SOCIAL SKILLS AND INTELLIGENCE IN YOUNG CHILDREN WITH NF-1

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**Purpose:** The current study investigates the social and intellectual functioning of young children with NF-1. Previous research has largely focused on older children and adults.

**Background & Significance:** Neurofibromatosis-1 (NF-1) is a genetic autosomal dominant genetic disorder affecting approximately 1 in 3,000 people. Individuals diagnosed with NF-1 may experience physical symptoms such as café-au-lait spots, and benign tumors located on or just under the skin. In addition to these physical symptoms, individuals with NF-1 may also experience cognitive and behavioral difficulties. A study conducted by Barton and North (2004) found that children with NF-1, between the ages 8-16 years old, had significantly poorer social skills than average on the SSRS-Parent form. The study also found that children with comorbid ADHD and NF-1 received the lowest scores from parents and teachers.

**Sample and Design:** Thirty-five children with NF-1, ages 3-8 years old (M= 5.60, SD= 1.87) and their parents participated in this study. Children included twenty-three males (65.7%) and twelve females (34.3%) and represented an ethnically diverse sample consisting of twenty-four Caucasians, 6 African Americans, 4 Latinos/as, and 1 Asian American. Parents of the children completed The Social Skills Rating Scale (SSRS). The Differential Ability Scales (DAS II) was administered to the children to assess intellectual functioning.

**Method:** Intellectual functioning was assessed with the Differential Ability Scales (DAS-II), which yields a General Conceptual Ability (GCA) score similar to an IQ score. Parents completed The Social Skills Rating Scale (SSRS). Performance on the DAS-II and SSRS was compared to standardized norms, and the relations between social skills and intellectual functioning were examined.

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

**Results:** In general, children with NF1 scored significantly lower than average on the GCA [t (34) = -3.60, p = .001], indicating some cognitive difficulties. No significant difference was detected between participant scores on the SSRS and established norms [t (34) = -1.71, p > .05]. A significant correlation was found between GCA scores and SSRS standard scores, (r=.459, p=0.006). While the majority of participants (20 participants, 57.1%) were rated as average or above when compared to normative data on the SSRS, the number of participants falling below average was higher than to be expected. Seven participants (20%) fell within the low average range, 3 participants were borderline (8.6%), and 5 participants scored in the delayed range (14.3%).

**Conclusions & Implications:** This study found that some children with NF-1 experience lower than average cognitive and social functioning. Early identification of these difficulties may aid in the prevention of future deficits in functioning. Future research could investigate the relationship between comorbid ADHD and NF-1 and social functioning skills in young children.
Purpose of the Study: This study is designed to identify the decision-making processes regarding adoption of insulin pump therapy in adolescents and their parents.

Background and Significance: Usage of insulin pump (continuous subcutaneous insulin infusion) therapy has been growing since the early 1990s and was a preferred treatment method by individuals with diabetes who have used the pump as well as their health care providers (Lenhard & Reeves, 2001). The American Diabetes Association (2009) recommended intensified therapy (IT), which involves multiple insulin injections or boluses to closely assimilate the natural secretion of insulin from the pancreas. Both insulin pump IT and pen-injected IT were found to have similar cost (Kanakis, Watts, & Leichter, 2002) and were recommended by the American Diabetes Association (2009). However, hypoglycemia rates were lower and patient acceptance rates were higher in pump users (Kanakis et al., 2002). Despite improvements in metabolic control compared to other ITs, pump usage is still limited in the diabetic population of the United States (Lenhard & Reeves, 2001; Pickup, 2006).

Metabolic control declines during adolescence, due to multiple physiological and psychological factors (Berlin et al., 2006; Hains et al., 2007), and can lead to poor health and quality of life (Skinner et al., 2000). For adolescent diabetics, therapy is likely chosen through a joint decision with the parent(s), making it important to investigate both the adolescent’s and the parent’s attitudes toward pump therapy.

Although research examining the general attitudes toward insulin pump therapy has found a number of common reasons for avoiding pump use (Seereiner et al., 2010), the findings were based on a small sample with low response rate, did not include younger adolescents or their parents, and there was no clarification between those who clearly reject and those who were open-minded to pump therapy. The Seereiner et al. (2010) study was mainly concerned with those participants who had already tried the pump and found only four significant reasons for never adopting pump therapy; leaving many questions about the decision-making process unanswered.

Method/Design: A questionnaire was developed to measure perceptions of insulin pump therapy by consulting with diabetes and health psychology professionals and emailing the lead author of Seereiner et al. (2010). Expected constructs of the questionnaire include social influences, emotional reactions, body image acceptance, technology self-efficacy, and diabetes health benefits. Some questions were based on the Seereiner et al. (2010), the Diabetes Distress Scale (Polonsky et al., 2005), and Diabetes-specific Health-related Quality of Life (Jacobson, 1994) measures. Metabolic control will be determined by most recent glycated hemoglobin (HbA1c) measure.
Sample Description/Population: The sample will consist of 100 participants with Type 1 diabetes and at least one of their parents. Participants will be between the ages of 9 and 20 years.

Setting and Procedure: Online survey

Conclusions/Implications: The findings of this study may help identify the similarities and differences of perceptions of insulin pump therapy between both the individuals and their parents. The findings may also help improve communication between the diabetes care team members and the individual regarding care decisions, diabetes-related education, and pump technology to make the treatment more patient-friendly.

Description of Team: This is a health psychology team consisting of graduate student and professor.
THE IMPACT OF TREATMENT ADHERENCE AND FAMILY CONFLICT ON THE QUALITY OF LIFE OF FAMILIES OF ADOLESCENTS WITH TYPE 1 DIABETES MELLITUS

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Purpose and Objective: Managing type 1 diabetes mellitus (T1DM) creates many challenges for adolescents including maintaining treatment adherence and handling family conflict. It is important to understand how these factors can impact the overall family quality of life (QOL).

Background and Significance: T1DM treatment adherence creates a variety of physiological and psychological challenges for adolescents, which may lead to increased levels of family conflict. The amount of diabetes-specific family conflict, good metabolic control, and a variety of family factors are associated with quality of life (QOL) among adolescents with T1DM and their families. A more comprehensive understanding of behavioral and affective components of QOL adolescents with T1DM and their families is necessary.

Method/Sample/Procedure: The present analysis included 62 adolescents diagnosed with T1DM and their paternal caregivers. Self-care behavior and family conflict were measured using paternal self-reports on the Self-Care Inventory (SCI) and the Diabetes Family Conflict Scale (DFCS). Family QOL was measured with the PedsQL Family Impact Module. The sample was largely homogeneous with regard to ethnicity (95% Caucasian), income level (87% of fathers earned > $60,000/year), education level (78% of fathers had completed some college), and marital status (88% of fathers were married). The mean age for paternal caregivers was 47.52 years (SD = 6.57), and the mean age for adolescents was 14.21 years (SD = 1.53). Survey packets were completed on paper or online by paternal caregivers and returned to the principal investigator.

Results: Bivariate correlation analyses demonstrated that higher levels of adherence were associated with better quality of life, \( r = .26, p < .05 \), and higher levels of family conflict were associated with lower QOL, \( r = -.33, p < .01 \). A stepwise multiple regression examined the contribution of paternal diagnosis of T1DM, paternal report of adolescent adherence, and paternal-reported family conflict in predicting family QOL. The total variance explained by the model was 11.5%, \( F (3, 57) = 2.46, p = .07 \).

Conclusions: This examination of potential predictive factors for family QOL illustrates the importance of assessing both modifiable and non-modifiable characteristics. The results underscore the need for future research to examine the impact of a paternal caregiver having T1DM on perceptions of adolescent adherence and family conflict.

Description of Team: The research team included undergraduate and graduate psychology students, psychologists, and an endocrinologist.
PROMOTING A SAFE TRANSITION FROM HOSPITAL TO HOME USING THE “TEACH-BACK” PROCESS

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Background / Significance: Hospitalized children and their families are often not adequately prepared for discharge. Shorter hospital stays, more complex discharge instructions, and low health literacy skills can all contribute to a lack of understanding with regard to discharge education. Nurses are in a unique position to assess families’ understanding of discharge teaching and can have a positive impact on the transition from hospital to home. The “teach-back” process is a simple way for nurses to educate patients and their caregivers as well as verify understanding, correct inaccurate information and reinforce new home care skills.

Purpose: This evidence based practice project examined the effect of an educational intervention for nurses on the “teach-back” process.

Sample / Setting: 40 registered nurses working on an inpatient surgical unit at Children’s Hospital of Wisconsin.

Framework: The Iowa Model of Evidence Based Practice.

Methodology: A descriptive pre/post test design was used. This eight week project consisted of anonymous pre and post surveys and a 20 minute staff in-service which utilized posters, videos, and role-playing of the “teach-back” process. This educational intervention was completed during normal staffing hours at minimal cost to the unit.

Results / Outcomes: Thirty-one pre-survey and twenty eight post survey responses were compared and three main themes were identified: knowing, doing, and valuing. The first theme revealed an increased knowledge of health literacy and the “teach-back” process. The next theme identified a positive change in nurse behavior, culture, and practice. While the last theme, confirmed in written responses by nurses, acknowledged the value of using the “teach-back” process especially with regard to correcting medication errors.

Conclusions / Implications: This educational intervention improved nurses’ use and understanding of the “teach-back” process while also empowering them to verify understanding, correct inaccurate information, and reinforce medication teaching and new home care skills with patients and families. Survey findings specifically demonstrated the importance “teach-back” could have on preventing medications errors which directly impacts the quality and safety of pediatric patient care.

Description of Team: Evidence Based Practice Fellows (2009-2010), Staff Nurses in the Post Anesthesia Recovery Unit, Infant Unit, and Surgical Unit at Children’s Hospital of WI.
Many young trauma patients experience significant traumatic stress symptoms associated with injuries due to motor vehicle crashes, bicycle crashes, burns, and blunt or penetrating injuries. Pediatric Trauma centers across the United States are often the first to provide care for young people with injuries. As a result, there has been a move among many Pediatric Trauma centers to promote early identification of traumatic stress symptoms among young people through screening trauma patients. Comprehensive trauma-related services often include the convergence of medical, nursing and psychology specialties. The development of an efficient traumatic stress screening program, therefore, necessitates a multidisciplinary, collaborative approach. The objective of the current project is to describe the coordinated, multidisciplinary implementation of a traumatic stress screening program for young trauma patients. At Children’s Hospital of Wisconsin (CHW), a multidisciplinary team of Psychologists, Advanced Practice Nurses, Nurses, and general surgery staff came together to select the Screening Tool for Early Predictors of PTSD (STEPP) screen, developed by Children’s Hospital of Philadelphia (2002), as the primary instrument, and to develop an appropriate plan of care to address positive screens. The 12-item questionnaire assesses psychological manifestations of child traumatic stress, physiological data pulled from the patient’s medical chart, and symptoms expressed by caregivers, among patients 8 years old or older, and is administered verbally by trauma APN and select nursing staff to trauma patients and their caregivers admitted to the trauma surgery service (or who was a trauma activation) at CHW. Positive screens are followed by administration of CHW-created teaching sheets identifying child traumatic stress symptoms. Additionally, positive screens trigger a formal psychology consultation for further assessment, and initial treatment, of a patient’s traumatic stress symptoms. Community treatment resources are provided to both the youth and their caregivers. As a result of this collaborative effort, between May 2010 to September 2010, approximately 60 STEPP screens were successfully performed clinically on trauma patients by the multidisciplinary team members. This resulted in an additional 20 psychology consultations and provided an opportunity for staff to discuss traumatic stress to both the patients and families. Given that this screening protocol is clinically viable, the multidisciplinary team is currently developing applied research targets which would systematically assess program outcomes, including successful facilitation of follow-up outpatient trauma-focused psychotherapy for this population.
VALIDATION OF THE PAIN FREQUENCY-SEVERITY-DURATION (PFSD) SCALE IN COMMUNITY YOUNG ADULTS

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Objective: The goal of the current study is to examine the validity of the PainFrequency-Severity-Duration Scale (PFSD) in a young adult community sample.

Background: Pain is usually assessed by obtaining pain intensity ratings on a numerical scale from 0 to 10 (von Baeyer, 2009). While pain intensity ratings are central to tracking changes associated with pain management, other valuable information is lost using a single dimension. The PFSD addresses this limitation by incorporating pain frequency and duration resulting in a measure of total pain intrusiveness. This study provides promising evidence that a multi-dimensional pain rating scale improves the ability to predict patient functioning.

Method: Participants were 584 young adults (51% female) between the ages of 18 and 24 years (M=21.13, SD=1.49) from an online community survey. Participants were predominantly Caucasian (83%). The PFSD asks respondents how many days in the last two weeks they had experienced pain (frequency). If they had pain, they were asked to rate their usual and worst levels (intensity) and how many hours the pain had lasted (duration). Composite scores were then compared to the Pain Catastrophizing Scale (PCS; Sullivan, Bishop, & Pivik, 1995) and the Short-Form Health Survey (SF-12) for criterion-related validity.

Results: Pain frequency ranged from 0-14 days (M=3.4; SD=3.71). Usual pain severity averaged 3.1 days (SD=1.7) whereas worst pain averaged 4.6 days (SD=2.4). Usual pain duration averaged 4.8 hours (SD=4.7), and worst pain duration averaged 3.9 hours (SD=3.7). Two PFSD composite scores were created for examination. The first was the product of the pain frequency and the usual and worst pain intensity scores. The second included pain frequency, severity, and duration. Pearson correlations examined the relationship between these composites and the other validated measures. The first composite was the best indicator of pain catastrophizing and quality of life. This composite showed medium effects with the SF-12 Physical Component Score (r= -.413, p<.01) and Mental Component Score (r= -.238, p<.01), as well as the subscales of the PCS: Rumination (r=.421, p<.01), Magnification (r=.332, p<.01), and Helplessness (r=.432, p<.01).

Conclusions: Examination of pain severity alone is insufficient for obtaining a complete picture of the effects of pain experience. The PFSD is a promising measure of pain intrusiveness. This study supports that a multidimensional pain assessment can significantly add to the clinical assessment of pain, and be time- and cost-efficient.
PEDIATRIC CHRONIC PAIN AND DIFFERENCES IN PARENTAL HEALTH-RELATED QUALITY OF LIFE

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Background: There is a paucity of research regarding fathers’ experiences parenting a child with chronic pain (Phares, et al., 2005). Research on pediatric chronic illnesses suggests that fathers, like mothers, are significantly affected by their child’s chronic pain (e.g., Katz & Krulik, 1999), however their experiences are qualitatively different from mothers (Pelchat, et al., 2007). This study aims to elucidate fathers’ experiences by examining differences in self-reported health related quality of life (HRQOL) by mothers’ and fathers' of children with chronic pain, while exploring the effects of child’s age and child’s HRQOL.

Methods: Families in an outpatient pain clinic at a pediatric hospital completed child and parent questionnaires. Of the 590 families that completed the questionnaires, 268 adequately completed the child, mother and father reports. The majority of children were Caucasian (85%), female (69%) and reported having chronic pain for longer than 6 months (62%). Children ranged from ages 8 to 18 (M=13.5, SD=2.7). Children completed the PedsQL (Varni, et al., 2001) to assess the child’s HRQOL while the parents completed the Family Impact Module (FIM; Varni, et al., 2004) to assess the parents’ HRQOL.

Results: Mothers reported worse HRQOL than fathers on the Total (t(534)=-2.17, p=.030), Parent HRQOL (t(532)=-3.60, p<.001), Physical (t(531)=-4.27, p<.001), Emotional (t(532)=-3.12, p=.002), Social (t(530)=-2.42, p=.016) and Cognitive Functioning (t(531)=-2.21, p=.027) scales. Of these parental differences, the Physical Functioning differences were predicted by the child’s age and HRQOL (R²=.029, F(2,222)= 3.308, p=.038), with the child’s HRQOL as a significant predictor (t(222)=2.39, p=.018) within the regression model. Both regression models predicting parental differences in the Parent HRQOL (R²=.021, F(2,222)=2.448, p=.089) and Cognitive Functioning (R²=.021, F(2,222)=2.358, p=.097) scores approached significance, with the child’s HRQOL as a significant predictor within the models (t(223)=2.197, p=.029 and t(222)=2.141, p=.033, respectively).

Conclusion: Mothers reported significantly poorer HRQOL than fathers on several scales. Additionally, large dyadic parental differences were predicted by poorer child-reported HRQOL. In other words, the lower the HRQOL of the child, the more discrepant the mother and father parent HRQOL. In contrast, child’s age was shown to be a poor predictor of parental differences, suggesting parental experiences do not differ more or less depending on the child’s age. Richer understanding of these parental differences in families dealing with pediatric chronic pain can lead to more effective family-oriented treatments.
CHILDREN AND THEIR PARENTS’ EVALUATIONS OF A COPING SKILLS TRAINING INTERVENTION

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Interdisciplinary Research Team

Objective: To present participant evaluation of CST study participation
Purpose: The purpose of this analysis was to determine children and their parents’
evaluation of Coping Skills Training (CST) intervention. This is a pilot study to adapt
Coping Skills Training (CST) interventions for feasibility and preliminary efficacy with
a sample of children 8-12 years of age and their parents.
Framework: This study is grounded in individual and family adaption to chronic
illness.
Background/significance: Many families with a child who has a chronic health
condition (CHC) are at increased risk for psychosocial challenges and challenges in
managing of the CHC. Interventions that address these issues are important.
Obtaining participants’ perception of such interventions is a crucial component of
determining effectiveness of the intervention.
Methods/Design: This was a randomized clinical trial with a wait list control group.
Twenty nine families have finished the intervention and provided evaluation data.
Evaluation data are collected at the end of the last (usually 6th) group session and
for a sub sample of participants at 3 months and 6 months. Quantitative questions
on helpfulness, enjoyability and intent to repeat (on a 1-5 scale) as well as open-
ended questions on “likes” and “dislikes.” Frequencies were used to describe the
quantitative data and content analysis was used to identify themes in the child and
parent evaluation data.
Sample: A sample of school-aged children 8 to 12 years of age with one of the four
targeted chronic health conditions (Rheumatologic Conditions, Epilepsy, Spina
Bifida, and Asthma) and their parents was used for this study.
Setting: The CST group intervention was held at Children’s Hospital of Wisconsin.
Results: Both parents and children reported CST was helpful (M=4.6 [SD .69];
M= 4.4 [SD=.91]) and enjoyable M=4.9 [SD=.46] and M=4.5 [SD=.57] respectively.
All would repeat the course. Themes identified in both parent and child data
included: Connecting with peers, Finding the common ground, and New skills/new
discoveries.
Conclusions: Both parents and children reported high satisfaction with the CST
program.
Team: This study was conducted by an interdisciplinary team of pediatric health
care professionals (disciplines, nursing, child life, chaplaincy, and psychology).
HOPE AMONG PARENTS OF CHILDREN WITH AUTISM

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Purpose: The purpose of this study was to pilot a modification to the State Hope Scale (Goals Scale for the Present, Snyder, 1991) to focus on parent hope in parenting children with special health care needs.

Framework: A resiliency model provides the framework for this study.

Background and Significance: Understanding resilience among families of children with autism is important for providing family-centered care. An approach to family resilience based on hope, in contrast to more typical considerations of stress, considers the inner resources a parent brings to caring for their child. The Hope Scale modified for this study examines hope as an interaction of determination (agency) and planning (pathways). We believe that these components of hope are highly relevant to parent advocacy for children with special health care needs.

Methods: Participants were solicited through an autism list serve, and each interested parent was mailed a series of self-report scales, including the modified Hope Scale, here called the Parent Hope Scale.

Sample: Twelve parents of children with autism participated in this study, mean age of 41.6 yrs (33-59). Eleven of 12 respondents were mothers. The sample was 8% Hispanic, 8% Asian, 25% African American, 50% Caucasian, and 8% “other.” Eighty-three percent of the parent responders were married, and only 1 of the parents identified as having a significant health condition. Educational levels included 16% HS, 8% trade/associates degree, 58% BS/BA, and 16% MS/MA. Sixty-six percent of the parent responders were employed, and those who were not, had a spouse or partner who was.

Procedure: Parents completed the original Hope scale (Snyder, 1991), as well as the modified scale for parents, plus a series of additional scales including WHO-Quality of Life (BREF); Childhood Autism Rating Scale (CARS-2) Parent/Caregiver Questionnaire (Schopler, et al, 2009); Parenting Stress Scale: Autism (PSS:A; Miles et al); Parent Worry scale (Miles et al), and a study-specific demographics form. All test forms were randomly ordered in the mailed packets to control for order effects.

Results: Parents rated their hope for themselves lower than their hope in parenting their child with autism, with a stronger sense of determination than planning for themselves, and no difference between the two components with regard to parenting their child. Overall the parents had a moderate sense of worry for their child and about their parenting, and they were most stressed about managing their child’s behavior and communication. Their self report of quality of life was good and they were satisfied with their health. Within subjects analyses are pending a larger sample; the study is ongoing.

Conclusions and Implications: The modifications to this Hope scale are being validated in a larger study. These results have implications for the role of intervention in supporting parent confidence in parenting and advocating for children with special needs.
Description of team: The interdisciplinary research team for this study includes professors from Physical and Occupational Therapy, a pre-med undergraduate student, and two graduate students from Occupational Therapy.
There has been improved survival for children who receive hematopoietic cell transplantation (HCT) for malignancies and non-malignancies. Prior to transplant, HCT patients receive myeloblastic chemotherapy with or without total body irradiation, which puts them at risk for medical, neurocognitive and psychosocial late effects. Further, the treatment and recovery process is lengthy, isolating the patient from school and peers. Despite this, longitudinal research has found no significant difference in psychosocial outcomes from pre-HCT to 1- and 2-years post-HCT. However, little is known about HCT psychosocial functioning beyond 2-3 years post-HCT. The purpose of this study was to investigate the psychosocial functioning of pediatric HCT survivors 4 or more years post-HCT.

The sample consisted of 22 females and 17 males, between 5 and 29 years of age ($M=13.8$ years, $SD=6.2$). On average, participants were 6.3 years post-HCT ($SD=1.8$, range= 4-12 years). The majority of participants were Caucasian (87.2%) and were initially diagnosed with leukemia (59.1%). Twenty-two participants had pre-HCT psychosocial data (Achenbach Child Behavior Checklist; CBCL), which was collected as part of the pre-transplant protocol. The six-year post-HCT psychosocial data was collected as part of a research testing battery consisting of cognitive, psychosocial, and quality of life measures, parent and survivor interviews, and demographic survey. Data analyzed for this study included the psychosocial CBCL scores (pre- and 6-years post-HCT) and an open-ended qualitative question on the Achenbach CBCL and Youth or Adult Self-Report forms asking what is most concerning (6-years post-HCT).

No statistically significant differences were found on the psychosocial CBCL scores (Total Problems, Internalizing & Externalizing) from pre- to 6-years post-HCT. The current findings extend the longitudinal psychosocial research to 6-years post-HCT. The qualitative analysis of the open-ended question found that HCT survivors reported school/cognitive problems as their greatest concern (40.8%), while their caregivers reported their child’s future health as their greatest concern (21.9%). The difference in survivor versus caregiver reported concerns may reflect the differential psychosocial impact of the HCT process on survivors and caregivers.

The multidisciplinary team for this study consists of a pediatric HCT nurse practitioner (LA) and two pediatric psychologists (MJK & KB) who conduct childhood cancer and HCT survivorship research as part of the Next Steps Long-term Follow-Up Clinic, along with a psycho-oncology research coordinator (RS; psychology doctoral candidate). Also, this abstract was the product of a mentored research training experience for a pre-med undergraduate student (KS) at UW-Madison.
LONG-TERM MEDICAL AND PSYCHOSOCIAL LATE EFFECTS IN CHILDHOOD CANCER AND BONE MARROW TRANSPLANT SURVIVORS

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Much has been learned about the late effects of treatment that many pediatric and BMT survivors face. Although research has shown that most survivors are resilient, there is a subgroup that struggle with life after treatment. This chart review study aimed to further investigate factors that are associated with long-term psychosocial problems in childhood cancer and BMT survivors seen in a survivorship clinic, using a quantitative and qualitative assessment approach. Preliminary results of this study were previously presented at two conferences (Bingen et al., 2004) using a smaller sample size. While the majority of survivors scored within normal limits on parent and self-report questionnaires evaluating emotional and behavioral functioning, the majority also reported one or more survivorship concerns during a psychosocial interview. For this study, 197 childhood cancer and BMT survivors were identified and data was collected from questionnaires, qualitative interviews and medical chart review.

The cohort consisted of 103 females and 94 males, between 2 and 34 years of age. The mean age at diagnosis was 6 years. On average, survivors were 9 years post diagnosis and 7 years post treatment completion. Leukemia accounted for 43.4% of initial diagnoses; and 30.6% were BMT survivors.

Similar to the original study, results indicated no significant difference between the BMT and No-BMT groups on psychological functioning. However, 62.5% of the BMT group reported cognitive/school functioning concerns during the interviews; as compared to 34.2% of the No-BMT group (p<.004). Survivors 10 or more years post-treatment (9.6%) and survivors 0-5 years post-treatment (2.6%) had more documented fatigue compared to survivors 6-9 years post-treatment (0%), which was unrelated to type of treatment, diagnosis or age. Identifying those survivors most at risk for long-term psychosocial problems and its impact on post treatment quality of life remains a challenge that needs further research.

The Next Steps Clinic is a multidisciplinary team of specialists who are experienced in the issues faced by childhood cancer survivors. The team includes an oncologist, nurse practitioner, nurse educator, psychologist, social worker, registered dietician, school teacher and physical therapist. In addition to providing clinical care, the Next Steps Team has an active research agenda investigating psychosocial outcomes, quality of life and medical late-effects associated with childhood cancer survivorship.
Objective: To document rates of general and abdominal pain in pediatric inflammatory bowel disease (IBD) and to examine demographic and psychosocial differences in those with and without pain.

Purpose: This study examines differences in demographic and psychosocial adjustment in pediatric IBD patients with and without pain.

Framework: A biopsychosocial framework was used.

Background and Significance: There has been little research on pain in pediatric IBD. This study examines if demographic and psychosocial correlates of pain in other pediatric populations, such as other chronic pain conditions, also are relevant in pediatric IBD.

Method/Design: This is a cross sectional study utilizing survey methods.

Sample: Participants are 58 adolescents (mean age 15 years, 59% male, 93% Caucasian, 41% with an annual family income under $100,000).

Setting/procedure: Participants were recruited in the Gastroenterology Clinic of Children’s Hospital of Wisconsin. After providing informed consent or assent, families completed questionnaires of psychological functioning and pain. We utilized the PedsQL to assess quality of life (QoL), the Pediatric Symptom Checklist to assess externalizing and internalizing behaviors and attention problems, the Family Assessment Device to assess family functioning, and a demographic survey. Teens provided ratings of general and abdominal pain in the last week.

Results: QoL was significantly lower and internalizing symptoms were significantly higher in adolescents reporting abdominal pain in the last week (t(47) = 2.9, p = .006; t(47) = -2.5, p = .017, respectively). Additionally, females reported more pain than males $\chi^2(1) = 4.4$, p = 0.036). No differences were found between abdominal pain and no pain groups on age, income, externalizing behaviors, or family functioning. General pain in the last week was not related to any demographic or psychosocial factors.

Conclusions: Like findings in other pediatric conditions, females with IBD report more abdominal pain than males, and abdominal pain (not general pain) is related to lower QoL and more internalizing symptoms. Improving pain may have positive implications for psychosocial functioning.

Description of Team: Advanced undergraduate student, pediatric psychologist, and pediatric gastroenterologist,
POSTER PRESENTATION: LINKING CONGENITAL CARDIOVASCULAR MALFORMATIONS TO NEUROBEHAVIORAL OUTCOMES IN A ZEBRAFISH MODEL: PRELIMINARY STUDIES. Daniel Weber, PhD; Cheryl Brosig, PhD; Paula North, MD PhD; Todd Peterson, MS; Ramani Ramchandran, PhD (Children's Environmental Health Sciences Center, University of Wisconsin-Milwaukee, (414) 382-1726, dweber@uwcm.edu)

Objective: To develop a tractable vertebrate model of congenital cardiovascular malformations that mimics the underlying bases and behavioral outcomes of congenital cardiovascular malformations. Purpose of Study: To establish a tractable vertebrate model for genetic, physiological, and behavioral analyses of congenital cardiovascular malformations and the interactions that trigger, amplify, or modify behavioral deficits associated with this disease in children.

Background & Significance: Congenital cardiovascular malformations, major sources of childhood mortality and morbidity, causes executive functioning deficits, lower cognitive processing speeds, inattention and hyperactivity, and decreased development of complex integrative brain functions. These behavioral deficits are associated with changes in fetal brain structure due to altered blood and O₂ flow. Zebrafish behaviors are associated with brain regions that are analogous to mammalian structures. Unlike rodent models in which in utero observations are difficult, zebrafish embryos are externally fertilized and transparent providing easy, real-time analyses without sacrificing embryos. Since zebrafish development is sensitive to hypoxia and grl⁺⁻ is a non-lethal mutant that displays aortic coarctation, using this species as a model gives insights into mechanisms of learning deficits caused by congenital cardiovascular malformations.

Methods: Behavior: Zebrafish receive mild shock upon entering incorrect T-maze arm. After reaching criterion (3 consecutive safe side choices) for initial learning task, shock delivered to safe side until reversal task criterion reached. N = 30 trials/d/3d. Genotyping: Fin tissue clip PCRs differentiated grl⁺⁻, grl⁺⁺ and grl⁻⁻ individuals. Experimenter blind to results until behavioral data collected. Histology: Proliferating cell nuclear antigen (PCNA) identified neuronal proliferative activity; H&E stained cells for counting cell bodies. PCNA Labeling Index was calculated. Results: Behavior: Gene expression, specifically the grl mutation, decreased long-term learning flexibility. Histology: grl mutants had fewer cell bodies in the dorsal and medial telencephalon. Conclusions: We demonstrated that this approach could evaluate changes in executive function and those changes correlate to neuroanatomical alterations in the developing brain. grl mutants showed decreased learning flexibility in a reversal test. Data build upon research with other vertebrate gene mutants for congenital cardiovascular malformations. Since a strong correlation exists between brain blood and oxygen flow to developing neurons, our preliminary data suggest a correlation between behavioral changes, brain hypoxia in grl mutants and altered neurodevelopment associated with this disease. Description of the Team: Cheryl Brosig: pediatric neuropsychology of congenital heart disease; Paula North: Director, Children's Hospital imaging/histology lab; Todd Peterson: psychology graduate student; Ramani Ramchandran: zebrafish cardiovascular development; Daniel Weber: fish neurobehavioral toxicology
RESpite Care - A Model Interdisciplinary Project to Support Families of Children with Special Health Care Needs (CYSHCN)

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The objective of this presentation is to present a model interdisciplinary project that was developed to help support families of CYSHCN. Caregivers of CYSHCN are often overwhelmed by the constant physical and emotional demands of caregiving. Respite care has been identified as a valuable resource for caregivers of CYSHCN, yet funding is limited and caregivers often find themselves on long waiting lists for respite care services. A respite project was developed at a Midwestern University as a way to expand available opportunities for respite care to families of CYSHCN and also provide a unique interdisciplinary service learning experience for students.

Children from birth to age 18, with various cognitive and physical disabilities, along with their siblings, had the opportunity to attend a fun-filled day of activities at the University’s field house. Students from various disciplines, including nursing, physical therapy, occupational therapy, and education, worked collaboratively, with supervision from faculty, to make the events possible.

Approximately 200 students volunteered at the event, which hosted approximately 100 CSHCN and their siblings. In order to better understand the experience of student volunteers, a 13-item survey was developed by the researcher and administered at the end of the respite event. Results indicated that the respite event was viewed as an extremely valuable experience for students and that they indicated they felt it was extremely valuable for families of CYSHCN, as well. Students not only grew in their knowledge about how to work with CYSHCN, but they gained an appreciation for the energy required to care for CYSHCN as well as the importance of respite for caregivers.

This project serves as a model for other nursing programs as a way to help expand respite services for families of CYSHCN while offering a unique interdisciplinary service learning experience for students.

The team responsible for this project consisted of a unique collaboration between a local non-profit organization and various departments of the university, including: nursing, physical therapy, occupational therapy, pharmacy, special education, and adaptive physical education.
PARENT EDUCATION IN PEDIATRIC CHRONIC PAIN

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Title and Objective: This presentation, titled “Parent Education in Pediatric Chronic Pain,” reports on the development, implementation, and assessment of an education program for parents of children with chronic pain conditions.

Purpose of the Study: The present study sought to create an education program that was helpful, acceptable, and satisfactory to parents and that was feasible to implement with an interdisciplinary team in an intensive pediatric pain program.

Background and Significance: Parents play an important role in the treatment of children with chronic pain. Parents’ responses to children’s pain, understanding of the treatment plan, and interaction with children during pain episodes are all factors that have been found to significantly impact children’s pain experience. However, few pediatric pain treatment programs have developed and evaluated a formal parent education program to address these important parental factors.

Method: Three separate parent education sessions were developed. A program evaluation measure was created to assess parents’ perceptions of the utility, relevance, clarity, and enjoyment of each session. Parents also reported on the perceived likelihood that they would make changes in how they handle their child’s pain based on the information covered in each session. Immediately after each session, parents rated five items on a five-point Likert scale, with item responses ranging from 0, “Strongly Disagree” to 4, “Strongly Agree.” The measure is scored so that higher scores reflect more positive ratings.

Sample: Participants were 36 caregivers; 26 mothers, 9 fathers, and 1 grandma.

Procedure: Parents participated in a total of three one-hour group education sessions offered on a weekly basis. Session one focused on education about chronic and neuropathic pain conditions and parent-child interactions around pain. Session two covered coping tools that children learn in the context of their treatment and how parents can promote children’s new coping skills. Session three focused on maintaining treatment success in the transition from the pediatric pain program to the home environment and positive family communication strategies.

Results: Overall, the mean composite score across all sessions was high; mean = 3.65, SD = .50, observed range 1.6 – 4, possible range 0 – 4. Individual item scores were also high across sessions. There were no significant differences between sessions overall or for any of the individual item scores; all were highly rated.

Conclusions: Parents gave high, positive satisfaction ratings for all three parent education sessions. They rated the education sessions as equally and highly useful, clear, enjoyable, and educational. Parents reported a strong likelihood of changing the way they handle their child’s pain based on the information presented in the education sessions. Developing and assessing parent education programs on pediatric pain in this manner has the potential to inform future interventions and to promote the positive involvement of parents in children’s pain treatment.

Team: Parent education sessions were co-developed and co-led by an interdisciplinary team of one nurse and two psychologists.
FAMILY MANAGEMENT OF A CHRONIC CONDITION: PERSPECTIVES OF ADOLESCENTS WITH SPINA BIFIDA

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Background: There are approximately 1,300 infants born with spina bifida (SB) every year in the U.S. They live their lives in families who deal with the demands of a chronic condition while faced with the challenges of family life. As both recipient and participant in the management of a chronic condition, adolescents with SB have distinctive experiences. The aim of this secondary analysis was to ascertain the adolescent’s perspective of family management of their chronic condition.

Methods: Participants in this descriptive qualitative analysis were adolescents with SB (n=25) from a study addressing adaptation (Sawin, Brei, Buran, Fastenau, 2002). The Family Management Style Framework (FMSF) provided the conceptual underpinnings for describing key aspects of adolescents’ perceptions of how the family incorporated condition management into everyday family life.

Results: Exemplars were identified for each of the components of the FMSF. Definition of the situation included descriptions of a positive perception of self for some participants while others described negative self perception focused on mobility issues such as gait pattern or use of the wheelchair. They described the impact of SB on themselves and their family. Management behaviors focused on the skills they had to learn necessitated by the presence of SB as well as their families’ strategies for the routine and the non-routine. Perceived consequences centered on college, marriage and children intermingled with concern about the ability to live on their own and the future impact on their family of origin.

Conclusion: Adolescents with SB are knowledgeable about their condition and about their families. Inclusion of adolescents with SB in future study of families may reveal how adolescents interact with and contribute to family management.
THE IMPACT OF PANDAS IN CHILDREN WITH TOURETTE SYNDROME (TS) and CHRONIC TIC DISORDER (CTD)

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Objective: To examine the awareness of and reported rate of PANDAS (Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcus infections) in children with Tourette Syndrome (TS) and Chronic Tic Disorder (CTD).

Purpose of the Study/Project: The dataset for this poster was derived from a larger scale project which examined clinical characteristics and functional impact of TS and CTD in a large community sample using an Internet sampling method. The current poster explores the impact and prevalence of PANDAS in children with TS.

Framework: This paper/poster uses the dataset from the project mentioned in B to explore the impact of PANDAS diagnoses in children with TS in terms of other Pediatric Behavioral Research.

Background and Significance: Tic Disorders, including TS and CTD, are defined by the presence of tics – rapid, purposeless movements or vocalizations. For some children, onset of tic or obsessive-compulsive disorder (OCD) symptoms has been noted to immediately follow streptococcus infection. This phenomenon has been described as Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcus infections (PANDAS; Moretti, Pasquini, Mandarelli, Tarsitani, & Biondi, 2008). PANDAS is currently not recognized by DSM-IV and research supporting the diagnosis has been mixed (Kurlan, & Kaplan, 2004). The current paper/poster examines the general awareness of PANDAS as well as reported diagnosis of PANDAS in an internet sample of children with TS and CTD.

Sample Description: Parents described their children in the sample and reported 596 males (80.5%), 143 (19.3%) females, and one child whose gender was not reported. The majority of the sample was white/Caucasian (85.7%, N = 634) and also included multiracial (6.5%, N = 48), Hispanic/Latino (3.2%, N = 24), Asian (1.5%, N = 11), and African-American (0.8%, N = 6) participants. Children had a mean age of 10.6 years (SD = 2.9, range = 4-17), and their median grade completed was fifth grade. Parents reported a previous formal diagnosis of TS in 96.1% (N = 711) of their children. Twenty nine percent (N = 214) had been diagnosed with Chronic Motor Tic Disorder and 18.5% (N = 137) with Chronic Vocal Tic Disorder. Fifty nine percent had heard of PANDAS, with 20% of those individuals having PANDAS suggested from a professional as a diagnosis. Only 2.6% had been given an actual diagnosis.

Setting: The survey was posted online for 6 consecutive months on Survey Monkey (www.surveymonkey.com), an Internet based survey administration program. A link to the study survey was posted on the home page of the Tourette Syndrome Association (TSA; www.tsa-usa.org).
Method/Design/Procedure: This poster examines rates of parents of children with TS/CTD who report awareness of PANDAS in addition to a suggested diagnosis of PANDAS. Children with a suggested diagnosis of PANDAS where compared with children without in measures of tic severity as well as rates of reported OCD diagnosis.

Results/Outcomes: Suggested diagnosis of PANDAS was not associated with higher tic severity than those without a suggested diagnosis of PANDAS $t(72)=-.018$, $p>.05$. However, these children with suggested PANDAS diagnosis were significantly more likely to also report diagnosis of OCD, $\chi^2(76)=6.45$, $p<.05$.

Implications: Results from these analyses indicate that children with tics who also report a suggested diagnosis of PANDAS do not have more severe tics than those without a suggested diagnosis of PANDAS. However, those suggested a PANDAS diagnosis are more likely to also report a diagnosis of OCD compared to those who have not been suggested a diagnosis of PANDAS. Future research is needed to explore the PANDAS diagnosis and its relationship to tics as well as OCD.

Description of Team: The main project involving the comprehensive internet survey was the product of several research sites. The current paper/project involves analyses of a subset of data from the main study and this is performed by a team of undergraduate students in clinical psychology at UWM under the supervision of Dr. Woods.


THE EFFECT OF SENSORY PROCESSING DISORDER ON THE INTENSITY OF
TICS ASSOCIATED WITH TOURETTE’S SYNDROME IN CHILDREN

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Objective: To examine the reported prevalence of Sensory Processing Disorder (SPD) in children with tics and Tourette’s Syndrome (TS)

Purpose of the Study/Project: The dataset for this paper/poster was derived from a larger scale project which examined clinical characteristics and functional impact of TS and CTD (chronic tic disorder) in a large community sample using an Internet sampling method. The current examines reported diagnosis of Sensory Processing Disorder in addition to TS/CTD.

Framework: This poster uses the dataset mentioned in item B to examine reported diagnosis of Sensory Processing Disorder and its relationship to tics.

Background and significance: Tics are sudden, purposeless movements that vary in intensity and frequency. The estimated prevalence of tic disorder (TS or CTD) is 3 to 8 per 1000 in childhood (Scahill, Sukhodolsky, Williams, & Leckman, 2005). Tics are often preceded by a very strong desire or urge to perform the tic; it may feel as though the patient has an itch or uncomfortable feeling (Bullen, Hemsley 1983). This urge is known as premonitory urge and may be related to certain sensory sensitivities in TS patients (Cohen, Leckman 1992). Sensory sensitivities have recently been classified by some as its own disorder - Sensory Processing Disorder (SPD). SPD is characterized by hypersensitivity to sensory stimuli (Flanagan 2009) including hypersensitivities sensitivity to touch, certain lighting and even the feeling of clothing against skin. Some of the sensitivities often reported in SPD have also been reported to exacerbate tics. For instance, thermal sensitivities have been associated with worsening tic symptoms (Scahill et al. 2001). While SPD is widely acknowledged, particularly in autism literature, it is not currently classified by DSM-IV. The current poster investigates the reported rate diagnosis of SPD in children with tics.

Sample Description: Parents described their children in the sample and reported 596 males (80.5%), 143 (19.3%) females, and one child whose gender was not reported. The majority of the sample was white/Caucasian (85.7%, N = 634) and also included multiracial (6.5%, N = 48), Hispanic/Latino (3.2%, N = 24), Asian (1.5%, N = 11), and African-American (0.8%, N = 6) participants. Children had a mean age of 10.6 years (SD = 2.9, range = 4-17), and their median grade completed was fifth grade. Parents reported a previous formal diagnosis of TS in 96.1% (N = 711) of their children. Twenty nine percent (N = 214) had been diagnosed with Chronic Motor Tic Disorder and 18.5% (N = 137) with Chronic Vocal Tic Disorder. Of the 740 participants 11% (N=79) reported being diagnosed with SPD. Additionally 7% (N=51) reported treatment for SPD, with treatment lasting for the majority one month or more.

Setting: The survey was posted online for 6 consecutive months on Survey Monkey (www.surveymonkey.com ), an Internet based survey administration program. A link to
the study survey was posted on the home page of the Tourette Syndrome Association (TSA; www.tsa-usa.org).

**Method/Design/Procedure:** In the data set, children with TS/CTD and SPD were compared to children with TS/CTD without SPD. They were compared on measures of tic severity and level of urge. The survey that was used was the *Parent Tic Questionnaire* (PTQ). An independent T test was run on the data.

**Results/Outcomes:** Preliminary analyses suggest that close to 11% of the sample reported diagnoses of SPD. In addition, children SPD reported having tics with significantly higher levels of intensity; t(70)= .027 p<.05, but not frequency; t(536)=1.252 p>.211, compared to those children without SPD.

**Implications:** Results from these analyses suggest that children with tics who also report diagnosis of SPD report higher intensity of tics. The results do not, however, indicate any differences in tic frequency for children who have reported these co-occurring disorders. It is possible that children with sensory issues – such that they have reported diagnosis of SPD – experience more intense premonitory urges and tics. Future research needs to examine the possibility of sensory processing issues in the relationship with tics as well as the overlap of SPD and tics. These results are significant for understanding sensory phenomenon and sensory stimuli in SPD in conjunction with TS. SPD may be potentially misdiagnosed because it is not a disorder classified in the DSM-IV. Future research should explore clarification of SPD and evaluate treatment and intervention procedures for SPD alone and in concurrence with TS.

**Description of Team:** The main project involving the comprehensive internet survey was the product of several research sites. The current paper/project involves analyses of a subset of data from the main study and this is performed by a team of graduate students in clinical psychology at UWM under the supervision of Dr. Woods.

**References:**


