PARENTS’ EXPECTATIONS OF THEIR CHILDREN’S PHYSICIANS AND UNCERTAINTY REGARDING THEIR CHILDREN’S HEALTH

By

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Abstract

Functional symptoms, defined as symptoms in the absence of organic disease, are common among pediatric patients. Parents of functional pain patients often experience great uncertainty regarding their children’s health status and have several expectations of physicians in their quest for answers. In terms of expectations, research suggests that parents expect that psychosocial concerns will be addressed and discussed and that symptoms will be acknowledged and explained – all in the context of an emotionally supportive encounter with the physician. As for uncertainty, research suggests that parental uncertainty is comprised of illness ambiguity, lack of illness information, lack of clarity (in the context of systems of care and relationships between parents and providers), and unpredictability. The current study assesses how type of diagnosis (organic versus functional) and presentation of medical information (biomedical versus biopsychosocial) influences parents’ uncertainty and the extent to which their expectations of the medical encounter are met. Mothers of school-age children were presented with a vignette describing a child with abdominal pain symptoms and completed a baseline questionnaire assessing their expectations about the information to be received from the physician following his evaluation of the child. Mothers then viewed one of four video vignettes that presented a medical evaluation of the child in the vignette that varied in its combination of presentation (biopsychosocial versus biomedical) and diagnosis (organic versus functional). After viewing the medical evaluation vignette, mothers then completed response questionnaires assessing the degree to which their expectations were or were not met as well as their uncertainty about the child’s illness in light of the medical information just provided. Among all conditions, it was expected that mothers who received a biomedical explanation and a functional diagnosis would perceive their expectations as met to a lesser degree and would experience greater uncertainty. This study extends the literature by examining parent expectations and uncertainty with respect to the manner in which physicians communicate information to parents.
CHAPTER 1

INTRODUCTION

Overview

The parent/physician relationship is of paramount importance to children’s health. Consequently, parents enter into this relationship with many expectations. Parents’ expectations of their children’s pediatricians are important as the literature shows that unmet expectations lead to lower patient satisfaction which, in turn, leads to lower adherence to the doctor’s orders and less symptom improvement. Unmet expectations can result in parental uncertainty regarding children’s health and this uncertainty, in turn, also has been linked to high levels of parents’ emotional distress which is linked to poor symptom improvement in children. Given that parents are responsible for maintaining their children’s health, parents’ expectations of physicians and degree of uncertainty regarding children’s health are important to study as these factors may ultimately determine children’s health.

Parents’ Expectations of Physicians

Very few investigations have studied parents’ expectations regarding their children’s pediatricians. However, the general literature on parent-physician relationships is relevant to understanding parents’ relationship with their children’s pediatricians, as parents are the intermediary between the child as patient and the physician. This literature suggests that parents’ satisfaction levels with their child’s physician are determined by how well parents perceive their expectations to have been met. A study by Williams, Weinman, Dale, and Newman (1995)
investigated satisfaction levels in 504 adult primary care patients whose expectations were either met or not met by their GP (general practitioner). Patients in the study were asked to fill out the Patients’ Intentions Questionnaire (PIQ) before their consultation and to complete the Expectations Met Questionnaire (EMQ) and the Medical Interview Satisfaction Scale (MISS) immediately following their consultation. Based on responses to these questionnaires, Williams et al. found that patients who indicated a higher number of met expectations experienced significantly greater patient satisfaction than patients who indicated fewer met expectations.

Parents’ satisfaction with their children’s physicians is important because it may have a direct effect on parents’ adherence to their children’s treatment plan and recovery from illness. Depending on whether or not particular parental expectations are met by the physician, this effect can be positive or negative. Bell, Kravitz, Thom, Krupat, and Azari (2002) set out to measure the consequences of met versus unmet expectations of 909 adults who saw a doctor for a health problem or concern. Of these patients, 11.6% reported at least one unmet expectation following their visit with a physician. In a post-visit follow-up conducted two weeks later, those patients who had reported an unmet expectation also reported less satisfaction with their visit, less symptom improvement, and weaker intentions to adhere than those patients who had reported that their expectations were met. Similar results were found in another study by Nock, Phil, and Kazdin (2001) that investigated the relationship between pre-treatment expectancies of the parents of 405 children and their children’s subsequent participation in child psychotherapy. The study found that parents whose treatment expectancies mirrored those of the actual treatment delivery were more likely to keep their children in treatment and to avoid premature withdrawal. Thus, this study suggests that children whose parents make it possible for them to enter and remain in treatment are more likely to make gains in symptom improvement than those children
whose parents do not accommodate the treatment plan. These findings by Bell et al. and Nock et al. highlight the critical importance of parental expectations and satisfaction.

If physicians are to meet parents’ expectations, they must know what parents expect of them. Thus, it becomes important to identify parents’ expectations of physicians regarding the care of their children. The present research focuses specifically on the expectations of parents whose children present with functional recurrent abdominal pain (pain that lacks an organic basis and often is triggered by psychological and/or social factors) and examines two kinds of potential expectations these parents might have of physicians: expectations regarding the discussion of psychosocial issues and expectations regarding the treatment of medically unexplained symptoms.

As the role of the pediatric provider evolves beyond that of an exclusively biomedical focus, more and more parents are coming to expect pediatricians to address the psychosocial concerns they have about their child (Burklow et al., 2001). Given that psychosocial issues may trigger and fuel functional pain complaints, the expectation of parents that psychosocial concerns be addressed is by no means unrealistic. Unfortunately, this expectation is not always met. For instance, Burklow, Vaughn, Valerius, and Schultz (2001) found that parents desire discussion of psychosocial issues during the medical consultation. Alarmingly, Burklow et al. also found that less than half of all parent-reported psychosocial concerns were actually discussed during the consultation.

Despite the expectation that psychosocial concerns be addressed, not all parents are comfortable initiating conversation on such sensitive information. This conflict between parents’ expectation that discussion occur and their reluctance to initiate the discussion leaves room for a dissatisfying consultation if the pediatrician does not take the lead in initiating candid discussion
about the parent’s psychosocial concerns. In a study examining parent-physician communication between the mothers of two hundred thirty-four children and 52 physicians in their second or third year of pediatric residency training, Wissow, Roter, and Wilson (1994) found that mothers were more likely to disclose psychosocial issues when physicians utilized certain “psychosocially oriented interviewing techniques.” These techniques included direct questioning of psychosocial concerns, the use of supportive and reassuring statements, expression of sympathy, and attentive listening. Results of this study suggest that if parents’ expectations regarding discussion of psychosocial concerns are to be met, pediatricians must interview parents in a manner that is likely to encourage openness and elicit their concerns.

When it comes to advocating for the care of a child with functional pain, parents not only have expectations regarding discussion of psychosocial concerns, but also regarding treatment for their children’s medically unexplained symptoms (MUS). Salmon, Ring, Dowrick, and Humphris (2005) found that what patients with medically unexplained symptoms want (or expect) from their doctors is emotional support – not increased somatic intervention. Thus, the perceived “influence” or pressure that doctors feel from patients with MUS stems not from the patient’s supposed desire for increased somatic intervention (which doctors tend to assume and consequently accommodate), but rather from their desire for extra emotional support.

In addition to emotional support, parents of children with medically unexplained symptoms also expect acknowledgement of their child’s pain and an explanation for it. Peters, Stanley, Rose, and Salmon (1998) found that patients commonly perceive GPs as having denied the reality or importance of their medically unexplained symptoms. Such an indifferent or belittling response from a physician can make the consultation frustrating and dissatisfying for the parent of a functional pain patient.
It is important to parents of children with medically unexplained symptoms that their pediatrician first acknowledge, and then go on to explain their child’s functional symptoms. Of the 228 patients with MUS that Peters et al. recruited, very few had their expectation for explanation met in a way that convinced them. Peters et al. concluded that patients need to have the problem named by their physician. When parents expect an explanation, they are not necessarily expecting a biomedical explanation from their doctors, but rather any explanation at all (be it physical or psychological). The study by Peters et al. confirmed this in that patients with MUS were not any less receptive to a psychological diagnosis than to a physical one. Interestingly, in a study by Ring, Dowrick, Humphris, Davies, and Salmon (2005) on how patients and general practitioners communicate, it was shown that nearly all patients in the study (95%) provided their GP with cues concerning psychosocial difficulties in an attempt to prompt an explanation for their symptoms. Clearly, parents are eager for their child’s doctor to produce an explanation of any kind. When physicians do acknowledge and name the problem, they provide relief for the anxious parents of functional pain patients. Thus, this is a critical move on the part of the physician.

The predominant limitation in research conducted so far on this topic is the use of patient self-report to identify met versus unmet expectations. Given that much of the results presented are obtained from the perception of the patient only, it would be helpful to know more about the patient’s actual encounter with the physician as far as what needs were voiced and what style of patient/physician communication was utilized. Thus, an objective assessment of the consultation and the physician’s behavior in addition to the patient’s subjective assessment of the encounter would be helpful in understanding patient expectations and satisfaction. A second limitation is that the research does not always distinguish among different types of expectations. For instance,
the existing research does not evaluate whether the expectations that patients’ perceive as unmet are reasonable expectations to have of one’s physician.

**Parental Uncertainty Regarding Children’s Health**

For parents of children who exhibit functional symptoms (symptoms in the absence of disease), the expectation of a positive diagnosis and label for their child’s illness often is not met by the physician. As a consequence, these parents often experience great uncertainty regarding their children’s illness. Parental uncertainty regarding illness in children has been conceptualized as “a parent’s or other family caregiver’s inability to determine meaning relative to illness in a family member, specifically a child” (Mishel, 1983 & Santacroce, 2001 as cited in Santacroce, 2003). Uncertainty regarding illness is the primary contributor to psychosocial stress in people affected by serious illness and this includes the parents of ill children (Koocher, 1985 as cited in Santacroce, 2003; Murray, 1993). One can only imagine the uncertainty and distress that would affect a parent who does not know the source of their child’s illness. The question then becomes, what determines parental inability to conclude meaning relative to illness in their own child? Mishel (1983) proposed that the uncertainty experienced by parents of ill children will be characterized by the following four dimensions: illness ambiguity, lack of information, lack of clarity, and unpredictability. Each of these dimensions will be addressed in terms of their contribution to overall parental uncertainty.

**Illness Ambiguity**

The first and most general characteristic of parental uncertainty is ambiguity about the child’s illness. Parents encounter ambiguity when they cannot obtain clear facts about their
children’s illness (Murray, 1993). Once disease is formally ruled out as an explanation for children’s functional symptoms, it is not uncommon for parents to continue to seek a cause for children’s pain through multiple follow-up medical visits (Kaplan, Ganiats, & Frosch, 2004). When continued medical visits fail to produce a cause for children’s symptoms, illness ambiguity is perpetuated. When an event is judged as ambiguous, uncertainty is fostered (Mishel, 1983). Studies have linked illness ambiguity with high levels of parental uncertainty, emotional distress, and protective parenting behavior (Stewart & Mishel, 2000), all of which can have negative implications for children’s health, behavior, independence, and eventual ability to self-manage their own illness (Santacroce, 2003).

Lack of information

A second characteristic of parental uncertainty is lack of information, which occurs when information regarding a child’s illness is not shared or known. An absent diagnosis is a primary example of lack information and also a significant contributor to parental uncertainty (Mishel, 1983). For example, much like parents of children with functional pain, parents of children with epilepsy often report great difficulty in finding adequate information about their children’s condition and in obtaining a clear and definitive diagnosis (Murray, 1993). In response to this, Murray set out to explore the pre- and post-diagnosis uncertainty levels of these parents. For many mothers in the study, several years had passed between their child’s first seizure and their acquisition of a diagnosis. As one parent of an epileptic child said prior to receiving a diagnosis, “Something is happening so drastically and there were no answers anyone could give you.” Murray found that after these parents received the more precise diagnosis of Lennox-Gastaut syndrome for their children’s epileptic condition, they experienced a huge sense of relief.
Following receipt of a diagnosis, a typical parental response was, “there is some comfort in having a degree of knowledge about my son’s condition instead of being completely in the dark.” The mere assignment of a label to the epileptic children’s ambiguous illness had helped to significantly reduce parental uncertainty (recall parents’ expectation that the physician name their child’s problem). Clearly, receipt of a diagnosis empowered parents with the information they needed to redirect their energy from that of worrying in the midst of uncertainty to that of actually learning about their child’s illness (Murray, 1993; Horner, 1997).

Lack of clarity

Lack of clarity, another characteristic of parental uncertainty, often results from incomplete or inadequate explanations provided by medical staff regarding the child’s illness (Mishel, 1983). Thus, it is essential to consider the systems of care and relationships between parents and providers when examining parental uncertainty (Santacroce, 2003). Horner (1997) examined the pre-diagnosis experience of mothers whose children had undiagnosed asthma. In this study, mothers described their ordeal in attempting to find a diagnosis for their child in the midst of repeated illness episodes in which their child struggled for air and no one could tell them why. After repeated visits to their physicians only to be given unsatisfactory explanations and additional ineffective medications, mothers became frustrated and more aggressive in their search for answers – which introduced confrontation into the parent-physician relationship. Mothers spoke of difficulties in convincing doctors that their child had a significant problem, only to be discounted and unsupported in their observations and concerns. One mother stated, “It was frustrating when… they wanted to treat you like you were stupid.” After finally receiving referrals to a specialist, however, the mothers’ suspicions were confirmed when their children
were diagnosed with asthma. Clearly, for many parents, the angst of negotiating the health care system breeds not only frustration, but also a lack of clarity contributing to uncertainty regarding the children’s illness.

Parental uncertainty is not a parent-specific problem – it is also a physician-specific problem and thus has implications for health professionals. Health professionals should strive to reduce uncertainty and enhance perceptions of control in every encounter with parents (Murray, 1993). The role of the physician is not only to diagnose the child, but also to educate, inform, and empower the parent, thereby alleviating parental uncertainty and subsequently improving pediatric health outcomes by helping parents be more effective in helping their children.

**Unpredictability**

The final characteristic of parental uncertainty is unpredictability of the child’s prognosis, quality of life, and ability to function (Mishel, 1983; Santacroce, 2003). When the child is ill, parents cannot forecast the probable course of the disease or what events may be in store for the child (Surveyer, 1976 as cited in Mishel, 1983). Inability to speculate about the child’s future results in unpredictability which fosters parent uncertainty. For example, the parents of children with uncontrolled epilepsy in Murray’s study reported that uncertainty about their child’s future was the greatest area of uncertainty for them (Murray, 1993).

Unpredictability concerns encompass not only the child as patient but also the parent as caretaker. For instance, parents of ill children are often unclear about what they can do to help their child (Murray, 1993), often standing by helplessly in the midst of their child’s pain and suffering. Former parental behavior toward the well child elicited a predictable response, but parents are often unsure what behavior is appropriate and effective for them to display toward
their ill child (Murray, 1993). Thus, when the well child becomes ill, the shift in predictability from certainty to uncertainty has implications for both the role of the patient as a developing child and the role of the parent as nurturer to that developing child.

Clearly, there are several dimensions of parental uncertainty that must be taken into account when considering ways to reduce uncertainty in children’s illness. The literature shows that in order for parents to perceive a sense of control regarding their children’s health, what they need is a definitive diagnosis, adequate illness information, clarity and communication from their physician, and a prognosis that allows for speculation about the child’s future and their own role as caretaker.

**Current study**

When it comes to the care of children with functional pain, parents are likely to expect that psychosocial concerns will be addressed and discussed and that medically unexplained symptoms will be acknowledged and explained – all in the context of an emotionally supportive encounter with the physician. When it comes to parental uncertainty regarding children’s health, dimensions characteristic of uncertainty include illness ambiguity, lack of illness information, lack of clarity (in the context of systems of care and relationships between parents and providers), and unpredictability. While the current literature has explored many issues pertaining to parent expectations and uncertainty, it has yet to examine these factors with respect to the manner in which physicians communicate information to parents. The present study will compare the biomedical model of presentation of medical information versus the biopsychosocial model of presentation for organic versus functional diagnoses of a child’s chronic abdominal pain.
Biomedical versus biopsychosocial model of presentation

The biomedical and biopsychosocial models of symptoms and disease differ significantly in their approach to explanation and treatment of symptoms. The biomedical model is strictly disease-based in its explanation of symptoms and may fail to offer a diagnosis or a treatment plan to parents of functional pain patients. The biopsychosocial model, however, acknowledges that disease is only one cause that may contribute to symptoms, thereby acknowledging that both biological and psychosocial factors can contribute to the clinical expression of illness and disease (Drossman, 1998). Consequently, the biopsychosocial model offers both a positive diagnosis and a treatment plan to parents that focuses on symptom reduction.

Organic versus functional diagnosis

Medicine has traditionally distinguished between organic and functional diagnoses. The organic diagnosis refers to symptoms that occur in the presence of identifiable organic disease. These symptoms are thought to be explained by biomedical markers that can be definitively identified by diagnostic procedures.

The functional diagnosis, however, refers to symptoms that occur in the absence of identifiable organic disease (Stone, Carson, & Sharpe, 2005). These symptoms are often attributed to environmental, psychological, and/or social stressors (Mayer, Naliboff, Chang, & Coutinho, 2001; Tache, Martinez, Million, & Rivier, 1999). In fact, the research shows special vulnerability toward functional symptoms among individuals whose central nervous systems have actually been altered by stressors (Mayer et al., 2001). In addition to stressors, individual differences in terms of physiology, attention, and sensitization to symptoms may make certain individuals more susceptible to experiencing and maintaining functional symptoms than others
(Rief & Sharpe, 2004). Thus, functional symptoms can be fueled by a combination of factors that are psychosocial and physiological alike.

Functional symptoms are time-consuming and costly to address, accounting for up to 85% of ambulatory care visits among children and adults annually (Kroenke & Mangelsdorff, 1989) and resulting in countless follow-up visits in pursuit of the cause of symptoms (Kaplan, Ganiats, & Frosch, 2004). Functional symptoms are prevalent in primary care and in almost all pediatric specialties, manifesting as heart palipitations in pediatric cardiology and functional abdominal pain in pediatric gastroenterology (Stone et al., 2005; Campo & Fritsch, 1994). Clearly, the prevalence of functional pain has great implications not only for the emotional and mental health of children and their families, but also for the finances of families as the cost of healthcare in America continues to rise (Kaplan et al., 2004; Kroenke & Mangelsdorff, 1989).

**Hypotheses**

The current study assesses how type of diagnosis (organic versus functional) and presentation of medical information (biomedical versus biopsychosocial) influences parents’ expectations and uncertainty regarding the illness and treatment of a child described in a vignette as having abdominal pain. Two main effects and an interaction are expected for each dependent variable.

First, based on the literature regarding parents’ expectations, it is hypothesized that mothers who receive a functional diagnosis (rather than an organic diagnosis) and a biomedical explanation (rather than a biopsychosocial explanation) for the child’s symptoms will have their expectations met to the least degree. Regarding diagnosis, it is likely that receipt of a functional diagnosis is less aligned with parents’ expectation of receiving definitive answers about the
source of the child’s illness versus an organic diagnosis that is disease-based and attributable to biological factors. Regarding presentation, a biomedical framework provides information solely from a medical perspective and thus is less likely to fulfill parents’ expectations compared to the more comprehensive biopsychosocial framework that includes information from multiple perspectives.

An interaction of the two independent variables is also expected; it is hypothesized that parents who receive a biomedical presentation of a functional diagnosis will have their expectations met to a lesser degree than parents who receive a biomedical presentation of an organic diagnosis or a biopsychosocial presentation of an organic or functional diagnosis. In addressing medically unexplained symptoms such as those characteristic of functional pain, the biomedical presentation of medical information may fail to recognize the validity of psychosocial concerns, fail to acknowledge the problem, and/or fail to give an explanation for children’s pain, all of which constitute parents’ expectations of the physician when it comes to the care of children with medically unexplained symptoms. In particular, the biomedical model as applied to functional symptoms is essentially ill equipped to meet parents’ expectation of having the child’s problem named.

Second, based on the literature regarding parental uncertainty about children’s health, it is also hypothesized that parents who receive a functional diagnosis (rather than an organic diagnosis) and a biomedical explanation (rather than a biopsychosocial explanation) will experience more uncertainty regarding their child’s condition. Regarding diagnosis, a functional diagnosis is most likely associated with higher parental uncertainty given its unfamiliarity and ambiguity compared to the commonly received organic diagnosis which offers definitive answers about the source of the child’s illness. Regarding presentation, the less comprehensive
explanation offered by the biomedical model compared to the biopsychosocial model is likely to result in greater parental uncertainty regarding children’s illness.

An interaction of the two independent variables is also expected; it is hypothesized that parents who receive a biomedical presentation of a functional diagnosis will experience the greatest amount of uncertainty regarding their child’s condition compared to parents who receive a biomedical presentation of an organic diagnosis or a biopsychosocial presentation of an organic or functional diagnosis. This is because the biomedical presentation of a functional diagnosis is likely less equipped to reduce illness ambiguity, provide illness information, predict the course of the illness and its treatment, or facilitate clear communication between providers and parents given its inability to deliver a disease label, positive diagnosis, or treatment plan for functional symptoms. Thus, in the case of a functional diagnosis, the biomedical approach may foster parental uncertainty to a greater degree than the biopsychosocial approach – an approach that is able to offer parents a label, positive diagnosis, and treatment plan.
Chapter II

Method

Participants

Participants were 160 mothers of children ages 8 through 16 years. Mothers were recruited through an email advertisement for research opportunities at the university’s medical center and were invited to participate in an online study.

Design

The study used an experimental design with two between-subjects factors. Participants were randomly assigned to one of four conditions. The conditions varied the combination of two factors: diagnosis (organic versus functional) and presentation (biopsychosocial versus biomedical). Thus, the four conditions were a) biopsychosocial information for children’s functional symptoms, b) biomedical information for children’s functional symptoms, c) biopsychosocial information for children’s organic disease, or d) biomedical information for children’s organic disease. There were equal numbers of participants in each condition.

Procedure

To experimentally control for maternal observation of children’s symptoms and provide a standard baseline from which maternal responses to children’s symptoms could be measured, mothers read a vignette depicting a child with severe abdominal pain and pain-related disability. Next, mothers viewed a video vignette according to one of the four study conditions, consisting
of a medical doctor giving diagnostic, treatment, and prognostic information from the child’s medical evaluation. Before they viewed the vignette, mothers completed a baseline questionnaire assessing their expectations about the medical information they expected to receive from the physician. After viewing the medical evaluation vignette, mothers completed the Expectations Questionnaire (identical in content to the baseline questionnaire except for a change from future to past tense) and the PPUS-Revised in light of the medical information just provided. Finally, mothers completed demographic forms and provided information about their own children’s health. Mothers were offered monetary compensation for study participation. The entire length of the study was approximately 30 minutes. The text of the child vignette and the four medical evaluation vignettes can be found in Appendix A.

Measures

Measures include the Expectations Questionnaire and the PPUS-Revised. These measures were added to a battery of measures from a larger study. A copy of both measures can be found in Appendix B.

Expectations Questionnaire

The pre- and post-vignette Expectations Questionnaire (EQ) was used to assess mothers’ expectations about the medical information they expected to receive from the physician before the medical encounter (pre-vignette EQ) and to assess how well those expectations about information received were met by the physician after the medical encounter was over (post-vignette EQ). The only difference between the pre- and post-vignette EQ was the wording of the tense, which went from future tense in the pre-vignette EQ (e.g., “The doctor will tell me what is
wrong.”) to past tense in the post-vignette EQ (“The doctor told me what is wrong.”).

The Expectations Questionnaire was developed for use in the current study. The questionnaire was created in a systematic process that began with a review of the literature on illness schema to determine the representations involved when people think about illness (Leventhal et al., 1980). Research has supported five main components of illness representations; identity, consequences, timeline, cause, and treatment (Hagger & Orbell, 2003). These components correspond to parents’ expectations for medical visits; receiving diagnostic, treatment, and prognostic information of children’s symptoms (Korsch et al., 1968). This information identified areas in which to develop content of the EQ.

The EQ is a 6-item self-report measure. For the pre-vignette EQ, participants were asked to rate how true each statement was for them regarding the information they expected to receive from the doctor on a five-point scale, with responses ranging from "not at all true" (0) to "very true" (4). For the post-vignette EQ, participants were asked to rate how true each statement was for them regarding the information they just received from the doctor on a five-point scale, with responses ranging from "not at all true" (0) to "very true" (4). Responses were summed and averaged to create an overall mean score for the pre- and post-vignette measures. Alpha reliability in the current study was excellent at .90 in the Pre-Vignette EQ and at .89 in the Post-Vignette EQ.

PPUS-Revised

The Parent Perception of Uncertainty Scale (PPUS) was used to assess mothers’ uncertainty regarding the child’s health (Mishel, 1983). The PPUS measures the uncertainty parents experience related to their child’s illness. It was developed from the original adult form
of the Mishel Uncertainty in Illness Scale, a reliable and valid measure of adults’ uncertainty regarding their symptoms, diagnosis, treatment, caregiver relationships, and future planning in relation to illness (Mishel, 1983). The PPUS was developed in a sample of parents of children with chronic illnesses and demonstrated good reliability and validity (Mishel, 1983).

The PPUS is a 31-item self-report measure. Participants rate how true each statement is for them on a five-point scale, with responses ranging from "not at all true" (0) to "very true" (4). Ten items are reverse-scored so that high scores reflect greater parental uncertainty about their child’s illness. Responses are summed and averaged to create an overall mean score.

Several changes were made to the PPUS for use in the current study. Unlike the sample in which the PPUS was developed for use, in the current study parents are asked to imagine a situation in which they are the mother of a child with chronic abdominal pain who have just received the results of a medical evaluation. Due to this specific, imagined scenario, items that were not applicable were deleted from the measure and some items were reworded to better reflect the imagined nature of the study scenario. These changes resulted in a 20-item PPUS, with 10 reverse-coded items as in the original measure. Alpha reliability in the current study was excellent at 0.93.
CHAPTER III

RESULTS

Data Analysis

Data reduction

All data were recorded and collected through an online survey system. Participants answered all measures in the online survey by entering their responses into a computer. Clauses were built into the survey to ensure that participants 1) could not answer a question with more than one answer, and 2) answered all items in a section before moving on to the next section. Once the participants’ responses were submitted via the survey, the data were downloaded into a spreadsheet. In this way, error was reduced by not having to manually enter and check the data.

Data analysis

This study uses a 2x2 design. The two independent variables are 1) type of diagnosis (organic versus functional) and 2) presentation of medical information (biopsychosocial versus biomedical model of symptoms and disease). The data were analyzed to test for two main effects (diagnosis and presentation style) and the interaction effect (diagnosis x presentation style) using ANOVA (analysis of variance). The two dependent variables are 1) parents’ change in expectations (as measured pre- and post-study), and 2) degree of parental uncertainty (as measured post-study). These comparisons were used to address the hypotheses that the biomedical presentation of a functional diagnosis would result in a lesser degree of expectations met and greater uncertainty among mothers of children with abdominal pain.

Expectations
Tables 1 and 2 present the pre-vignette EQ and post-vignette EQ means, standard deviations, and ranges.

*Table 1. Means, Standard Deviations, and Ranges of Pre-Vignette EQ Items*

<table>
<thead>
<tr>
<th>Pre-Vignette EQ Item</th>
<th>Mean</th>
<th>Standard Deviation</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. The doctor will tell me what is wrong.</td>
<td>3.00</td>
<td>.86</td>
<td>1.00-4.00</td>
</tr>
<tr>
<td>2. The doctor will tell me what to do.</td>
<td>3.21</td>
<td>.77</td>
<td>1.00-4.00</td>
</tr>
<tr>
<td>3. The doctor will tell me how long the stomachaches will last.</td>
<td>2.34</td>
<td>1.17</td>
<td>.00-4.00</td>
</tr>
<tr>
<td>4. I will feel relieved after talking to the doctor.</td>
<td>3.01</td>
<td>.89</td>
<td>1.00-4.00</td>
</tr>
<tr>
<td>5. The doctor will know whether the stomachaches are related to a serious illness.</td>
<td>3.18</td>
<td>.86</td>
<td>1.00-4.00</td>
</tr>
<tr>
<td>6. The doctor will give me answers to my questions.</td>
<td>3.09</td>
<td>.87</td>
<td>1.00-4.00</td>
</tr>
</tbody>
</table>

*Table 2. Means, Standard Deviations, and Ranges of Post-Vignette EQ Items*

<table>
<thead>
<tr>
<th>Post-Vignette EQ Item</th>
<th>Mean</th>
<th>Standard Deviation</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. The doctor told me what is wrong.</td>
<td>3.12</td>
<td>1.25</td>
<td>.00-4.00</td>
</tr>
<tr>
<td>2. The doctor told me what to do.</td>
<td>3.24</td>
<td>1.06</td>
<td>.00-4.00</td>
</tr>
<tr>
<td>3. The doctor told me how long the stomachaches will last.</td>
<td>1.44</td>
<td>1.40</td>
<td>.00-4.00</td>
</tr>
<tr>
<td>4. I feel relieved after talking to the doctor.</td>
<td>2.84</td>
<td>1.26</td>
<td>.00-4.00</td>
</tr>
<tr>
<td>5. The doctor knew whether the stomachaches were related to a serious illness.</td>
<td>3.24</td>
<td>1.05</td>
<td>.00-4.00</td>
</tr>
<tr>
<td>6. The doctor gave me answers to my questions.</td>
<td>3.20</td>
<td>1.04</td>
<td>.00-4.00</td>
</tr>
</tbody>
</table>

Controlling for baseline, there was a main effect of diagnosis (organic versus functional) on the degree to which mothers’ expectations were met; F (155) = 67.19, p < .001. Examination of the
means revealed that mothers who received a functional diagnosis had their expectations met to a lesser degree than mothers who received an organic diagnosis. This effect is depicted in Figure 1.

*Figure 1. Main Effect of Diagnosis on Mothers’ Expectations (**pre-video watching and post-video watching means)**

There was also an interaction of diagnosis (organic versus functional) by presentation of medical information (biopsychosocial versus biomedical) on mothers’ met expectations; F (155) = 17.00, p < .001. Examination of the means revealed that mothers’ expectations were met to a lesser degree when they received the combination of a functional diagnosis and a biomedical presentation compared to all other combinations of diagnosis and presentation. This interaction effect is depicted in Figure 2.
Figure 2. Interaction Effect of Diagnosis and Presentation on Mothers’ Expectations

(**pre-video watching and post-video watching means)

There was a main effect of diagnosis (organic versus functional) on maternal uncertainty; F(156) = 125.48, p < .001. Examination of the means revealed that mothers who received a functional diagnosis experienced greater uncertainty than those who received an organic diagnosis. This effect is depicted in Figure 3.

There was also a main effect of presentation of medical information (biomedical versus
biopsychosocial) on maternal uncertainty; F(156) = 5.67, *p < .05. Examination of the means revealed that mothers who received a biomedical presentation experienced greater uncertainty than those who received a biopsychosocial presentation. This effect is depicted in Figure 3 also.

*Figure 3: Main Effects of Presentation and Diagnosis on Maternal Uncertainty*

Finally, there was an interaction of diagnosis by presentation of medical information on maternal uncertainty; F (156) = 22.85, *p < .001. Examination of the means revealed that mothers who received the combination of a functional diagnosis and a biomedical presentation experienced the greatest amount of uncertainty compared to all other combinations. This interaction effect is illustrated in Figure 4.
Relation of Expectations and Uncertainty

The correlation value between the post-vignette EQ sum score and the PPUS-Revised sum score was -.82, indicating that when expectations were met to a greater degree, mothers experienced less uncertainty. Three of the six items on the Post-Vignette EQ were highly correlated with reduced uncertainty (with correlation values lower than -.7). These uncertainty-reducing items included the doctor having told the parent what to do (“The doctor told me what
to do.”), the parent feeling a sense of relief (“I feel relieved after talking to the doctor.”), and the parent perceiving their questions as answered (“The doctor gave me answers to my questions.”).

Table 3. The Correlation of Post-Vignette EQ Items with Uncertainty

<table>
<thead>
<tr>
<th>Post-Vignette EQ Item</th>
<th>r</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. The doctor told me what is wrong.</td>
<td>-.64</td>
</tr>
<tr>
<td>2. The doctor told me what to do.</td>
<td>-.71</td>
</tr>
<tr>
<td>3. The doctor told me how long the stomachaches will last.</td>
<td>-.57</td>
</tr>
<tr>
<td>4. I feel relieved after talking to the doctor.</td>
<td>-.79</td>
</tr>
<tr>
<td>5. The doctor knew whether the stomachaches were related to a serious illness.</td>
<td>-.49</td>
</tr>
<tr>
<td>6. The doctor gave me answers to my questions.</td>
<td>-.75</td>
</tr>
</tbody>
</table>
CHAPTER IV

DISCUSSION

Overview

Differences between the biomedical and biopsychosocial models of illness result in
differences in the approach to treatment of patients with functional symptoms. Research
examining differences between the models and patients’ responses to the models is lacking. The
current study initiated research in this area by examining mothers’ expectations of physicians in
a medical encounter as well as maternal uncertainty regarding children’s abdominal pain
following presentation of a functional versus organic diagnosis from a biomedical versus
biopsychosocial approach. The discussion reviews the results of this study in relation to relevant
literature. Clinical implications of the findings for parents and physicians are discussed. Finally,
limitations of the study and ideas for future research are considered.

Review of Study Findings

Hypothesis Testing

Study hypotheses were largely supported for the two dependent variables examined,
mothers’ expectations of the medical encounter and maternal uncertainty regarding the child’s
condition. As predicted, type of diagnosis (organic versus functional) had a main effect on
expectations and uncertainty. Mothers’ expectations were met to a lesser degree when they
received a functional diagnosis rather than an organic diagnosis for the child’s symptoms.
Mothers who received a functional diagnosis also experienced significantly more uncertainty regarding the child’s condition than mothers who received an organic diagnosis. Also as expected, presentation of medical information (biomedical model versus biopsychosocial) had a main effect on uncertainty. Mothers who received medical information from a biomedical approach reported significantly greater uncertainty about the child’s symptoms (as presented in the child vignette) than mothers who received medical information from a biopsychosocial approach.

The predicted interaction effects qualified the main effects described above. The least degree of expectations met and the greatest uncertainty following the physician’s explanation was observed for mothers who received a functional diagnosis for children’s symptoms from a biomedical presentation.

*Interaction effect of diagnosis and presentation on expectations and uncertainty*

Parents of children with medically unexplained symptoms experience uncertainty regarding the source of their children’s symptoms and expect that their child’s symptoms will be acknowledged and explained by the physician (Peters et al., 1998). When the pediatric medical encounter fails to meet these expectations, parents experience frustration (Walker et al., 1997) and dissatisfaction (Williams et al., 1995). Dissatisfaction may serve to weaken parental adherence to the child’s treatment plan, which ultimately serves to weaken symptom improvement in the child (Bell et al., 2002; Nock et al., 2001). Additionally, parental uncertainty as fueled by illness ambiguity and lack of illness information (Mishel, 1983) has been associated with high levels of emotional distress and protective parenting behavior (Stewart & Mishel, 2000), both of which can have negative implications for children’s health (Santacroce, 2003).
Given the potential for parents’ illness uncertainty and dissatisfaction with unmet expectations to negatively affect children’s health, it is imperative to ask how healthcare providers can best meet parents’ expectations and alleviate their uncertainty – especially when it comes to presenting parents with a functional diagnosis for the child’s symptoms. It has been suggested that parents’ expectations, such as receiving diagnostic, treatment, and prognostic information of children’s symptoms, are less likely to be met and parental uncertainty is more likely to be fueled when a functional diagnosis is presented from a biomedical compared to a biopsychosocial model (Drossman, 1998). This study was the first to empirically test the hypothesis that a functional diagnosis would interact with a biomedical presentation to produce the greatest amount of unmet expectations and uncertainty in mothers of children with abdominal pain.

Indeed, in accordance with study hypotheses, analyses revealed significant interaction effects of diagnosis and presentation on expectations and uncertainty. Compared to mothers in other conditions, mothers who received a biomedical presentation of a functional diagnosis reported that their expectations were met to a significantly lesser degree and that they experienced significantly greater uncertainty after viewing the medical evaluation vignette. This finding emphasizes the importance of presentation style of medical information in understanding parents’ responses to children’s symptoms in the pediatric medical encounter, especially in the case of a functional diagnosis being presented.

In addition to the interaction effect, the correlation of expectations met and uncertainty was examined. As expected, to the degree that mothers’ expectations were met, maternal uncertainty was significantly and inversely related. Specifically, examination of individual expectation items and maternal uncertainty showed that parents felt most empowered and certain
about their child’s condition when they received instruction, relief, and answers from the physician. The strong relation between expectations and uncertainty shows their interrelatedness, lending further relevance to the two separate but clearly related constructs explored in this study.

Clinical Implications

Functional symptoms are symptoms in the absence of organic disease (Stone, Carson, & Sharpe, 2005) that are often attributable to environmental, psychological, and/or social stressors (Mayer, Naliboff, Chang, & Coutinho, 2001; Tache, Martinez, Million, & Rivier, 1999). Such ambiguous symptoms provoke great uncertainty in parents while simultaneously building up parents’ expectations of the physician to acknowledge, explain, and name the child’s medically unexplained symptoms (Peters et al., 1998). Given that the biomedical approach only acknowledges the validity of organic symptoms and thereby fails to provide a diagnosis or treatment plan for functional symptoms, providers who attempt to address functional symptoms from a biomedical approach are ill equipped at the outset to meet parents’ expectations or alleviate their uncertainty.

In the current study, the provider in the “functional biomedical vignette” told parents of functional pain patients, “Test results have come back and they’re normal. So there is no evidence of any disease or any other abnormality. Your child seems to be perfectly healthy. Her history, physical exam and test results don’t show anything wrong with her. You know, physically, there’s really no reason for her to have any type of pain. So there’s really nothing medically we can do for her” (Williams, 2007). This biomedical style of presentation for a functional diagnosis, as depicted in this particular vignette, reflects the failure of this style to deliver a disease label, positive diagnosis, or treatment plan. Consequently, mothers in this
condition fared poorly.

Presentation of a functional diagnosis from a biopsychosocial approach, in contrast, resulted in expectations being met to a significantly greater degree and significantly less uncertainty experienced among mothers in the functional biopsychosocial condition compared to mothers in the functional biomedical condition. Unlike the biomedical model, the biopsychosocial model acknowledges that organic disease is only one cause of symptoms and that symptoms can be caused by another source such as psychosocial factors (Drossman, 1998). Given the biopsychosocial model’s acceptance of a mind-body connection embedded in a more holistically-oriented health philosophy, the model is able to offer a positive diagnosis to functional pain patients as well as a treatment plan focused on symptom reduction.

Thus, providers who attempt to address functional symptoms from a biopsychosocial approach may be more equipped to meet parents’ expectations and alleviate their uncertainty than providers who attempt to address functional symptoms from a biomedical approach. For instance, the provider in the “functional biopsychosocial vignette” told parents of functional pain patients, “There is no evidence of any disease or any other abnormality. Given that the results of the lab tests and the results from the endoscopy were normal, your daughter has functional abdominal pain. She may be hypersensitive to sensations in her stomach. In patients with functional abdominal pain, emotions and stress can intensify the sensations and make them more painful. As far as what we can do for your daughter, I’ve got this great psychologist who can help her cope with the stress and teach her some pain management techniques” (Williams, 2007). In this particular vignette, the provider acknowledges, explains, and names the child’s condition – all of which are expectations that have been cited among parents of children with medically unexplained symptoms. Furthermore, utilization of the biopsychosocial approach likely reduced
mothers’ uncertainty by reducing illness ambiguity, providing illness information, offering predictability, and facilitating clear communication between providers and parents (any lack of which contributes to illness uncertainty) (Mishel, 1983; Stewart & Mishel, 2000). This biopsychosocial style of presentation for a functional diagnosis, as depicted in this particular vignette, reflects the capability of this style to deliver a disease label, positive diagnosis, and treatment plan. Consequently, mothers in this condition fared significantly better than mothers in the functional biomedical condition.

Based on the findings of the current study, it is recommended that in the case of pediatric functional symptoms, physicians should present parents information about that diagnosis from a biopsychosocial approach as opposed to a biomedical approach. The biopsychosocial approach is better equipped to address and treat functional symptoms than the biomedical approach in that it meets parents’ expectations and reduces their uncertainty in the midst of the general ambiguity, frustration, and anxiety that surrounds parents’ quest to have children’s symptoms named and treated. Consequently, when met expectations and reduced uncertainty cause mothers to feel satisfied with the pediatric medical encounter, they are more likely to adhere to the child’s prescribed treatment plan and the child’s odds of learning to manage their functional pain are greatly improved. The manner in which a functional diagnosis is presented has important implications for optimizing physician communication with parents and subsequently parents’ care of their children.

**Limitations**

A limitation of the current study was asking participants to imagine themselves as the mother of a hypothetical child described as having debilitating chronic abdominal pain. Had
mothers been responding to questions about their own child, their reported uncertainties regarding the child’s condition and expectations of the medical encounter might have been very different. It is possible that mothers’ responses may have been stronger had they been asked about their own children.

An additional limitation of the current study was the gender of the participants recruited and the gender of the child in the vignette, both of which were female. Mothers were recruited for the study because of their frequent role as caregivers to ill children, thus allowing them to pull from a larger knowledge base when answering questions posed in the study. Fathers’ responses are equally important to consider, but were not within the scope of this study to evaluate. Furthermore, based on the finding that girls exhibit functional abdominal pain at a greater frequency than boys (Apley, 1975), a female was selected as the hypothetical child described in the vignette. Mothers’ responses might have been very different had they been asked to imagine themselves as the mother of a son with chronic abdominal pain. Perhaps mothers have different expectations for medical visits and fewer health uncertainties about sons compared to daughters.

The setting of the medical evaluation vignettes was another limitation of the current study. The medical evaluation vignettes depicted a specialty care setting in which a pediatric gastroenterologist relayed information regarding the hypothetical child’s condition. Had the vignettes instead depicted a pediatric primary care setting in which a general pediatrician relayed information, mothers’ reported uncertainties and expectations might have been very different as well. For instance, perhaps mothers have more clearly defined expectations of the commonly visited general practitioner versus a lesser-seen specialist, or perhaps mothers experience less uncertainty after receiving more in-depth medical information from a specialist versus a
generalist. Thus, setting of the medical evaluation vignettes may have had an impact on mothers’ responses.

A final limitation of the study was the online format in which it was conducted. Mothers were allowed to complete the online study at their convenience and without surveillance by a study research assistant. While mothers were instructed to complete the study in one sitting free of distractions and to read all information and vignettes thoroughly, there is no guarantee that these conditions were adhered to.

**Future Directions**

Doing a naturalistic study in which parents are asked about their own child versus an imagined child could serve to extend the current study. Furthermore, following the child’s medical evaluation, outcomes measures could be administered to assess parents’ satisfaction with the medical encounter and their adherence to the child’s treatment plan. Since the existing research shows that unmet expectations and ongoing illness uncertainty lead to negative health outcomes in children, such an extension of the current study would lend relevance to the idea that what occurs in the medical encounter influences what occurs at home, and consequently, how children fare in the long run.

Further research in this field of study would increase knowledge of the best ways for physicians to relay medical information to parents about their children’s symptoms. A benefit of research in this area of children’s health is the potential to strengthen communication between parents and physicians, thus preparing and equipping parents to provide their children with the best care possible.
References


APPENDIX A

Child Vignette

“Imagine you are the mother of an 11-year-old girl. Your daughter has been having stomach aches off and on for several years. She has stomach aches two to three times a week and the pain lasts for at least an hour or more each time. Recently, the stomach aches have been getting worse, becoming even more painful and frequent than ever. Sometimes she cries and doubles over in pain. Your daughter has to stay home from school once or twice a week because of the pain. She has missed two weeks of school already this semester. You can tell that your daughter’s pain is really severe. It is keeping her from doing a lot of things she used to do. You’ve taken her to your primary care physician’s office several times, but they have not been able to determine what’s causing this pain. The doctors haven’t found anything to help relieve her pain.”

“Now, imagine that you are the mother of this child who has been having pain on and off for the last several years, which has become even more severe in the past couple of weeks. You are going to fill out a set of questionnaires. Please answer the questions as if you are the mother of this child with abdominal pain.”
MD presents evaluation results:
Hi, good to see you again. We have the results of your daughter’s evaluation. As you might remember, we sent some samples of her blood and urine to the lab the last time you were here. Those tests have come back and they’re all normal. We also at that time did an endoscopy and that’s when we put the tube down inside of her stomach and took a look around and also took some biopsies at that time. The biopsy results have come back and they show some mild inflammation in some of the cells in her stomach.

Parent asks: What is her diagnosis?
The results of the stomach biopsy tells us that your daughter has gastritis. What that means is there’s some areas in the lining of her stomach that are mildly inflamed.

Parent asks: Why is she having such severe pain?
Inflammation isn’t the only thing that can be causing her pain. Other things such as emotions and stress can also intensify pain signals. When you think it about, when you’re upset or you’re stressed, pain has a tendency to get worse, it’s kind of like turning up the volume on the television. And then the other thing we also have a tendency to see is that when patients focus on pain, it can make it worse as well.

Parent asks: What can you do for her?
You know, as far as what we can do for her pain, I can give her some medication that’s going to help reduce the acid in her stomach so that’ll allow the inflammation that she has there currently to heal. I think the other thing that we see is that stress can also aggravate pain, so many patients, like your daughter, can get some control over their pain by learning some stress and some pain management techniques. I’ve got a great psychologist who I work with who can help her cope with her pain and with her stress and teach her some pain management techniques. For example, she can learn how to use relaxation and distraction to turn down the volume of the pain signals.

Parent asks: What if she keeps having pain?
That’s a great question. I’ll be seeing her again in a couple of weeks to see how she’s doing. I’ll give her a different medication if the one that I give her today doesn’t work. The other thing is the psychologist will keep working with her on her strategies to cope with stress and help her manage her pain.

Parent asks: Can she go to school?
Oh yes, she can go back to school and continue her normal activities. In fact, being involved in activities will help distract her from the pain and make her feel better.
MD presents evaluation results:
Hi, good to see you again. We have the results of your daughter’s evaluation. As you might remember, we sent some samples of her blood and urine to the lab the last time you were here. Those tests have come back and they’re all normal. We also at that time did an endoscopy and that’s when we put the tube down inside of her stomach and took a look around and also took some biopsies at that time. The biopsy results have come back and they show some mild inflammation in some of the cells in her stomach.

Parent asks: What is her diagnosis?
The results of the stomach biopsy tells us that your daughter has gastritis. What that means is there’s some areas in the lining of her stomach that are mildly inflamed.

Parent asks: Why is she having such severe pain?
Even some minor inflammation in the stomach can cause a lot of pain. The stomach lining is red and irritated, so it’s very sensitive to the stomach acid that digests food. And that combination of inflammation in the stomach plus the acid that’s already there can irritate nerves that send pain signals.

Parent asks: What can you do for her?
As far as what I can do for her, what I’d like to do is give her a prescription for Reduxal. This is a medicine that should reduce the acid in her stomach so that the inflammation can heal. This medicine comes in either a liquid form or a tablet form, but I usually like to use the liquid form in kids her age. What I’d like to do for the first week is give her a tablespoon in the morning right before she eats breakfast and then also have her take a tablespoon at night right before she goes to bed. After that first week, she’ll only need to take a tablespoon at night. I’m going to give you a one month prescription of the medicine.

Parent asks: What if she keeps having pain?
That’s a great question. I’ll be seeing her again in a of couple weeks to see how she’s doing. I’ll give her a different medicine if this one doesn’t work. There are several different kinds of medicines that are out there that can be used to reduce stomach acid.

Parent asks: Can she go to school?
Oh yes, she can go back to school and continue her normal activities. This medication should start working pretty quickly and should make her feel better.
MD presents evaluation results:
Hi, good to see you again. Well we have the results of your daughter’s evaluation. As you know, the last time you were here we sent some samples of her blood and urine to the lab. Those test results have come back and they’re normal. At that time we also did an endoscopy and that’s when we put the tube down inside of her stomach and when I took a look at that time everything looked normal. While I was down there, I took some biopsies and those results are back and those are normal as well. So there is no evidence of any disease or any other abnormality.

Parent asks: What is her diagnosis?
Given that the results of the lab tests and the results from the endoscopy were normal, your daughter has functional abdominal pain. She may be hypersensitive to sensations in her stomach.

Parent asks: Why is she having such severe pain?
In patients with functional abdominal pain, emotions and stress can intensify the sensations and make them more painful. When you think about it, when you’re upset or stressed, pain gets worse, it’s sort of like turning up the volume on the television. Also, what we tend to see is that focusing on pain can make it worse as well.

Parent asks: What can you do for her?
You know, as far as what we can do for your daughter, you know stress can aggravate pain, so many patients can get some control over their pain by learning stress and pain management techniques. I’ve got this great psychologist who I work with who can help her cope with the stress and teach her some pain management techniques. You know, for example, she can learn how to use relaxation and distraction to turn down the volume of her pain signals, and that should help her cope with the pain.

Parent asks: What if she keeps having pain?
That’s a great question. I’ll see her again in a couple of weeks to see how she’s doing. In the meantime, the psychologist will be seeing her weekly to teach her strategies to cope with her stress and help her manage her pain.

Parent asks: Can she go to school?
Oh yes, she can go back to school and continue her normal activities. In fact, being involved in activities will help distract her from the pain and make her feel better.
Medical Evaluation Vignette 4: Functional Biomedical

MD presents evaluation results:
Hi, good to see you again. Well we have the results of your daughter’s evaluation. As you know, the last time you were here we sent some samples of her blood and urine to the lab. Those test results have come back and they’re normal. At that time we also did an endoscopy and that’s when we put the tube down inside of her stomach and when I took a look at that time everything looked normal. While I was down there, I took some biopsies and those results are back and those are normal as well. So there is no evidence of any disease or any other abnormality.

Parent asks: What is her diagnosis?
Your child seems to be perfectly healthy. Her history, physical exam and test results don’t show anything wrong with her.

Parent asks: Why is she having such severe pain?
You know, physically, there’s really no reason for her to have any type of pain. You know, we’ve done all the tests that were indicated and they all came back normal. You know, the pain is probably caused by stress or emotions. This seems to be more of a psychological problem and not a medical problem.

Parent asks: What can you do for her?
You know, as far as what we can do for your daughter, I can tell you that she’s in good health. When I looked down into her stomach with the endoscopy, it looked just fine. The lining of her stomach is nice and pink and healthy-looking. The results of the biopsy in addition to the blood and the urine tests were all normal. We’ve ruled out a number of conditions, such as infections, food allergies, ulcers, and Crohn’s disease that can cause abdominal pain. So there’s really nothing medically we can do for her.

Parent asks: What if she keeps having pain?
You know, that’s a great question. You know, at this point, there’s really nothing more that I can do for her. Since this is not a physical problem, I would suggest seeing a psychiatrist if the pain continues. I can give you the name of a great child psychiatrist if you want one.

Parent asks: Can she go to school?
Oh yes, she can go back to school and continue her normal activities. She's not physically sick, so there's really no reason for her to stay home.
### APPENDIX B

**Expectations Questionnaire (Pre-Vignette)**

How true are each of the following statements *for you* regarding the information you expect to receive from the doctor?

<table>
<thead>
<tr>
<th>Statement</th>
<th>Not at all true</th>
<th>A little true</th>
<th>Some true</th>
<th>Mostly true</th>
<th>Very true</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. The doctor will tell me what is wrong.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. The doctor will tell me what to do.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. The doctor will tell me how long the stomach aches will last.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4. I will feel relieved after talking to the doctor.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5. The doctor will know whether the stomach aches are related to a serious illness.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>6. The doctor will give me answers to my questions.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
Expectations Questionnaire (Post-Vignette)

How true are each of the following statements for you regarding the information you just received from the doctor?

<table>
<thead>
<tr>
<th></th>
<th>Not at all true</th>
<th>A little true</th>
<th>Some true</th>
<th>Mostly true</th>
<th>Very true</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. The doctor told me what is wrong.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. The doctor told me what to do.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. The doctor told me how long the stomach aches will last.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4. I feel relieved after talking to the doctor.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5. The doctor knew whether the stomach aches were related to a serious illness.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>6. The doctor gave me answers to my questions.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
Parent Perception of Uncertainty Scale (PPUS)—Revised

How true are each of the following statements *for you* given the information you just received about your child’s stomach aches?

<table>
<thead>
<tr>
<th>Statement</th>
<th>Not at all true</th>
<th>A little true</th>
<th>Some true</th>
<th>Mostly true</th>
<th>Very true</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. The doctors don’t know why my child has pain.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. I have a lot of questions without answers.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. The explanations they gave for my child’s pain seem hazy.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4. The purpose of the treatment for my child’s pain was clear to me.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5. I understood everything explained to me about my child’s pain.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>6. The doctor said things about my child’s pain that could have many meanings.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>7. The cause of my child’s pain is too complex to figure out.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>8. It is unclear to me what to do about my child’s pain.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>9. The doctor gave my child a specific diagnosis.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>10. The doctor did not find anything wrong with my child.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>11. My child’s diagnosis is definite and will not change.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>12. The seriousness of my child’s illness has been determined.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>13. It is unclear to me what the doctor did to help me and my child.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>14. The doctor used every day language so I understood what he was saying.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>15. I don’t know anymore now about my child’s pain than I did before this evaluation.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
16. The doctor told me exactly what is wrong with my child.  
   Not at all true | A little true | Some true | Mostly true | Very true
   0 | 1 | 2 | 3 | 4

17. The doctor didn’t tell me what to do when my child in pain.  
   Not at all true | A little true | Some true | Mostly true | Very true
   0 | 1 | 2 | 3 | 4

18. The doctor told me what I can do to help my child.  
   Not at all true | A little true | Some true | Mostly true | Very true
   0 | 1 | 2 | 3 | 4

19. The doctor believed my child’s pain is real.  
   Not at all true | A little true | Some true | Mostly true | Very true
   0 | 1 | 2 | 3 | 4

20. The doctor will keep trying to find a cure for my child's pain, no matter how long it takes.  
   Not at all true | A little true | Some true | Mostly true | Very true
   0 | 1 | 2 | 3 | 4