to 6 years old.

**Results:** In Tower of Patience, children with NF1 verbally prompted more significantly than Typically developing children (NF-1: mean = 4.41, sd = 4.41; TD: mean = 2.45, sd = 2.785;  $t = 2.095$ , Sig = 0.040). Typically developing children also did not prompt significantly more than NF-1 kids (TD: mean = 5.18, sd = 1.380; NF1: mean = 4.28, sd = 1.776;  $t = -2.367$ , Sig = 0.021).

In Snack Delay, children typically developing children waited significantly more than children with NF1 (TD: mean = 5.64, sd = 0.699; NF1: mean = 5.14, sd = 1.182;  $t = -2.186$ , Sig = 0.033). Children with NF1 also physically prompted significantly more than typically developing children (NF1: mean = 2.79, sd = 3.988; TD: mean = 0.46, sd = 1.291;  $t = 3.464$ , Sig = 0.001).

**Conclusion & Implications:** Children with NF1 experience more difficulty on the Tower of Patience, verbal prompting and on Snack Delay, physical prompting. Typically developing children had an easier time waiting for the bell to ring during Snack Delay and also not prompt on the Tower of Patience.

**Setting & Description of Team:** The study was conducted through the Child Neurodevelopment Research Laboratory (CNRL) at UW-Milwaukee in collaboration with the University of Chicago. Graduate and undergraduate students work in the CNRL under the direction of Dr. Klein-Tasman.

## DEMOGRAPHIC PREDICTORS OF READINESS TO ADOPT SELF MANAGEMENT APPROACHES IN CHILDREN WITH CHRONIC PAIN

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**Background:** It is estimated that 25% of children experience chronic pain (Kashikar-Zuck, et al., 2001). Due to this high prevalence it is important to understand what characteristics adolescents may have that translate to their readiness for treatment to begin and how ready they are to implement self management techniques into their normal routine (Guite, et al., 2011). The purpose of this study was to examine if readiness to adopt a self management approach (i.e., readiness to change) was related to the child's age or gender.

**Methods:** Participants included 174 youth who attended a multidisciplinary pain clinic at a large Midwestern hospital for treatment of complex chronic pain (66% female; 78% Caucasian, age = 12-18 years,  $M = 15.22$ ,  $SD = 1.52$ ). Patients and their parents were asked to complete the Pain Stages of Change Questionnaire-Adolescent Form (PSOCQ-A) independently prior to their intake appointment.

This measure examines whether participants depend on their physician for the management of their pain or if they use self management approaches (Guite, et al., 2011). On the questionnaire, participants are asked to rate statements one through five (one being strongly disagree and five being strongly agree) to understand how likely they are to use self management approaches to pain.

**Results:** The sample's average scores on the scales of the PSOCQ-A were: Precontemplation ( $M = 3.59$ ,  $SD = 0.88$ ), Contemplation ( $M = 3.26$ ,  $SD = 0.68$ ), and Action/Maintenance ( $M = 2.82$ ,  $SD = 0.77$ ). Differences in scores between males and females were not significant for Precontemplation  $t(166) = -.71$ ,  $p = .48$  or Action and Maintenance  $t(158) = .01$ ,  $p = .99$ . There was a significant difference between males and females' scores on Contemplation  $t(156) = -2.18$ ,  $p = .03$ ; with females scoring higher than males ( $M = 3.10$ ,  $SD = .67$  and  $M = 3.34$  and  $SD = .68$  respectively). There was no significant correlation between age and the Precontemplation scale  $r = -.01$ ,  $p = .92$ , or the Action and Maintenance scale  $r = .04$ ,  $p = .65$ . There was a significant correlation between age and the Contemplation scale  $r = .18$ ,  $p = .02$ .

**Discussion:** Adolescents in this sample rated items on the Precontemplation scale slightly higher than items on the Contemplation scale, while items on the Action/Maintenance scale were rated lowest. There is a positive correlation between scores on the contemplation stage and the age of the adolescent. Although many adolescents still endorse higher scores on the Precontemplation scale, the results from this study may indicate that as children get older they become more aware that they have some ability to control their pain and are considering change in their behavior. Furthermore, it appears that female adolescents score higher on Contemplation than males.

**Title:** NURSES' METHOD OF LEARNING AND DECISION MAKING PRACTICES: ARE THEY RELATED TO PERCEIVED BARRIERS TO PEDIATRIC PAIN MANAGEMENT?

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**Presentation Preference:** Please consider for paper *or* poster; **Pain Topic area**

**Objective:** To determine whether nurses' perceptions of barriers to their ability to provide optimal pain management are related to the *ways in which* nurses learned about pain management and the *sources they use for decision making*. A secondary aim was to determine whether the findings changed over time.

**Significance:** Barriers to optimal pain management may potentially influence how well nurses manage pain; however, little has been documented on where nurses learned about pain management and what resources they use to make pain related decisions. **Method:** At 2 time points (Time 1 (T1) and 3 years later = Time 2 (T2)), Children's Hospital of Wisconsin nurses in all patient care settings were asked to complete a survey: "Barriers to Optimal Pain Management." Data reflects 2 of the questions that have not been previously reported. Descriptive statistics were used to summarize responses across time. T-tests were used to determine differences in perceptions of barriers between groups (as determined by response to the focus questions). **Procedure:** At T1, 272 paper and pencil surveys were completed; at T2, 442 surveys were completed electronically,

**Results:** Excepting inclusion of more departments at T2, no demographic differences were found between respondents at either timepoint. At T1, when asked to pick three ways they "*personally learned about pain management*," 81% of nurses reported learning by personal experience (not an option at T2). In contrast, the top choice at T2 was "nurses on the unit" (68% compared to 36% at T1). "Nursing school" was the second most frequent choice at both timepoints. Little change was observed from T1 to T2 regarding nurses' sources for making pain related decisions. In both waves, "assessment of infant or child" was the most frequent choice (96% T1 and T2), followed by "parents' or child's request" (66% T1 and 78% T2). The third most frequent choice was "nurses' report from previous shift" at T1 (30%) vs "physician order" at T2 (43%). The perception of several barriers differed as a function of how nurses learned about pain management: Nurses who learned primarily in nursing school viewed "patient's reluctance to report pain" and "patient's reluctance to take meds" as significantly greater barriers ( $p < .05$ ) than nurses who learned primarily from other nurses on the unit. Those who learned primarily in nursing school also saw the APS involvement as significantly more positive ( $p < .05$ ). **Conclusions:** These data suggest that some perceived barriers may be affected by how nurses learned about pain management, but not by decision making practices. Future studies are needed to determine how education plays into perceived barriers, and ultimately, clinical care. **Description of Team:** This interdisciplinary team brings nursing expertise in acute pain management, medical and psychosocial approaches, and research design and analysis.

## **AN EXAMINATION OF PARENTING STRESS IN TWO PEDIATRIC POPULATIONS**

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Amy V. Van Hecke, Ph.D. & Jessica C. Kichler, Ph.D.*

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### **Poster – Intersection of Mental & Physical Health**

#### **Introduction**

This investigation sought to better understand similarities and differences in parenting stress and correlates of parenting stress among caregivers of children with pervasive developmental difficulties, such as autism spectrum disorders (ASD), and caregivers of children with chronic illness, such as type 1 diabetes mellitus (T1DM). It is important to understand group differences as well as how parenting may be related to other aspects of adolescent and family functioning.

#### **Methods**

Following IRB approval, data from two studies was aggregated for analyses. In both studies, parents completed the Stress Index for Parents of Adolescents (SIPA; Sheras & Abidin, 1998), which identifies areas of stress in parent-adolescent interactions. Parents of youth with ASD completed the Confusion, Hubbub, and Order Scale (CHAOS) assessing family functioning, while parents of youth with T1DM completed the Behavior Rating Inventory of Executive Functions (BRIEF). Both groups (ASD and T1DM) consisted of mothers of adolescents between the ages of 11 and 16. To compare groups, independent samples t-tests were conducted. In addition, associations between scores from the CHAOS (ASD) and BRIEF (T1DM) and SIPA Total Stress scores were evaluated to assess construct validity of these measures.

#### **Results**

Both samples consisted of 21 mothers each. Families were predominantly Caucasian (93%) and most adolescents were male (82%). Independent samples *t*-test indicated that parents of children with ASD reported significantly higher levels of total parenting stress ( $M = 234, SD = 41.2$ ) than parents of children with T1DM ( $M = 177, SD = 36.4$ ),  $t(41) = 4.78, p < .001$ . Bivariate correlation analyses suggested moderate, positive associations between the CHAOS total score and the Total Stress score on the SIPA for the ASD group ( $r = 0.48, p = 0.024$ ). Very strong associations were found between the BRIEF General Executive composite score and SIPA Total Stress score ( $r = 0.71, p < 0.01$ ).

#### **Conclusions**

These findings help in understanding the types of stress experienced by parents of children with developmental disabilities and chronic illness diagnoses. The SIPA appears to be related to a measure that broadly assesses family organization. Associations between the SIPA and BRIEF underscore the need to further examine whether the BRIEF assesses executive function or parent distress. Future research should explore the functional outcomes of parenting stress and its roles in the management/treatment of these disorders.

**Description of Team:** The team consists of graduate researchers and faculty at Marquette University in collaboration with Dr. Kichler, a pediatric psychologist.

POSTER: PAIN

AUTONOMY WHEN ADMINISTERING PAIN ALLEVIATION TECHNIQUES INCREASES AS AGE INCREASES

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**Objective, background and significance:** Children often experience some sort of pain on a daily basis (Craig, Lilley & Gilbert, 1996). The current study assesses if children's age affects their self-administration of pharmacological and non-pharmacological techniques to alleviate their pain at home. Pharmacological treatment techniques refer to those that involve pharmaceutical medications. Non-pharmacological pain treatment techniques do not involve either topical or ingested pharmaceutical medication. **Purpose:** This study will focus on the influence of children's age on their self-administration of pharmacological and non-pharmacological techniques to treat their pain experiences at home.

**Method, Sample/Population Description:** A community sample of parents, with children between 6 to 17 years of age, completed a survey including questions regarding use of pharmacological and non-pharmacological techniques to alleviate pain at home. The survey included parent-report on questions regarding the children's pain, and patterns of use of pharmacological and non-pharmacological techniques. The participants in the study were mostly women (65.2%), married (69.2%), self-identified as Caucasian (77.9%), and were highly educated with the majority having at least an associate's or bachelor degree (69.7%). The mean age of the children was 11.55 ( $SD = 3.5$ ). The sample of children was almost evenly divided on gender (45.5% male). **Setting and procedure:** Undergraduate students at the participating university recruited parents to participate in an online survey about their children's health. The survey was anonymous and informed consent was obtained prior to participation.

**Results and Conclusion:** Children's self-administration of both medications and non-pharmacological techniques increased with children's age ( $\chi^2(22, N = 488) = 293.80, p = 0.000$  and  $(\chi^2(22, N = 471) = 64.03, p = 0.000)$ , respectively). By 12 years of age, 50% of children were self-administering non-pharmacological techniques, and at 14 years of age 50% of children were self-administering medications after checking with their parents and at 16 years of age without checking with their parents. As hypothesized, as children get older they are more likely to self-administer both pharmacological and non-pharmacological techniques on their own with or without their parents' permission and knowledge. It is important to note that as children get older, their autonomy in treatment increases. This increase in autonomy should be taken into consideration by providers discussing treatment options with parents and children.

**Description of team:** The team consists of undergraduates, graduates, and faculty of the University of Wisconsin-Milwaukee, as well as faculty at Children's Hospital of Wisconsin and Medical College of Wisconsin.

## ETHICAL DILEMMAS IN PEDIATRIC END OF LIFE CARE

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**Objective:** improve interdisciplinary team members' self-efficacy regarding care of pediatric patients and their families at the end of life. Relevant ethical dilemmas at end of life include management of refractory pain, withdrawal or withholding of treatment, phase I trials, and do-not-resuscitate orders.

**Purpose of the study:** evaluate the effects of an educational intervention that discusses ethical dilemmas faced in the care of pediatric patients at the end of life. Content from the End of Life Nursing Education Consortium's Pediatric Course will be included.

**Framework:** Deontological Ethics as a Decision-making Framework

**Background and significance:** decision-making at the end of life is understandably difficult, especially when the patient is a child. It is imperative that decisions are based on the ethical principles of justice, beneficence, and respect for persons. Health care professionals must ensure that parents and pediatric patients are informed and their autonomy is respected. By improving self-efficacy in dealing with ethical dilemmas, the quality of discussions with patients and their families at the end of life may be improved.

**Method/design:** develop content and case studies that address key ethical issues identified in the literature regarding care of children at the end of life. Pre-test/post-test evaluations of self-efficacy will be completed.

**Sample description/population:** nurses, physicians including attendings, interns, and medical students, discharge planners, social workers, and pastoral care staff at a pediatric hospital.

**Setting and procedure:** the educational intervention, incorporating a case-based approach, will occur at a pediatric, acute care hospital.

**Results/outcomes:** we anticipate improved self-efficacy in health care professionals after the educational intervention.

**Conclusions/implications:** the interdisciplinary team members' self-efficacy for working through ethical dilemmas in the care of pediatric patients at the end of life will be increased.

**Description of team:** academic nursing faculty, pediatric oncologist, pediatric oncology research nurse/doctoral student, discharge planner, social worker, pastoral care staff, and advanced practice nurse.

## A. MEASURING BODY COMPOSITION IN CHILDREN WITH SPINA BIFIDA: A PILOT STUDY

**Objective:** Discuss the effectiveness of the behavioral health intervention to facilitate coping during the BOD Pod Measurement

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**B. Purpose:** The purpose of this study is to examine the feasibility of obtaining and comparing various methods of height and body composition measurements in children with SB, delineate the cost and effort of each measure, and determine effectiveness of a behavioral intervention to enhance coping with BOD Pod measurement.

**C. Framework:** Individual stress and coping theory. **Background:** Individuals with Spina Bifida (SB) are at a higher risk of overweight or obesity due to: a) decreased height velocity, lean body mass, and lower metabolic rate, b) decreased physical activity or energy expenditure due to altered mobility, and c) overall decreased energy needs when compared to their same age and gender counterparts. Currently a Body Mass Index (BMI) calculation is the recommended tool to categorizing body fat. Obtaining an accurate estimate of body fat in a child with SB has proven difficult due to the complexity associated with obtaining an accurate height and estimate of lean body mass.

**D. Method/Design:** Prospective descriptive correlational pilot study. The purpose of this study is to examine the feasibility of obtaining and comparing various methods of height and body composition measurements in children with SB and to delineate the cost and effort of each measure.

**E. Sample:** 26 children with SB who receive care at CHW and who are between the ages of 4-18 years of age with a minimum of eight children and at least one of each gender in each of the following age categories: 4-8, 9-13 and 14-18 years of age. Recruitment will ensure that 50% the sample will use a wheelchair as their primary means of mobility in the household or community.

**F. Procedure:** Weight, four methods of obtaining height (arm span, wall mounted stadiometer, segmental length and recumbent length, and five methods of measuring body composition BMI, BOD Pod, DEXA, BIA and skin fold measurements will be obtained and compared. Evaluation of procedures will be obtained by data collectors, parents and children > eight years of age. A behavioral intervention will be used to prepare the child and assist them with coping in the BOD Pod.

**G. Data Analysis/Results:** Means, percentages (95% CI), Bland Altman plots and concordance correlations (CC) (95% CI) will be used for analysis. We will compare the four heights as pairs and compare fat mass estimates to the gold standard DEXA measurement using the CC. In addition, we will use nurse, parent and child data to evaluate the ability of the behavioural intervention to facilitate child coping with the procedures and the ability to obtain BOD Pod measures.

**H. Results:** Data collection and analysis are in process. **I. Conclusion:** We anticipate this preliminary data will determine if the BOD Pod can be used in place of the DEXA and provide preliminary data for larger multi-site study. In addition, we will have data to evaluate the manualized behavioral intervention and revise it if indicated.

**J. Team:** This interdisciplinary team consists of nurses, child life specialists, physical therapists, and a statistician. The consultant on the project is a physician.

**A. Title:** THE RELATIONSHIP OF FAMILY VARIABLES TO DEVELOPMENTAL COMPETENCES IN ADOLESCENTS AND YOUNG ADULTS (AYA) WITH SPINA BIFIDA

**Objective:** Discuss the relationship of family variables to overall self-esteem and domain specific developmental competencies in adolescents and young adult (AYA) with Spina Bifida.

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**B. Purpose:** The purpose of this study using the Ecological Model of Secondary Conditions and Adaptation in Spina Bifida was to: (a) identify the relationship of family variables to overall self-esteem in adolescents and young adult (AYA) with Spina Bifida; and (b) explore the relationship of family variables to domain specific developmental competencies (Scholastic competence, Social acceptance, Athletic competence, Physical appearance, Job competence, Romantic appeal, Behavioral conduct, and Close friendship

**C. Framework:** The Ecological Model of Secondary Conditions and Adaptation in Spina Bifida.

**D. Background:** Every year, about 1,500 infants are born with Spina Bifida. It is a common birth defect often leading to major disabilities for children and adults.

**E. Methods and Sample:** In this multi-site descriptive study, data was collected from 126 AYA with SB and their parents through telephone interview. Data analysis included frequencies, correlations, and multiple regression.

**F. Procedure:** Family variables included: 1) Cohesion (FACES II); 2) Satisfaction (Family APGAR); 3) Mastery/family resources (FIRM); and 4) Family activities (AAI-Family Scale). Developmental competencies were measured using the Harter's Self-Perception Profile.

**G. Results:** AYA and their parents reported high levels of family factors, high overall self-esteem and variable domain specific developmental competence scores. Even though mastery/family resources and family activities had significant bivariate correlation with overall self-esteem, only mastery/family resources remained significant when both were used in a multiple regression. Family variables were correlated with scholastic competence, athletic competence, physical appearance, and behavioral competence ( $r = 0.18$  to  $0.23$ ). Adolescent report of family variables also had small relationships to developmental competencies.

**I. Conclusions:** While family variables explained a small percentage of developmental competencies, other unknown variables also contributed. The family variables may contribute indirectly to developmental competencies. Further research needs to investigate other possible contributing variables such as severity of AYA chronic condition, adolescent resilience, peer relationships, social support, and indirect relationship of family variables.

**J. Team:** This interdisciplinary team consists of a physician and nurses.

## **Parent- and Teacher-Reported Executive Functioning in Young Children with NF1**

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Poster submission, Intersection of Mental & Physical Health or Other Pediatric Behavioral Research

**Purpose:** The purpose of this study was to examine the correspondence between parent and teacher reported levels of executive functioning in young children with NF1.

**Background and significance:** Neurofibromatosis-1 (NF1) is a genetic disorder that affects approximately 1 in 3,000 people. Physical manifestations of NF1 include benign tumors called neurofibromas and pigmentation patches of the skin referred to as café-au-lait spots. Difficulties with executive functioning have been found in individuals with NF1.

**Method & Design:** The Behavior Rating Inventory of Executive Function (BRIEF) was completed by parents and teachers of children with NF1. For children younger than 6 years old, parents and teachers completed the preschool version of the BRIEF (BRIEF-P). Responses were then analyzed for correspondence.

**Sample Description:** The parents and teachers of 26 (13 males, 13 females) children with NF1 completed the BRIEF or BRIEF-P. Children were between 3 and 8 years old ( $M = 5.32$  years).

**Results:** Reports of EF by parents and teachers showed significant convergence for Working Memory ( $r = .48, p < .05$ ), Inhibition ( $r = .46, p < .05$ ), and General Executive Composite ( $r = .44, p < .05$ ). No significant differences in parent and teacher ratings were seen for any scales or indices.

**Conclusion & Implications:** The results indicate that there is consistency in the everyday executive functioning behavior of children with NF1 in the home and school settings, with some variability. Implications will be discussed.

**Setting & Description of Team:** The study was conducted through the Child Neurodevelopment Research Laboratory (CNRL) at UW-Milwaukee in collaboration with the Genetics Center at Children's Hospital of Wisconsin and the University of Chicago Neurofibromatosis Program. Graduate and undergraduate students work in the CNRL under the direction of Dr. Klein-Tasman.

## KNOWLEDGE, A KEY TO SUPPLEMENT ADHERENCE IN PEDIATRIC INFLAMMATORY BOWEL DISEASE

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- A. **Title:** KNOWLEDGE, A KEY TO SUPPLEMENT ADHERENCE IN PEDIATRIC INFLAMMATORY BOWEL DISEASE
- B. **Purpose:** To summarize rates of supplement adherence in youth with inflammatory bowel disease (IBD); to examine youth knowledge about supplements; to determine if greater knowledge predicted adherence.
- C. **Framework:** A biopsychosocial framework guided this investigation.
- D. **Background and Significance:** Adherence to prescription oral medications for children and adolescents with chronic conditions is generally below 50%. Yet, no research has examined rates of supplement adherence in youth with IBD. It is important to look at supplement adherence in youth because disease and medication side effects can cause nutritional deficiencies, which may have implications for long term growth and health in pediatric IBD.
- E. **Method/Design:** A prospective longitudinal design was used.
- F. **Sample:** 53 adolescents ages 11 to 18 years participated. 62% were male and 93% were Caucasian, 85% were diagnosed with Crohn's disease.
- G. **Setting/procedure:** Supplement adherence and supplement knowledge was measured using the Medical Adherence Measure (a validated semi-structured interview) via phone at seven monthly follow-ups. We examined adherence to the following supplements: Calcium, Iron, Multivitamin, and Vitamin D. Patients' knowledge responses were placed into one of seven categories, and their most sophisticated response over the 7-month interval was used for analyses.
- H. **Results:** Adherence rates were variable, with an average rate of 46% adherence (Range = XX% to XX%). Supplement knowledge was also variable. Many youth provided just the label (i.e., "it's a vitamin), or gave a description of how the supplement was good for them without mention of its specific role in IBD. For all four supplements, increased knowledge was related to higher adherence. Most effect sizes were of medium to large magnitude (Cohen's d range = .XX to .XX).
- I. **Conclusions:** Supplement adherence was poor, as was supplement knowledge. Higher knowledge of supplements correlated with higher adherence rates.

## PARENT INTENDED PARTICIPATION AND ATTITUDES TOWARD OPT-IN AND OPT-OUT RECRUITMENT METHODS

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**Purpose/Background:** An increasing number of institutional review boards require opt-in recruitment methods, believing that this provides protection from intrusive or coercive recruitment. Opt-in methods may result in a smaller and more biased sample than opt-out strategies (Junghans et al., 2005; Trevena et al., 2006). This investigation will examine parents' intended participation and attitudes towards opt-in and opt-out methods of recruitment for pediatric research.

**Methods/Sample:** Parents ( $n = 408$ , 63% female, 80% Caucasian) ranging in age from 20 to 62 years ( $M = 37.21$ ,  $SD = 9.55$ ) were asked to complete an online survey keeping in mind their oldest child within an age range of 2 to 18 years. Children (50% male) ranged in age from 2 to 17 years ( $M = 8.10$ ,  $SD = 5.40$ ). Parents were asked to imagine that they were recruited to participate in a research study of psychosocial aspects of their child's chronic medical condition by receiving a letter that either required them to opt-in to the study or opt-out of being contacted. They reported their likely response to each method of recruitment and attitudes towards each recruitment method.

**Results:** Forty-nine parents (13%) reported that they would opt-in to the study, and 59% ( $n = 216$ ) were unsure of their response to the opt-in letter. Similarly, 22% ( $n = 81$ ) of parents reported that they would opt-out of participating in the study, and 54% (198) were unsure of their response. Assuming that those who were unsure would withhold a response, a conservative estimate yields 13% of participants eligible for recruitment by using an opt-in letter, and 78% by using an opt-out letter.

Compared to the opt-out letter, parents rated the opt-in letter significantly higher in acceptability ( $M = 7.18$ ,  $M = 7.63$ ,  $t(374) = -2.830$ ,  $p < .01$ ), and lower in coerciveness ( $M = 2.93$ ,  $M = 2.46$ ,  $t(370) = 4.17$ ,  $p < .001$ ) and intrusiveness ( $M = 3.39$ ,  $M = 2.71$ ,  $t(375) = 4.67$ ,  $p < .001$ ). The opt-out and opt-in letters did not differ in their ratings of worry about their child's care being affected by nonparticipation in research. Parents rated their likelihood of participating significantly higher for the opt-out letter than the opt-in letter ( $M = 4.94$ ,  $M = 4.44$ ,  $t(370) = 3.90$ ,  $p < .001$ ).

**Conclusions/Implications:** Opt-out letters were related to higher levels of participation, both by rating and report of the parents' likely response to receiving a letter in the mail. However, parents frequently reported that they were unsure of their responses to recruitment efforts. An opt-in approach requires higher motivation on the part of the family to participate. Therefore, opt-in strategies lead to smaller sample sizes and potentially a significant decrease in external validity. Although statistically different both strategies were rated as having relatively high acceptability, and low levels of worry about their child's care. While coerciveness and intrusiveness were rated differently, both were relatively small concerns. Furthermore, opt-out approaches provide potential participants two opportunities to refuse participation in research. Decisions about recruiting should continue to be examined and consider parental comfort and obtaining representative samples to increase external validity.

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## THE ROLE OF CHILDHOOD ADHD AND EPILEPSY ON MATERNAL PARENTING STRESS

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**SIGNIFICANCE/PURPOSE:** Childhood epilepsy is the most common pediatric neurological disorder, affecting 0.5-1% of children from birth to 16 years of age (Hocaoglu & Koroglu, 2011; Reilly, 2011). It is a chronic illness impacting both the child and family, as parents of children with epilepsy face a daily struggle due to the uncertainty that characterizes seizure-related disorders. Previous research has found that parenting stress in parents of children with epilepsy is significantly higher than parents of children without a chronic illness (Lv et al., 2009). Lv and colleagues (2009) also found that parents of children with epilepsy not only report lower quality of life, but also increased anxiety and depression in comparison to parents of healthy children. Furthermore, childhood epilepsy is often coupled with both cognitive and behavioral problems that impact the child's academic and social functioning (Dunn & Austin, 1999; Hocaoglu & Koroglu, 2011).

ADHD is one of the most common childhood mental health disorders, affecting 3-7% of school-aged children in the general population (American Psychological Association [APA], 2000). It is characterized by symptoms of inattention, hyperactivity, and impulsivity, which can impact both academic and social functioning of the child. Just as childhood epilepsy impacts parental functioning, parents of children with ADHD also are affected by their child's disorder. Parents of children with ADHD often have increased parenting stress, decreased parental efficacy, and higher rates of depression and substance abuse than parents of healthy children (Anastopoulos, Shelton, DuPaul, & Guevremont, 1993; Chronis et al., 2004; Gerdes, Haack & Schneider, 2010).

As a result of the symptom similarities observed in children with epilepsy and children with ADHD, recent literature has studied the prevalence of ADHD in children with epilepsy and found that rates vary from 26-32% (Hermann et al., 2007; Jones et al., 2007; Thome-Souza et al., 2004). Although this relationship is complex and not entirely understood, it is important to look at the impact these disorders and related symptoms may have on the child, as well as the family. Thus, the goal of the current study was to investigate parenting stress in mothers of children with ADHD versus mothers of children with epilepsy. It was predicted that both groups of mothers would report high levels of parenting stress, but mothers of children with epilepsy would report more than mothers of children with ADHD given the daily unpredictability about their child's health with which these parents live.

**METHOD:** Participants were 60 mothers of children between the ages of 6-12 years diagnosed with ADHD or epilepsy who participated in a larger study conducted at a medical center in Southeastern Wisconsin. Demographic information about the families can be found in Table 1. Mothers were recruited for participation in the study following their arrival at the clinic for their child's

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neuropsychological evaluation. While the child was being evaluated, participating parents filled out a variety of measures looking at parenting stress, efficacy, and behavior, as well as parent-child interactions. The only measure of interest for the current study is the Parenting Stress Index-Short Form (PSI-SF), a measure of parenting stress.

**RESULTS:** A one-way analysis of variance (ANOVA) was conducted to compare parents of children with ADHD to parents of children with epilepsy on parenting stress. Results revealed that there were no significant difference between the means of the two groups ( $F(1, 59) = .779, p < .05$ ). Interestingly, although not statistically significant, visual inspection of the group means actually revealed that parenting stress was greater for mothers of children with ADHD ( $M = 82.11, SD = 20.49$ ) than mothers of children with epilepsy ( $M = 76.63, SD = 16.28$ ).

**CONCLUSIONS:** In closing, support for the current prediction that maternal parenting stress would be greater for mothers of children with epilepsy than mothers of children with ADHD was not found. This could possibly be explained by differing social responses toward a medical disorder versus a behavioral disorder in our society. It is possible that parents of children with ADHD receive less social support in that they are blamed for their child's behavioral problems, whereas parents of children with epilepsy are provided with greater support both from within their social network, as well as the general public. This is an important area of research that needs further examination, as it may lead to improved methods of treating these families and may help alleviate stress that both groups of parents are experiencing.

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Table 1

*Parent and Child Demographics*

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Mother Demographics

Marital Status, <i>n</i> (%)		
Married	44	(73.3)
Divorced	3	(5.0)
Single/Never Married	7	(11.7)
Separated	3	(5.0)
Education, <i>n</i> (%)		
Graduated high school or GED	16	(26.7)
Some college or specialized training	19	(31.7)
College or graduate degree	11	(18.3)
Graduate degree-professional training	11	(18.3)
Income, <i>n</i> (%)		
Less than \$25,000	2	(3.3)
\$25,001 – 50,000	34	(56.7)
\$50,001 – 69,000	18	(30.1)
Race, <i>n</i> (%)		
Caucasian	49	(81.7)
African American	7	(11.7)
Latino	2	(3.3)
Other	1	(1.7)

Child Demographics

Age, <i>M</i> ( <i>SD</i> )	8.38	(1.69)
Gender, <i>n</i> (%)		
Boys	41	(68.3)
Girls	19	(31.7)

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*Percentages do not equate the total sample size as a result of missing data*

*N* = 59