

**Parental Factors in Medical Decision-Making for Their  
Children with Functional Abdominal Pain Disorders:  
Testing Utility of the Health Belief Model**

by

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**A thesis submitted in partial fulfillment  
of the requirements for the degree of  
Master of Science  
(Psychology)  
in the University of Michigan-Dearborn  
2022**

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## **Acknowledgements**

This research comes to fruition with the help of so many. I would like to thank my parents for listening to me talk about this work for days on end just to see if it made sense when I said it out loud. I would like to thank my partner, Connor, who although was over 600 miles away managed to keep me sane during the most pivotal moments of this research. I would like to thank all of the amazing people in my cohort for trudging through the bulk of the pandemic, and subsequent pandemic of thesis due dates with me. I also want to acknowledge those at the Mardigian Library, who have celebrated the little things with me.

This research would not have been possible without the support of Dr. David Chatkoff and Dr. Michelle Leonard. Throughout the years Dr. Chatkoff and Dr. Leonard have been absolutely vital to my academic career and personal growth. Dr. Chatkoff has taught me to “put it in paws,” and I continue to be grateful for everything he has given me. Dr. Leonard has provided me with some of the best clinical experience and advice that I could have dreamed of. I will be eternally grateful for your continued guidance, and shared laughter throughout the years.

Standby to Standby, Standby.

## Table of Contents

<b>Acknowledgments.....</b>	<b>i</b>
<b>List of Tables.....</b>	<b>v</b>
<b>List of Appendices.....</b>	<b>vi</b>
<b>Abstract.....</b>	<b>vii</b>
<b>Chapter I.....</b>	<b>1</b>
<b>Introduction.....</b>	<b>1</b>
Diagnosis.....	2
Assessments.....	3
Epidemiology.....	4
Biopsychosocial Etiology.....	5
Biological Influences.....	5
Psychological Influences.....	6
Social Influences.....	7
Parental Influences.....	8
Biopsychosocial Implications.....	10
Functioning of the Child.....	10
Functioning of the Parent(s).....	11
Current Treatments.....	12
Medical Treatments.....	13
Psychological Treatments.....	14

Multidisciplinary Treatments.....	15
Parent Healthcare Decision-Making.....	16
Vaccine Hesitancy as a Proxy.....	17
Communication Between Physicians and Parents.....	18
Health Belief Model.....	19
The Health Belief Model.....	20
Utilization of the Health Belief Model.....	21
Current Study.....	23
<b>Chapter II.....</b>	<b>25</b>
<b>Methods.....</b>	<b>25</b>
Participants.....	25
Inclusion Criteria.....	25
Exclusion Criteria.....	25
Measures.....	25
Demographics.....	25
Child Treatment Scale.....	26
Parent Psychological Flexibility Questionnaire.....	26
Big Five Inventory.....	27
Health Belief Model.....	27
Procedures.....	28
Data Analysis.....	28
<b>Chapter III.....</b>	<b>29</b>
<b>Results.....</b>	<b>29</b>

Hypotheses and Post-Hoc Hypotheses.....	30
Hypothesis 1.....	30
Hypothesis 2.....	31
Hypothesis 3.....	31
Hypothesis 4.....	32
Hypothesis 5.....	32
Hypothesis 6.....	33
Post-Hoc Exploratory Analysis.....	33
<b>Chapter IV.....</b>	<b>35</b>
<b>Discussion.....</b>	<b>35</b>
Susceptibility, Severity, and Threat.....	36
Benefits and Barriers.....	37
Modifying Factors: Parental Personality Factors and Psychological Flexibility.....	39
Cues to Action: Parent-Physician Communication and Knowledge.....	40
Post-Hoc Discussion.....	42
Future Clinical Implications.....	43
Limitations.....	44
Conclusions.....	46
<b>References.....</b>	<b>69</b>

## **List of Tables**

Table 1: Frequencies and Percentages of Demographic Variables.....	48
Table 2: Means and Standard Deviations of Demographic Variables.....	50
Table 3: Means, Standard Deviations, and Cronbach’s Alphas for Predictor Scales.....	51
Table 4: Frequencies and Percentages of Outcome Variables.....	52
Table 5: Means and Standard Deviations for Outcome Variables.....	54
Table 6: Correlations between Subscales of Physician Knowledge, Communication, and Parent Knowledge.....	55
Table 7: Correlations between Multidisciplinary Acceptance and Parental and Physician Factors.....	56
Table 8: Post-Hoc Correlations Between Care Considerations and Aspects of the Health Belief Model.....	57
Table 9: Effect Sizes Between Participants Who Have Heard of Multidisciplinary Care, and Those Who Have Not.....	58

## **List of Appendices**

Appendix A: Demographics Questionnaire.....	59
Appendix B: Child Treatment Scale.....	62
Appendix C: Parent Psychological Flexibility Questionnaire.....	63
Appendix D: Big Five Inventory.....	64
Appendix E: Health Belief Model Scale.....	65
Appendix F: Informed Consent for Research.....	68

## **Abstract**

**Introduction:** Childhood functional abdominal pain disorders (FAPD) affect approximately 13.5% of children and can result in significant functional impairment (Nightingale & Sharma, 2020). Multidisciplinary programs including medical and psychological treatments have been found to improve outcomes compared to medical treatment alone. It is known that parents play a majority role in decision-making for pediatric patients, especially when they are younger. Furthermore, the Health Belief Model (HBM) has been previously conceptualized as a decision-making model for one's own engagement in treatment and has also been used to assess parent beliefs about pediatric care aspects, such as childhood vaccination choice (Chen et al., 2011). This study investigated a potential proxy decision-making model utilizing theoretical aspects of the HBM.

**Methods:** A sample of 501 parent participants were recruited via Prime Panels, an online survey software. Parents were eligible if they had a child under the age of 18 who was currently diagnosed with a FAPD. A series of surveys, including the Parent Psychological Flexibility Questionnaire, Big-Five Inventory, and an adaptation of the Champion (1984) Health Belief Model Scale, including perceived susceptibility, severity, and threat, perceived benefits/barriers, parent and physician knowledge, and parent-physician communication were administered.

**Results:** Parents who had not heard of multidisciplinary care reported still being open to receiving these services for their child. Furthermore, aspects of the HBM, including perceived susceptibility, severity and threat, perceived benefits, modifying factors such as parent



psychological flexibility, and cues to action such as parent-physician communication significantly predicted consideration and acceptance of multidisciplinary and psychological care

Discussion: This adaptation of the HBM scale predicted parental consideration and acceptance of multidisciplinary care and thus indicates potential utility as a clinical tool for aiding clinicians in “pre-treatment” decision-making. That is, assessment using the theoretical structure of the HBM of parents’ beliefs regarding their child’s diagnosis may help clinicians better understand how they can best help the family during the treatment decision-making process.

Conclusion: Future studies should analyze the potential utility of a short-form Health Belief Model Scale to be implemented in pediatric settings at the point of functional abdominal pain diagnosis in order to increase parental use of multidisciplinary treatments for their children.

## **Chapter I**

### **Introduction**

Pediatric chronic pain has become increasingly prevalent, with estimates of 6 to 38% of children suffering from a chronic pain condition at any given moment (Tumin et al., 2018; Neville et al., 2020). These patients also experience diagnostic uncertainty, which can contribute to diminished health-related quality of life (Neville et al., 2020). Furthermore, pediatric chronic pain is often first seen and treated by pediatricians, and only a small number of children and families will utilize the assistance of a specialty care clinic, such as multidisciplinary care (Tumin et al., 2018). The most common diagnoses of pediatric chronic pain include primary headaches, affecting anywhere from 19.4% to 66.4% of patients, and gastrointestinal disorders affecting up to 31.2% of the same population (Tutelman et al., 2021). Gastrointestinal pain disorders are perhaps some of the more serious, causing higher levels of functional impairment in children (Cunningham et al., 2017).

With multiple different pain diagnoses possible in children, one particular gastrointestinal disorder impacts a significant minority of children. Functional abdominal pain disorders (FAPD) is a broad term that encapsulates a variety of nonspecific abdominal pain issues in children with unknown etiologies, differing from typical gastrointestinal issues such as constipation, colic, and abdominal migraines (Reust & Williams, 2018; Robin et al., 2018). FAPD is estimated to impact up to 13.5% of children, with conditions such as irritable bowel syndrome (IBS), functional abdominal pain not otherwise specified, and functional dyspepsia all considered

## PARENTAL DECISION-MAKING FOR FAPD

factors in the broader diagnosis (Friesen et al., 2021; Nightingale & Sharma, 2020). Generally, FAPD is described as a period of at least three months in which there are three or more episodes of abdominal pain that causes either hospitalization or other clinically significant impairment to a child (Campo et al., 2004; Reust & Williams, 2018).

Compas et al. (2012) state that FAPD impacts a significant number of children and adolescents, with these pediatric patients reporting higher levels of daily stressors than their peers. Children are often diagnosed after months of pain and hardship within their school system, and further difficulties within the family, and diagnosis can cause struggles with activities of daily living (Abbott et al., 2018). Furthermore, this condition causes children to miss school and other important activities throughout their lives, with Reust and Williams (2018) reporting that the duration of FAPD episodes last on average seven and a half months, which can compromise the majority of the school year when an episode occurs during the school months. Additionally, families of children diagnosed with FAPD face many challenges, socially, medically, and economically. Families may have to forgo their previous lifestyles to adapt to their child's condition. It often requires a high number of in-clinic visits, substantial financial and insurance costs, and may create overall stress on the family unit (Groenewald et al., 2014). It is imperative that children and adolescents with FAPD get the proper treatment.

### **Diagnosis**

Both ROME IV and the International Classification of Diseases (Hyams et al., 2016; ICD-11, 2019) describe functional abdominal pain as a gastrointestinal disorder. They each identify several classifications of functional abdominal pain, including functional dyspepsia, IBS, as well as the undifferentiated diagnosis of FAPD (Hyams et al., 2006; Sprenger et al., 2011). Functional abdominal pain not otherwise specified may also be diagnosed, in which there

## PARENTAL DECISION-MAKING FOR FAPD

is noticeable discomfort in the abdomen for at least six months, which is further described as unrelated to food intake or expulsion (ICD-11, 2019). Diagnosing unspecified abdominal pain as FAPD in children proves difficult, as all possible biological causes must be ruled out in order to determine the functionality of diagnosis (McClellan & Ahlawat, 2021).

### **Assessments**

For FAPD to be diagnosed in a child, multiple assessments may need to be completed at the discretion of the treating clinician (Llanos-Chea & Saps, 2019). Assessments include both a physical from the doctor, as well as a number of psychological batteries to ensure that there are no pre-existing mental health issues that may be causing the child to somaticize their pain (Reust & Williams, 2018). Reust and Williams (2018) further describe a number of tests that are done to determine any organic source of the pain, such as a complete blood count, potential kidney infection, as well as sexually transmitted infections.

Routine lab work may also include urinalysis and inflammatory markers (Llanos-Chea & Saps, 2019). An abdominal ultrasound may also be conducted; however, this may not significantly contribute to a diagnosis of FAPD. Llanos-Chea & Saps (2019) discuss that these tests may not be as salient due to the mysterious etiology behind FAPD. One such study found that although 17% of children received laboratory testing, and 14% received radiology testing, only 3% of children received a diagnosis as a direct result of such testing (Wallis & Fiks, 2015). Other diagnostic tests to consider include analysis of stool biomarkers and esophagogastroduodenoscopy, however, these tests can become costly, time-consuming, and potentially traumatic for children (Llanos-Chea & Saps, 2019).

A key aspect in the assessment of a child with potential FAPD, as stated by Van Oudenhove and colleagues (2016), is the relationship between the patient, their family, and the

## PARENTAL DECISION-MAKING FOR FAPD

physician. The clinician should, ideally, discuss the patient's risk for FAPD, as well as conduct a psychosocial assessment as a screening for potential risk factors (Van Oudenhove et al., 2016). Psychological tests the child may encounter include a health-related quality of life assessment, functional disability inventory, and the child self-efficacy scale, all of which are validated self-report measures that can be used by clinicians to further capture the scope of impairment due to the child's pain (Vetter, 2011).

### **Epidemiology**

While all biopsychosocial factors contributing to the causality of FAPD in children are unknown (Sparks et al., 2015), there are some agreed-upon determinants in the epidemiology of the illness, mainly that FAPD appears to be more prevalent in girls and children with psychological disorders, such as anxiety and depression (Kortnerink et al., 2015a). Indeed, children with FAPD report these psychological conditions, as well as missing more school days than their healthy counterparts (Kortnerink et al., 2015a).

There also appears to be a spike in symptoms prior to children reaching the age of one, as well as a secondary spike in symptoms between the ages of eight and ten (Chitkara et al., 2005). It has been found that children in single-parent households reported more frequent episodes of recurrent abdominal pain, as well as children whose mother exhibited traits of neuroticism and families in lower socioeconomic environments (Chitkara et al., 2005). There are minimal differences in prevalence of FAPD across geographic regions, with Europe exhibiting a prevalence of 10.5%, and South America exhibiting a prevalence of 16.8% (Kortnerick et al., 2015b).

## PARENTAL DECISION-MAKING FOR FAPD

### **Biopsychosocial Etiology**

Biological and psychosocial causes have each been implicated as potential causal factors of FAPD. Thus, it becomes complicated to diagnose and treat in a short period of time (Chiou & Nurko, 2011). Diagnoses that may need to be ruled out include appendicitis or cystic fibrosis (Stone & Barbero, 1970), as well as similar functional disorders, including cyclic vomiting syndromes (Hyams et al., 2006). It is noteworthy that IBS has been identified as an independent diagnosis that can be considered when ruling out FAPD; however, IBS has also been classified under the umbrella of FAPD within the ROME IV criteria (Robin et al., 2018). When a potential alternative diagnosis has been ruled out, physicians begin to target possible emotional disorders and distress that may be manifesting physically through abdominal pain (Stone & Barbero, 1970). Diagnoses such as anxiety and depression are often considered when a child is complaining of abdominal pain, particularly in children who miss multiple school days as a result of their pain (Shapiro & Nguyen, 2010). There are a number of possible contributors to somatic complaints of abdominal pain in children, oftentimes it becomes a conglomerate of biological causes and psychosocial stressors (Lackner, 2014).

### **Biological Influences**

There are a variety of biological factors that may contribute to the development of FAPD in children, as FAPD is typically considered an illness of the gut-brain axis (Chiou and Nurko 2011).. Some common risk factors for the development of FAPD in childhood include poor diet, food allergens, dysmotility, gastrointestinal inflammation, visceral hypersensitivity, and helicobacter pylori infections (Friesen et al., 2021; Rasool et al., 2021).

One of the main factors that seemingly indicate a development of FAPD is that of visceral hypersensitivity, a heightened awareness of gastrointestinal intolerance, and gut

## PARENTAL DECISION-MAKING FOR FAPD

stimulation (Chiou & Nurko, 2011; Farmer & Aziz, 2013). The exact cause of visceral hypersensitivity is still relatively unknown; however, some evidence suggests children can develop visceral hypersensitivity in a variety of biopsychosocial ways. Thapar and colleagues (2020) discuss that infants and young children who are exposed to early pain or trauma, familial stress, abuse, or the early use of antibiotics are more likely to suffer from visceral hypersensitivity or dysmotility. As children age, other factors, such as inflammation from infections or allergies, as well as pre-existing motility issues, can contribute to the development of a FAPD as a result of visceral hypersensitivity (Thapar et al., 2020). Family histories of FAPD, such as IBS, have also been linked to childhood gastrointestinal difficulties (Thapar et al., 2020).

Chiou and Nurko (2011) further discuss the genetic and gastrointestinal factors involved in the development of FAPD. Gastrointestinal factors include that of mucosal inflammation, dysregulation of intestinal immunity, as well as small intestine bacterial overgrowth. Friesen and colleagues (2021) discuss mast cell inflammation in IBS and the biological mechanisms behind stress resulting in an altered intestinal microbiome. With this wide variety of genetic factors, there is no predetermined cause for children to develop FAPD, and with this, it becomes difficult to diagnose and treat (Chiou & Nurko, 2011).

### **Psychological Influences**

Because of the complexity of potential biological markers to identify FAPD in pediatrics, psychological causes are also considered. Children with anxiety and/or depression are more likely to have somatic complaints, occasionally warranting a diagnosis of FAPD caused by these psychological conditions (Kortterink et al., 2015a). About 30% of children with FAPD are also

## PARENTAL DECISION-MAKING FOR FAPD

suffering from mood disorders, and additionally, 15-38% of patients with IBS, as a subset of FAPD, experience suicidal ideation (Van Oudenhove et al., 2016).

Anxiety disorders are most commonly linked to FAPD in the pediatric setting, with up to half of patients experiencing these comorbidities (Van Oudenhove et al., 2016). Mood and anxiety disorders in singularity can cause significant functional impairment in childhood, coupled with those children who are subject to lower levels of health-related quality of life due to FAPD can worsen overall outcomes. These children oftentimes are likely to carry these psychosocial impairments into adolescence and adulthood (Friesen et al., 2021).

Friesen and colleagues (2021) also discuss the cyclical nature of psychological disorders and the diagnosis of FAPD. Because FAPD are a type of “rule out” diagnosis, it can become difficult to determine which of the symptoms causes the other. In other words, do anxiety and depression cause children to form FAPD, or do FAPD cause children to become more anxious and experience symptoms of depression? This also breeds the question of when to consider a child’s abdominal pain, that is in conjunction with anxious and depressed symptoms, as a solely somatic disorder, or treated as an unexplained medical diagnosis, such as FAPD (Van Oudenhove et al., 2016).

### **Social Influences**

There is a robust literature on the effect of life events and health (Thapar et al., 2020; Van Oudenhove et al., 2016; Walker et al., 2001). Walker and colleagues (2001) discuss the potential impact of negative life events on the somatic complaints of children with FAPD and found that major life events had less of a negative impact on children's somatic complaints than the everyday stressors they encountered. They reported that daily logging of stressors could more easily determine a child's somatic complaint episodes than having the family describe events



## PARENTAL DECISION-MAKING FOR FAPD

triggering episodes over the past few weeks to years. These daily minor stressors, such as taking a test at school, or an argument with a friend, seem to make children more prone to develop a worsening case of functional abdominal pain than their peers.

Other social factors that have been implicated in the pediatric development of FAPD include sleep disturbances, as one such study demonstrated that children and adolescents with sleep onset difficulties, and subsequent somnolence, were more likely to perceive functional impairment than their healthy peers (Schurman et al., 2012). Other social factors that have been implicated in the diagnosis of FAPD include early childhood adverse experiences, such as abuse, chronic physical punishment, and lack of social support (Van Oudenhove et al., 2016).

### **Parental Influences**

It is widely known that children model behaviors displayed by their parents (Chen et al., 2015), and when parents become worried for their child's health, the child may also become concerned. Stone and Barbero (1970) found that children who appeared more relaxed at the time of hospital admission became more easily frustrated and hostile as their stay continued. This is presumably because the hospital team is unsure of a proper diagnosis, and parents become increasingly worried without an explanation for their child's pain. Furthermore, it was found that children worry about their own parents' health while the child is hospitalized; and often feel disregarded when their pain is minimized or deemed as simply psychological by their physicians or parents (Stone & Barbero, 1970).

There are still many uncertainties with FAPD in children and how it affects their lives in biopsychosocial aspects. What is known is somewhat limited because of the ambivalence surrounding the diagnosis itself. The child's relationship with their parents does appear to have some significant standing (Donnelly & Jaaniste, 2016), and should be further investigated to see

## PARENTAL DECISION-MAKING FOR FAPD

if there are any contributing factors to worsen or aid in the progression or maintenance of this type of chronic pain diagnosis. Donnelly and Jaaniste (2016) suggest that a child's attachment to their parents in early childhood can create both exacerbatory and protective factors in a child's experience of chronic pain. Children with insecure attachment styles may be less able to manage psychological distress associated with pain, use maladaptive coping strategies, and are less likely to adhere to treatment regimens (Donnelly & Jaaniste, 2016). Children with insecure attachment styles are also more likely to develop mood and anxiety disorders (Laird et al., 2016).

Furthermore, parent attitudes toward a child's pain may appear as though they do not line up with their child's actual experience (Jaaniste et al., 2016). These issues may cause a prolonged period of distress in the child, causing issues within the family dynamics and overall impacting the child's health. Indeed, studies have found that parent psychological flexibility could influence a parent's treatment of their child's chronic pain condition, along with other potential implications for their child's overall health and quality of life (McCracken & Gauntlett-Gilbert, 2011b). With this, there is a complexity within the family dynamic, and by improving parental psychological flexibility there may be significant improvements in treatment outcomes. Additionally, there have been decreases in childhood anxiety and depressive symptoms through having a full support system without diminishing the child's feelings of pain (Sieberg et al., 2011). Parents who exhibit lower levels of confidence in their child's functional capabilities while still experiencing pain were found to have higher levels of monitoring, child-protectiveness, and higher levels of parental catastrophizing which, in turn, result in poor coping strategies for the child and family (Jaaniste et al., 2016).

### **Biopsychosocial Implications**

#### **Functioning of the Child**

Given the complexity of FAPD, it is not surprising that it can significantly impact the functioning of not only the child but the entire family unit (Sparks et al., 2015). It can also impact the child's overall emotional and physical development throughout their childhood and adolescence (Vetter, 2011). The functional status of children and adolescents with FAPD is known to be much lower than that of their peers (Campo et al., 2004). Indeed, children with FAPD have an overall poorer quality of life, meaning they may find themselves having issues in their schooling and social lives (Saps & Dhroove, 2011). With children missing multiple school days, social events, and other extracurricular activities due to the pain they are experiencing, pediatric patients may feel as though they are losing their lives and develop a lower sense of self-efficacy (Campo et al., 2004).

Additionally, FAPD may be exacerbated by psychological symptoms of a cyclical nature. As mentioned previously, if a child is diagnosed with depression and/or anxiety, this can contribute to FAPD developing as a somatic complaint, and if a child is diagnosed with functional abdominal pain, they can and are more likely to, develop symptoms of anxiety and depression (Campo et al., 2004). Thus, the nature surrounding the exact causality of the diagnosis of FAPD becomes rather difficult to unpack in terms of functional impairment, as younger children can often not differentiate between the complexities of their pain, only knowing their anxious feelings and somatic complaints they have. With this, it is rather unlikely that a parent will connect these in a cyclical fashion, perhaps leading to a misdiagnosis and an underrepresented population of children diagnosed with FAPD (Robin et al., 2018).

## PARENTAL DECISION-MAKING FOR FAPD

### **Functioning of the Parent(s)**

Parents may experience significant distress when their child is in pain, not only worrying about their child but also about their own lives and potentially their other children (Palermo et al., 2014). Stone and Barbero (1970) discuss the feelings of parents as they experience their child's diagnostic process. These parents often described their children as wise beyond their years, however, also stated that their children are still immature in a variety of ways. The process of diagnosis can be extremely disruptive to a family's life, and parents themselves can reinforce maladaptive coping strategies in the child, contributing to a greater loss of independence and a child's reliance on their parents (Palermo et al., 2014).

Parents may also experience significant financial impacts as well. Oftentimes, parents are taking time off to attend numerous doctor's appointments, staying home while their child is home from school, and agreeing to numerous diagnostic tests that can become very costly (Groenewald et al., 2014). If enrolled in a multidisciplinary program, parents may also attend appointments and sessions both with and without their child present, adding to the total number of hours per week that may be spent solely on their child and diagnosis (Simons et al., 2010). These commitments can often create tension between a working parent's home and work life, and thus can cause stress to the family.

Given the efficacy of multidisciplinary approaches in pain treatment and the relatively low rate of their utilization (Simons et al., 2010), it is important to understand the process by which the parents make treatment decisions. Surprisingly, little research has examined the factors that predict parental openness to multidisciplinary treatments for children suffering from FAPD. Given factors that have been found to influence treatment decision-making for children with FAPD, such as physician acceptance of multidisciplinary treatments and use of shared medical

## PARENTAL DECISION-MAKING FOR FAPD

decision-making (Aarthun & Akerjordet, 2014), parental psychopathology (McKillop et al., 2016), parental education (Kortering et al., 2015a), potential parental illness history and pain conditions (Palermo et al., 2014; Stone & Barbero, 1970), parent psychological flexibility (McCracken & Gauntlett-Gilbert, 2011b), and parent-child relationships in reporting their pain (Jaaniste et al., 2016; Scott et al., 2020), it may be useful to conceptualize these factors and their interactions within the context of an established theoretical framework.

Indeed, the Health Belief Model (HBM) may provide a useful framework for conceptualizing the parental treatment decision process. The HBM has been utilized in a number of interventional studies, including making mental healthcare decisions for others (Guadagno, 2017; Henshaw & Freedman-Doan, 2009) and mothers' caregiving behaviors toward their premature infant's needs (Ghomi et al., 2020). Parents may benefit from such a model, as it may help them navigate the diagnostic process, as well as create multidimensional treatment options to facilitate parental freedom in decision-making for what's best for their child.

### **Current Treatments**

As described above, a diagnosis of FAPD results in significant impairments for both the child and the family. There is a significant body of literature indicating efficacious treatments for FAPD and other childhood gastrointestinal disorders. Common treatments for children with FAPD include both multidisciplinary approaches and unidimensional treatments such as pharmacological treatments (e.g. oral steroids; Rohan & Verma, 2020), as well as strictly psychosocial interventions, such as behavioral and cognitive therapies (Friedrichsdorf et al., 2016; Nelson & Coakley, 2018). Richardson and colleagues (2020) discuss the biopsychosocial nature of treatment for pediatric chronic pain, utilizing aspects such as cognitive-behavioral therapy and physiological self-regulation. While there is evidence for the efficacy of medical and

## PARENTAL DECISION-MAKING FOR FAPD

psychological treatments individually, the most efficacious treatments involve a multidisciplinary approach in which all aspects of the child's disorder are included (Nelson & Coakley, 2018). Despite this, multidisciplinary treatments are underutilized (van Tilburg, 2020).

While a variety of treatments are available including medical and psychosocial interventions (Abbott et al., 2018; Andrews et al., 2020), it is noteworthy that approximately 80% of children having recurrent pain episodes ultimately result in an adult diagnosis of a chronic pain condition (Friedrichsdorf et al., 2016). This reflects a potential need to further assess the efficacy and choice of available treatments, as well as what factors may prevent the choice of a multidisciplinary treatment when available.

### **Medical Treatments**

Common medical interventions for children with chronic illnesses often cite pharmacological usage (Abbott et al., 2018). Indeed, pharmacological treatments for chronic pain conditions are, in many instances, needed in order to have a patient return to normal functioning. However, pharmacological use for children experiencing FAPD is limited, and therefore, psychosocial interventions may be more salient (Thapar et al. 2020). Pediatric pharmacological treatments for FAPD include antispasmodics, tricyclic antidepressants, as well as antibiotic usage (Abbott et al., 2018). Drugs often given will target the brain-gut axis, the interaction between the central nervous system and the gastrointestinal tract (Chiou & Nurko 2011). While these drugs can benefit a child during the pain period, their prolonged use has yet to be adjudicated (Martin et al. 2017). It may benefit pediatricians to consider multidimensional treatments dependent on the circumstances surrounding the diagnosis, as discussed previously.

## PARENTAL DECISION-MAKING FOR FAPD

Although beyond the scope of this paper, establishing the utilization of pharmacological treatments is necessary because of its use in the pediatric setting. However, using a substantial number of drugs during childhood and adolescence can cause substantial harm to the body, as well as become somewhat dependent on the medication used in order to alleviate symptoms (Pielech et al., 2020). Andrews and colleagues (2020) discuss several drugs and supplements that have been used to aid children with FAPD. Fiber, for instance, may have a practical use, however, has not shown much significance in trials. Antispasmodic drugs, such as mebeverine and buscopan, as well as some antidepressants, have shown a decrease in pain in children (Andrews et al., 2020).

### **Psychological Treatments**

Psychological treatments have been shown to be efficacious in the treatment of FAPD and other chronic pain conditions (Law et al., 2019). These treatments include psychotherapy (Brusaferrero et al., 2018), support groups for children and families dealing with chronic pain diagnoses (Nelson & Coakley, 2018), and home-based interventions, such as online relaxation trainings (Bonvanie et al., 2017). Numerous studies and randomized controlled trials have been done to assess the effectiveness of psychological therapies for children with chronic pain conditions. It has been found that both in-person (Abbott et al., 2018) and online deliveries (Palermo et al., 2016) of cognitive-behavioral therapies have been shown to improve activity levels and quality of life in children and adolescents diagnosed with a chronic pain condition. Furthermore, group programs like the *Comfort Ability* have been shown to deliver effective cognitive treatment to children with chronic pain and their parents through brief intervention and skill training formats (Coakley et al., 2018).

## PARENTAL DECISION-MAKING FOR FAPD

Beyond general chronic pain treatments, specialized programs for children and adolescents with FAPD prove efficacious as well. Cognitive-behavioral therapy, biofeedback therapy, and social-learning therapy, as well as some self-regulatory techniques like guided imagery and hypnotherapy all show improvements in outcomes for the child. Children and adolescents who participated in such therapies experienced improved quality of life, a reduction in overall pain and pain intensity, as well as a reduction in overall gastrointestinal symptoms (Coakley & Wihak, 2017). Meta-analyses done by Bonvanie and colleagues (2017), as well as Coakley and Wihak (2017) further confirmed that psychological interventions improve children's pain outcomes, resulting in a reduction in fatigue and abdominal symptoms.

### **Multidisciplinary Treatments**

While there are a number of psychological and medical treatments for childhood chronic pain, including FAPD, there is evidence that demonstrates multidisciplinary treatment regimens, including both medical and psychological interventions are more effective than single-armed interventions alone (Law et al., 2019). While they are seemingly the most comprehensive, one study found that only 46% of children with chronic pain conditions receive these treatments (Simons et al., 2010). One recent study found that those children that engaged in multidisciplinary treatment experienced up to 30% improvement in symptoms (Beinvogl et al., 2019). These multidisciplinary approaches include a variety of interventions such as relaxation and stress reduction strategies for the child, while simultaneously providing education and stress management techniques to parents as part of the overall treatment (Sparks et al., 2015). Despite the evidence for the effectiveness of multidisciplinary treatments for children with chronic pain conditions, relatively little information exists regarding multidisciplinary care for children with FAPD.



## PARENTAL DECISION-MAKING FOR FAPD

While further research needs to be conducted for the use of multidisciplinary care for children with FAPD, a further concern involves the relatively low rates of engagement in multidisciplinary care and parental decision-making regarding these treatments. Gorodzinsky and colleagues (2012) discuss general perceptions of multidisciplinary care from the parent perspective, stating that parents who engaged in multidisciplinary care for their children felt more hopeful about their child's pain after their first appointment at the clinic. Parents also reported that the engagement of all aspects of the care, including school reintegration, medication usage, and mental health treatment led to feelings of reassurance and satisfaction with the care being delivered. While some multidisciplinary programs for FAPD such as Comfort Ability exist (Coakley et al., 2018), their number and availability remain limited.

### **Parental Healthcare Decision-Making**

As described above, there are many biopsychosocial treatments and some multidisciplinary programs available. Despite this, and a body of research exploring parental decision making to a variety of health conditions for their children, the process by which parents choose treatments for their children with FAPD is largely unknown. That is, it is unknown what personal, relational, knowledge, and other relevant variables are involved in the parental choice about treatment engagement for their children.

Currently, limited research exists about what particular factors contribute to the decisions parents will make about their child's care, both for behavioral health and medical ailments (Guadagno, 2017). Studies thus far have focused on the parents' opinions and choices impacting the outcome after they have made a decision about the treatment plan enacted for the child (Simons et al., 2010; Stremmer et al., 2017). Additionally, research has found that parent psychological flexibility has an impact on childhood chronic pain outcomes. Particularly, parents

## PARENTAL DECISION-MAKING FOR FAPD

who exhibit higher levels of psychological flexibility are more often likely to be accepting of potentially adverse experiences in both their own lives and their child (McCracken & Gauntlett-Gilbert, 2011). This flexibility could then extend to the child's own thought pattern and increase better treatment adherence and outcomes. However, minimal steps beyond psychological flexibility have been taken to determine what factors in parents result in more engagement with behavioral health treatments, and which do not.

A significant literature exists pertaining to parental choices and how they may impact the child and their health outcomes. For example, parents often refrain from giving their child the flu vaccine based on the perception of the threat the influenza virus poses to their child, along with other psychosocial factors (Cheney & John, 2013). However, it's also been found that parents struggle to make these decisions without the guidance of physicians and other healthcare professionals (Boland et al., 2019; Kerr et al., 2020).

Physicians may also struggle to educate parents on options that are available to them and their children and may lack communication skills to be able to clearly demonstrate these choices (Bašnáková & Hatoková, 2017; Kerr, 2014). It has been found that multidisciplinary teams make parents feel the most at ease regarding their choices (Gorodzinsky et al., 2012), and this results in a better quality of life for both the child and the parents (Carroll et al., 2012).

### **Vaccine Hesitancy as a Proxy**

Literature focusing on parent opinions regarding vaccination of their children appear to be the most salient in terms of parental decision-making models. Damnjanovic and colleagues (2018) assess a host of potential factors parents may weigh when choosing if and when to vaccinate their child. In a series of pilot studies, they determined that parents have a multitude of relationships with the information they are receiving and how this may influence their

## PARENTAL DECISION-MAKING FOR FAPD

decisions. Reinforcing factors in parent vaccination choice include a trust toward authority figures, both a social and scientific consensus about the safety and benefit of the vaccines, the amount of information available about any given vaccine, as well as an overall sense of openness (Damnjanovic et al., 2018).

Furthermore, Cheney and John (2013) assessed the underutilization of flu vaccines following the H1N1 virus outbreak. In this case, parents felt that a flu vaccine may or may not be necessary for their child based upon factors of perceptions held by the parents. Aspects of their child's susceptibility to getting the virus, the threat of getting the virus itself, and the possible benefits of getting vaccinated were all found to be important indicators leading to the decision parents made about getting the vaccine for their child.

### **Communication Between Physicians and Parents**

Although both parents and physicians have the best intentions when it comes to caring for a child, there can be breakdowns in communication about their care (Lotto et al., 2017). Kerr (2014) discusses the issues that may arise between parents and physicians and how best to cope with potential contention that they may face when making shared decisions about their child's care. Struggles in making these decisions are not limited to a lack of education regarding multidisciplinary treatment regimens for FAPD (Pas et al., 2018), but also include how parents and physicians and/or a multidisciplinary team approach their conversational style, the level of comfort that parents feel in their community, stigma, and other similar factors (Bašnáková & Hatoková, 2017; Boland et al., 2019; Kerr, 2014).

Openness and other personality factors may also impact how a parent takes in information about treatment modalities that can be used for their chronically ill child (Damnjanovic et al., 2018; Vigouroux et al., 2017). Vigouroux and colleagues (2017) look at the

## PARENTAL DECISION-MAKING FOR FAPD

five factors of personality (openness, conscientiousness, agreeableness, extraversion, and neuroticism) in the case of parental burnout, finding that parents who felt burnt out had high scores on neuroticism, low scores on agreeableness, and low scores on conscientiousness. This may be telling in terms of the parental decision-making process when looking at their child with functional abdominal pain.

Given the potentially complex number and interaction between variables influencing parental decision-making, shared medical decision-making may be important in helping parents to make the best choice for their situation. While a full discussion of shared medical decision-making is beyond the scope of this paper, parent-physician interactions may contribute significantly to the use or lack of use of multidisciplinary programs. Studies such as Amin and colleagues (2016) have discussed how parent and physician opinions about the care methods that are utilized for a child may change the potential outcomes based on opinions alone, as well as how aspects of the health belief model may play into decision-making. Furthermore, being able to have care teams acknowledge potential setbacks and challenges of care that may impact families' decisions could aid in the process of choosing more multidisciplinary care options.

### **Health Belief Model**

Given the lack of data concerning parental healthcare decision-making for children with FAPD and the large number of variables that may be relevant to this process, it may be useful to use a theoretically validated model of healthcare decision-making as a structural framework. The Health Belief Model (HBM) has been a widely applicable biopsychosocial approach to behavior change (Carpenter, 2019). Because of its varying utility, it has been conceptualized as a model that can be used in a variety of factors, such as vaccine hesitancy in both individuals and parents of children (Cheney & John, 2013), a model for use in shared decision-making (Guadagno,

## PARENTAL DECISION-MAKING FOR FAPD

2017), as well as an overall use for engagement in behavior change in mental health care (Henshaw & Freedman-Doan, 2009).

The uses of the HBM extend far beyond its original inception and can now be utilized in a variety of clinical settings, no longer limited to behavioral health care. This particular use of the HBM has been conceptualized as a potential way of understanding and developing interventions to improve the utilization of multidisciplinary treatments for children with chronic pain.

### **The Health Belief Model**

The HBM is a widely utilized framework for health behavior research. Synthesized in the 1950s by social psychologists such as Hochbaum (1958), and Rosenstock (1960; 1974), it was later broadened to a wide variety of research interests, such as responses to illness and medical adherence (Becker, 1974).

The main components of the HBM interact in various ways in order to explain change and maintenance of health-related behaviors (Champion & Skinner, 2008). The interaction of these variables aids in the promotion of public health, in part, by identifying where people fall short in preventative health behaviors (Carpenter, 2019). The first of these aspects, susceptibility, encompasses the idea of what a person perceives themselves to be vulnerable to in terms of negative health outcomes (Green et al., 2020). That is, a person who believes they are highly susceptible to negative health outcomes is more likely to engage in preventative behaviors in accordance with the model.

Perception of the severity of these potential negative health outcomes also indicates someone's adherence to more preventative measures (Carpenter, 2019). Severity can include how dire the situation may be to the individual or what risks are associated with deciding one

## PARENTAL DECISION-MAKING FOR FAPD

way over the other (Green et al., 2020). Further perceptions that influence one's health behavior include what one perceives to be beneficial to them engaging in preventative health treatments. This belief in the benefits of engaging in preventative health behavior may also play into feelings of self-efficacy, the belief in one's self that they can follow through with a given behavior change or healthcare decision (Green et al., 2020). However, one can also perceive barriers to receiving preventative care, as this can create conflict within an individual (Carpenter, 2019).

Barriers to preventative care can include both societal and personal reasons. These can include costs of care, access to equitable care, beliefs regarding access to care, and societal norms or general stigma (Carpenter, 2019). Cues to action may also contribute to an individual's engagement (or disengagement) in preventative health measures and health decision-making. These cues include outside influences, such as conversations with family and peers, advertisements promoting healthy behaviors, and conversing with health care professionals frequently regarding preventative care (Carpenter, 2019; Green et al., 2020).

### **Utilization of the Health Belief Model**

Utilization of the HBM as a decision-making model for others is somewhat scarce, and minimal literature can be found regarding the use of the HBM for parental decision-making regarding their children. However, there is a substantial amount of literature indicating its use to guide decision-making about oneself. Victoria Champion (Ph.D., RN; 1984) created a scale to assess aspects of the HBM in light of preventative breast cancer screening. This assessment, utilizing aspects such as perceived barriers, benefits, and susceptibility, has been shown to be efficacious for women with worries about breast cancer screenings. Furthermore, this scale has been revised and adapted to include other health conditions, such as prostate cancer (Cantürk &

## PARENTAL DECISION-MAKING FOR FAPD

Gözüm, 2011) and diabetes (Gutierrez & Long, 2011). Using a similar method to assess decision-making via a proxy, such as a parent, may prove to be of use and serve as a baseline for parent concerns for their children with FAPD.

In terms of parent-child decision-making, Ghomi et al. (2020) sought to examine caring components of mothers of infants within the domains of the HBM, however, the HBM did not provide significant findings in this particular circumstance, citing insufficient knowledge about the use of the HBM on others. Despite the findings of this particular study, the HBM may still provide a theoretical framework for parental decision-making for their children. What is still relatively unknown is if the HBM will provide a structure for interventional activities with parents needing to make decisions regarding their child's behavioral health plan, when diagnosed with chronic illnesses, particularly FAPD.

Guadagno (2017) concluded that the HBM could serve as a useful framework when making healthcare decisions for others; however, this study did not examine parent-child relationships. A very limited body of research exists for decision-making for children with chronic illness, only focusing on vaccination hesitancy of parents and decisions needing to be made for children with special needs. Parent-physician communication may also cross into many of the domains of the HBM. For example, parental understanding of illness as a true medical condition, illness susceptibility, and severity as well as perception of availability and benefits of various treatments often comes from their interaction with the physician (Amin et al., 2016).

Additionally, one study conducted by Chen and colleagues (2011) utilized aspects of the HBM to investigate parents' choice to administer the influenza vaccine to their child. They found that aspects of the HBM were significant in predicting their choice in vaccinating their children. Of note, the instrument developed by Chen and colleagues consisted of 19 questions and was

## PARENTAL DECISION-MAKING FOR FAPD

validated with a Chinese sample. To date, no standardized instrument has been utilized for parent-child decision-making.

### **Current Study**

While a notable body of research exists regarding the origins and treatments for FAPD, little is known regarding parental decision-making in the selection of treatment modalities that are available for this specific condition. It is important to assess what parents may analyze and consider when making a decision for their child's care. Thus, it is equally as important to assess pre-existing factors that may influence parents' decisions. In order to provide a theoretically sound framework, the current study aims to explore aspects of the HBM in parental decision-making as a method of pre-diagnostic interventional activity.

Because the HBM is a widely accepted theoretical framework for healthcare decision-making, this study uses it as a potential framework for assessing the likelihood of parents choosing a multidisciplinary approach to their child's treatment for functional abdominal pain. Should this model prove useful in understanding parental decision-making, further studies should assess the utility of developing interventions to help maximize treatment options for children diagnosed with FAPD. Thus, the following associations were hypothesized:

- Within the modifying factors domain, a positive association will be found between parental scores of psychological flexibility and acceptance of multidisciplinary forms of care for their child.
- Within the domain of perceived susceptibility, severity, and threat, a positive association will be found between parental perception of disease severity, the potential threat of the disease, and susceptibility, and acceptance of multidisciplinary care for their child.



## PARENTAL DECISION-MAKING FOR FAPD

- Within the domain of perceived benefits and barriers, an inverse association will be found between parents' perceived barriers to care and acceptance of multidisciplinary care for their child.
- Again, within the domain of perceived benefits and barriers, a positive association will be found between parents' perceived benefits of multidisciplinary treatment and their acceptance of these treatments.
- Within the cues to action domain, positive associations will be found between parental education, knowledge, and physician communication, and acceptance of multidisciplinary care.
- Again, within the modifying factors domain, positive associations will be found between parent personality factors, and parental acceptance of multidisciplinary care for their child.

Given the novel nature of the current study, exploratory analyses will be conducted to examine for potential group differences.

## **Chapter II**

### **Methods**

#### **Participants**

Participants were recruited using Cloud Research's service Prime Panels. Due to the lack of existing data and effect sizes, an a priori analysis was not conducted.

#### **Inclusion Criteria**

Parents of children under 18 who have been diagnosed with functional abdominal pain, English as the first language, 6th-grade reading level.

#### **Exclusion Criteria**

Nonparents, parents of children over 18 with chronic pain conditions, parents of children with cancer pain, migraines, or other neuropathic pain not in the abdomen, parents of children with FAPD due to a surgical procedure.

#### **Measures**

##### **Demographic Measurements**

Basic demographic information was collected at the start of the study. Information collected included parent age and gender, ethnicity, household income, education level, and insurance coverage. Participants were also asked about their family medical, chronic pain, and psychiatric history, as well as general questions about their child's condition. Questions about their child included their child's age, gender, age of diagnosis, and any comorbid medical and

## PARENTAL DECISION-MAKING FOR FAPD

psychiatric conditions that the child may have. The demographic questions can be found in Appendix A.

### **Child Treatment Scale**

The child treatment scale (Appendix B) was created for the purposes of this study. It includes a series of questions regarding the child's current treatment, and care for their functional abdominal pain condition. Questions include topics such as forms of treatment and consideration and engagement in multidisciplinary treatment. These represent the outcome variables of interest in the treatment decision-making process.

### **Parental Psychological Flexibility**

The Parent Psychological Flexibility Questionnaire (PPFQ) is a commonly used and empirically validated measure for gauging overall psychological flexibility in parents, specifically conceptualized as a measure for use with parents of adolescents with chronic pain (McCracken & Gauntlett-Gilbert, 2011b). It is a 31-item self-report inventory that is internally consistent in the literature ( $\alpha = 0.91$ ). The initial implication of this scale was tested against both the Adult Responses to Child's Symptoms scale (ARCS) for adults and the Bath Adolescent Pain Questionnaire for teens (McCracken & Gauntlett-Gilbert, 2011b). Comparing the PPFQ to both an adult survey as well as an adolescent one allowed the researchers to demonstrate construct validity related to the adolescent's reported pain outcomes. Parents are asked to rate items depending on "how true it is for you" and given a Likert scale of 0 (Never True) to 6 (Always True). Subscales derived from the PPFQ are Values-Based Action, Emotional Acceptance, Pain Acceptance, and Pain Willingness (McCracken & Gauntlett-Gilbert, 2011b). The PPFQ can be found in Appendix C, reverse scored items are indicated (McCracken & Gauntlett-Gilbert, 2011a).

## PARENTAL DECISION-MAKING FOR FAPD

### **Big Five Personality Traits**

The Big Five Inventory (BFI) is a well-validated and highly utilized assessment tool to measure five of the main personality factors within a person. The domains measured by the BFI include openness, conscientiousness, extroversion, agreeableness, and neuroticism. It is a 44-item self-report inventory that is internally consistent ( $\alpha = 0.83$ ; John et al., 2008). The 44-item version was chosen as opposed to the short versions because of its more accurate and comprehensive nature. The BFI was found to be reliable against other common measures of personality, the Trait Descriptive Adjectives Inventory (TDA) and the Neuroticism, Extraversion, Openness Personality Inventory (NEO-PI). Respondents are asked to rate statements on a Likert scale based upon how true the item is about themselves, with the starting prompt being, "I see myself as someone who," followed by a variety of statements that identify certain factors of personality (John et al., 2008). The BFI can be found in Appendix D, reverse scored items are indicated.

### **Health Belief Model**

The Health Belief Model Scale (HBMS) is a validated instrument for a variety of health decisions, including breast cancer (Champion, 1984) and revised for prostate cancer (Cantürk & Gözüm, 2011). Each of these scales measures aspects present in the health belief model itself. These aspects include susceptibility, barriers, benefits, and seriousness. The original measure was internally consistent, with subscale Cronbach alpha's ranging from .75 to .88 (Champion, 1999). In order to capture beliefs relevant to parental decision-making for the care of children with RAP, the original scale was revised and adapted for this purpose (Appendix E). While the scale utilized in this study is not validated it follows the style set by previous HBMS assessments. This scale measures parents' beliefs regarding their child's susceptibility, severity,

## PARENTAL DECISION-MAKING FOR FAPD

and threat, benefits, barriers, as well as an additional set of questions to target cues to action and general knowledge about the condition itself. There are four subscales written into this version of the HBMS, parent perceived susceptibility, severity, and threat; parent perceived benefits; parent perceived barriers; parent perceived physician and self-knowledge. Reverse scored items are indicated.

### **Procedures**

Participants recruited via Cloud Research received an informed consent statement (Appendix E). Cloud Research screened for participants currently residing in the United States and meeting the required inclusion criteria. All questions from the above instruments were administered to the participants via Qualtrics. Participants were able to opt out at any time throughout the administration by exiting the survey. Participants were compensated for completion of the survey. Following the conclusion of the survey, participants were redirected back to Cloud Research and thanked for their participation in the study.

### **Data Analysis**

Primary hypotheses were assessed using bivariate correlations. In addition, consistent with previous literature (Simons et al., 2010), it was found that a significant number of participants had not heard of multidisciplinary care treatments (47.4%;  $n = 237$ ). Thus, hypotheses were re-analyzed using multidisciplinary care consideration, and psychological care consideration, in order to examine potential semantic misunderstandings. It was also decided to analyze a potential for group differences between those who have heard of multidisciplinary care, and those who have not. Results of the hypotheses will be presented along with their corresponding Post-Hoc analysis for clarity. An additional Post-Hoc analysis section to examine overall group differences will also be presented.

## **Chapter III**

### **Results**

A total of 583 participants were recruited via Cloud Research. Seventy-nine participants were excluded and not compensated, either due to incompleteness, completion under 5 minutes, or issues with qualitative answers (e.g. endorsing a family history of chronic pain, then stating there were no such conditions) as mentioned in the methods section. Three additional participants were compensated and excluded from analysis due to greater than 50% of items unanswered. The remaining sample included 501 participants. The final sample was 62.2% female ( $N = 311$ ) and participant ages ranged from 18 to 67 years ( $M = 38.47$ ;  $SD = 7.898$ ). All subscales and scales were examined for skewness and kurtosis, as well as outlier examination, no further data were excluded, and no transformations were necessary.

Frequencies and percentages of relevant demographic variables can be found in Table 1. Means and standard deviations for relevant demographic variables can be found in Table 2. Means and standard deviations for predictor scales and subscales are shown in Table 3. In addition, given the current study's adaptation and addition of the Champion HBMS, Cronbach's Alphas for predictor scales and subscales are also presented in Table 3. Frequencies and percentages for outcome variables are presented in Table 4. Means and standard deviations for outcome variables are presented in Table 5. Preliminary reliability measures were performed on all instruments. For the validated scales (BFI, PPFQ) it is important to note that Cronbach's alpha values were consistent with prior reports in the literature, as described in the methods.

## PARENTAL DECISION-MAKING FOR FAPD

Cronbach's alpha values for the subscales of the Health Belief Model Scale (HBMS), modified from the Champion HBMS (Champion, 1984), were within reason (see Table 3), with one exception. The prior subscale of physician communication yielded a Cronbach's alpha of 0.309. Item deletion analysis was performed, and two different constructs emerged. The scale, consisting of five total questions, was divided into one two-question subscale of physician knowledge, and another three-question subscale of parent-physician communication (Table 3). Given this differentiation in constructs, analyses were run accordingly, and hypothesis analyses were adjusted. No other items from any of the HBMS subscales were deleted.

The primary aim of this study was to examine relationships between parent factors, including personality and psychological flexibility, as well as the use of the HBM to predict parental acceptance of multidisciplinary care. As demonstrated below, in general, the hypotheses were supported, suggesting the utility of the HBM as a tool to potentially increase the use of multidisciplinary care for children with FAPD.

### **Hypotheses and Post-Hoc Hypotheses**

**Hypothesis 1 Within the modifying factors domain, a positive association will be found between parental scores of psychological flexibility and acceptance of multidisciplinary forms of care for their child.**

Parental scores of psychological flexibility and acceptance of multidisciplinary forms of care for their child demonstrated a significant positive correlation ( $r = .125; p < .01$ ). Post-Hoc analysis found significant positive correlations were found between consideration of multidisciplinary care and parental psychological flexibility ( $r = .151; p < .001$ ), as well as consideration of psychological care and psychological flexibility ( $r = .162; p < .001$ ). Multidisciplinary consideration in the context of psychological flexibility accounted for  $r^2 =$

## PARENTAL DECISION-MAKING FOR FAPD

2.3% of the variance, with psychological care consideration accounting for only  $r^2 = 2.6\%$  of the variance.

**Hypothesis 2: Within the domain of perceived susceptibility, severity, and threat, a positive association will be found between parental perception of disease severity, the potential threat of the disease, and susceptibility, and acceptance of multidisciplinary care for their child.**

Parental perception of disease severity, the potential threat of the disease, and susceptibility, and acceptance of multidisciplinary care for their child showed a positive correlation ( $r = .174$ ;  $p < .001$ ). Post-Hoc analysis found significant positive correlations were found between consideration of multidisciplinary care and perceived susceptibility, severity, and threat ( $r = .236$ ;  $p < .001$ ). Consideration of psychological care and perceived susceptibility, severity, and threat also demonstrated a significant correlation ( $r = .237$ ;  $p < .001$ ). Additionally, variances for these relationships were  $r^2 = 5.5\%$ , and  $r^2 = 5.6\%$ , respectively.

**Hypothesis 3: Within the domain of perceived benefits and barriers, an inverse association will be found between parents' perceived barriers to care and acceptance of multidisciplinary care for their child.**

No relationship between perceived barriers to care of FAPD in children and acceptance of multidisciplinary care was found ( $r = -.045$ ;  $p = .315$ ). It is noteworthy that of the items that load onto the perceived barriers subscale, alternative forms of treatment taking too much time ( $r = -.100$ ;  $p < .05$ ), and stigma associated with taking a child to a psychologist ( $r = -.093$ ;  $p < .05$ ) were inversely associated with multidisciplinary acceptance. Post-Hoc analysis found no relationship between consideration of multidisciplinary care and perceived barriers. There was a significant positive correlation found between psychological care consideration and perceived



## PARENTAL DECISION-MAKING FOR FAPD

barriers ( $r = .127$ ;  $p < .005$ ), however, this relationship only accounts for  $r^2 = 1.6\%$  of the variance.

**Hypothesis 4: Within the domain of perceived benefits and barriers, a positive association will be found between parents' perceived benefits of multidisciplinary treatment and their acceptance of these treatments.**

Parents' perceived benefits of multidisciplinary treatment and their acceptance of these treatments showed a significant positive correlation ( $r = .291$ ;  $p < .001$ ). Post-Hoc analysis demonstrated positive significant relationships between consideration of multidisciplinary care and perceived benefits to care ( $r = .239$ ;  $p < .001$ ), as well as consideration of psychological care and perceived benefits ( $r = .379$ ;  $p < .001$ ). There is also a significant difference between these correlations ( $Z = -2.436$ ;  $p = .007$ ), indicating that parents are more likely to consider psychological care within the context of perceived benefits to such treatments.

**Hypothesis 5: Within the cues to action domain, positive associations will be found between parental education, knowledge, and physician communication, and acceptance of multidisciplinary care.**

Due to the division of the physician communication scale, analyses were run with the two subscales (parent-physician communication and physician knowledge) and multidisciplinary acceptance, as well as the associated scale of parent knowledge. A positive association was found between parent knowledge and multidisciplinary acceptance ( $r = .304$ ;  $p < .001$ ). There was a positive association found between parent-physician communication and acceptance of multidisciplinary treatments ( $r = .277$ ;  $p < .001$ ), indicating that parents involved in direct communication with their physician regarding treatment options were more likely to be accepting of multidisciplinary care. Additionally, a positive correlation was found between

## PARENTAL DECISION-MAKING FOR FAPD

perceived physician knowledge and acceptance of multidisciplinary treatments ( $r = .261$ ;  $p < .001$ ). Each of these three subscales was also significantly correlated with one another. These correlations can be found in Table 6. Post-Hoc analysis of the cues to action domain revealed significant correlations between consideration of multidisciplinary care and parent knowledge ( $r = .231$ ;  $p < .001$ ), physician knowledge ( $r = .190$ ;  $p < .001$ ), and parent-physician communication ( $r = .140$ ;  $p < .005$ ). There were also significant correlations found between consideration of psychological care and parent knowledge ( $r = .194$ ;  $p < .001$ ), physician knowledge ( $r = .144$ ;  $p < .01$ ), and parent-physician communication ( $r = .181$ ;  $p < .001$ ).

**Hypothesis 6: Within the modifying factors domain, positive associations will be found between parent personality factors, and parental acceptance of multidisciplinary care for their child.**

Associations between multidisciplinary acceptance and parent personality factors can be found in Table 7. Results indicate significant correlations between three of five personality facets, openness, neuroticism, and extraversion. Post-Hoc analysis of modifying factors found significant positive correlations between consideration of multidisciplinary care and aspects of parent personality traits, including extraversion ( $r = .116$ ;  $p < .01$ ), agreeableness ( $r = .111$ ;  $p < .05$ ), conscientiousness ( $r = .157$ ;  $p < .001$ ), and openness ( $r = .196$ ;  $p < .001$ ). There was a significant negative correlation found between consideration of multidisciplinary care and neuroticism ( $r = -.132$ ;  $p < .01$ ). There was a significant correlation between consideration of psychological care and the parent personality trait of openness only ( $r = .099$ ;  $p < .05$ ).

### Post-Hoc Exploratory Analysis

In examining demographic data, it was found that 47.4% of the sample reported that they have not heard of multidisciplinary care. This was concerning and may be an important factor in

## PARENTAL DECISION-MAKING FOR FAPD

the results obtained above. Furthermore, this could reflect important considerations to be made by health care providers in communication and training regarding treatment options for children with FAPD (see hypothesis 5). Thus, the possibility of group differences in acceptance of multidisciplinary care was explored. Findings of the Post-Hoc hypotheses are comprehensively located in Table 8.

Indeed, similar group differences were found for the items of consideration of multidisciplinary care  $t(495) = 3.995, p < .001$ , with those who have heard ( $M = 3.85; SD = 1.09$ ) more likely to consider multidisciplinary care than those who have not heard ( $M = 3.47; SD = 1.01$ ). The same relationship was true of consideration of including psychological treatment  $t(495) = 1.988, p < .05$ , with those than have heard ( $M = 3.80; SD = 1.08$ ) more likely to consider than those who have not ( $M = 3.61; SD = 1.03$ ). Further details of these results can be found in Table 9.

As expected, those who had heard of multidisciplinary care ( $n = 180$ ) were more likely to be currently or previously engaged in such care relative to those who had not heard of multidisciplinary care ( $n = 47$ )  $X^2(2, 496) = 123.132, p < .001$ . It is also noteworthy that there was a significant correlation between parental consideration of multidisciplinary care and psychological care ( $r = .611; p < .001$ ). This association continued even when controlling for whether the participant had or had not heard of multidisciplinary care. Hierarchical regression with having heard of multidisciplinary care entered in step one and consideration of psychological care in step two yielded a step two change in  $R^2 = .39, F(1, 494) = 289.902, p < .001$ .

## **Chapter IV**

### **Discussion**

The primary aim of this study was to examine parent beliefs regarding the varying treatment options (i.e. multidisciplinary and/or psychological care) available for their children with FAPD, if they were open to such treatments, and what internal and external factors are related to make a decision either way. Furthermore, parental beliefs, personality factors, and psychological flexibility were conceptualized using the HBM as a theoretical framework, adapted from the Champion Health Belief Model Scale (1984).

The HBM is a widely understood and accepted biopsychosocial model that is utilized to understand behavior change within an individual (Carpenter, 2019). Since its creation in the 1950s, it has become a widely used framework for understanding behavior change in oneself medically, psychologically, and in decision-making (Hochbaum, 1958; Henshaw & Freedman-Doan, 2009; Rosenstock, 1960; Rosenstock, 1974). It has also served a purpose in shared medical decision-making (Guadagno, 2017), and understanding parent vaccine hesitancy (Chen et al., 2011). However, it has yet to be directly utilized in parental decision-making for children with chronic pain conditions and thus, this study sought to utilize the HBM within a novel decision-making process.

The HBM consists of several aspects in order to conceptualize a person's internal and external influences that may then contribute to a decision regarding health. For the purpose of this study, the HBM assessed parental beliefs regarding perceived susceptibility, severity, and

## PARENTAL DECISION-MAKING FOR FAPD

threat, perceived benefits and barriers, parental personality factors and psychological flexibility, and parent-physician communication and knowledge, all within the context of children suffering from FAPD. Aspects of the health belief model were assessed in order to capture parental expectations, attitudes, and perceptions regarding care for their child with FAPD, and if there were subjects that could lead to potential interventional activities. The Health Belief Model Scale, as created by Victoria Champion (PhD, RN), had the original intent of increased acceptance and use of preventative breast cancer screenings. It has since become a tool used for multiple forms of cancer screenings to gain an understanding of an individual's belief system about preventative maintenance (Cantürk & Gözüm, 2011; Gutierrez & Long, 2011).

Overall, the findings of this study support the predictive use of the HBM in predicting parental decision-making regarding acceptance and use of multidisciplinary treatments for their child with FAPD. All of the assessed domains of the HBM including perceived susceptibility, severity, and threat, perceived benefits/barriers, modifying factors, and cues to action predicted acceptance of multidisciplinary care (i.e., consideration of multidisciplinary care, consideration of psychological care, awareness of multidisciplinary care, and current or previous enrollment in multidisciplinary care programs).

### **Susceptibility, Severity, and Threat**

Parental perception of their child's susceptibility to abdominal pain symptoms, along with how severe they believe the condition is and how threatening to their child they believe it to be, was predictive of parental openness to a variety of treatment options, including multidisciplinary care. This was consistent with what was hypothesized, indicating that parental perception of their child's condition plays an important role in the potential choice of treatment. In decisions regarding the self, it has been found that an individual's perceived susceptibility to a

## PARENTAL DECISION-MAKING FOR FAPD

poor outcome, along with their perception of the potential severity of a potential health behavior change, and how threatening this change may be to the individual, may impact their decision-making greatly (Carpenter, 2019).

The results of the current study are consistent with prior findings in proxy decision-making, such as vaccine hesitancy, in which a parent's values and beliefs continue to impact decision-making for their children (Chen et al., 2011). Given the current findings, it may be helpful for clinicians to explore parental beliefs regarding the severity and threat of their child's FAPD to assess the accuracy and urgency of the child's prognosis. This, in turn, may allow clinicians to provide early interventional education regarding early diagnosis, prognosis, and treatment options.

### **Benefits and Barriers**

Additional factors under consideration in the HBM include perceived benefits to care or behavior change, along with perceived barriers to these same concepts. Consistent with the hypothesis, parents who perceived greater benefits to treatment are more likely to be open to, and accepting of, multidisciplinary treatments for children with FAPD. This was also supported in the post-hoc analysis indicating that perceived benefits also predicted consideration of both multidisciplinary care and psychological care. Other literature has documented the effect of perceived benefits as a recent study found that those who perceive a greater number of benefits to seeking mental health treatment are more likely to engage in such treatments (Green et al., 2020). Again, this speaks to a potential target for clinicians to assess and intervene in order to improve outcomes for children through the use of multidisciplinary care. Through brief analysis of parental perceived benefits, clinicians may be able to assist parents in understanding the

## PARENTAL DECISION-MAKING FOR FAPD

benefits and positive outcomes that are associated with engagement in multidisciplinary care, such as traditional medical intervention combined with psychological care.

Unexpectedly, perceived barriers was not a significant predictor of either the acceptance or consideration of multidisciplinary care. While this was an unexpected finding, as previous studies have found perceived barriers to be inversely associated with outcome variables such as vaccination choice (Chen et al., 2011), it is possible that the language of the scale may have caused confusion among participants. Due to the pilot nature of this study's HBMS, it is possible that there was a broad misunderstanding of the direction of response. With the perceived barriers subscale consisting of nine total questions, all of which were negatively connotated (i.e. "I don't think that psychological treatments can help with medical conditions such as pain"), as well as the Likert scale indicating that lower scores are negative perceptions (i.e. 1 = strongly disagree), it is possible that the double negative could have caused complications in participant response. The subscale itself did, however, show internal consistency ( $\alpha = 0.92$ ). In previous studies utilizing similar assessments of barriers, Cronbach's alphas were similar to this study's (Champion, 1984; Chen et al., 2011).

Due to the novel nature of the study, and the adaptation of the Champion HBMS, the perceived barriers subscale focused heavily on the psychological aspects of barriers to care. Questions included in the subscale covered psychological stigma and external opinions (i.e. taking my child to a psychologist for their pain will make people think differently of me), rather than on the traditional institutional barriers to care covered in the literature. In decision-making regarding vaccine hesitancy, barriers covered include both the time spent in office receiving a vaccination, along with lack of information and communication barriers (Bašňáková & Hatoková, 2017). Indeed, it may be that traditional institutional barriers may play a more salient

## PARENTAL DECISION-MAKING FOR FAPD

role in parental decision-making relative to the psychological factors assessed as part of the current study.

In addition to the lack of support for the initial hypothesis, the post-hoc analysis indicated a significant positive correlation between perceived barriers and parental consideration of psychological care. It is unclear why such an association was found and indeed it is inconsistent with other studies that have found those who perceive there to be greater barriers are less likely to seek such services (Henshaw & Freedman-Doan, 2009). This could potentially be due to the double negatives mentioned previously.

### **Modifying Factors: Parental Personality Factors and Psychological Flexibility**

In examining a potential interventional activity in the parental decision-making process, external cues to action, such as parental psychological flexibility and personality factors, yield an important look at how providers can then interact with parents in a mutually beneficial fashion. Results from the study show that psychological flexibility within the individual indicates a willingness to adapt to and better cope with potentially strenuous situations. In the case of a parent, this may allow for a child's experience to be put at the forefront of the family, and allow for more adaptive coping strategies, such as acceptance and mindfulness, to be at play (Timmers et al., 2019). The significant positive association between a parent's psychological flexibility and their willingness to engage in a multidisciplinary treatment for their child demonstrates a more adaptive environment for a child experiencing abdominal pain. Identifying lower levels of parental psychological flexibility could serve as a pre-treatment target for clinicians. Providers may want to engage with these parents and use therapeutic modalities in line with increasing psychological flexibility, such as Acceptance and Commitment Therapies. Thus, increasing



## PARENTAL DECISION-MAKING FOR FAPD

parent psychological flexibility and, in turn, create better treatment decision-making for their child.

In general, our hypotheses were supported in terms of personality traits and parental consideration of multidisciplinary care. Openness, extraversion, and neuroticism were all found to be significantly correlated in the expected direction with openness to engaging in multidisciplinary care, however, only 1.2% to 3.8% of the variance being explained. From a clinical perspective, personality factors overall are rather unmalleable, and results indicate that they are not overall predictive of acceptance of multidisciplinary care. Therefore, it is reasonable to assume that other modifying factors, such as parental psychological flexibility, may serve as a better target for clinicians.

### **Cues to Action: Parent-Physician Communication and Knowledge**

Parents who believed their physician to be knowledgeable regarding their child's condition were more likely to be accepting of multidisciplinary care. Hypotheses and post-hoc analyses were supported for parent knowledge, physician knowledge, and parent-physician communication. There is an important alliance between the physician and the parent when it comes to pediatric care, as it is associated with parent satisfaction and treatment adherence (Nobile and Drotar, 2003). If parents feel as though their pediatrician is not confident in a particular treatment, they may be less willing to engage in more complex treatments, such as multidisciplinary care. Through increasing both parental awareness along with potentially improving pediatrician-parent communication, engagement in multidisciplinary treatment programs may become more likely.

It should also be noted that in a study from Koechlin and colleagues (2020), it was found that only 20% of pediatricians felt comfortable treating childhood chronic pain. This is

## PARENTAL DECISION-MAKING FOR FAPD

particularly relevant considering that 88.02% of parents in this study seek care from their child's primary care pediatrician. Thus, there may be a lack of knowledge regarding FAPD or the available treatment options on the part of physicians. This may also influence parental perceptions of physician knowledge, parental perceptions of their own knowledge and partially account for the relatively low rates of multidisciplinary enrollment.

As discussed previously, parents who are more psychologically flexible, perceive greater benefits to treatment, and perceive their child as more susceptible to FAPD, are more likely to be accepting of multidisciplinary treatment modalities. However, parents must first be introduced to these options before they can make decisions, and providers must become familiar with the concept of multidisciplinary care in general. Indeed, the HBM has been utilized in parent-child relationships, but they have mostly focused on pre-existing influences without intervention. There has been a discernible lack of resources that can be used specifically in the pediatric primary care setting. Pediatric primary care settings lack theoretical models that can encapsulate the family's experience to a physician in simple terms (Nobile and Drotar, 2003). Additionally, it is known that a pediatrician's interview style can have implications not only on what parents disclose about their child but also serves to the autonomy of decision-making within the parent. When pediatricians are trained in more empathetic conversational styles and reflective listening techniques, parents are more likely to engage in open conversation regarding their child's health (Wissow et al., 1994).

One study found that pediatricians only referred about 35% of pediatric patients with obesity to multidisciplinary care clinics (Gehring et al., 2021). Findings in the current study suggest that physicians are perhaps familiar with the concept of multidisciplinary care, and have informed a large number of parents about these options, however, there is a significant minority

## PARENTAL DECISION-MAKING FOR FAPD

of parents who have not been informed regarding such conditions and are, at face value, open to such treatments.

### **Post-Hoc Discussion**

Due to the aforementioned significant minority of parents who had not heard about multidisciplinary care techniques, post-hoc analyses were warranted. It is concerning that almost half of the sample had not been familiar with multidisciplinary care and suggests that knowledge of treatment options may be a significant barrier to optimal care for children with FAPD.

Furthermore, post-hoc analysis suggested that even if parents were not aware of multidisciplinary treatments, they were still open to and accepting of such care options including the use of psychological care. This may indicate that parents are willing to engage in both multidisciplinary and psychological services despite a history of stigma in mental health care, particularly for those with medical diagnoses and children. Additionally, this may reveal potential systemic biases within the healthcare system, as the study finds that parental awareness of multidisciplinary care differed by both income  $t(496) = 5.42, p < .001$  and education  $t(492.905) = 6.84, p < .001$ . With those having higher incomes (\$50,000 per year or above;  $M = 4.03$ ;  $SD = 1.67$ ) and higher levels of education (Associates degree or higher;  $M = 5.05$ ;  $SD = 2.04$ ) more likely to have heard of multidisciplinary care.

Finally, the post-hoc analyses highlight the importance of parent-provider communication. This is reflected in current literature regarding vaccine hesitancy, as such studies have found that more open and frequent lines of communication between parents and physicians lead parents to vaccinate their children against ailments such as swine flu (Cheney & John, 2013; Kerr, 2014). Parents may be open to receiving multidisciplinary treatments, however, due to their own lack of knowledge, as well as providers potentially not conversing about options, they may

## PARENTAL DECISION-MAKING FOR FAPD

be unable to bring these treatments up in conversation with their child's provider, thus cutting short a potential avenue before it can even be explored.

### **Future Clinical Implications**

The current study suggests the need for overall greater communication between providers and parents of pediatric patients regarding the treatment options available for children with FAPD. A new proxy decision-making model, based on the HBM, may be an important factor in the treatment decision process. Given that current literature indicates improved outcomes from multidisciplinary treatment, and the results of this study suggesting that almost half of the participants had not heard of this option, greater clinical training and communication may be warranted.

Future studies could examine potential semantic issues between multidisciplinary care and psychological care, as well as where this potential communication breakdown occurs. The use of terms such as "multidisciplinary care" and "psychological care" may be poorly understood by parents and/or patients. This semantic difference may be present in the context of parental decision-making for their children, as parents may perceive psychological care for a pain condition to mean that the physician does not take their child's pain seriously if they are not adequately educated by the treatment provider (van Tilburg et al., 2009). Likewise, the use of terminology such as multidisciplinary care could create a misunderstanding, as the results of this study suggest there is a significant amount of parents who are unfamiliar with such a treatment, despite programs such as the Comfort Ability existing and being expanded upon (Coakley et al., 2018).

The concept of multidisciplinary treatments, although inclusive of psychological treatment, may also serve as a type of filter for those who perceive barriers to mental health

## PARENTAL DECISION-MAKING FOR FAPD

treatment. In other words, parents may be more comfortable with stating that they “take their child to a multidisciplinary clinic,” rather than stating that they “take their child to a psychologist.” While the semantics of such technical terms should not serve as an explanation for decision-making, there may be differences found when the language of a certain treatment modality has been changed, for both mental health and physical health treatments. This semantic difference may be present in the context of parental decision-making for their children, as parents may perceive psychological care to be highly associated with poor outcomes such as stigma and believing as though their child’s physical condition is the result of a psychological concern.

Given the findings from this study regarding the potential effectiveness of the various domains of the HBM in predicting acceptance and use of multidisciplinary care, it may be useful to develop a brief screening instrument that may be given to parents by providers. This instrument may be designed to gather collateral information about parental knowledge and beliefs, as well as other contributing factors, such as psychological flexibility and personality factors, regarding their child’s new diagnosis. Additionally, this brief instrument can inform providers in belief style and guide conversations about specific options and treatments based upon an individual family system, making multidisciplinary treatment engagement more likely. This “pre-planning” could also create easier avenues for interventional activities that may mitigate the exacerbation of the child’s pain, and in turn, lessen the likelihood of an adult chronic pain diagnosis.

### **Limitations**

Due to the exploratory nature of utilizing the HBM as a proxy-decision-making construct, there are limiting factors that must be taken into account. Firstly, and partially due to the

## PARENTAL DECISION-MAKING FOR FAPD

continuing COVID-19 pandemic, data were collected via Cloud Research's service Prime Panels. While this service guarantees qualified participants, reaching parents of children with FAPD can be difficult to do through online based software. There are also known limitations of online survey software such as sampling bias (Newman et al., 2021). Indeed, it is noteworthy that 79.2% of the sample reported as White. Other limitations of online data collection include difficulties in generalizability to the general population, as well as issues of participant contamination (Andrade, 2020).

Additionally, although the Champion HBMS is independently reliable and validated, the current adaptation has not been empirically validated. This HBMS was internally consistent, and questions regarding the core elements of the HBM (benefits, barriers, cues to action, susceptibility, severity, and threat) hung together as they have in previous adaptations. It is still worth mentioning that this scale in the context of proxy decision-making, particularly in parental decision-making, is in its early developmental stages and should be considered for further research.

The utilization of the HBM as a decision-making model is widely researched and understood, for both medical and behavioral health concerns (Carpenter, 2019). There have been few studies examining parental behavior utilizing the HBM (Chen et al., 2011; Salari & Filus, 2016), however, none have extensively examined the use of the HBM as a parental decision-making model in the context of childhood chronic pain. Thus, findings serve industrious utility for further research and validation with samples that have been vetted and in families coping with other childhood chronic illnesses or pain.

While the concept of multidisciplinary care includes psychological aspects, such as second and third-wave therapeutic interventions, analyses indicate that parents are more likely to

## PARENTAL DECISION-MAKING FOR FAPD

act on psychological interventions individually. Perhaps this is due to a lack of understanding regarding aspects of multidisciplinary care, as mentioned in the discussion section. A limitation of the current study is a lack of an acceptance scale for psychological care. Because of the inclusion of psychological aspects in multidisciplinary acceptance, there is no equal comparison between acceptances, only consideration of different care aspects. Future research should include psychological acceptance as a concept as an outcome variable.

### **Conclusions**

The primary purpose of this study was to conceptualize parental understanding and decision-making for their child with FAPD, utilizing the HBM as a theoretical framework. Results indicate the HBM can serve as a decision-making model in order to identify both internal and external factors for parents when considering treatment options for their child. Additionally, post-hoc analyses conclude that even those parents who had not heard of multidisciplinary care tactics were open to utilizing such treatments. This is indicative of the physician-parent relationship, as providers may not be offering alternative treatment modalities to parents, or, may not be aware of such treatments themselves. Due to the wide prevalence of childhood chronic pain, specifically pediatric FAPD, it is important to consider why physicians may not be aware of such treatments, as well as what can be done in early diagnosis and contact to mitigate negative outcomes and encourage comprehensive care. Literature thus far has demonstrated a lack of understanding of pediatric chronic pain on behalf of physicians, and this may be improved through professional education and brief instrument development to help create a conversation between parents and providers.

Parents who are informed of such options are more apt to utilize them, thus improving outcomes for the child. Better prognosis for the child, in turn, creates a healthier adult,

## PARENTAL DECISION-MAKING FOR FAPD

potentially ceasing the cycle of chronic pain treatments, such as opioid use or invasive medical procedures to reduce pain. Giving children the skills that are available in multidisciplinary care programs, such as relaxation techniques, cognitive-behavioral therapy, as well as pharmacological treatments, can allow them to utilize techniques so often used in chronic pain treatments early on. This inception of the HBM serves as a preliminary effort to gain insight and traction in the parents of children with FAPD, with the hope to create brief instruments that will examine parent decision-making factors, and continue into long-term multidisciplinary treatment use. Future studies should look into the development of a brief, HBM-based screening that can be delivered to parents in office in the early stages of a child's FAPD diagnosis. Doing so will open doors in both conversations and treatment options to better serve families and children diagnosed with FAPD.



PARENTAL DECISION-MAKING FOR FAPD

**Table 1**

Frequencies and Percentages of Demographic Variables

<b>Variable</b>	<b>Frequency</b>	<b>Percentage</b>
<b>Child Age Range</b>		
5 years or younger	40	8.0
6 to 8 years	98	19.6
9 to 12 years	146	29.1
13 to 15 years	116	23.2
16 to 17 years	101	20.2
<b>Gender of Child</b>		
Male	269	53.7
Female	229	45.7
Non-Binary/Third Gender	2	0.4
Prefer not to say	1	0.2
<b>Marital Status</b>		
Single	123	24.6
Married or Domestic Partnership	316	63.1
Widowed	5	1.0
Divorced	40	8.0
Separated	16	3.2
<b>Ethnicity</b>		
Indigenous American or Alaskan Native	10	2.0
Asian	14	2.8
Black or African American	79	15.8

PARENTAL DECISION-MAKING FOR FAPD

Native Hawaiian or Pacific Islander	1	0.2
White	397	79.2
Respondents of Hispanic, Latino, or Spanish Origin	64	12.8
<hr/>		
<b>Education</b>		
<hr/>		
Less than a High School Diploma	11	2.2
High School Diploma	91	18.2
Some college, no degree	112	22.4
Trade school	13	2.6
Associates Degree	77	15.4
Bachelor's Degree	112	22.4
Master's Degree	65	13.0
Professional Degree	9	1.8
Doctoral Degree	11	2.2
<hr/>		

## PARENTAL DECISION-MAKING FOR FAPD

**Table 2**

Means and Standard Deviations of Demographic Variables

<b>Variable</b>	<b>Mean</b>	<b>Standard Deviation</b>
Parent Age	38.47	7.898
Child Age	11.44	4.038
Child Age at Diagnosis	8.69	4.044

PARENTAL DECISION-MAKING FOR FAPD

**Table 3**

Means, Standard Deviation, and Cronbach's Alphas for Predictor Scales

<b>Scale</b>	<b>Mean</b>	<b>SD</b>	<b>Range</b>	<b>Cronbach's Alpha</b>
<b>Health Belief Model Scale</b>				
Susceptibility, Severity, and Threat	20.94	4.11	6-30	0.699
Barriers	30.54	8.81	9-45	0.917
Benefits	25.92	5.04	7-35	0.854
Parent knowledge	11.56	2.60	4-16	0.736
Parent-Physician Communication	5.71	1.17	3-7	0.586
Physician Knowledge	7.25	2.01	2-10	0.868
<b>Parent Psychological Flexibility Questionnaire</b>				
	142.46	19.26	78-203	0.856
<b>Big Five Personality Traits</b>				
Openness	35.45	5.50	15-50	0.707
Conscientiousness	33.33	6.27	14-45	0.802
Agreeableness	33.09	5.78	18-45	0.719
Extraversion	25.21	5.44	8-40	0.727
Neuroticism	24.28	6.24	8-40	0.809

PARENTAL DECISION-MAKING FOR FAPD

**Table 4**

Frequencies and Percentages of Outcome Variables

	Frequency	Percent
<b>My child's care has included:</b>		
Primary Care Physician	441	88.02%
Specialty Physician (i.e. Gastroenterology)	259	51.70%
Psychologist or Social Worker	134	26.75%
Physical Therapy	104	20.76%
Dietician or Nutritionist	130	25.95%
Attendance in a Support Group	49	9.78%
Holistic Medicine (e.g. homeopathic care, acupuncture, chiropractor)	55	10.98%
No Formal Treatment	12	2.40%
<b>Attendance in a Multidisciplinary Care Clinic</b>		
Yes, has attended	159	31.7%
Yes, is attending	70	14.0%
No	269	53.7%
<b>Have you heard of multidisciplinary care for pediatric chronic pain conditions?</b>		
Yes	261	52.1%
No	237	47.4%
<b>Has your immediate family been supportive of you and your child seeking medical care for your child's condition?</b>		

## PARENTAL DECISION-MAKING FOR FAPD

Not at all supportive	23	4.6%
Somewhat supportive	179	35.7%
Very supportive	297	59.3%

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**Has your immediate family been supportive of you and your child seeking psychological care for your child's condition?**

---

Not at all supportive	51	10.2%
Somewhat supportive	217	43.3%
Very supportive	231	46.1%

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## PARENTAL DECISION-MAKING FOR FAPD

**Table 5**

Means and Standard Deviation for Outcome Variables

	<b>Mean</b>	<b>Standard Deviation</b>	<b>Range</b>
<b>Multidisciplinary Acceptance</b>	12.68	2.37	6-17
<b>I would consider including a multidisciplinary program for my child's pain condition</b>	3.67	1.07	1-5
<b>I would consider including psychological care for my child's pain condition</b>	3.71	1.06	1-5

PARENTAL DECISION-MAKING FOR FAPD

**Table 6**

Correlations between Subscales of Physician Knowledge, Communication, and Parent Knowledge

	<b>Parent Knowledge</b>	<b>Parent-Physician Communication</b>
<b>Physician Knowledge</b>	.734**	.390**
<b>Parent-Physician Communication</b>	.348**	

\*\*  $p < .001$



PARENTAL DECISION-MAKING FOR FAPD

**Table 7**

Correlations between Multidisciplinary Acceptance and Parental and Physician Factors

	<b>Extraversion</b>	<b>Agreeableness</b>	<b>Conscientiousness</b>	<b>Neuroticism</b>	<b>Openness</b>
<b>Multidisciplinary Acceptance</b>	.114*	.001	.059	-.121**	.152**
<b>Big Five Personality Traits</b>					
<b>Openness</b>	.413**	.384**	.407**	-.276**	
<b>Extraversion</b>		.154**	.301**	-.357**	.413**
<b>Agreeableness</b>			.622**	-.348**	.384**
<b>Conscientiousness</b>				-.475**	.407**
<b>Neuroticism</b>					-.276**
<b>I would consider including a multidisciplinary program for my child's pain condition</b>	.116**	.111*	.157**	-.132**	.196**

\* $p < .05$  \*\* $p < .01$

PARENTAL DECISION-MAKING FOR FAPD

**Table 8**

Post-Hoc Correlations Between Care Considerations and Aspects of the Health Belief Model

	<b>I would consider including a multidisciplinary program for my child's pain condition</b>	<b>I would consider including psychological care for my child's pain condition</b>
<b>I would consider including psychological care for my child's pain condition</b>	.611**	
<b>Health Belief Model Scale</b>		
Susceptibility, Severity, and Threat	.236**	.237**
Benefits	.239**	.379**
Barriers	.022	.127**
Parent Knowledge	.231**	.194**
Physician Knowledge	.190**	.144**
Parent-Physician Communication	.140**	.181**
<b>Parent Psychological Flexibility Questionnaire</b>	.151**	.162**
<b>Big Five Personality Traits</b>		
Extraversion	.116**	.004
Agreeableness	.111*	.009
Conscientiousness	.157**	.013
Neuroticism	-.132**	.079
Openness	.196**	.099*

\* $p < .05$ ; \*\* $p < .001$

PARENTAL DECISION-MAKING FOR FAPD

**Table 9**

Effect Sizes Between Participants who have Heard of Multidisciplinary care, and Those who Have Not

	<b>t</b>	<b>Significance</b>	<b>Cohen's d</b>	<b>Confidence Interval</b>	
				<b>Lower</b>	<b>Upper</b>
<b>Multidisciplinary Consideration</b>	3.995	<.001	.359	.181	.536
<b>Psychological Consideration</b>	1.988	<.05	.179	.002	.355

## PARENTAL DECISION-MAKING FOR FAPD

### Appendix A

- 1) What is your age?
- 2) What is your gender?
  - a) Male
  - b) Female
  - c) Non-binary/Third gender
  - d) Prefer not to say
- 3) Please select your yearly household income:
  - a) Less than \$20,000
  - b) \$20,000-\$34,999
  - c) \$35,000-\$49,999
  - d) \$50,000-\$74,999
  - e) \$75,000-\$99,999
  - f) Over \$100,000
- 4) Please select your marital status:
  - a) Single (never married)
  - b) Married or Domestic Partnership
  - c) Widowed
  - d) Divorced
  - e) Separated
- 5) Are you of Hispanic, Latino, or of Spanish origin?
  - a) Yes
  - b) No
  - c) Prefer not to say
- 6) How would you describe yourself?
  - a) Indigenous American or Alaskan Native
  - b) Asian
  - c) Black or African American
  - d) Native Hawaiian or Pacific Islander
  - e) White
- 7) Please select your highest level of education completed
  - a) Less than a high school diploma
  - b) High school diploma or equivalent (e.g. GED)
  - c) Some college, no degree
  - d) Trade schooling (e.g. welding, mechanics, other technical degree)
  - e) Associates degree
  - f) Bachelor's degree
  - g) Master's degree

## PARENTAL DECISION-MAKING FOR FAPD

- h) Professional degree (e.g. MD, DDS, DVM)
  - i) Doctoral degree (e.g. PhD, EdD)
- 8) Do you have health insurance?
- a) Yes, provided by my place of employment or my partner's place of employment
  - b) Yes, through Medicaid
  - c) Yes, purchased through the market
  - d) No, I do not have health insurance
  - e) Prefer not to say
- 9) Are you the primary caregiver for your child (i.e. you care for your child over 50% of the time)?
- a) Yes
  - b) No
  - c) Prefer not to say
- 10) Are you employed?
- a) Yes, full-time
  - b) Yes, part-time
  - c) No, my partner is full-time
  - d) No, my partner is part-time
  - e) No
- 11) Do you have a family history of any chronic medical conditions?
- a) Yes
    - i) What condition(s)?
  - b) No
  - c) Prefer not to say
- 12) Do you have a family history of chronic pain conditions?
- a) Yes
    - i) What condition(s)?
  - b) No
  - c) Prefer not to say
- 13) Do you have a family history of any psychiatric conditions?
- a) Yes
    - i) What condition(s)?
  - b) No
  - c) Prefer not to say
- 14) What is your child's age?
- 15) Please select your child's gender
- a) Male
  - b) Female

## PARENTAL DECISION-MAKING FOR FAPD

- c) Non-binary/Third gender
  - d) Prefer not to say
- 16) At what age was your child diagnosed with recurrent or functional abdominal pain?
- 17) Does your child have any medical conditions associated with their abdominal pain?
- a) Yes
    - i) What condition(s)?
  - b) No
  - c) Prefer not to say
- 18) Does your child have any psychiatric conditions associated with their abdominal pain?
- a) Yes
    - i) What condition(s)?
  - b) No
  - c) Prefer not to say
- 19) Did your child have any significant medical or psychiatric conditions prior to their abdominal pain?
- a) Yes medical
  - b) Yes psychiatric
  - c) Yes both
  - d) No
- 20) Has your child received any surgical procedures?
- a) Yes
    - i) If yes, was the surgery related to the abdomen?
  - b) No

**Appendix B**

1. My child's care has included (select all that apply)
  - Care from primary care physician
  - Care from a specialty physician (e.g. gastroenterology)
  - Care from Psychologist or Social Worker
  - Care from Physical Therapy
  - Care from a dietician or nutritionist
  - Attendance in a support group
  - Holistic medicine (e.g. homeopathic care, acupuncture, chiropractor)
  - No formal treatment
  - Other (please specify): \_\_\_\_\_
2. **My child has attended or is attending a multidisciplinary care clinic or program for their pain.**
  - Yes, has attended
  - Yes, is attending
  - No
3. I would consider including a multidisciplinary program for my child's pain condition
  - Definitely Not
  - Probably Not
  - Might or Might Not
  - Probably Yes
  - Definitely Yes
4. I would consider including psychological care for my child's pain condition
  - Definitely Not
  - Probably Not
  - Might or Might Not
  - Probably Yes
  - Definitely Yes
5. **I have or have not heard of multidisciplinary care for pediatric chronic pain conditions.**
  - I have heard
  - I have not heard

**Questions in bold indicate reverse scored items.**

### Appendix C

Instructions for the PPFQ direct the parent's attention to the series of items and ask them to "rate each statement according to how true it is for you." Each item is rated on a scale from 0 (Never True) to 6 (Always True). 0 = Never True, 1 = Very Rarely True, 2 = Seldom True, 3 = Sometimes True, 4 = Often True, 5 = Almost Always True, 6 = Always True

1. When my child is in pain the most important goal is to make it stop.
2. I am able to tolerate how it feels to watch my child suffer.\*\*
3. Even though my child has pain we can continue to do things that are important and enjoyable.\*\*
4. When my child has pain episodes I am able to realize at the time that it will pass.\*\*
5. My child will live a good and happy life only when his/her pain is controlled.\*\*
6. It is wrong that a parent should have to suffer over a child's pain.
7. Despite my child's pain, we are able to pursue activities that are important to our family.\*\*
8. When my child has pain episodes I am able to remain aware of our goals and other things that are important to us as a family.\*\*
9. I avoid situations where my child will have pain.
10. I would do anything to avoid feeling what I feel when I see my child in pain.
11. It is possible to live a normal life while my child suffers with pain.\*\*
12. There are concerns in my child's life that are more important than their pain.\*\*
13. Pain control must come first whenever my child does activities.
14. I can only help my child's pain experiences by thinking positively.
15. When my child has pain, I am able to help them continue to do what they most want to do.\*\*
16. I notice that I worry over my child's pain and can keep these issues in perspective.\*\*
17. When my child is suffering with pain I feel that I have to make it stop.
18. I need to control my own feelings about my child's pain.
19. Even though my child's pain is distressing, I can still do activities well.\*\*
20. I am overwhelmed by my child's pain and cannot think of much else.
21. Controlling my child's pain is my number one priority.
22. I suffer terribly from my child's pain and need to make this suffering stop.
23. When my child struggles with pain I am overwhelmed by it.
24. My child must avoid activities that lead to pain.
25. I would give up important things in my life to suffer less over my child's pain.
26. My child's pain makes it impossible to focus on anything else.
27. It's OK for my child to experience pain.\*\*
28. I am overwhelmed by worry over my child's pain.
29. We need to concentrate on getting rid of my child's pain.
30. I feel like I am fighting for control over my child's pain.
31. I struggle with my own thoughts and feelings about my child's pain.

\*\* indicates items that have been reversed scored



## PARENTAL DECISION-MAKING FOR FAPD

### Appendix D

Here are a number of characteristics that may or may not apply to you. For example, do you agree that you are someone who likes to spend time with others? Please write a number next to each statement to indicate the extent to which you agree or disagree with that statement. Disagree Strongly = 1, Disagree a little = 2, Neither agree nor disagree = 3, Agree a little = 4, Agree Strongly = 5

I see myself as someone who...

- |  |   |
|--|---|
| 1. Is talkative                            | 24. Is emotionally stable, not easily upset**     |
| 2. Tends to find fault with others**       | 25. Is inventive                                  |
| 3. Does a thorough job                     | 26. Has an assertive personality                  |
| 4. Is depressed, blue                      | 27. Can be cold and aloof**                       |
| 5. Is original, comes up with new ideas    | 28. Perseveres until the task is finished         |
| 6. Is reserved**                           | 29. Can be moody                                  |
| 7. Is helpful and unselfish with others    | 30. Values artistic, aesthetic experiences        |
| 8. Can be somewhat careless**              | 31. Is sometimes shy, inhibited**                 |
| 9. Is relaxed, handles stress well**       | 32. Is considerate and kind to almost everyone    |
| 10. Is curious about many different things | 33. Does things efficiently                       |
| 11. Is full of energy                      | 34. Remains calm in tense situations**            |
| 12. Starts quarrels with others**          | 35. Prefers work that is routine**                |
| 13. Is a reliable worker                   | 36. Is outgoing, sociable                         |
| 14. Can be tense                           | 37. Is sometimes rude to others**                 |
| 15. Is ingenious, a deep thinker           | 38. Makes plans and follows through with them     |
| 16. Generates a lot of enthusiasm          | 39. Gets nervous easily                           |
| 17. Has a forgiving nature                 | 40. Likes to reflect, play with ideas             |
| 18. Tends to be disorganized**             | 41. Has few artistic interests**                  |
| 19. Worries a lot                          | 42. Likes to cooperate with others                |
| 20. Has an active imagination              | 43. Is easily distracted**                        |
| 21. Tends to be quiet**                    | 44. Is sophisticated in art, music, or literature |
| 22. Is generally trusting                  | ** indicates items that have been reversed        |
| 23. Tends to be lazy**                     | scored  |

## Appendix E

The items for the Health Belief Model Scale are rated on a five-point scale with the following options: 1 = Strongly Disagree, 2 = Disagree, 3 = Neither Agree Nor Disagree, 4 = Agree and 5 = Strongly Agree.

### Susceptibility/Severity/Perceived Threat

1. It is likely that my child has a chronic abdominal pain condition.
2. My child's chances of a continuing chronic abdominal pain condition in the next few years are great.
3. I feel like my child's condition will worsen over time.
4. \*My child's pain condition may adversely affect their future.
5. **\*I don't believe my child has a medical condition.**
6. \*I am worried that I may be missing something in my child's care.

### Benefits

1. \*If my child receives medical treatment, I will have less to worry about.
2. \*If my child receives psychological treatment, I will have less to worry about.
3. \*If my child received both medical and psychological treatment things will be better than medical treatment alone.
4. \*If my child received both medical and psychological treatment things will be better than psychological treatment alone.
5. If my child receives both psychological and medical treatment, the impact of their pain on their functioning may not be as bad.
6. Having both medical and psychological treatment is the best way to manage my child's pain.
7. Having medical and psychological treatment for my child will decrease their chances of adverse events in their future.

### Barriers

1. **\*I don't think that psychological treatments can help with medical conditions such as pain.**
2. **I am afraid for my child to have psychological treatment because I don't understand what will be done.**
3. **\*I don't believe that psychologists can help people with their problems.**
4. **Having my child get treatment takes too much time.**
5. **Having my child engage in psychological treatment can be harmful to my child and/or family.**
6. **My child is too young to need psychological treatment.**
7. **\*Taking my child to a psychologist for their pain will make people think differently of me.**

## PARENTAL DECISION-MAKING FOR FAPD

8. **\*Taking my child to a psychologist for their pain will cost too much.**

9. **\*Taking my child to a psychologist for their pain will take too much time.**

### Physician Cues and Knowledge

- 1) \*When your child was diagnosed, did your physician discuss the several medical treatment options available with you and your child?
  - a) Yes
  - b) No
- 2) \*When your child was diagnosed, did your physician discuss the several psychological treatment options available with you and your child?
  - a) Yes
  - b) No
- 3) \*How knowledgeable would you consider yourself to be about your child's diagnosis?
  - a) Not knowledgeable at all
  - b) Slightly knowledgeable
  - c) Moderately knowledgeable
  - d) Very knowledgeable
  - e) Extremely knowledgeable
- 4) \*How knowledgeable would you consider your physician to be about your child's diagnosis?
  - a) Not knowledgeable at all
  - b) Slightly knowledgeable
  - c) Moderately knowledgeable
  - d) Very knowledgeable
  - e) Extremely knowledgeable
- 5) \*How knowledgeable would you consider yourself to be about the several treatment options available for your child?
  - a) Not knowledgeable at all
  - b) Slightly knowledgeable
  - c) Moderately knowledgeable
  - d) Very knowledgeable
  - e) Extremely knowledgeable
- 6) \*How knowledgeable would you consider your physician to be about the treatment options available for your child?
  - a) Not knowledgeable at all
  - b) Slightly knowledgeable
  - c) Moderately knowledgeable
  - d) Very knowledgeable
  - e) Extremely knowledgeable
- 7) \*Did your physician ever suggest and/or refer you to a specialist for your child?

## PARENTAL DECISION-MAKING FOR FAPD

- a) No
- b) Yes suggested
- c) Yes referred

(1) What type of specialist were you referred to?

- 8) \*Have you and your physician discussed options for your child on one or more occasions?
  - a) Yes, once
  - b) Yes, multiple times
  - c) No
- 9) \*Has your immediate family been supportive of you and your child seeking medical care for your child's condition?
  - a) Not at all supportive
  - b) Somewhat supportive
  - c) Very supportive
- 10) \*Has your immediate family been supportive of you and your child seeking psychological care for your child's condition?
  - a) Not at all supportive
  - b) Somewhat supportive
  - c) Very supportive

\*Indicates questions added in addition to those adapted from the original scale

**Items in bold have been reversed scored**

## Appendix F

### Informed Consent for Research

Principal Investigator: Alicia Forsythe, B.A., University of Michigan-Dearborn

Faculty Advisor: David K. Chatkoff, Ph.D., University of Michigan-Dearborn

You are invited to participate in a research study about parental factors in choice regarding multidisciplinary treatment options for children with functional abdominal pain disorder

If you agree to be part of the research study, you will be asked to fill out several surveys, each of which gather your opinions and perceptions of multidisciplinary treatments, as well as factors of personality and beliefs about psychological care.

Benefits of the research: Your participation is anonymous, and participation will take around **10 to 20** minutes. You will be compensated following the conclusion of the survey.

Risks and discomforts: There are no foreseeable risks to you from your participation, some questions may be slightly uncomfortable for you, but you may discontinue or skip questions at any time.

Compensation: You will be compensated following completion of the surveys. Your answers will be reviewed to ensure quality of the data collected prior to compensation. You will not be compensated more or less depending on how long it takes for you to complete the items, also take your time and answer items truthfully and to the best of your ability. Participants who complete the survey in an exceptionally short amount of time (i.e. 5 minutes or less) will not be compensated.

Participating in this study is completely voluntary. Even if you decide to participate now, you may change your mind and stop at any time. You may choose not to answer questions or fill out responses for any reason.

We will protect the confidentiality of your research records. To avoid any confidentiality risks associated with participating, no personally identifiable data about you is gathered or stored.

If you have questions about this research study, please contact Alicia Forsythe, B.A. ([apforsyt@umich.edu](mailto:apforsyt@umich.edu)) or David K. Chatkoff, Ph.D. ([chatkoff@umich.edu](mailto:chatkoff@umich.edu)).

The University of Michigan Institutional Review Board Health Sciences and Behavioral Sciences has determined that this study is exempt from IRB oversight.

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