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# Novel Interventions in Children's Healthcare for Youth Hospitalized for Chronic Pain

Michael A. Harris, PhD<sup>a</sup>, David V. Wagner, PhD, Anna C. Wilson, PhD, Kim Spiro, PhD, Matthew Heywood, MPH, and Dana Hoehn, MS Oregon Health & Science University Portland, Oregon

# Abstract

The purpose of this study was to pilot the implementation of the Novel Interventions in Children's Healthcare (NICH) program for youth with chronic pain who utilized a disproportionate amount of health care. Three youth (2 males and 1 female, aged 11 to 15 years) participated. The intervention consisted of a combination of family-based problem-solving, care coordination, and case management, with the inclusion of technology-assisted treatment delivery (e.g., text messages, video chat) to reduce costs. Both objective (i.e., hospitalization records) and subjective (e.g., interventionist reports) outcomes were examined to assess changes over the course of treatment. Two of the three youth demonstrated reductions in the number of days hospitalized and associated costs. In addition, interventionist reports indicated improved quality of life for family and youth served. Although further research is needed, NICH appears to be a promising intervention for youth with chronic pain and high health care utilization and shows the potential to result in improved youth health and reduced monetary costs for families, providers, and the healthcare system.

Youth with chronic pain and their families often encounter complex psychosocial challenges as they navigate healthcare and school systems in the context of having a chronic pain condition. Chronic pain in youth is associated with substantial costs (Sleed, Eccleston, Beecham, Knapp, & Jordan, 2005), including increased office visits and prescription medication (Toliver-Sokol, Murray, Wilson, Lewandowski, & Palermo, 2011). Parents also miss employment time for medical appointments and for supervision of their child, resulting in lost productivity. Using estimations provided by the 2010 Medical Expenditure Panel Survey (MEPS), Groenewald and colleagues (2014) concluded that the societal cost of adolescent chronic pain is approximately \$19.5 billion per year in the United States. Furthermore, a small subset of youth with chronic pain (5%) account for a large proportion (30%) of total costs (Groenewald, Essner, Wright, Fesinmeyer, & Palermo, 2014). A relatively small subset of youth with chronic pain access the emergency room or are hospitalized for their pain problem (Coffelt, Bauer, & Carroll, 2013; Perquin et al., 2001), however, admission rates for chronic pain problems have increased 800% in recent years (Coffelt et al., 2013) suggesting that overall hospitalization costs in this population are

<sup>&</sup>lt;sup>a</sup>Corresponding author contact information: Michael A. Harris, PhD, Institute on Development & Disability, Oregon Health & Science University, 3181 SW Sam Jackson Park Rd, Mailstop CDRC, Portland, OR 97239, Phone: (503) 494-8942, Fax: (503) 494-6868, harrismi@ohsu.edu.

increasing. Youth who are hospitalized may represent a group who does not respond to typical multidisciplinary outpatient care for chronic pain, and likely incur higher direct and indirect costs than typical youth with chronic pain. Effective interventions for this subset of youth with chronic pain and high healthcare utilization would likely result in substantial savings for families and society.

Poor family and parental functioning are associated with greater pain-related disability in children and adolescents (Palermo, Valrie, & Karlson, 2014). Additionally, family factors such as parent substance use, parent mental health problems, and financial insecurity are related to poor psychosocial outcomes and overutilization of medical care (e.g., Janicke, Finney, & Riley, 2001; Riley et al., 1993). For families with poorer baseline functioning or fewer resources, the high burden and cost associated with a child's chronic pain (e.g., Ho et al., 2008; Toliver-Sokol et al., 2011) may be an even larger family stressor. Thus, the subset of youth with chronic pain who are repeatedly hospitalized are likely at increased risk for associated negative short- and long-term outcomes, including individual (e.g., mental health concerns, opioid dependence, academic struggles, social isolation) and family (negative parent-child interaction patterns, high parental stress, low family cohesion) problems, than typical youth with chronic pain who avoid pain-related hospitalizations (Coffelt et al., 2013; Zernikow et al., 2012).

There is substantial evidence that outpatient psychological therapies, most often cognitive and behavioral treatments, produce large effects in pain reduction (Palermo, Eccleston, Lewandowski, Williams, & Morley, 2010). Substantial research efforts have made these treatments more accessible to families (e.g., Internet or computer administered; Connelly, Rapoff, Thompson, & Connelly, 2006; Palermo, Wilson, Peters, Lewandowski, & Somhegyi, 2009), have tailored treatment programs to specific presenting problems (e.g., school functioning; Logan & Simons, 2010), and have involved parents in treatment (e.g., Levy et al., 2010). More intensive multidisciplinary treatment programs including psychological treatment, such as day treatment and inpatient programs, are also effective at reducing pain and disability (e.g., Eccleston, Malleson, Clinch, Connell, & Sourbut, 2003; Hechler et al., 2009; Logan et al., 2012). However, some portion of youth do not respond to existing treatments, which were not specifically developed to target the subset of youth who have the highest utilization of medical care. To our knowledge, interventions for youth with chronic pain are typically office- or hospital-based, likely resulting in barriers to treatment progress by limiting service access for youth and families with limited resources, and impeding the ability of providers to assess and intervene in the youth's natural environment (e.g., home, school). Office- and hospital-based approaches may also be poorly-suited to directly address the complex needs of families (e.g., parent substance use, financial insecurity) that may be related to overutilization (e.g., Janicke et al., 2001; Riley et al., 1993). Given the likely high rates of psychosocial problems and barriers to accessing traditional treatment approaches among youth with chronic pain who are repeatedly hospitalized (Janicke et al., 2001; Riley et al., 1993), effective intervention for this subset of very high-risk youth requires a multifaceted, ecologically valid, and flexible approach.

Intensive behavioral health interventions delivered to youth with other complex medical conditions (e.g., type I diabetes) and their families have proven effective in improving

psychosocial functioning and reducing avoidable hospitalizations (Ellis et al., 2008; Harris & Mertlich, 2003; Wysocki et al., 2007). Based on this research, Novel Interventions in Children's Healthcare (NICH; Harris et al., 2013) was developed to specifically account for the multifaceted, difficult-to-treat nature of chronic and complex medical conditions (e.g., type 1 diabetes, chronic pain) in youth who are hospitalized and incur high medical costs. The theoretical foundation of NICH is consistent with the theory of social ecology (Bronfenbrenner, 1979), which assumes that youth health behaviors (e.g., adherence, pain coping, activity level) are related to key factors in the multiple systems in which the youth is embedded. NICH delivers several integral treatment components in the child's natural environments. First, each family receiving NICH is provided with an intensive form of Behavioral Family Systems Therapy (BFST; Robin & Foster, 1989; Wysocki, Greco, Harris, Bubb, & White, 2001). BFST addresses psychosocial barriers (e.g., dysfunctional family interactions) to youth health behaviors by utilizing a combination of family-based, skillsbased interventions (i.e., family systems interventions, communication skills training, problem solving, and cognitive restructuring) and has demonstrated efficacy in improving youth health (e.g., Wysocki et al., 2001). Second, care coordination is delivered to facilitate successful collaboration between the multiple care providers involved, the youth with chronic pain, and their family members to result in effective delivery of health care services. As part of care coordination, NICH providers serve as liaisons between the youth, family, and medical team to ensure effective communication, maximum treatment adherence, and collaborative problem-solving as needed around the child's treatment regimen. Third, families participating in NICH receive case management services related to the multiple systems in which the youth is embedded. NICH interventionists interact with schools, child protective services, and other agencies (e.g., mental health providers, employers) that are directly involved with the youth and family and assist youth and their family members with accessing pertinent resources through community agencies.

Given the need for an intervention that comprehensively addresses the multiple problems associated with complex medical conditions (e.g., chronic pain), we have completed the early stages of piloting NICH with youths with chronic pain and high healthcare utilization. The purpose of this paper is to describe the implementation and preliminary outcomes of NICH provided to three youths with chronic pain. More specifically, findings will include detailed case examples and hospital utilization outcomes. We discuss the implications of our work for the treatment of chronic pain and the continued development of the NICH model.

#### Method

#### **Procedure and Eligibility**

The current evaluation of NICH utilizes a retrospective case study of three adolescents with chronic pain. A retrospective pretest–posttest design was used to assess whether it was feasible to apply NICH to youth with chronic pain and their families. Referrals to the pilot (n = 3) were made by providers at a children's hospital at a major academic medical center on the West Coast of the United States. Eligible youth were identified by medical staff as having experienced more than one potentially avoidable hospitalization (i.e., hospital admission, emergency department visit) and not responding to typical medical interventions.

Inclusion criteria for participation included youth between birth and 18 years of age who (1) have been identified as experiencing chronic pain, (2) have experienced adverse psychosocial outcomes as a result of chronic pain, and (3) have experienced hospitalizations that were deemed to be avoidable by care providers. Exclusion criteria included youth or primary caregivers with (1) an intellectual disability or (2) an untreated severe mental illness (e.g., schizophrenia). No families of youth with chronic pain were excluded. Families referred to treatment services were initially contacted by a NICH provider to assess their interest in receiving treatment. Initial data collection was completed for the purpose of treatment evaluation. Youth and families included in this project have completed the NICH program, and retrospective chart reviews were conducted to collect information. Potential identifying information has been changed to protect patient identity. All research procedures were approved by the university Institutional Review Board.

#### **NICH Program Description**

The NICH intervention and a case example have been described previously (Harris et al., 2013; Harris et al., 2014). At the time of this study, NICH services were being provided by three masters-level interventionists with caseloads of approximately 10 to 15 patients and families each. Supervision is provided by doctoral-level providers, and NICH interventionists receive 2 hours of weekly group supervision as well as weekly individual supervision and phone support as needed. NICH interventionists are in frequent (e.g., daily) contact with families during the initial stages of treatment and are available to families 24 hours per day, seven days per week. Interventionists provide services in the hospital, in outpatient clinics, at the youth's home, over the phone, and over the computer via email and video chat. The frequency, duration, and setting of interventionist contact vary based on perceived need. Technology-assisted communication (e.g., text messages, video chat) was used whenever possible in order to maximize service provision while minimizing costs. Patients are discharged from NICH based upon a combination of a reduction in medical utilization, improvement in youth health, and observations suggesting that the youth's ecosystem can support treatment gains. Discharge plans vary from youth to youth depending on perceived need but often include ensuring that families have necessary information regarding additional community resources and the offer of scheduled or as-needed future booster sessions. Specific examples of the course of treatment for youth with chronic pain are described in Case Study 1, 2, and 3 below.

#### **Chart Review Measures**

In addition to descriptions of the course of treatment, chart reviews were conducted to capture healthcare utilization during the 6 months prior to NICH provision and 6 months following treatment initiation. More specifically, chart reviews were used to examine the number of pain-related hospital admissions and emergency department (ED) visits, the number of days spent in the hospital, and the reasons for admissions and ED visits. The term "hospital utilization days" denotes the sum of days admitted and ED visits. The electronic medical system used allows for records review through the four major medical systems in the larger metropolitan area surrounding the university. Only pain-related admissions were included. Chart reviews also included interventionist treatment notes, which provided information regarding course of treatment, frequency of contact, type of interventions used,

and subjective reports of youth and family functioning, as well as other information detailed below. Chart reviews were conducted by a trained research staff member uninvolved in treatment provision.

#### **Cost Estimation**

We examined cost outcomes using the 2012 estimates provided by Groenwald and colleagues (2014), which were based upon the 2010 Medical Expenditure Panel Survey (MEPS). We approximated medical costs by multiplying the average cost of ED visits and days spent admitted in the hospital by the number of such events per patient. The average estimated cost for an ED visit was \$771.20, and an average day admitted was estimated at \$3,385.20.

#### **Participants**

The participants were "Thomas," "Jennifer," and "Matthew." Thomas, Jennifer, and Matthew were 14, 15, and 11 years-of-age, respectively, at the start of treatment. The combined number of hospitalizations and emergency department visits for these three patients ranged from 4 to 22 in the 6 months prior to treatment (see Table 2). All were Medicaid recipients. Additional demographic characteristics are described below in Case Study 1, 2, and 3. Youth and family psychosocial risk factors are provided in Table 1.

# Results

#### Case Study 1

Thomas, a 14-year-old Caucasian male, was referred to NICH services due to complaints of generalized chronic pain, mostly focused on his back and legs. In the 6 months prior to NICH involvement, Thomas experienced 4 pain-related hospital admissions, for a total of 11 days, and 11 pain-related ED visits. Thomas lived with his mother, older sister, younger brother, and, intermittently, his mother's boyfriend. He had withdrawn from previous physical and enjoyable activities (e.g., school soccer team) and acknowledged experiencing a high level of pain-related anxiety. Thomas reported few effective coping strategies, and relied upon prescription medication and ED visits for pain management. He was not attending school, was sedentary (i.e., spent majority of day playing video games), and was socially isolated. Thomas's mother reported high anxiety regarding Thomas's pain and frequently attended to his pain behavior (e.g., moaning) by asking questions such as "Where are you hurting?" and "Can I take you to the emergency room?". Thomas also slept on the floor of his mother's room, which appeared to function to relieve their shared pain-related anxiety. From a behavioral perspective, his pain behaviors appeared to be positively reinforced (e.g., parental attention, access to video games) and negatively reinforced (e.g., escape from stressful situations, such as school) by his mother.

As with all patients in NICH, Thomas and his family received interventions in their natural environment (e.g., home, community, hospital). Sessions typically occurred in the family's home but sometimes took place in the community or during outpatient appointments. On average, Thomas's NICH interventionist met with Thomas and/or his family twice per week, averaging 3–4 hours total per week. His interventionist provided weekly care coordination,

as he met with members of Thomas's medical team and was in regular contact with them throughout treatment. The interventionist also delivered case management, connecting Thomas's mother with a mental health provider to address her anxiety, helping Thomas become more socially active through volunteer opportunities, and assisting the family with accessing a gym to promote increased physical activity. In order to increase Thomas's ability to actively cope with pain, the interventionist helped create a daily exercise plan with low impact exercises and provided relaxation training (e.g., progressive muscle relaxation, diaphragmatic breathing). As part of BFST, problem-solving was completed to address school difficulties and barriers to active coping. In addition, cognitive restructuring was undertaken with Thomas's mother to address her fears related to Thomas's pain experiences. Communication skills training was utilized to modify the language that the family used to describe and respond to pain behavior (e.g., suggesting alternatives to the ED). Finally, family structuring was provided to assist Thomas's mother with engaging in more effective caregiving strategies and reducing her reinforcement of his pain behavior. During his first six months of NICH involvement, Thomas did not experience any pain-related or other ED visits or hospitalizations. According to interventionist notes, improvements were noted for the patient's quality of life (e.g., improved mood, increased activity level), his mother's quality of life (e.g., decreased anxiety, increased self-efficacy related to parenting), and his family's functioning (e.g., reduced conflict).

#### **Case Study 2**

Jennifer is a 15-year-old Caucasian female who was referred for complaints of chest and flank pain. The onset of her pain coincided with a respiratory infection that was eventually diagnosed as pneumonia. Her pain persisted despite effective treatment of her pneumonia. In the six months prior to NICH enrollment, Jennifer experienced a 6-day hospitalization and 2 ED visits for pain-related concerns. At the onset of treatment, Jennifer was living with her mother, brother, and mother's boyfriend. She had previously been diagnosed with depression and an anxiety disorder. One year prior to NICH involvement, Jennifer had an incident of self harm behavior (cutting). Due to pain, Jennifer had not attended school for several months and reported that pain interfered with her sleep. Jennifer was overweight, socially isolated, and was sedentary much of the day. She had few effective strategies for coping with pain, and was relying upon prescription medications to manage her pain and anxiety. Records indicated that Jennifer's caregivers had a high level of conflict with medical providers, particularly in response to resistance from providers to continue prescribing opiates and lorazepam. Both caregivers also evidenced a high level of anxiety related to Jennifer's pain, often questioning whether her symptoms were a sign of a more serious medical condition (e.g., cancer). Regarding case conceptualization, Jennifer's reliance on medication for pain reduction likely led to short-term pain relief but also contributed to factors associated with long-term pain-related behaviors (e.g., sedentary activities, social isolation, avoidant coping, weight gain).

Jennifer received interventions in her home and community. On average, Jennifer's NICH interventionist met with Jennifer and/or her family once per week for approximately 1–2 hours. As part of care coordination, her interventionist met frequently with members of her medical team. Case management services were delivered to address Jennifer's academic

difficulties, as her interventionist met with the family and school officials to develop a plan to help her re-engage in school and assisted the family with exploring alternative educational options (e.g., online coursework). Problem-solving was provided to address difficulties with school attendance, homework completion, and effective coping. Family structuring was used to help Jennifer's mother increase household structure, including education and assistance related to appropriate rewards for desired behavior and removal of privileges for Jennifer's lack of follow through with house rules. Jennifer's NICH interventionist also assisted Jennifer with learning more adaptive coping techniques and set up contingency plans related to school attendance, homework completion, and use of active coping strategies. In order to increase Jennifer's level of physical activity, her interventionist helped her design an exercise plan that included low impact exercises (e.g., walking, swimming) and provided case management services to assist her with accessing a gym. Jennifer and her mother participated in communication skills training to modify maladaptive interactions related to pain and other stressors and were provided with frequent positive reinforcement for their efforts to accomplish daily goals. Her interventionist also assisted Jennifer with accessing volunteer opportunities that matched her interests (e.g., working at an animal shelter) and with utilizing individual therapy to address depression and anxiety. During her first 6 months following initiation of NICH, Jennifer did not experience any pain-related or other ED visits or admissions. Interventionist notes described quality of life improvements for the patient (e.g., improved mood, increased engagement in educational activities) and improved family functioning (e.g., reduced conflict, increased warmth).

#### **Case Study 3**

Matthew, an 11-year-old Caucasian male, was referred to NICH services due to abdominal pain and soon developed related non-epileptic seizures. Matthew was reportedly experiencing frequent and severe abdominal pain and was having seizure-like behavior as often as two to three minutes apart, but his medical team neither observed seizures nor could they find an organic reason for his pain and reported seizures. Ultimately, these seizure-like episodes were deemed to be non-epileptic seizures. In the 6 months prior to NICH, Matthew visited the ED 1 time and was hospitalized once for 3 days due to pain and seizure-like episodes. The initial evaluation by the NICH interventionist suggested that there was a high level of parental conflict between Matthew's parents following their recent divorce. The timing of Matthew's pain behavior and non-epileptic seizures appeared related to contact between his parents such as during custody changes. In response to Matthew's pain behavior and non-epileptic seizures, Matthew's parents spent increased time with one another to support Matthew, and Matthew indicated that he believed he could bring his parents back together. Ultimately, Matthew's pain and non-epileptic seizures were both positively reinforced (e.g., parents spending time together, parents giving special attention to Matthew) and negatively reinforced (e.g., would not have to attend school) by his parents. Moreover, due to his medical team's suspicion of a non-organic etiology for Matthew's seizures, Matthew's parents and his medical team had a less-than-ideal relationship. More specifically, Matthew's father would become so verbally aggressive during medical appointments that he was routinely escorted out of care meetings by a health provider on the medical team.

Matthew's family received a blend of care coordination, case management, and BFST in their home and in the hospital. On average, Matthew's NICH interventionist met with Matthew and/or his family once per week for approximately 2–3 hours. Care coordination for Matthew included assisting Matthew's medical team with incorporating alternative communication methods to be used with the family, especially for communication regarding the hypothesized cause of Matthew's pain and non-epileptic seizures. As part of BFST, problem-solving was implemented to help parents reinforce coping strategies when Matthew was in pain. Cognitive restructuring was used to address parental anxiety regarding whether Matthew had an actual medical cause for his pain behavior and seizure episodes. Communication skills training was used with Matthew's parents to formulate alternative approaches to interacting with Matthew's care providers as well as each other. Finally, family structuring was used to assist Matthew's parents with finding new methods of sharing custody of Matthew that resulted in less conflict as well as to increase their use of positive attention to Matthew for non-pain behavior. During his first 6 months of NICH involvement, Matthew experienced 2 pain-related hospitalizations that lasted for a total of 5 days. One was within a week of starting NICH treatment. The second was a planned inpatient stay; Matthew's interventionist provided case management services by helping his medical team connect Matthew with an inpatient rehabilitation program to monitor non-epileptic seizures outside of the presence of his family. Although the overarching goal of Matthew's treatment was to reduce unnecessary hospitalizations and medical costs, the NICH team concluded that a short-term inpatient stay in which Matthew was separate from his parents would be the most efficient way to rule out an organic cause of pain and seizure-like behavior. The team hoped that, despite a short-term increase in medical costs, the results of this stay would lead to reduced frequency of future hospitalizations and long-term costs. During this three day stay, Matthew was monitored using video electroencephalogram and did not experience seizures. Following discharge, his parents displayed increased understanding regarding the possible factors influencing pain and seizure-like behavior, and his family employed new skills upon his return home. According to interventionist notes, quality of life improvements were noted in the patient (e.g., increased social support from friends, improved mood) and his parents (e.g., improved mood, reduced stress), and family function improved (e.g., decreased conflict).

#### Summary of Hospitalization Days, ED Visits, and Costs

The number of hospitalizations and emergency department (ED) visits as well as the number of days spent in the hospital prior to and during treatment are included in Table 2. Two cases demonstrated reductions in hospital days after initiation of treatment. One case displayed a slight increase in hospital days, but as described above, one of these hospital stays was a planned admission. Based on hospitalization data, two of the three participants experienced decreased costs while the third participant experienced an increase in costs related to hospitalization. Mean reduction was \$20,524.93 per youth over a 6 month period. Overall, participation in NICH was associated with less total hospitalization-related costs than prior to treatment (see Table 2).

# Discussion

This series of case studies is part of the beginning of a program of research focusing on the development of a treatment model for youth with complex and chronic medical conditions who are not responding to traditional medical and/or psychological care. These cases demonstrate that NICH may be a promising intervention for youth with chronic pain and associated high healthcare utilization. Indeed, two of the three youth in this study demonstrated decreases in healthcare utilization and costs from pretreatment to six months following treatment initiation. Anecdotal observation also showed improved quality of life for these youth. Across the 3 cases, changes in hospitalizations were estimated to result in substantial reductions in hospitalization-related costs over a 6 month period. Because this estimate does not include the costs of NICH provision, it does not represent total cost savings. However, this estimate also does not include possible reductions in indirect (e.g., parental employment, transportation) and direct (e.g., diagnostic procedures, surgery) costs, which may show additional cost savings.

There are several strengths of the NICH program and the current case study. The NICH treatment program addresses some of the limitations of previous psychological treatments involving youths with chronic pain. Unlike many typical treatments for youth with chronic pain, the NICH program targets youth whose families are unable to bring them in for officebased appointments due to challenging living conditions and psychosocial problems (see Table 1). As such, the youth included may be more representative of the most difficult-totreat youths with chronic pain and their families. In addition, this case study includes objective (e.g., healthcare utilization data) measures of treatment outcomes as opposed to relying solely upon youth and parent report. Finally, because the NICH program does not exclude youth with multiple presenting problems (e.g., multiple medical and/or mental health problems), this study includes youth with complex presentations who might otherwise be removed from other programs and research. For example, Matthew was included despite the fact that he presented with non-epileptic seizures in addition to pain. Although inclusion of patients with complex problems may result in a less clear diagnostic picture and the potential for greater variation in treatment response, such youth also likely represent the more difficult-to-treat patients encountered in real-world medical settings.

There are also a number of strengths associated with the development and implementation of NICH. As noted in a recent report (Berry, Agrawal, Cohen, & Kuo, 2013), many of the interventions implemented for youth with complex medical conditions tend to lack coordination, are reactive (as opposed to proactive), underappreciate the psychosocial contributions to youth health, and neglect the role of parents. In contrast, the provision of NICH is consistent with the model of care recommended in this report. That is, NICH is provided by a single interventionist who comprehensively addresses multiple needs (i.e., acute and chronic medical, functional, and psychosocial), coordinates care among health professionals, and formulates effective intervention plans to increase youth functioning while proactively assisting families with problem-solving around adherence problems that are likely to occur in the future. Taken together, NICH aims to maximize youth functioning, minimize the impact of chronic pain on the youth and family, be as time-limited as possible, and reduce avoidable hospitalizations and associated healthcare costs.

Although an examination of the specific mediators of treatment effects was beyond the scope and power of the current case study, the improvements observed may be due in part to the explicit focus of NICH on addressing youth, parent, and family problems in the natural environment. Given the wealth of evidence regarding the relationship between parental response and youth pain experiences (e.g., Langer, Romano, Levy, Walker, & Whitehead, 2009; Lynch-Jordan, Kashikar-Zuck, Szabova, & Goldschneider, 2013; Welkom, Hwang, & Guite, 2013), it seems possible that NICH interventions targeting parent-child interaction patterns would result in improved youth pain experience and decreased healthcare utilization. It is also possible that NICH interventionists improved the overall family environment by reducing overly controlling parenting or increasing adolescent autonomy, which have also been associated with poor outcomes in youth with chronic pain (Palermo, Putnam, Armstrong, & Daily, 2007; Sil et al., 2013). In these cases the NICH interventionists often used BFST approaches to address maladaptive pain-related interactions between youth and their parents, including parental responses to pain (e.g., overly solicitous, catastrophizing). When assisting the family with modifying these interactions, the NICH interventionist would help problem-solve alternative ways for parents to respond to their child's pain (e.g., model calm demeanor while validating pain experience, encourage engagement in day-to-day activities despite pain). NICH interventionists routinely coached both youth and their caregivers in the use of adaptive coping skills (e.g., behavioral activation, relaxation strategies). Alternative strategies that may have also led to reductions in healthcare utilization include assisting youth with re-engaging in day-to-day activities (e.g., attending school, accessing social supports) and increasing youth activity level through the use of low-impact exercise plans, gym memberships, and behavioral contracts. Ultimately, NICH interventionists tailored treatment to the specific needs of each family in their environments, resulting in several pathways by which NICH may have directly or indirectly influenced medical utilization.

The provision of care coordination and case management may have also resulted in decreased utilization. These families reported having had poor access to intensive, preventative, and effective healthcare. Families reported having few resources and indicated that significant life stressors (e.g., financial insecurity) were considerable barriers to treatment adherence. In addition, these families were seeing multiple providers who may not have given consistent recommendations, and both the families and care providers reported conflict associated with the care relationship. NICH interventionists assisted families with accessing an appropriate level of care, developing a decision-making process around healthcare use, and effectively communicating with care providers. Regarding case management, the NICH interventionist was in contact with educational staff and community agencies to ensure re-engagement in school and prosocial activities and increase the families' access to pertinent resources (e.g., transportation, exercise facilities). Ultimately, additional research is needed to evaluate the mechanisms by which NICH leads to decreased hospitalizations in youths with chronic pain.

Given the retrospective nature of this study, we were unable to follow some of the case study guidelines (Ernst, Barhight, Bierenbaum, Piazza-Waggoner, & Carter, 2013), resulting in several limitations. First, with no control group it is possible our results reflect normal variability and/or regression to the mean. Second, due to small sample size the statistical

power is limited. Third, although chart reviews did encompass the youth's primary care facility as well as all other major facilities in the region, it is possible that some youths were hospitalized at other hospitals. Fourth, given that we have yet to tease apart NICH program costs specifically related to serving youth with chronic pain from the overall program costs, we are unable to draw firm conclusions regarding the extent to which NICH leads to actual cost savings. Finally, evaluation of psychosocial outcomes relied upon interventionist report, limiting the conclusions that could be drawn regarding mediational processes. Relatedly, the use of interventionists as reporters of outcome and as authors introduces bias. However, including treatment team members as authors on case studies and feasibility studies is a common practice and does not invalidate the objective results (i.e. hospitalization records). Future evaluations of NICH will benefit from a study design with a control group, a larger sample size, improved measurement of psychosocial outcomes, and an expanded exploration of hospitalization records as well as program- and utilization-related costs. Future work might also develop screening tools and procedures to help identify this subgroup of youth, which could prevent high utilization by implementing intervention earlier.

Despite limitations, the outcomes from our preliminary work support the further application and evaluation of NICH for youth with chronic pain. Ultimately, clinical trials with larger sample sizes are needed to determine whether NICH is efficacious for youth with chronic pain. However, given the considerable cost and poor psychosocial outcomes evidenced in this population of youths, interventions such as NICH warrant consideration by care providers, institutions, and governing bodies when determining service provision for this population.

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## Table 1

Psychosocial Risk Factors and Comorbid Problems of Youth and Families Enrolled in NICH

| Variable  | Case 1 | Case 2 | Case 3 |
|---|--------|--------|--------|
| Youth:  |        |        |        |
| Opiate Prescription                               | Yes    | Yes    | Yes    |
| Truancy from school                               | Yes    | Yes    | Yes    |
| Psychological or mental health diagnosis          | Yes    | Yes    |        |
| Alcohol and/or drug use                           | Yes    | Yes    |        |
| Sexually active                                   |        | Yes    |        |
| Primary Caregiver/Family:                         |        |        |        |
| Caregiver unemployed or under-employed            | Yes    | Yes    |        |
| Unstable housing                                  |        | Yes    |        |
| Caregiver mental health diagnosis                 | Yes    | Yes    | Yes    |
| Caregiver history of alcohol and/or drug problems | Yes    | Yes    | Yes    |
| Caregiver history of domestic violence            | Yes    | Yes    |        |

## Table 2

Hospital and emergency visits and estimated costs in the 6-month period Pre- and Post-NICH program initiation

|           | Hospital Admissions | Emergency Department Visits | Total Days Spent in Hospital |
|-----------|---------------------|-----------------------------|------------------------------|
| Pre-NICH  |                     |                             |                              |
| Thomas    | 4                   | 11                          | 22                           |
| Jennifer  | 1                   | 2                           | 8                            |
| Matthew   | 1                   | 1                           | 4                            |
| Post-NICH |                     |                             |                              |
| Thomas    | 0                   | 0                           | 0                            |
| Jennifer  | 0                   | 0                           | 0                            |
| Matthew   | 2                   | 0                           | 5                            |

|           | Admission Costs | <b>Emergency Department Costs</b> | <b>Total Hospitalization Costs</b> |
|-----------|-----------------|-----------------------------------|------------------------------------|
| Pre-NICH  |                 |                                   |                                    |
| Thomas    | 37,237.20       | 8,483.20                          | 45,720.40                          |
| Jennifer  | 20,311.30       | 1,542.40                          | 21,853.60                          |
| Matthew   | 10,155.60       | 771.20                            | 10,926.80                          |
| Post-NICH |                 |                                   |                                    |
| Thomas    | 0               | 0                                 | 0                                  |
| Jennifer  | 0               | 0                                 | 0                                  |
| Matthew   | 16,926.00       | 0                                 | 16,926.00                          |