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Final DNP Project Report

Title: Stress in Parents of Children with Type 1 Diabetes

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July 31, 2015

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DNP Practice Inquiry Project Overview

Pediatric healthcare providers across the country care for many children with complex chronic diseases. Many of these children are not developmentally mature enough to manage their disease process, leaving the parent of the chronically ill child to manage their disease. The parent of the chronically ill child may experience stress related to their child's illness, termed pediatric parenting stress, and may have difficulty dealing with this stress (Streisand, Kazak, & Tercyak, 2003). The manuscripts in this Practice Inquiry Project further investigate the relationship between pediatric parenting stress and the health of the parent and the chronically ill child. The instruments used to measure pediatric parenting stress are also examined as well as their use in parents of children with different chronic illnesses. Finally, pediatric parenting stress is examined in a small cohort of parents of children with type 1 diabetes, the results of the data are examined, and the practice implications of this data for pediatric healthcare providers are discussed.

Importance of Stress Identification in Parents of Diabetic Children

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Abstract

Pediatric providers across the United States often deal with a variety of chronic illnesses in their patient population. Type 1 diabetes is a condition that is often difficult for parents to manage and can cause significant stress in parents who cannot learn to deal with their child's illness (Carpentier, Mullins, Chaney, & Wagner, 2006; Streisand et al., 2008). In an effort to help recognize pediatric parenting stress, researchers have been developing and testing stress measurement tools in parents of children with type 1 diabetes. Two of these tools include the Pediatric Inventory for Parents and the Parenting Stress Index. It is important to recognize stress in parents of children with type 1 diabetes to prevent future psychological problems in both the parent and child and to facilitate coping (Streisand et al., 2008). Health professionals who commonly see parents of children with type 1 diabetes should recognize this problem and assess their parent population to determine whether adequate coping with stress is taking place. This assessment by providers can help improve the health of the parent, the child with diabetes, and the entire family unit.

Introduction

Type 1 diabetes (DM1) is a complex pediatric chronic illness. For providers, one of the complexities of managing the disease process lies in the modifications that are made to the treatment regimen as the child develops. This can often be a challenge as the child's glycemic control can vary as the child grows, sometimes causing frequent hyperglycemic and hypoglycemic episodes which require therapy adjustments (Hatton, Canam, Thorne, & Hughes, 1995; Patton, Dolan, Smith, Thomas, & Powers, 2011; Streisand, Swift, Wickmark, Chen, & Holmes, 2005). One aspect of this illness often not addressed by providers is how the family of the diabetic child is coping with this illness. Many children who are diagnosed with DM1 are not developmentally capable of managing their disease independently; therefore, parents must comprehend and assist in managing their child's treatment regimen. These additional responsibilities often add to the already stressful job of being a parent. Streisand et al. (2008) noted that parents of children with DM1 who were stressed about their child's disease were at greater risk for developing psychological problems later, such as anxiety or depression. Furthermore, parents' psychological symptoms caused by stress have been previously linked to an increased risk of depression in children (Streisand et al., 2008). Since the relationship between parent stress and parent and child well-being was established, much research has been focused on providing more evidence about the relationship, designing tools to measure parent stress levels, and providing interventions to facilitate psychological coping with stress in parents of children with type 1 diabetes.

Linkage of Parental Stress and Child's Diabetes

Stress is one of many factors that can affect the psychological functioning and outcomes of adults and children. Boyd and Canfield (2008) refer to Lazarus and Folkman's 1984 research,

which defines “stress as a relationship between the person and the environment that is appraised by the person as taxing” which triggers the individual to fear that his or her well-being is threatened (p. 222). Inability to cope with stress by individuals can lead to either the worsening or development of mental health problems (Boyd & Canfield, 2008). A variety of mental health problems can be associated with high levels of unalleviated stress. Two mental health problems in particular associated with the negative psychological consequences of unalleviated stress include anxiety and depression (Schneiderman, Ironson, & Siegel, 2005). In parents of children with chronic illnesses, a specific type of stress, termed “pediatric parenting stress”, has been identified. This pediatric parenting stress is defined as “stress related to caring for a child with a medical illness” (Streisand, Kazak, & Tercyak, 2003, p. 245). In order to prevent mental illness and improve the health of individuals, early identification and treatment of inadequate coping with pediatric parenting stress is crucial.

Pediatric parenting stress has been researched in a variety of different populations of parents of children with chronic illnesses. Parents of children with type 1 diabetes have been found to have high levels of stress associated with managing their child’s chronic medical condition (Moreira, Frontini, Bullinger, & Canavarro, 2014; Streisand et al., 2008; Lewin et al., 2005; Hilliard, Monaghan, Cogen, & Streisand, 2011). However, this stress appears to be limited to the primary caregiver of the child, since Mitchell et al. (2009) found particularly low levels of stress in their sample of fathers of children with type 1 diabetes. It should be noted that in the study conducted by Mitchell and colleagues (2009), many of the fathers in their sample were not responsible for the majority of the disease management for their child. Nevertheless, parents with high levels of pediatric parenting stress are at risk for psychological distress, including anxiety or depression (Patton et al., 2011; Streisand, Mackey, & Herge, 2010;

Streisand et al., 2008; Streisand et al., 2005; Carpentier, Mullins, Chaney, & Wagner, 2006; Mullins et al., 2004). Partially in-line with these findings, Moreira et al. (2014) found pediatric parenting stress was a risk factor for elevated anxiety levels in their parents of children with type 1 diabetes sample, but not a risk factor for depression. The growing body of evidence on pediatric parenting stress points to an undermet need of an intervention for psychological coping in this population of parents to promote improved mental health and functioning.

Unresolved pediatric parenting stress can also cause problems in the child with the chronic illness. High levels of parental stress may be sensed by the child with type 1 diabetes, putting the child at risk for developing negative psychological problems (Moreira et al., 2014; Sweeney, Mackey, & Streisand, 2014; Mullins et al., 2004). These negative problems can include anxiety and depression. It is also important to note that parents with higher levels of unresolved parenting stress report more frequent child behavior problems (Hilliard et al., 2011; Lewin et al., 2005; Hoff et al., 2005). Mitchell et al. (2009) noted these same problems in their sample of fathers of children with type 1 diabetes. Sweeney et al. (2014) noticed in their study that pediatric parenting stress appeared to negatively affect the relationship between parenting demeanor and child misbehavior. Sweeney et al.'s (2014) findings might help explain the findings of Hilliard et al. (2011), who noted that the reported misbehavior of the child with DM1 may be behavior that is developmentally appropriate for the child's age. The parents may be oversensitive to the behavior of the child with type 1 diabetes due to their high levels of parenting stress (Sweeney et al., 2014; Hilliard et al., 2011). Based on the current literature, there is a need for healthcare providers to adequately assess pediatric parenting stress and how family members of children with DM1 are coping. If indicators of dysfunction are present then these issues should be addressed to prevent further long-term complications.

Purpose

The purpose of this review is to examine the current literature surrounding pediatric parenting stress in parents of children with DM1. Second, two psychometric tools that have been used to assess pediatric parenting stress in parents of children with DM1 will be identified, examined, and one tool will be recommended based on the current literature. Other tools are available to assess parent stress in adults, but the two tools discussed have been commonly used to specifically examine pediatric parenting stress in parents of children with DM1 in current research. Third, gaps in the current literature surrounding stress in this parent population will be identified and recommendations on changing future healthcare practice will be suggested.

Methods

A systematic method was used to review the literature on this topic. In order to collect information about this topic, CINAHL, PsychInfo, Medline, PubMed and Google Scholar databases were utilized because of their wealth of information on psychology topics. The search terms that were applied were the following: parent stress, parental stress, type 1 diabetes, Pediatric Inventory for Parents, Parenting Stress Index, and psychometric. Articles were excluded if: the sample population of the study was not parents of children with DM1, if parent stress related to the child's DM1 was not examined, if the caregivers in the studies did not manage their children's diabetes primarily, and if no psychometric tools used to examine the parents' stress were listed. Articles were also excluded if they were published prior to 1995 or if no English print version was available. With these search terms, the relevant literature was reviewed to learn more about the impact of pediatric parenting stress on parents of children with DM1, the tools used to measure pediatric parenting stress, and current methods being trialed to improve parental stress and coping. Approximately 150 articles were critically reviewed to find

the most relevant, appropriate information on this topic and 10 cross-sectional studies, 3 cohort studies, one randomized-controlled trial, and one descriptive study were selected. Additional information about the psychometric tools was also found on the American Psychological Association's website.

Summary of Psychometric Tools

Two tools, the Pediatric Inventory for Parents and the Parenting Stress Index, have been used to evaluate parental stress in parents of children with DM1. The Pediatric Inventory for Parents (PIP) tool was originally developed and used to measure stress in the parents of children with cancer by the Children's Hospital of Philadelphia (Streisand, Braniecki, Tercyak, & Kazak, 2001). Broad questions were developed by the researchers constructing the PIP to make the tool generalizable to all parents of children with an illness. A variety of members from different specialties reviewed the tool and divided the questions into four domains: emotional functioning, role functioning, communication, and medical care (Streisand et al., 2001). The questions in these domains cover a variety of different responsibilities or emotions parents of children with DM1 will face.

The PIP is comprised of 42 questions, with a frequency and difficulty subscale which measures how frequently parents have stress associated with their child's illness and how difficult this stressor is for the parent. The PIP allows the surveyor to rate their stress based on a 5-point Likert scale ranging from one being "not at all" to five being "extremely" (Streisand et al., 2001). In the original study testing the PIP, the instrument demonstrated excellent internal consistency, with a coefficient alpha of 0.95 for the frequency subscale and a coefficient alpha of 0.96 for the difficult subscale (Streisand et al., 2001). The reliabilities for each domain demonstrated coefficient alphas greater than 0.80 as well. Based on these findings, the original

PIP appeared to be a reliable measure of pediatric parenting stress in parents of children with chronic illnesses (Streisand et al., 2001). In an attempt to generalize the instrument, other researchers have applied this tool to parents of children with DM1. From the data collected so far, the Pediatric Inventory for Parents appears to be a statistically valid and consistent method in measuring pediatric parenting stress in parents of children with DM1 (Hilliard et al., 2011; Mitchell et al., 2009). For the Frequency subscale, the internal consistencies range from 0.92 to 0.94 in parents of children with DM1 (Hilliard et al., 2011; Streisand et al., 2008; Streisand et al., 2005; Lewin et al., 2005). For the Difficulty subscale, the internal consistencies in the parents of children with DM1 population range from 0.94 to 0.96 (Sweenie et al., 2014; Hilliard et al., 2011; Streisand et al., 2008; Streisand et al., 2005; Lewin et al., 2005). Total internal consistency scores for the PIP range from 0.95 to 0.97 (Mitchell et al., 2009; Lewin et al., 2005). Therefore, the PIP appears to be a reliable option for use in measuring pediatric parenting stress in parents of children with DM1.

The Parenting Stress Index (PSI) is another scale that has been used to measure parenting stress in parents of children with chronic illnesses, including type 1 diabetes. This index was created in the United States in 1983 (American Psychological Association (APA), 2015) and it was originally developed to examine “parent-child interactions” that can cause stress (Fallahpour, Nathell, Rössler, Stieglitz, 2009). The tool contains three domains that contribute to stress: the “child characteristics” domain, the “parent characteristics” domain, and the “situational [or] demographic life stress” domain (APA, 2015). The child domain examines child behaviors that can cause stress in the parents, such as the child’s mood or hyperactivity (Fallahpour et al., 2009). The parent domain examines parental parenting behaviors and other factors that can add stress to the parent-child relationship, such as the parent’s health or their

relationship with their spouse. The final domain examines stressors that occur in everyday life that can affect the parent's relationship with their child over the last year. There are 120 questions on the PSI and it takes approximately 20 minutes to complete (APA, 2015). The demonstrated reliability of the child domain ranges from 0.78 to 0.88 and the reliability of the parent scale ranges from 0.75 to 0.87 (APA, 2015).

A shorter form of the PSI, designated the Parenting Stress Index-Short Form (PSI-SF), is available as well. The domains in the short form include: the "parental distress, parent-child dysfunctional interaction[,] and difficult child" domains (APA, 2015). The index contains approximately 36 questions and takes about 10 minutes to finish. The PSI-SF has been used in parents of children with DM1 to assess parental stress. Moreira et al. (2014) used a Portuguese translation of the PSI-SF to assess stress in their parents of children with DM1 and the tool demonstrated a reliability of 0.88. Mullins et al. (2004) had better results using the PSI-SF in their parent population, with a reliability of 0.96.

However, there are several criticisms of the PSI/PSI-SF when compared to the PIP and its use in parents of children with chronic illnesses. First, the PSI was not developed for all pediatric populations. The PSI was originally developed to assess stress in parents with children whose ages ranged from one month of age to twelve years old (APA, 2015). Therefore, this tool may not be applicable to parents of older adolescents with DM1. Second, the PSI was developed to measure the parent stress in generic parent-child relationships. The PIP was developed to specifically look at pediatric parenting stress in parents of children with chronic illnesses, such as cancer and diabetes (Streisand et al., 2001; Streisand et al., 2005). Third, few studies have used PSI/PSI-SF to examine stress in parents of children with type 1 diabetes (Mullins et al., 2004; Moreira et al., 2014). Further research would be needed to demonstrate that the PSI/PSI-SF

provides a more accurate or reliable evaluation of pediatric parenting stress in parents of children with chronic illnesses over the PIP. Therefore, based on the current literature available, it may be prudent to use the PIP as a tool to evaluate pediatric parenting stress levels in the practice setting instead of the PSI.

Discussion

Despite the promising findings of the available research, there are several issues with the literature that should be addressed in the future. The first problem involves the samples used in present data. Most of the studies involved relatively small, homogenous samples of primarily Caucasian, middle to upper class, well-educated families (Hilliard et al., 2011; Mullins et al., 2004; Carpentier et al., 2006; Streisand et al., 2008). This tends to limit the generalizability of this information. Parents from different backgrounds with different resources may have greater levels of pediatric parenting stress. For example, Streisand et al. (2010) and Streisand et al. (2005) found higher levels of pediatric parenting stress in high risk groups of the parents of children with DM1 population. Factors such as low socioeconomic status, non-Caucasian race, and limited supportive resources all increase the level of stress these parents face (Streisand et al., 2010; Streisand et al., 2005). Therefore, more information is needed on sample populations involving minority, less educated, and lower income parents. By gathering information and testing the psychometric tools available in different populations, a thorough, consistent method can be developed for evaluating all parents of children with DM1 who are not coping psychologically with their pediatric parenting stress.

The current literature also does not provide consistent and reliable advice on how to accurately assess pediatric parenting stress. First of all, no one tool has been deemed the “gold standard” when recognizing pediatric parenting stress in parents of children with DM1. Certain

researchers seem to use the PIP while others use the PSI to measure parent stress (Streisand et al., 2008; Mullins et al., 2004). Perhaps one tool is more effective at measuring certain kinds of stress in parents of children with type 1 diabetes and more explanation should be provided about this in the literature. Another problem with the tools being used to identify pediatric parenting stress is that most rely on self-report scales, which are not always reliable. The PIP itself is a self-report measure tool (Mitchell et al., 2009). The disadvantage of self-report measures is that they depend upon the sample population being mentally capable of answering the tools honestly and not exaggerating the answers to the questions. This dependence on mental competence proves problematic in parents of children with DM1 who may not be adequately coping with pediatric parenting stress, which could skew the results of the data.

Future Research and Practice Recommendations

There are several avenues on which researchers should focus their efforts in the future. First, more data should be collected on parents from different backgrounds that may be at greater risk for inadequate coping with pediatric parenting stress. This includes more information on minority populations, parents with differing educational levels, and parents from different socioeconomic spheres. The psychometric tools and interventions targeted at measuring and improving stress and coping in parents of children with DM1 should also be evaluated in these subsections of the population. Second, more data should be collected on the psychometric tools being used to measure stress in parents of children with DM1. If possible, a “gold standard” tool should be identified in order to adequately measure pediatric parenting stress in these parents. Steps should also be taken, if possible, to limit bias and error in these self-report measures. Third, interventions targeting at improving stress and coping in parents of children with DM1 should be tested thoroughly to determine what method of treatment best benefits parents who are

having trouble dealing with pediatric parenting stress. Much of the literature states that parental stress should be assessed and appropriate referrals made if inadequate coping is found, but no details are given as to what method of assistance would be best to help parents of children with DM1 cope with their stress. Also, more information should be collected on influencing factors that can help improve stress coping in parents of children with DM1. Rigorous testing should be completed on the intervention when developed, with data from several randomized controlled trials supporting the intervention if possible.

Despite the obvious gaps in the literature, the information speaks for itself. Inadequate management of pediatric parenting stress affects the entire family unit. It is essential that healthcare providers assess, identify, and make appropriate referrals for parent psychological problems early to prevent further family dysfunction (Sweenie et al., 2014; Patton et al., 2011; Hilliard et al., 2010; Streisand et al., 2010; Streisand et al., 2008; Carpentier et al., 2006; Streisand et al., 2005; Lewin et al., 2005). Prevention of further dysfunction leads to better outcomes and improved quality of life for all members of families with a child with DM1.

Conclusion

Pediatric parenting stress in parents of children with type 1 diabetes can pose many problems in families already dealing with the rigorous management of a chronic disease. If the stress is not adequately managed by the parents initially, then future psychological problems may occur in the parents and the child with DM1. It is important for future researchers to focus their efforts on determining a consistent method of assessing and treating those parents who are not adequately coping with their pediatric parenting stress. Once the tools for diagnosis and treatment are developed, the information can be disseminated to healthcare providers in the community. These providers can implement the evidence based information to help improve the

health of this at-risk population and promote the best quality of life for families of diabetic children.

Using the Pediatric Inventory for Parents to Evaluate Chronic Illness-Related Parenting Stress

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Abstract

Chronic illnesses are lifelong conditions that require meticulous surveillance in order to ensure adequate management. Parents of children with chronic illnesses are often responsible for their child's disease management, since the child often is not able to manage their own illness independently (Hatton, Canam, Thorne, & Hughes, 1995; Patton, Dolan, Smith, Thomas, & Powers, 2011). Chronic disease management can place a burden on the parents of children with chronic illnesses, and parents often develop associated stress. If parents cannot effectively cope with their stress, they often have difficulty managing their child's illness, leading to poorer outcomes for the child (Alves, Guirardello, & Kurashima, 2013). Practitioners should assess stress levels in parents to identify parents experiencing stress and assist in providing solutions for effective coping. The Pediatric Inventory for Parents (PIP) may be a useful tool for measuring stress levels in parents of children with chronic illnesses. Future research should focus on evaluating this tool's use parents of children with different chronic illnesses in order to validate the PIP for further use.

Description of the Problem

Throughout the country, many individuals and families are dealing with chronic illnesses. According to the Centers for Disease Control and Prevention (CDC) (2012), of the total number of deaths each year in the United States, 70 percent are due to chronic conditions. Chronic diseases are often complicated and costly to individuals and their families. Children with chronic conditions have unique needs. Younger children may not be developmentally capable to comprehend or manage their condition independently, so these management responsibilities often fall to the parents (Hatton et al., 1995; Patton et al., 2011). This can be extremely stressful for parents. Not only are parents charged with raising their child, but they must also learn how to cope with and manage their child's diagnosis until the child is able to take over their own disease responsibilities (Hatton et al., 1995; Konradsdottir & Svavarsdottir, 2011). In addition to this added role as a disease manager, the parent may also be raising other children or may have work obligations outside the home to provide for their family.

The disease management role may place an enormous burden on parents of children with chronic illnesses. Parents are often overwhelmed by the stress they experience related to the management of their child's chronic condition and have difficulty coping (Hatton et al., 1995; Merkel & Wright, 2012; Patton et al., 2011). This stress is termed pediatric parenting stress and is defined as "parenting stress related to caring for a child with a medical illness" (Streisand, Kazak, & Tercyak, 2003). Unresolved pediatric parenting stress has been linked to the development of mental health issues, such as anxiety and depression (Alves, Guirardello, & Kurashima, 2013; Guilfoyle, Denson, Baldassano, & Hommel, 2011; Patton et al., 2011; Streisand et al., 2008). Parents of children with chronic health conditions often have

responsibilities that include others, so it is essential that they develop coping strategies to prevent further complications that could jeopardize the health and functioning of the family unit.

Significance of the Problem for Advance Practice Nurses

Pediatric parenting stress in parents of children with chronic illnesses poses an extreme problem for advanced practice nurses, especially those specializing in pediatric healthcare. If parents of chronically ill children are expected to supervise their child's medical condition, but are unable to cope with high stress levels, it may put the chronically ill child and family at risk. Previous research has shown a link between parental stress levels and mismanagement of a child's chronic disease. Guilfoyle et al. (2011) noted that parental inability to cope with stress can affect the child's medical condition. Pediatric parenting stress has also been found to affect the chronically ill child in a negative psychological fashion, placing the child at risk for depression (Sweenie, Mackey, & Streisand, 2014; Moreira, Frontini, Bullinger, & Canavarro, 2014; Mullins et al., 2004). It is only logical that being unable to cope with stress as a parent would affect the parent's ability to handle their parenting responsibilities as well.

In order for advanced practice nurses to combat this problem, pediatric parenting stress and coping should be assessed frequently in families of children with chronic illnesses. Practitioners can assist families by acknowledging the stress associated with certain aspects of the child's chronic illness and by providing coping strategies to obstacles the parents or families will face. By assessing pediatric parenting stress levels and offering appropriate psychological support resources, pediatric advance practice nurses can strive for better medical management of their pediatric patients (Streisand et al., 2008; Hilliard, Monaghan, Cogen, & Streisand, 2011).

Intent of Integrative Review

The intent of this integrative review is to explore the use of one tool used to measure pediatric parenting stress levels of parents with children that have chronic illnesses. This review will specifically examine the Pediatric Inventory for Parents (PIP) and its application in parents of children with chronic conditions. If this tool is found to be applicable in different settings, advanced practice nurses may find it useful for integration in the clinical setting. By using a standardized tool to periodically evaluate stress levels in parents of children with chronic illnesses, medical providers can strive to provide the best quality of care for their patients by helping to improve the medical and psychosocial outcomes of the family.

Pediatric Inventory for Parents

The Pediatric Inventory for Parents (PIP) was designed specifically to measure the levels of pediatric parenting stress in parents of children with chronic illnesses. The tool was originally tested in parents of children with pediatric cancers at the Children's Hospital of Philadelphia (Streisand, Braniecki, Tercyak, & Kazak, 2001). The scale consists of 42 questions and responses are based on a 5-point Likert scale. The scale is divided into two subsections, with one subsection looking at how individuals feel about certain events (termed difficulty) and the other subsection examining how often certain events occurred within the last week (termed frequency) (Streisand et al., 2001). Four domains are present in both the frequency and difficulty subsections: emotional functioning, medical care, communication, and role functioning (Streisand et al., 2001). The questions in each domain evaluate certain aspects of pediatric parenting stress. For example, the communication domain examines how parents feel in communicating with medical providers or family members about their child's disease. If the parents are uncomfortable with conferring with their practitioner, the communication domain in

the difficulty portion of the PIP will indicate difficulties with this issue. The medical care domain of the PIP is of particular interest to medical personnel, since parental inability to fulfill their responsibilities in managing their child's condition will appear in this section if it is present. Streisand et al. (2001) noted coefficient alphas of 0.95 for the Frequency subsection and 0.96 for the Difficulty subsection of the PIP in their original study. The coefficient alphas for each domain were also 0.80 or higher (Streisand et al., 2001). Since the original research by Streisand and colleagues (2001), research has been conducted on the PIP to determine its usability in different subpopulations of parents of children with chronic illnesses.

Methods

In order to gather information regarding the PIP in parents of children with different chronic conditions, a CINAHL database search was undertaken, due to its wealth of information on psychology topics. Search terms used to locate relevant articles included chronic illness, Pediatric Inventory for Parents, and parent stress. Approximately 43 articles were found using the search keywords. Articles were excluded if the sample population studied did not involve parents of children with chronic illnesses. Only articles that used the PIP to examine parental stress in their sample population were included. All articles prior to the year 2005 and articles that were not available in English translations were also excluded. This yielded one descriptive article, three cross-sectional articles, and one quasi-experimental article examining pediatric parenting stress in parents of children with different chronic illnesses.

Synthesis of Literature

All five studies reviewed used the PIP to examine parental stress levels in parents of children with chronic illnesses and found the scale useful at measuring this pediatric parenting stress (see Table 1). According to Gray, Graef, Schuman, Janicke, & Hommel (2013), the PIP

was “specifically designed to assess chronic illness-related parenting stress in a pediatric cancer population and” it was “later validated in diabetes” (p. 237). The PIP has previously been reported to have an internal consistency between 0.80 and 0.96, but for the reviewed studies the internal consistency was higher (Guilfoyle et al., 2011). For example, in their samples, Hilliard et al. (2011) and Guilfoyle et al. (2011) reported an internal consistency greater than 0.94 in both their diabetes and inflammatory bowel disease (IBD) parent populations, respectively. This suggests that the PIP is a reliable tool that could be used in different parents of children with chronic illnesses populations. However, the PIP still needs further evaluation in other conditions in order to ensure that the scale reliably measures pediatric parenting stress levels.

Several researchers have attempted to validate the use of the PIP for measuring pediatric parenting stress in IBD in order to ensure the cross-sensitivity of the tool in chronic diseases other than those previously studied (cancer and diabetes). Gray et al. (2013) found that the PIP accurately measured parental stress levels in their sample population of parents of children with IBD, especially in the parents of children with Crohn’s disease. The more severe the disease symptoms in their children with Crohn’s disease, the higher the parental scores were in the difficulty and frequency domains of the PIP. Guilfoyle et al. (2011) compared their PIP parental scores in their IBD parent population to the PIP scores from different studies on other parents of children with chronic diseases and found that the PIP scores in parents of children with IBD “were similar to [the scores seen in] caregivers of youth diagnosed with type 1 diabetes” (p. 277). These similar scores could suggest that the PIP might be a reliable measure for examining pediatric parenting stress in both parents of children with type 1 diabetes and IBD. The PIP was also shown to be accurate in measuring parental stress as it related to the medical management of the child’s regimen in parents of tubefed children (Didehbani, Kelly, Austin, & Weichmann,

2011). Since the treatment regimens and disease progressions are totally different in these three populations, it would seem that the PIP may be a useful tool for measuring pediatric parenting stress levels in parents of chronically ill children.

The data provided by the articles reviewed identifies certain groups of parents who are at risk for limited ability to cope with their stress levels related to their child's chronic illness. Parents who are younger in age, have children who are younger in age, have fewer resources (social support or financial resources), and those parents of children who were recently diagnosed are more at risk for not adequately coping with their stress levels (Alves et al., 2013; Guilfoyle et al., 2011). If these parents are not able to effectively cope with the stress they are experiencing, the parent may externalize their stress which can negatively impact the child. Gray et al. (2013) found that adolescents were affected negatively by the stress levels of their parents, putting them at risk for increased depressive and anxiety problems. Younger children may react to parental stress by misbehaving or acting out, making it more difficult for the parent to manage their child's disease (Hilliard et al., 2011). In order for the child to have a better quality of life and healthier psychological outcomes, parents of children with chronic illnesses need to effectively manage their stress levels.

Another theme divulged from these articles details how pediatric parenting stress affects parent's own ability to function and do what is needed. Parents of children with type 1 diabetes often over-exaggerate behavior issues in their children, when the behavior their child is exhibiting may be developmentally appropriate for the child (Hilliard et al., 2011). These parents may be oversensitive to their child's behavior, which stems from their inability to cope with their pediatric parenting stress. Parents who ineffectively cope with their stress levels may also be at risk for increased anxiety and possible depression, which may affect their ability to

care for their child (Alves et al., 2013). It is essential that parental stress be adequately managed in parents of children with chronic illnesses, in order for the parents, family, and child to have a higher quality of life and for the child to have better outcomes in the treatment of their chronic conditions.

Critique of the Literature

The five studies reviewed on the PIP examined small cohorts of parents with children who have chronic conditions (see Table 1). Two studies examined between 100 and 150 parents (Alves et al., 2013; Gray et al., 2013), while the remaining studies had sample populations of less than 75 parents (Hilliard et al., 2011; Guilfoyle et al., 2011; Didehbani et al., 2011). Three of the studies used observational designs (Alves et al., 2013; Guilfoyle et al., 2011; Gray et al., 2013) and one study used a cross-sectional design (Hilliard et al., 2011) to gather data at a single point in time about parental stress levels. Although the chronic illness variability across the reviewed studies provides more validity for the usefulness of the PIP in different populations, future studies using randomized controlled trial or quasi-experimental designs in larger sample populations could improve the current research on the PIP.

Homogeneity of the samples used in the research studies limits the generalizability of the findings to all parents of children with chronic illnesses. One problem with the parent demographics is that most of the parents examined for stress were the mothers of the children and few fathers participated in the studies (Alves et al., 2013; Hilliard et al., 2011; Guilfoyle et al., 2011). Mothers and fathers may cope differently with the stress of managing their child's condition and it would have been more beneficial to include more fathers as participants in the studies. The demographics of the parents in several of the studies were similar; most were parents who were Caucasian, most were married, and most had an income of greater than 50,000

dollars annually (Hilliard et al., 2010; Guilfoyle et al., 2011). Parents from different socioeconomic backgrounds may have less social support, lower incomes, and may cope differently. Therefore, in the future it would be beneficial to examine pediatric parenting stress in parents with different racial, ethnic, financial, and educational backgrounds. Hilliard et al.'s (2011) sample consisted of parents of mostly younger children, either preschool or young school-aged, making it difficult to generalize the data to other parents of children from other age groups.

The inclusion and exclusion criteria of some of the studies may also have affected the findings about overall stress scores collected from the parents in the sample populations. Alves et al. (2013) specified in their data collection methods that parents of children “who. . .showed exacerbated feelings of sadness” were left out of the study for fear that these feelings could “interfere with the[ir] judgment capacity” (p. 357). Some research studies omitted parents of children with multiple chronic medical problems or parents who did not have English fluency. Parents of children with multiple chronic illnesses were omitted from the study by Hilliard et al. (2011). Guilfoyle et al. (2011) chose to recruit parents of adolescents with IBD for participation, but parents of adolescents with other illnesses besides IBD or families who were non-English speaking were not allowed to participate. Gray et al. (2013) excluded parents of adolescents who: had other medical conditions besides IBD, who were on corticosteroids (“>1 mg/kg/day”), or families who were not primarily English speaking (p. 238). These decisions to omit certain groups of parents could have affected the validity of the results from the reviewed studies and affected their interpretation of the findings.

There were some limitations to the methods employed in certain studies. Didehbani et al. (2011) investigated an intervention that demonstrated progress at decreasing parental stress and increasing the caloric intake of the children, but the setting of the intervention as well as the

resources available (and used) limits the findings of this study related to pediatric parenting stress. The study participants were housed on site during this study and an exorbitant amount of time was spent by the clinic staff in assisting parents, feeding the children, and collecting data (Didehbani et al., 2011). Their results demonstrated a decrease in the frequency and difficulty of pediatric parenting stress related to the medical care of the child over a period of time (Didehbani et al., 2011). However, the setting and intervention being employed by the researchers may have affected their PIP results related to the medical care of the tubefed children, since “medical staff were available for assistance” throughout the study (Didehbani et al., 2011). Parent stress levels could have been affected by the availability of medical personnel to assist in the treatment of their child.

Gaps in the Literature

Although the studies reviewed provide data that will assist in using the PIP to identify stress in parents of children with chronic illnesses, there are gaps in the literature that should be addressed. More information should be gathered about the use of the PIP in parents of children with other chronic conditions. So far the PIP has been examined in conditions that include cancer, obesity, IBD, bladder exstrophy, diabetes, and sickle cell anemia but more research is needed in parents of children with other chronic diseases such as arthritis, cystic fibrosis and asthma (Gray et al., 2013). Before the PIP is validated as an accurate measure of stress, it should be tested in other populations of parents to ensure that it accurately measures pediatric parenting stress in all parents of children with chronic illnesses populations.

Table 1: Review of Literature Concerning the PIP

Complete Citation	Alves, D.F.S., Guirardello, E.B., & Kurashima, A.Y. (2013). Stress related to care: The impact of childhood cancer on the lives of parents. <i>Revista Latino-Americana de Enfermagem</i> , 21(1). Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/23546319	Hilliard, M.E., Monaghan, M., Cogen, F.R., & Streisand, R. (2011). Parent stress and child behaviour among young children with type 1 diabetes. <i>Child: Care, health and development</i> , 37, 224-232. doi: 10.1111/j.1365-2214.2010.01162.x	Guilfoyle, S.M., Denson, L.A., Baldassano, R.N., & Hommel, K.A. (2011). Paediatric parenting stress in inflammatory bowel disease: Application of the pediatric inventory for parents. <i>Child: Care, health and development</i> , 38, 273-279. doi: 10.1111/j.1365-2214.2010.01200.x	Gray, W.N., Graef, D.M., Schuman, S.S., Janicke, D.M., Hommel, K.A. (2013). Parenting stress in pediatric IBD: Relations with child psychopathology, family functioning, and disease severity. <i>Journal of Developmental and Behavioral Pediatrics</i> , 34, 237-244. doi: 10.1097/DBP.0b013e318290568a	Didehbani, N., Kelly, K., Austin, L., & Weichmann, A. (2011). Role of parental stress on pediatric feeding disorders. <i>Children's Health Care</i> , 40, 85-100. doi: 10.1080/02739615.2011.564557
Research Question/ Study Purpose	To examine stress levels in parents of children with cancer and possibly find correlations between certain factors that may influence stress levels in these parents.	To examine parental stress and child behavioral problems in toddlers and preschoolers with type 1 diabetes. The researchers tested the hypothesis that there would be more complaints of child misbehavior in parents with higher stress levels. Blood glucose data was also obtained to see if this affected parental stress levels and/or reports of child misbehavior.	To examine stress levels in parents of children with IBD and discover whether any specific sociodemographic factors affect stress levels. Also, the PIP data obtained in this study was compared to the PIP data in other chronic illnesses to determine whether the PIP is a valid tool to examine stress in the IBD parent population.	To examine the PIP in the IBD population and to examine how parental stress affects family functioning and management of a child's IBD by the parents.	To answer several questions during the course of their intervention including: does parental stress change throughout the proposed study program? Do children with feeding disorders misbehave more when their parents are feeding them? Does parenting stress correlate between both the objective and subjective measures used? As parental stress decreases, does the caloric intake of the child increase?
Study Design	Descriptive or Observational design	Cross-sectional/ Correlational design	Descriptive or Observational design	Descriptive or Observational design	Quasi-experimental design
Independent Variable	Factors affecting stress	Parent stress levels; Blood glucose levels	Factors affecting parental stress, disease type	Parental stress levels	Parental stress (objective and subjective measures)

Dependent Variable	Parental Stress Levels	Child misbehavior; (parent stress levels-only when looking at blood glucose levels)	Parental Stress Levels	Management of child's medical condition; family functioning	Child misbehavior, child caloric intake
Sample	101 parents recruited who had children with cancer from pediatric clinic; parents ages ranged from 28-44 years; majority of parents were female, years of education for parents varied; children's ages ranged from 8 months-18 years and majority were being treated for cancer at time of interview of parents	73 children and parents; child had to be between 2 and 6 years old and have diabetes for longer than 6 months; 97% of parents were mothers, 80% earned more than 50,000\$ a year, 90% of parents were married; >50% of children were girls, almost 70% of children were white, and three-quarters of the children were on a conventional insulin regimen	62 adolescents (who were undergoing treatment for IBD) and one guardian; 49 had Crohn's and 13 had Ulcerative Colitis; majority of adolescents white, 45% female, and were 14-17 years old; parents were 40-50 years old, largely female, mostly married, and 90% earned more than 50,000\$ a year	130 teenagers and their parents; majority of adolescents were Caucasian, female, and suffered from Crohn's disease; majority of parents were mothers of child, were married, and belonged to the middle to upper class financially	18 families with children who were tubefed; ages of children- 23 months-11 years of age; parents-26-48 years of age; 14 children/parents were white, 2 children/parents were Hispanic, one parent/child was African American and one child/parent was Asian
Setting	Pediatric Clinic at <i>Hospital do Câncer A.C. Camargo</i> and from <i>Associação dos Pais e Amigos da Criança com Câncer e Hemoglobinopatias</i>	Participants selected from a "mid-Atlantic city" clinic specializing in diabetes (clinic part of a pediatric hospital)	Data collected at clinic visits at 2 hospitals in northeast and Midwest; other data obtained via telephone interview	Gastroenterology clinic that specializes in pediatrics in South, Northeast, or Midwest US (sample taken from a larger study population using 3 hospitals in these locales)	Our Children's House Clinic in Dallas, TX (at Baylor)
Conceptual Framework	Hans Selye's Stress Theory; Orem's Self Care Deficit Theory; Roy's Adaptation Model	Hans Selye's Stress Theory; Roy's Adaptation Model; Health Belief Model	Hans Selye's Stress Theory; Roy's Adaptation Model	Hans Selye's Stress Theory; Roy's Adaptation Model; Orem's Self Care Deficit Theory	Hans Selye's Stress Theory; Health Belief Model; Roy's Adaptation Model
Data collection methods	Parents interviewed in the clinic setting and demographic information was obtained; two questionnaires to evaluate parental stress levels were also	Questionnaires filled out by parents during scheduled appointments, by phone, or returned by mail; blood glucose data collected 3 times-initially by	Data collected during clinic visits or by telephone interview; data about severity of child's illness obtained from child's gastroenterologist; monetary	Participants approached at clinic visits; adolescents and parents offered questionnaires to fill out independently; monetary compensation provided for participation	Total caloric intake was tabulated by a nutritionist during each child's meal; parent stress levels were assessed at 3 different time periods during the intervention: at the beginning of phase 1

	administered; data collected over a 6 month period in the clinic setting	questionnaire and then in two subsequent telephone check-ups; monetary compensation provided for participation	compensation provided for participation		(parent observation and staff feeding child), at the beginning of phase 3 (when parent begins to assist in feeding child), and prior to discharge
Data collection measures	Brazilian versions of the Pediatric Inventory for Parents (PIP) [42 questions; two subsections concerning frequency and difficulty; four domains that examine role function, communication, medical care, and emotional functioning; 5 point Likert Scale] and the State Trait Anxiety Inventory (STAI) [examines state anxiety and trait anxiety; only state anxiety examined in this study; 40 questions; 4 point Likert Scale]	Pediatric Inventory for Parents (PIP) and State Trait Anxiety Inventory (STAI) [same as previously described] used to evaluate parental stress; Eyeberg Child Behavior Inventory (ECBI) [36 questions, 7 point Likert scale] used to evaluate child misbehavior; daily recall used to monitor blood glucose in child; sociodemographic questionnaire	Demographic questionnaire; Pediatric Inventory for Parents (PIP) [same as described previously] used to evaluate stress in parents; Pediatric Crohn's Disease Activity Index (PCDAI) [evaluates physical exam findings, growth, and lab values] and the Lichtiger Colitis Activity Index (LCAI) [looks at eight Ulcerative Colitis symptoms] were used to evaluate disease severity in adolescents	Sociodemographic questionnaire; Pediatric Inventory for Parents (PIP) [same scale as previously described] used to assess parental stress; McMaster Family Assessment Device (FAD) used to look at family dynamics [6 domains, 4 point Likert scale]; Youth Self-Report (YSR) and Child Behavior Checklist (CBCL) used to assess functioning of child; Pediatric Crohn's Disease Activity Index (PCDAI) [short form] and Lichtiger Colitis Activity Index (LCAI) used to examine severity of IBD	Subjective measures of parent stress included the Pediatric Inventory for Parents (PIP) and the State Trait Anxiety Inventory (STAI) [same as previously described]; Objective measure of stress was salivary cortisol levels
Reliability and Validity		PIP consistency of .94-.96, STAI consistency of .88-.93, and ECBI consistency of .92 in this study	Previous consistency of PIP of .80-.96 and .95-.96 in this study; PCDAI consistency of 0.95, and LCAI consistency of .85 in this study	Previous PIP reliability in cancer population of .95-.96; reliability for FAD in this sample was .86	PIP previously demonstrated reliabilities ranging from .80-.96; STAI previously demonstrated reliabilities of 83-.94
Statistical Analysis	Descriptive statistics; inferential statistics; significance testing	Descriptive statistics; Welch's <i>v</i> statistic; chi square; root-mean-square error of approximation;	Descriptive statistics; analyses of variance; t-tests	Descriptive statistics; significance testing; t-tests; analyses of variance	Descriptive statistics; analyses of variance; significance testing

		standardized root square mean residual; chi-square difference testing			
Key Findings	According to the results from the PIP questionnaires, parents experienced stress from procedures being performed on their child, the child's hygiene regimen, from feelings related to the possible terminal prognosis of their child's cancer, concerns about the child's future, and concerns about illnesses of other children; the PIP results also showed that parents who were younger in age, who had younger children, and had children just recently diagnosed experienced more stress; the STAI showed limited income as being a stressor as well; the PIP and STAI showed moderate to strong correlation in measuring stress in most of their domains	STAI stress scores higher than normal for mothers examined; PIP scores not significantly high, but higher than parents of older children with diabetes; ECBI scores higher concerning child behavior problems than normal children; positive correlation between child behavior issues and parental stress levels; no positive or significant correlation between glucose levels and parental stress/child behavior issues; hypothesis confirmed in this sample population because significant, positive correlation demonstrated in sample between parental stress levels and reported child behavior problems	t-tests elucidated no differences in the frequency and difficulty domains of PIP between different chronic illnesses and IBD; younger parents were found to have higher PIP scores; parents who had higher levels of education had lower PIP scores; PIP scores in IBD were found to be lower than in other pediatric chronic illnesses; the PIP scores in this study were found to be similar to PIP scores of parents with children with Type 1 Diabetes	Consistencies for both subsections of PIP were .96; consistencies for four domains of PIP were .77-.93; in families who exhibited lower levels of family functioning on the FAD, the parents showed higher levels of stress on the PIP scale; parents with higher levels of stress reported greater amounts of externalizing and internalizing symptoms in their teenager; adolescents reported more internalizing behavior when their parents were more stressed; higher PIP scores correlated with higher scores on the PCDAI; however, when higher scores were evident on the LCAI, higher PIP scores were not seen in the sample	Statistically significant changes in seen in the role function and medical care sections of the PIP over time, which correlated with significant changes in parental cortisol levels; caloric intake of the children also significantly increased over time; there was a significant positive correlation between misbehavior during feeding and the parents feeding their children; the PIP and STAI significantly correlated in 1-2 parameters at data collection points two and three; STAI stress levels correlated with caloric intake of the child from phase 1 to 3, where the PIP and cortisol levels did not correlate at these time points
Limitations	Convenience sampling used to recruit sample; non-legal guardians of children or parents who were considered "overly-emotional" were excluded from	Children with other chronic health issues (other than type 1 diabetes) excluded; not generalizable due to homogeneity of sample; mostly mothers	Only parents of adolescents examined; adolescents with other medical conditions or non-English speaking families were excluded from the	Only adolescents with IBD and their parents recruited; adolescents with other medical conditions, on corticosteroids (>1 mg/kg/day), or non-English	Only participants were tube-fed children, no variety in children with eating disorders; sample size was small; limited cultural variability of sample group; levels of

	recruitment; majority of parents sampled were mothers	interviewed; data collected once- not generalizable due to rapid development of children during this time in this age group; no specific parameters for blood glucose data collection methods for parents (didn't have to consult meter for example); some newer diagnosed children may be in honeymoon phase	study; only adolescents on a certain treatment pathway used (on 5-ASA or 6-MP or aziothiaprine used); sample size of study population was small; children with IBD had similar demographics; mostly mothers interviewed in this sample	speaking were excluded; mostly mothers interviewed; sociodemographics of sample group were relatively the same	social support and ability to cope not measured in parents, which can affect stress levels; time consuming intervention may not be cost-effective (program involved different hospital staff, parents/children participated for mean of 28 days); parents may have underreported levels of stress on self-report questionnaires
Results and/or implications	Demographic data showed that mothers usually provide the care for their children with cancer and that children rely on their parents for their emotional needs in dealing with the disease and treatments; many mothers also do not work in order to provide care for their child, which was consistent with previous findings; parents found to be at risk for greater stress were: those who were younger in age, those whose children were recently diagnosed (having not been able to cope yet), and those who had younger children (younger children are less independent and able to care for	In younger children with type 1 diabetes, parental stress levels appear to correlate with higher reports of child behavior issues; behavior issues may be appropriate for these children (developmentally) but these issues may increase parent's difficulty in managing the child's disease and therefore increase parental stress levels; metabolic problems that may occur with the child's diabetes do not significantly impact parental stress levels or child behavior issues according to this study; parents who experience higher levels of stress may report more	Parents who were younger in age had more difficulty in dealing with stress related to their child's IBD, particularly when it relates to communicating with healthcare providers; lack of social support may have contributed to higher parental stress in parents who were younger in this population; parents of children with IBD have lower levels of stress than parents of children with other chronic illnesses; the lower levels of stress in the IBD parent population may be due to the fact that most of the adolescents in the sample had a mild	Based on the results of this study, the PIP can be used to evaluate parental stress levels in parents of children with IBD; PIP may be useful for examining stress in other populations of parents of children with chronic diseases; parents in families that are dysfunctional have higher levels of stress, putting the parents and children in these families at risk for ineffective coping and inadequate disease management; parental stress can affect the emotional well-being of adolescents with IBD; parents of children with Crohn's disease reported greater levels of stress when the teenager was in the severe phase of the	The stress of parents regarding their child's medical care declined across the intervention as measured by the medical care section of the PIP, which was probably due to the fact that the intervention took place in a clinic setting with medical personnel available to the parents; cortisol stress levels increased from phase 1 to phase 3, indicating parent's stress levels increased; however, stress levels showed no increase on the STAI or the PIP scales from phase 1 to phase 3, meaning the parents probably under-reported their stress levels, which has occurred in previous studies; child misbehavior during

	<p>themselves); parents who have children with cancer are often hypervigilant about their child's health and worry about the disease worsening or re-emerging; the emotional portion of the PIP correlated with the state version of the STAI, meaning that parent's emotional functioning was impaired by the stress/anxiety they were experiencing, which can affect their ability to care for their child and take care of themselves and their family; parents of children with chronic illnesses should be administered tools to evaluate their levels of stress and coping in order to facilitate functioning at the family level and ensure that the ill child's condition can be managed well by the parents; by helping the parents cope with their stress, medical staff create a rapport with the family</p>	<p>frequent or difficult behavior problems with their child, due to their heightened sense of vigilance over their child's behavior; healthcare providers can assist in decreasing parental stress levels in this population by discussing difficulties parents may be having with managing their child's medical regimen or behavior, which can lead to better outcomes for the family as a whole</p>	<p>stage of the disease during the study or may be due to IBD not being an illness with a high mortality rate; the adolescents examined in this study could help manage their illness, which may have assisted in lowering parental stress levels in this sample; the parents in this sample may have had access to more assistance (resources) due to their demographic makeup; parents from lower socioeconomic groups may exhibit higher stress levels in dealing with their child's chronic illness; future studies should examine parental stress during different phases of IBD to see if parental stress levels change as the child's illness changes; PIP may be a valid tool that can be used to evaluate parental stress levels in the pediatric IBD population</p>	<p>disease process (however, this correlation was not present in parents of adolescents with ulcerative colitis- could be since the severity of ulcerative colitis is usually less than that of Crohn's disease); since stress can negatively affect parents of children with IBD (and with other chronic conditions) parents should be assessed by healthcare professionals regularly; the PIP is a quick and easy tool that can be distributed during clinic appointments in order to measure stress</p>	<p>feeding increased when parents began feeding their children in the study although the caloric intake of the children increased throughout the intervention; STAI and PIP correlated concerning parental stress at discharge; the intervention appears effective since child caloric intake increased throughout the program despite the changes in parental stress levels; one implication for practice is the necessity for practitioners to monitor parental stress levels in order to help parents cope with this stress, since parental stress can affect their ability to monitor their child's condition as well as affect the behavior and feelings of the child</p>
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Recommendations for Nursing Practice

Assessing and managing the stress levels in parents of children with chronic illnesses is important to promote the health of the family unit (Gray et al., 2013; Hilliard et al., 2011). Based on the current literature, it would be beneficial for providers to use the PIP to assess pediatric parenting stress levels in parents of children with certain chronic illnesses such as: cancer, type 1 diabetes, IBD, tubefed children, bladder exstrophy, obesity, and sickle cell anemia (Gray et al., 2013; Hilliard et al., 2011; Streisand et al., 2001; Didehbani et al., 2011). Providers in all settings should modify their practice to incorporate an evidence-based method of assessing pediatric parenting stress in parents of children with chronic conditions. This parent population cares for children who often are not capable of managing their conditions independently. If stress is not managed by parents, the health of the parents and children may suffer. Providers should be especially vigilant in recognizing at-risk populations, such as younger parents or parents with younger children, and intervene early in their stress management process in order to promote better outcomes (Hilliard et al., 2010). Advance practice nurses in the community and acute care settings must recognize pediatric parenting stress in parents of children with chronic conditions and develop a plan of action to assist parents in developing healthy coping skills.

To develop a successful plan of action in this parent population an evidence-based tool must be utilized to identify stress in these parents. The PIP is a useful tool providers could implement in their practice, despite its not being assessed in all different populations of parents of children with chronic diseases as of yet. Gray et al. (2013) commented on the brevity of the scale and noted that this makes the tool ideal for use in a clinic setting, where the appointments are often brief. Children with chronic conditions typically are followed in a clinic setting

regularly, which would allow providers to follow up with the parents in a timely manner.

Regular appointments would also allow providers to trend the stress of the parent over a longer period of time, to see if the parent is beginning to develop adequate coping strategies to manage their pediatric parenting stress. By addressing how the parent is coping with the child's illness, medical providers may foster a sense of trust with parents. This sense of trust can help create a rapport with parents, opening the channels of communication which can help ensure that parents have a better understanding and management of their child's condition.

Conclusion

The current literature available demonstrates an important undermet need to assess pediatric parenting stress in parents of children with chronic illnesses (Didehbani et al., 2011; Gray et al., 2013). The PIP appears to be a promising tool to assist providers in assessing pediatric parenting stress in parents of children with certain chronic conditions (Gray et al., 2013; Hilliard et al., 2011; Streisand et al., 2001). Hopefully future research on the tool will generalize its use to parents of children of all chronic diseases. Advance practice nurses and other healthcare providers can assist these parents by assessing their stress levels and providing solutions to assist parents in developing healthy coping strategies (Hilliard et al., 2011). By assisting parents of children with chronic illnesses, providers can improve the health of the child, parent, family, and community.

Using the Pediatric Inventory for Parents to Evaluate Stress in Parents of Diabetic Children

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Abstract

Diabetes is one of the most common chronic diseases in the U.S (Centers for Disease Control (CDC), 2013). As with other childhood chronic health conditions the parent is often responsible for understanding and developing skills to manage their child's condition. This can be a daunting experience for parents. Recent research has demonstrated that parents of children with diabetes encounter a great deal of stress, and are at risk for anxiety and depression related to the diagnosis and management of their child's condition (Hatton, Canam, Thorne, & Hughes, 1995; Streisand et al., 2008). This can often have detrimental psychological effects on both the parent and the child (Mullins et al., 2004). In order to promote effective coping and promote the health of the family unit, providers should assess the stress levels in parents of children with chronic illnesses and offer support and resources. The Pediatric Inventory for Parents has demonstrated effectiveness in measuring stress in parents of children with Type 1 diabetes and may prove useful in assessing stress levels in this parent population (Streisand et al., 2008, Hilliard, Monaghan, Cogen, & Streisand, 2011). This study strove to assess the stress levels of a small sample of parents of Type 1 Diabetic children in a clinic setting in Central Kentucky. These parents were also provided a resource packet of information to promote coping and development of social support resources.

Background and Literature Review

A challenging problem in healthcare today is the management of chronic diseases. Many chronic problems occur in the pediatric subset of the population. One of these challenging diseases is type 1 diabetes. According to the Juvenile Diabetes Research Foundation (2015), over one million people in the United States suffer from this disease, including 200,000 children. According to the National Diabetes Statistics Report (2014) the incidence of type 1 diabetes is greater in the pediatric population, with approximately 78% of the total youth diabetic population having type 1 diabetes in 2008 and 2009. Persons with type 1 diabetes suffer from a complete insulin deficiency, due to autoimmune destruction of the pancreatic beta cells that normally produce insulin. Metabolically active cells are then unable to use the glucose obtained from the diet (American Diabetes Association, 2014). This results in chronic hyperglycemia, which can be life threatening and cause permanent organ damage long-term if this condition is not treated effectively.

Type 1 diabetes mellitus can develop at any age. It is estimated that most type 1 diabetic cases occur in children younger than age ten, with approximately 18,500 children being given a diagnosis annually (CDC 2014). Children are rarely diagnosed under one year of age (Jones, McCance, & Huether, 2010). At the time of diagnosis, education begins with both the child and the family, along with a complex medical management plan. Only when the child becomes a mature adolescent are they developmentally and cognitively able to independently manage their type 1 diabetes (Konradsdottir & Svavarsdottir, 2011). Since every child matures and develops at a different rate, there is no set standard age to begin teaching a child or adolescent how to manage their own chronic condition. Due to the developmental immaturity of children, parents are often left with the responsibilities of managing the disease process for their child (Hatton et

al., 1995; Mitchell et al., 2009). Parents may have difficulty with learning how to administer insulin, manage hypoglycemia, monitor blood sugars, and count carbohydrates in addition to coping with the devastating diagnosis of their child's condition.

Stress related to management of a child's chronic condition can be an obstacle for parents trying to adapt and cope. Boyd and Canfield (2008) refer to Lazarus and Folkman's 1984 research, which defines "stress as a relationship between the person and the environment that is appraised by the person as taxing" which triggers the individual to fear that his or her well-being is threatened (p. 222). It is crucial that parents are able to cope in order to prevent the negative impacts of stress. Inability to cope with stress by individuals can lead to either the worsening or development of mental health problems (Boyd & Canfield, 2008). Mental health problems in particular that can be associated with unresolved stress include anxiety and depressive disorders (Schneiderman, Ironson, & Siegel, 2005).

Anxiety is described as an unrelenting "vague, uneasy feeling" (Myers, 2006, p. 123). According to the Diagnostic and Statistical Manual of Mental Disorders (DSM) 5, "anxiety disorders differ from developmentally normative fear or anxiety by being excessive or persisting beyond developmentally appropriate periods," usually greater than 6 months in adults (American Psychiatric Association, 2013). Anxiety can manifest itself differently in adults, and a variety of anxiety disorders can occur based upon how the anxiety affects the individual. Depression is another mental health disorder that can affect adults who do not learn to adequately cope with stress. According to the DSM 5, depressive disorders share common characteristics including "the presence of sad, empty, or irritable mood, accompanied by somatic and cognitive changes that significantly affect the individual's capacity to function" (American Psychiatric Association, 2013). Depression can negatively impair an individual's ability to function in a variety of roles,

including work, home, and social roles (Boyd & Canfield, 2008). Psychological problems, such as chronic anxiety or depression, can not only impact the health of an individual, but also affect the people that surround that individual.

In parents of children with chronic illnesses a specific kind of unresolved stress, termed pediatric parenting stress, can cause problems. Pediatric parenting stress is defined as “stress related to caring for a child with a medical illness” (Streisand, Kazak, & Tercyak, 2003, p. 245). Recent research has focused on evaluating parents of children with type 1 diabetes and has documented significant parent stress, anxiety, and even depression related to their child’s diagnosis and the management of their child’s condition (Streisand et al., 2008; Streisand, Mackey, & Herge, 2010). These psychological problems are often related to the daily diabetes care regimen surveillance and responsibilities, such as insulin injections, fingersticks, and fear of hypo- or hyperglycemia (Hatton et al., 1995; Hilliard et al., 2011; Streisand et al., 2010; Streisand et al. 2008). It is critical for parents to learn how to cope with their pediatric parenting stress in order to prevent mental health issues caused by unresolved stress. In learning to cope with their stress, the parent will also be able to function as a parent and appropriately manage for their child. Lewin et al. (2005) found that unresolved stress related to their child’s chronic illness affected the parent’s ability to function as an effective caretaker. It also negatively impacted work obligations and adversely affected their ability to effectively communicate with family members. These research findings highlight a problem that is often not considered in treating families of children with diabetes: that chronic pediatric diseases can negatively affect parental psychological health and coping.

The inability of the parent to adequately manage stress can also negatively impact the children. Unalleviated parent stress can affect the child’s psychological well-being. Inadequate

coping with stress may be inadvertently communicated to the child, which can put the child at risk for development of depression (Mullins et al., 2004; Streisand et al., 2008). This can cause the child to act out in school or at home. Stress can also make parents hypersensitive to their child's behavior, causing them to report frequent child behavior problems while the behaviors may be appropriate for the child's developmental age (Lewin et al., 2005; Hilliard et al., 2011). Inadequate coping with stress by the parent may strain the relationship with their child with diabetes.

It is crucial for parents to be able to cope with their stress related to their child's type 1 diabetes diagnosis as well as the management of their condition. Since the health of children with diabetes so often depends on the capabilities of their parents, improving parental coping with stress can improve the quality of life for both the parent and child (Hatton et al. 1995; Streisand et al., 2010). Suggested interventions to help improve stress and coping in parents and families include building "social support systems" (Merkel & Wright, 2012; Lewin et al., 2005). Provider assessment of parents of children with type 1 diabetes is crucial to identify parents who may be experiencing problems coping with stress (Streisand et al., 2008). Management of the parenting stress in parents of children with type 1 diabetes can help ensure positive outcomes in the lives of both the parents and the child.

Since unresolved pediatric parenting stress related to the child's type 1 diabetes is common, parents of children with type 1 diabetes may be at risk for future problems (e.g. anxiety and depression). The primary objective for this study was to assess the level of stress using the Pediatric Inventory for Parents (PIP) instrument in a sample of 20 parents of children with type 1 diabetes from the Kentucky Pediatric Endocrinology Clinic population. Upon completion of the stress measurement tool, the parents were also provided with informational, mental health, and

social support Internet resources designed to assist parents of children with type 1 diabetes. Demographic information was also self-reported by the parents in the study sample, and relationships between parental stress levels and these demographic variables were assessed using SPSS 22 statistical software.

Methods and Procedure

Study Demographics and Setting

The Kentucky Pediatric Endocrine Clinic is located in the Kentucky Clinic, which is a subset of the UK HealthCare network, located in Lexington, Kentucky. The Kentucky Pediatric Endocrine Clinic has three providers that see approximately 40 children per week with type 1 diabetes ages birth to 20 years. The Kentucky Pediatric Endocrine Clinic primarily cares for children with diabetes from Eastern, Central, and Southern Kentucky. The demographics of their patient population are consistent with the demographics of children with diabetes in Kentucky. Kentucky's population in 2013 was over 88 percent Caucasian (U.S. Census Bureau, 2015) and most residents of the state live in rural areas (UK College of Public Health, 2005). Each year approximately 18,000 children in the United States are told they have type 1 diabetes (CDC, 2014). The CDC (2014) also estimates that Caucasian children have the highest rates of type 1 diabetes, with one being diagnosed in approximately 370 children. The population seen for treatment at the Kentucky Pediatric Endocrine Clinic reflects these demographics. The Kentucky Endocrine Clinic currently has over 800 pediatric patients with Type 1 and Type 2 diabetes. Although African-American, Hispanic, and Asian children with diabetes are also seen at the Kentucky Pediatric Endocrine Clinic, they make up less than three percent of children seen by the providers. The parents who were approached for participation in this study were recruited from this population of parents of children with type 1 diabetes.

Study Approval

Prior to implementation of the study, approval was obtained from the Institutional Review Board through the University of Kentucky. Permission was also obtained from the American Diabetes Association, Juvenile Diabetes Research Foundation, Children with Diabetes website, and the Kentucky Cabinet for Health and Family Services to use their Internet resources in the resource packet. Special permission to use the PIP was obtained from Dr. Randi Streisand, Associate Professor of Psychiatry and Pediatrics at the George Washington University. Permission to use the Kentucky Pediatric Endocrine Clinic for recruitment of subjects was obtained from Dr. Jackson Smith, who is Chief of the Division of Pediatric Endocrinology at the Kentucky Clinic. The study took place from February to April 2015.

Sample and Inclusion/Exclusion Criteria

Convenience sampling was used to recruit 20 parents of children with type 1 diabetes for participation in the study upon their arrival for one of their child's clinic appointments at the Kentucky Pediatric Endocrine Clinic. Parents were invited from the available population of parents with children with type 1 diabetes from the Kentucky Clinic. Inclusion criteria for the parents included: the parent must be a primary care provider for the child, the parent must have learned English as a first language, the parent must have internet access at home, and the child must be between the ages of three and twelve. Only one parent per child with diabetes was included in this study. There were no requirements as to how long the child had type 1 diabetes or the presence of other chronic conditions.

The reason for the specific age range for the child is due to the fact that the parents are usually the primary disease managers for the child at these ages. Around the age of twelve, which is typically the beginning of adolescence, the child may start assuming some of their

disease responsibilities if they are developmentally able (Konradsdottir & Svavarsdottir, 2011). Also, children are not typically diagnosed with Type 1 diabetes as infants or toddlers (Jones et al., 2010). Parents who have children with diabetes and are the primary disease managers for their children typically have higher levels of stress than those parents of older children who can assist in managing some of their own disease-related tasks (Hilliard et al., 2011; Streisand et al., 2008).

Exclusion criteria for the parents included: parents who were emancipated minors, parents who were blind, parents who did not complete the sixth grade, parents with a child younger than three years old, parents with a child older than 12 years old, and parents who did not have Internet access at home. The rationale for these exclusion criteria related to the resources made available in the resource packet. All of the resources in the packet were exclusively in English and the resources did not have translations of other languages available. The resources available in the packet were also written at around a sixth grade reading level. Finally, the resources provided were exclusively from the Internet, making availability of the Internet a necessity for the parent to access the resources.

Instrument

Parental stress as it relates to the child's diabetes will be measured in this study. The Pediatric Inventory for Parents (PIP) was the instrument used to measure the stress levels in this study population of parents. The PIP includes two scales: a frequency scale and a difficulty scale. The frequency scale examines how often stressful events occurred in the last week; the difficulty scale examines how challenging the stressful event was for the parent to manage (Streisand, Braniecki, Tercyak, & Kazak, 2001; Streisand et al., 2008). The stressful events will be those related to the child's type 1 diabetes. The questions in each of these scales are divided

into four different domains when the final stress score is tallied. These domains include: role functioning, emotional functioning, medical care of the child, and communication (Streisand et al., 2001; Streisand et al., 2008). The communication domain identifies the frequencies or difficulties the parents may have in communicating with family members or healthcare providers about their child's condition due to stress. The role functioning domain describes the frequencies or any difficulties the parent may have in performing their regular parental duties due to stress. The emotional functioning domain examines the emotional toll the child's illness has on the parents. The medical care domain examines the how stressful the child's diabetic care regimen is for the parents.

An instrument key is available that divides the questions on this instrument into each domain, to allow for easier scoring. The scores in each domain of the PIP range from 42 to 210, with higher scores on the 5 point Likert scale indicating higher levels of stress (Streisand et al., 2001). For this study, a score of 75% of the maximum score (score of 158) was deemed a high level of stress. The PIP has demonstrated discriminant reliability and consistency in the population of parents of children with type 1 diabetes (Hilliard et al., 2011; Lewin et al., 2005). Internal consistencies for the difficulty domain range from 0.94 to 0.96 and internal consistencies for the frequency domain range from 0.92 to 0.94 (Hilliard et al., 2011; Streisand et al., 2008; Streisand, Swift, Wickmark, Chen, & Holmes, 2005).

Subject Recruitment and Study Procedures

The objectives, process, and implementation of this study were explained to the front office staff, nursing staff, diabetic educators, and providers at the Kentucky Pediatric Endocrine Clinic prior to initiation of study recruitment. Kentucky Clinic staff members were instructed to provide an informational flyer and a demographic information sheet to parents when they arrived

at the registration desk for their child's appointment. The informational flyer provided information about the objectives and purpose of the study, and the inclusion criteria for participation. At the bottom of the informational flyer, a note instructed the parents to fill out the demographic information sheet if they were interested in participating in the study. Therefore, if parents deemed themselves or their child ineligible, or did not want to participate in the study, they could return the flyer and information sheet to the registration desk.

The parents read the informational flyer and filled out the demographic information sheet if they were interested in participating in the study while they waited in the lobby to be brought back to a treatment room. The self-reported data provided from the information sheet included the parent's race, gender, age, county of habitation, highest level of education, and whether the parent had Internet access at home. It also revealed whether the child had type 1 diabetes, how long the child had suffered from the disease, and the age of the child. The demographic information sheet assisted the primary investigator in determining whether the parent was eligible to participate in the study.

When the parent and child were brought back to a treatment room for their appointment, the information sheet was attached to the child's chart by the nursing staff and the chart was placed in the chart holder on the other side of the treatment room door. This allowed the primary investigator to determine whether the parent was interested in participating in the study and whether the parent was eligible based on the self-reported information provided in the information sheet. The parent was then approached in the treatment room, explained the study using a standard script, and informed consent was obtained from the parent. A copy of the signed informed consent document was provided to the participant. The parent was then provided the PIP to complete.

Once the instrument was completed, the researcher collected the instrument and provided the resource packet to the parents. The resource packet contained printed copies of Internet resources and information to assist the parents in learning more about their child's diabetes and where to find social support resources within the diabetic community. The Internet resources were collected from the American Diabetes Association, Juvenile Diabetes Research Foundation, and the Children with Diabetes website. In addition, the resource packet also contained printed Internet mental health resources from the Kentucky Cabinet for Health and Family Services.

At the conclusion of the study, the researcher calculated the stress score for the parent generated by the PIP using an instrument key included with the PIP. The data provided from the information sheet was also collated including the parent's race, gender, age, county of habitation, highest level of education, how long their child had suffered from diabetes, and the age of the child. Descriptive statistics were used to analyze the stress scores calculated from the PIP instrument and the demographic data collected about the parents in the study. Two-tailed Pearson r correlations were used to investigate relationships between parent age, child age, and duration of child's diabetes to the PIP subsection and domain scores, with significance noted at the level of 0.05. Independent t -tests were used to examine the relationship between parent gender, rural or urban county of habitation, and level of education to the subsection and domain scores from the PIP with a 95% confidence interval.

Results

The demographic and PIP stress scores were analyzed using descriptive statistics. The demographics of the 20 participants from our study population followed the typical demographics of the type 1 diabetes patient population in Kentucky (see Table A). The ages of the parents who participated in the study ranged from 27 to 49 years of age, with the average age

of the parents in the sample being 35.9 years of age. The average age of the child was 8.6 years. 85 percent of the study participants were female. The race of the study participants was homogenous, with 100 percent of the parents being Caucasian. The level of education of the parents varied, with seven of the parents having less than or equal to a high school degree. The remaining 12 parents had education ranging from some college to post-graduate level education. The average duration of the children's diabetes, as reported by the parents on the demographic information sheet, was 39.15 months (or a little over three years). The duration of the child's diabetes ranged from two months to over seven years since diagnosis with type 1 diabetes. Approximately 40 percent of the parents resided in Central Kentucky, but parents from Southern and Eastern Kentucky were represented in the sample population as well. See Table A for further details.

The scores of the PIP were analyzed and tabulated. As mentioned previously, the scores in each domain range from 42 to 210. For the purposes of this study, a domain score of greater than 158 was considered as having a high level of stress, since it was 75 percent of the maximum allowable score on the PIP. The overall analysis of the PIP scores for each participant demonstrated only one score of 158 or higher in the PIP domains, meaning none of our parents sampled had relatively high levels of stress when surveyed (see Table B and Figure A). The PIP frequency domain scores ranged from 74 to 137, with an average score of 109.3. The median stress frequency score was 116. The standard deviation from the average was approximately 21.02. The modal frequency stress score was 119. The difficulty domain scores ranged from 51 to 158, with an average score of 102.8. The median difficulty stress score was 112.5. The standard deviation from the average for the difficulty scores was approximately 30.01. The modal difficulty stress score was 122.

The stress scores gathered from our sample population demonstrated a normal distribution. The information collected in this study was examined using SPSS 22 software to determine correlations and relationships between variables. The overall scores from the Pediatric Inventory for Parents from the Frequency and Difficulty subsections demonstrated a parametric (normal) distribution. The Kolmogorov-Smirnov statistics calculated from the distributions of the PIP Frequency and Difficulty subsections were not statistically significant ($p=0.110$ and 0.132 respectively). This demonstrated the normative curvature of the data collected from the PIP.

As stated previously, two-tailed Pearson product moment correlations were used to examine relationships between parent stress scores and the demographic variable data collected in this study, with significance being denoted at the 0.05 level. The results can be viewed in Table C. No statistically significant relationships were present between the total PIP Frequency and Difficulty scores and parental age. However, when the subsections were further divided into their respective domains and examined, several statistically significant relationships were discovered. A statistically significant, negative correlation between parental age and the PIP Frequency Communication domain was present ($p= -0.033$). Also, a statistically significant, positive correlation was present between parental age and the PIP-Difficulty Communication domain ($p= 0.027$).

Several statistically significant relationships were found between parental PIP scores and the age of the child as well. There was a statistically significant, negative relationship between the PIP-Frequency score and the age of the child ($p= -0.048$). There was a statistically significant, positive relationship between the PIP-Difficulty score and the age of the child (0.011). When the subsections of the PIP were further divided into their respective domains,

statistically significant relationships were found between certain domains and the age of the child. There was a statistically significant, positive relationship between the age of the child and the PIP-Frequency Emotional Distress domain ($p=0.033$). There was also a statistically significant, positive relationship between the PIP-Difficulty Communication domain and the age of the child ($p=0.045$). There was a statistically significant, negative relationship between the PIP-Difficulty Medical Care domain and the age of the child ($p= -0.013$).

One statistically significant relationship was found between the duration of the child's diabetes and the parental PIP scores. When the PIP subsection scores were further divided into their respective domains for analysis, a statistically significant, negative relationship was found between the PIP-Frequency Emotional Domain score and the duration of the child's diabetes ($p= -0.010$). No other statistically significant relationships were discovered between the PIP scores and the duration of the child's diabetes.

Independent t-sample tests were used to investigate the relationship between the PIP scores and the sex of the participants (male or female). No statistically significant relationship was found between the sex of the parents and either the PIP total subsection scores or the PIP domain scores. No statistically significant relationships were found between the geographic residence (urban or rural) of the parents and the parental PIP stress scores as well. The counties of residence the participants self-reported were separated and placed in two categories: urban or rural counties. The counties were classified based on the BEALE classification system that ranks counties with a numerical value based on their proximity to an urban, metro center (U.S. Department of Education, n.d.). Nine of the participants were from rural areas, ten participants were from rural counties, and one participant did not self-report the question correctly (answered country instead of county of residence). When the relationship between geographical area and

PIP total subsection scores were examined using independent t-testing, no significant relationship was discovered. No statistically significant relationships were found after using independent t-testing to examine the correlations between education levels of the parents and their PIP total subsection or PIP domain scores. Eight of the participants had a high school education and the remaining 12 participants had some level of post-secondary education. The results can be seen in Table D.

Discussion

Overall, the sample of parents appeared to have moderate, but not high levels of stress as measured by the PIP. Only one parent (parent number three) demonstrated a high level of stress in the Difficulty domain of the PIP. As mentioned previously, a high level of stress is graded as 75 percent of a maximum score on each subsection, which is a score of 210. Limited information can be gleaned from the statistical analysis of the relationships between the different demographic variables and the PIP scores from our parent sample population. However, a few statistically significant relationships were determined in our analyses and are important to mention.

The statistically significant relationships elucidated in our research are important to note. The statistically significant relationships between parental age and the PIP-Frequency and Difficulty Communication domains suggest communicating with healthcare providers and family members about their child's diabetes is often frequent and difficult for parents in our parent sample. The negative relationship between the PIP-Frequency Communication domain and parental age suggests that younger parents in our sample increasingly discuss or argue with family members or healthcare providers about their child's condition. The positive relationship between the PIP-Difficulty Communication domain and parental age, suggests that older parents

in our sample find it increasingly difficult to communicate with their family members or healthcare providers about their child's illness.

The statistically significant relationships between the total PIP subsection scores and the age of the child are important to note. This suggests that the age of the child is a key factor in parenting stress related to their child's diabetes for our sample of parents. The directions of these statistically significant relationships are important to mention as well. There appears to be an inverse correlation between the child's age and the PIP-Frequency subsection score, meaning parent stress is reported more frequently in parents of younger children with type 1 diabetes in our sample. There is a positive correlation between the child's age and the PIP-Difficulty subsection score, meaning the difficulty in dealing with parent stress related to the child's type 1 diabetes appears to increase as the child ages in our sample of parents.

The positive, statistically significant relationship between the PIP-Frequency Emotional Distress domain and the age of the child suggests that as the child ages the frequency of emotional problems in dealing with the child's diabetes increases in the parents in our sample population as well. The positive, statistically significant relationship between the child's age and the PIP-Difficulty Communication domain suggests that as the child ages, the parents in our sample have more difficulty in communicating with family members and/or healthcare providers related to their child's diabetes. This increase in difficulty could be due to problems communicating with the child about their diabetes, but this relationship is unclear in our current analysis. Adolescence is a difficult time for parents of children with type 1 diabetes, especially since the parents are assisting their child in transitioning to managing their own diabetes while the child is still not fully mature (Konradsdottir & Svavarsdottir, 2011; Sweenie, Mackey, & Streisand, 2014). The transitioning of the medical care from the parent to the child might also

explain our statistically significant findings when comparing the age of the child and the PIP-Difficulty Medical Care domain. The negative, statistically significant relationship suggests that parents of younger children in our sample have more difficulty in dealing with the stress of managing their child's diabetic medical care. This would make logical sense, because parents are more responsible for the child's medical regimen when the child is younger than when they are older and beginning to manage their own medical condition.

The remaining statistically significant relationship was discovered between the duration of the child's diabetes (in months) and the PIP-Frequency Emotional Distress domain. The direction of the relationship suggests that the parents of newly diagnosed diabetics in our sample have more frequent emotional issues in dealing with their child's diabetes. This is consistent with the current literature noting that the time after diagnosis of a child with type 1 diabetes is extremely stressful and emotional for parents, and intervention to promote coping is essential (Hoff et al., 2005; Carpentier et al., 2006; Streisand et al., 2008).

The relationships between parent sex, education level, and the PIP stress scores by subsection and domain were examined using independent t-testing. No statistically significant findings were reported, meaning no significant relationship could be found on whether the sex or education level of the parent increased their reported stress levels in our sample population. This was also the case with the geographic location of residence, as no statistically significant relationships could be found between parent-reported levels of stress and the rural/urban residence of the parents in our sample.

There may be a variety of reasons why this sample of parents did not exhibit high levels of stress. First, few of the parents' children were recently diagnosed diabetics. The child with the shortest duration of the disease had been diagnosed for two months, giving the parents some

time to adjust. Only four of the children of the parents in our sample had been diagnosed for less than one year. The time of adjustment for our parent population may have played a role in decreasing their overall level of stress. Previous research has demonstrated that the time period after a child has been diagnosed with type 1 diabetes provokes overwhelming amounts of stress in parents (Streisand et al., 2008). Effective interventions by diabetic educators and medical professionals can help alleviate this stress post-diagnosis (Carpentier, Mullins, Chaney, & Wagner, 2006; Streisand et al., 2008). The relative time of adjustment for our parent sample may have assisted in lowering their initial stress levels concerning their child's illness.

Second, given that many of the parents in our sample had children that had diabetes for a period of time, these parents may have developed coping strategies to reduce their stress levels to a manageable degree. Hatton et al. (1995) noted that after an initial period of anxiety and possibly depression, parents come to terms with their child's illness and the fact that it will not disappear. This "coming to terms" causes the parents to learn how to cope with their stress, usually by achieving support from medical professionals or their peers (Hoff et al., 2005; Merkel & Wright, 2012). Merkel & Wright (2012) noted that the Internet and the resources it provides might be useful tools to help parents develop social support connections in order to deal with their pediatric parenting stress associated with their child's chronic illness. The resource packet provided to parents in this study was aimed at promoting the development of these connections, if they were not already in place.

Limitations

There were a number of limitations to this study. First, our sample population was relatively homogenous. All of our participants were Caucasian, most were female, and our parents were relatively well-educated. The youngest parent in our population was 27, meaning

most of our parent population was older. This may have affected the stress scores of our parents. Previous research has noted that parents who are younger in age, who have limited social support or financial resources, and are of “non-white” races are at a greater risk of being unable to cope with the stresses associated with a child’s chronic illness (Streisand et al., 2008; Streisand et al., 2010). Parents with higher levels of education generally have less difficulty with financial resources. In the future, it would be beneficial to assess the stress levels of parents of diabetic children from different socioeconomic backgrounds. It would also be beneficial to collect more male stress scores to determine whether there is a difference in the way males and females deal with stress related to their child’s chronic illness. Convenience sampling was also used to recruit our participants, which might have limited the variability in our study sample.

Second, the sample size of our population was relatively small, with only 20 parents participating in the study. The small sample size may have affected our ability to generate statistically significant relationships between the self-reported demographic variables collected and pediatric parenting stress scores. In the future, it would be important to incorporate more parents from different backgrounds into a larger sample. Important relationships between parent demographic variables and parent-reported stress may be elucidated in larger samples, which may help point out important risk factors that may place parents in danger of ineffective coping processes.

Another limitation to this study is that stress is often not a constant state. Fluctuations in stress are common. These fluctuations often can occur at certain periods in a diabetic child’s lifetime, such as when the child is requiring more insulin due to growth or may be becoming cognitively aware of their diagnosis and rebelling (Hatton et al., 1995). These periods can often provoke increased levels of stress in parents, which would affect their scores on the PIP. This

study only allotted for one time point of stress measurement. In the future, it would be beneficial to follow parents over a period of time to assess their stress levels at different points in their child's chronic disease process. It also should be mentioned that the effectiveness of the resource packet provided to parents was not assessed due to the one point in time assessment of the parents' stress levels. In future studies, it would be interesting to evaluate the effectiveness of these resources six months to one year later and if the parents actually used the packets to develop support resources outside the clinic setting.

There were also some limitations with the instrument used to measure stress. To date, no clinical cutoffs are established for the PIP delineating what constitutes low, moderate, and high levels of stress. This would allow a more standardized measurement of stress across the population as opposed to developing one clinical standard per study, which was implemented in this study with our 75 percent of the maximum score per subsection cutoff. The PIP is also a self-reported instrument, which may have affected the stress scores of our study depending on whether the parents were over- or under-reporting their symptoms. Hopefully in the future, further research will continue to evaluate parents of children with type 1 diabetes using the PIP and clinical cutoffs for high levels of stress will be established. More information should also be gathered about the overall stress scores of parents of children with type 1 diabetes in general. In coping with their children's illness, this parent population may learn to tolerate a certain amount of stress and moderate levels of stress may be normative for this population. More research needs to be completed to answer this question, however.

Conclusions and Recommendations

The current literature and research emphasizes the importance as a health care provider in assessing for adequate coping in parents of children diagnosed with type 1 diabetes to prevent

further psychological problems in the parent and their family members. By assessing these parents for unresolved pediatric parenting stress related to their child's chronic illness, providers can help promote the health of the entire family unit by providing education and resources tailored to assisting parents in coping with their stress. One of the challenges presented to health care providers who recognize inadequate coping in parents due to stress is an appropriate instrument to measure stress in this population of parents. The PIP is an ideal instrument to measure pediatric parenting stress, since the instrument has been validated for use in parents of children with diabetes (Hilliard et al., 2011). Given the PIP's use in parents of children with other chronic illnesses to measure pediatric parenting stress (Alves, Guirardello, & Kurashima, 2013; Guilfoyle, Denson, Baldassano, & Hommel, 2011; Gray, Graef, Shuman, Janicke, & Hommel, 2013), pediatric providers who see children with chronic conditions should integrate this tool into their practice. The brevity of the tool makes it ideal for use in clinical settings (Gray et al., 2013), and would allow providers to monitor how parents of children with chronic illnesses are coping with their pediatric parenting stress.

Another problem that presents itself to providers is where to refer parents for psychological support who are inadequately coping with stress once this issue is identified. Lack of resources has often been determined to be a stressful factor for parents who have a child with a chronic illness (Carpentier et al., 2006). These resources include education and social support resources from family members or other social support groups. Pediatric health care providers may encounter parents in the clinical setting who are inadequately coping with stress, but may not have the time or resources to adequately assess or assist them. A stress measurement instrument and a resource packet for parents of children with type 1 diabetes may provide an effective intervention for medical providers to use when they encounter these stressed parents in

the community setting. Streisand et al. (2008) stated that healthcare provider's assessment of parents' stress and coping, as well as their understanding of the diabetic disease process and management following their child's diagnosis is essential. This parental stress assessment by providers allows for recognition of inadequate coping or understanding in the parents, and gives the providers the opportunity to make appropriate referrals to mental health professionals or to provide additional diabetic education resources.

Table A: Table of Parent Self-Reported Demographic Data

Patient Number	Age	Sex	Level of Education	Race	County of Residence	Age of Child	Duration of Child's Diabetes
1	37	F	GED	White	Greenup	11	3 years
2	42	F	Post-Graduate	White	Error (USA)	12	4 years
3	35	M	Bachelors	White	Fayette	8	4 years
4	38	F	Graduate	White	Fayette	10	4 years
5	37	F	High School	White	Estill	10	2.5 years
6	36	F	Bachelors	White	Montgomery	11	7 years
7	49	F	Graduate	White	Wayne	11	7 years
8	33	F	College	White	Boyle	7	2.5 years
9	28	F	11th grade	White	Woodford	10	3-4 years
10	34	M	Bachelors	White	Montgomery	8	4+ years
11	44	F	Associate's	White	Anderson	10	3 years
12	27	F	Bachelors	White	Montgomery	3	2 years
13	42	F	High School	White	Clay	9	10 months
14	28	F	Bachelors	White	Jessamine	4	8 months
15	36	F	High School	White	Laurel	11	7 months
16	36	F	Graduate	White	Fayette	10	2 months
17	30	F	GED	White	Leslie	7	7 years
18	34	F	College	White	Fayette	8	6 years
19	36	M	High School	White	Fayette	3	1.5 years
20	36	F	High School	White	Fayette	9	2 years

Table B: Pediatric Inventory for Parent Stress Scores by Participant

Patient Number	Pediatric Inventory for Parents Difficulty Score	Pediatric Inventory for Parents Frequency Score
1	137	124
2	119	120
3	124	158
4	101	113
5	128	125
6	131	122
7	84	99
8	119	122
9	100	93
10	80	51
11	85	67
12	80	70
13	110	90
14	132	116
15	116	112
16	74	60
17	116	65
18	136	139
19	126	136
20	88	74
Average	109.3	102.8

Figure A: Comparison of Pediatric Inventory for Parents Frequency and Difficulty Domain Scores

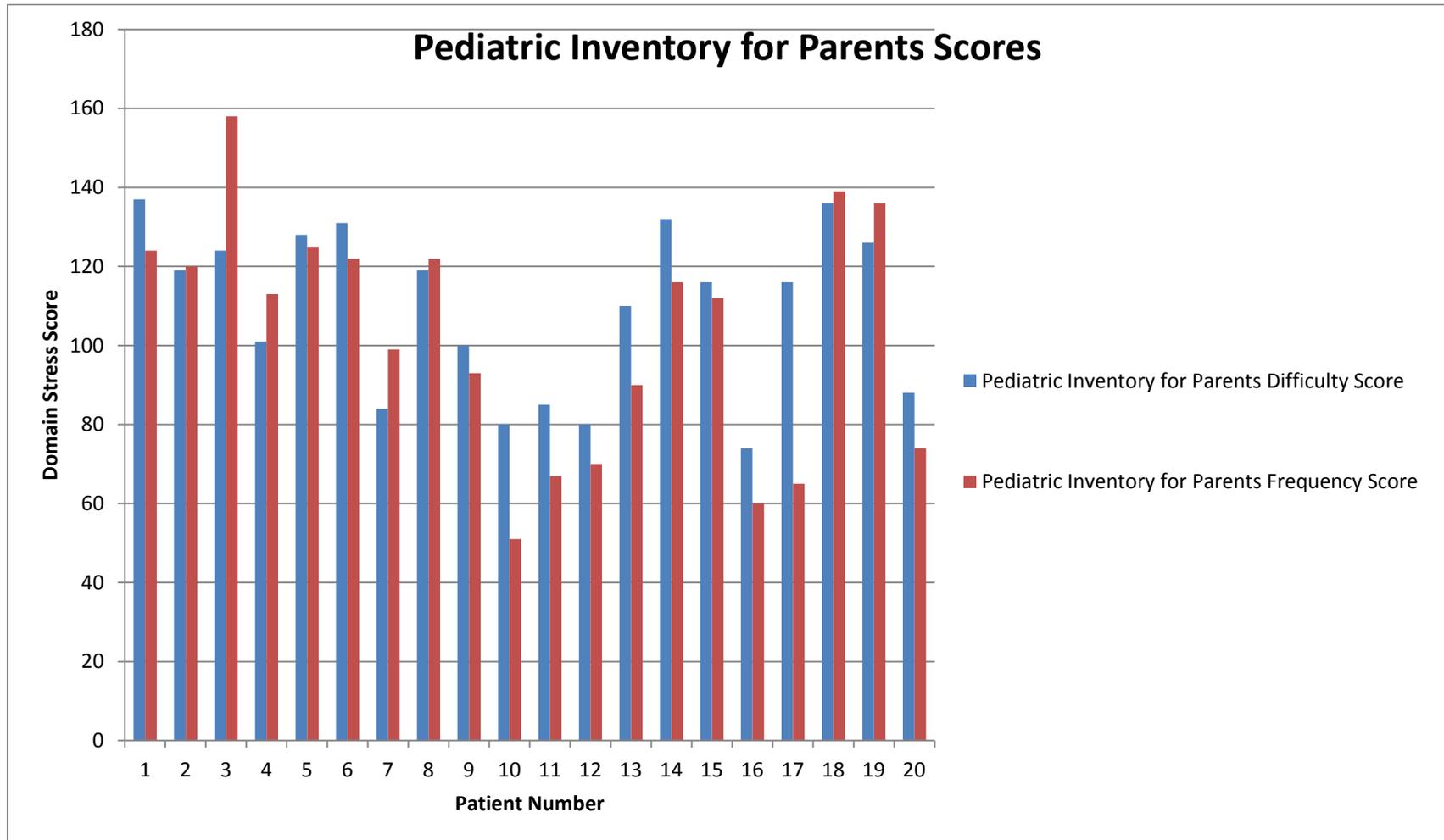


Table C: Pearson Product Moment Correlations Between Variables Results

	PIP-Frequency Score	PIP-F-C Score	PIP-F-MC Score	PIP-F-ED Score	PIP-F-RF Score	PIP-Difficulty Score	PIP-D-C Score	PIP-D-MC Score	PIP-D-ED Score	PIP-D-RF Score
Parent Age	-0.161	-0.033	-0.228	-0.084	-0.217	0.053	0.027	0.173	0.132	-0.138
Age of Child	-0.048	0.058	-0.050	0.033	-0.216	0.011	0.045	-0.013	0.139	-0.202
Duration of Child's Diabetes (in months)	0.134	0.099	0.297	-0.010	0.163	0.107	-0.092	0.146	0.142	0.135

Key: *PIP-F-C*= PIP Frequency Communication Domain Score; *PIP-F-MC*= PIP Frequency Medical Care Domain Score; *PIP-F-ED*= PIP Emotional Distress Domain Score; *PIP-F-RF*= PIP Frequency Role Function Domain Score; *PIP-D-C*= PIP Difficulty Communication Domain Score; *PIP-D-MC*= PIP Difficulty Medical Care Domain Score; *PIP-D-ED*= PIP Difficulty Emotional Distress Domain Score; *PIP-D-RF*= PIP Difficulty Role Function Domain Score

Note: Significance at <0.05 level

Table D: Independent t-Test Relationships Between Variables

	PIP-Frequency Score	PIP-F-C Score	PIP-F-MC Score	PIP-F-ED Score	PIP-F-RF Score	PIP-Difficulty Score	PIP-D-C Score	PIP-D-MC Score	PIP-D-ED Score	PIP-D-RF Score
Parent Sex (Male/Female)	0.952	0.764	0.388	0.802	0.863	0.705	0.352	0.677	0.809	0.591
Residence (Rural/Urban)	0.421	-	-	-	-	0.155	-	-	-	-
Level of Education (High School/ Post-Secondary)	0.287	0.116	0.30	0.256	0.663	0.961	0.489	0.821	0.979	0.57

Key: *PIP-F-C*= PIP Frequency Communication Domain Score; *PIP-F-MC*= PIP Frequency Medical Care Domain Score; *PIP-F-ED*= PIP Emotional Distress Domain Score; *PIP-F-RF*= PIP Frequency Role Function Domain Score; *PIP-D-C*= PIP Difficulty Communication Domain Score; *PIP-D-MC*= PIP Difficulty Medical Care Domain Score; *PIP-D-ED*= PIP Difficulty Emotional Distress Domain Score; *PIP-D-RF*=PIP Difficulty Role Function Domain Score

Note: Significance at <0.05 level

DNP Capstone Conclusion

The current literature regarding pediatric parenting stress in parents of children with chronic illnesses outlines an important need for providers in the pediatric setting to assess pediatric parenting stress levels in practice. Unresolved pediatric parenting stress can negatively impact the life of the caretaker and the chronically ill child. The Pediatric Inventory for Parents is an easy-to-use instrument that should be implemented in practice to assess pediatric parenting stress in parents of children with chronic illnesses. Healthcare providers will then be able to recognize inadequate coping with stress on the part of the parent and refer the parent and family for appropriate support.

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