

**THE ROLE OF UNCERTAINTY IN COPING EFFICACY:
THE EXPERIENCE OF PARENTS OF CHILDREN
WITH UNDIAGNOSED MEDICAL CONDITIONS**

by

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ABSTRACT

Background: Uncertainty pervades all aspects of illness and health care and is especially relevant for those individuals with rare and undiagnosed medical conditions. Research has demonstrated that uncertainty can be a significant source of psychological distress and may affect adaptation. This study explores the perceived uncertainty, accounting for personality traits, among parents of a child with an undiagnosed medical condition.

Methods: A cross-sectional, mixed methods design was used to examine the relationships among perceptions of uncertainty, coping efficacy, and coping, accounting for personality traits (tolerance of uncertainty, resilience, and optimism). The study design was informed by Lazarus and Folkman's Transactional Model of Stress and Coping. Measures included a newly developed Parental Uncertainty of Children's Health Scale which examined parents' perceptions of uncertainty and the importance of resolving the uncertainty. Parents of children with undiagnosed medical conditions were recruited through online support and advocacy groups. All participants completed the survey electronically.

Results: Among the 94 respondents, the majority were biological mothers (94%), Caucasian (94.7%), and married (76.6%). A slight majority of the children were female (57.6%) and were, on average, 8.0 years old. On average, parents perceived greater uncertainty than certainty about areas of their child's undiagnosed condition that are important to them. Multivariate analysis revealed that optimism predicted perceptions of uncertainty ($p < 0.01$), and that perceptions of uncertainty, optimism and resilience predicted coping efficacy ($p < 0.05$). Additionally, multivariate analysis showed that coping efficacy and resilience predicted problem-focused coping ($p < 0.01$) while

resilience and tolerance of uncertainty predicted emotion-focused coping ($p < 0.05$).

Analysis revealed that perceptions of uncertainty greatly influence appraisals of coping efficacy such that higher perceptions of uncertainty result in lower coping efficacy.

Conclusion: This study suggests that parents of children with undiagnosed medical conditions perceive uncertainty related to social support and medical management, which they view as important to resolve. The findings also suggest that personality traits contribute to the type of coping strategies parents choose to employ. Finally, this study contributes to the broader understanding of perceptions of uncertainty and the impact of these perceptions for parents of children with undiagnosed medical conditions.

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BACKGROUND

Studies have shown that, in the United States, there are 25 million individuals with rare diseases, which together represent 6 to 10 percent of human medical illness (NCOD, 1989, and Guillem, *et al*, 2008). New technologies and health care models work to provide a diagnosis for many of these individuals who previously would have remained undiagnosed. However, even with the advent of new technology, uncertainty remains a central feature for most individuals with rare and undiagnosed conditions.

In clinical genetics it is not uncommon to encounter children with multiple congenital anomalies indicative of an underlying syndrome and yet have a diagnosis remain elusive. For parents of these children the uncertainty surrounding the lack of a diagnosis and details related to prognosis permeates many aspects of life (Cohen, 1993). Research has shown that certain factors, such as disease severity, perceived control and optimism, are associated with perceptions of uncertainty among these parents (Madeo, *et al*, 2012). Additional research has also suggested that a diagnosis produces a reduction in uncertainty as it provides a label, an explanation of cause, prognosis, opportunities for treatment, acceptance of the condition, and social support (Rosenthal, *et al*, 2001).

However, it is not fully understood how the uncertainty that arises when a diagnosis is absent affects parental coping efficacy and coping and how personality traits affect perceptions of uncertainty.

Living with Uncertainty and Illness

Uncertainty pervades all aspects of illness and arises from many factors including an absent or vague diagnosis and missing information about prognosis (Han, *et al*, 2011). Many studies that have looked at the experiences of patients who lack certainty about

their illness have found that the uncertainty is a large source of stress, specifically leading to psychological distress. Research investigating sources of distress in patients with chronic illnesses have described uncertainty as “probably the greatest single psychological stressor facing the patient” and their families (Koocher, 1984). In a world where uncertainty is pervasive, there are individuals who are better able to cope with known unknowns. However, what distinguishes these people from those who are less able to cope with known unknowns has been insufficiently investigated.

Raising a child with a chronic medical condition is an affective, cognitive and physical burden (Canam, 1993). When the child’s condition is unidentified, the situation is more difficult. Studies have found that the uncertainty surrounding a diagnosis negatively affects parental coping (Rosenthal, *et al*, 2001; Graungaard & Skov, 2006; and Lipinski, 2006). Further research suggests that the consequences of parental uncertainty include anxiety, depression, and helplessness, all of which have significant health costs for both the parents and children (Grootenhuis & Last, 1997b and Raphael, *et al*, 2010). One study, however, has shown that uncertainty about prognosis for their child may provide some parents the ability to focus on the possibility of a more positive outcome for their child (Rosenthal, *et al*, 2001). While medical uncertainty most often has negative psychological consequences, uncertainty may also be viewed as offering opportunity. Therefore, it may be how an individual appraises the uncertainty that, in part, determines their ability to adapt.

A few qualitative studies have sought to better understand what parents of children with undiagnosed medical conditions are most uncertain about, or most interested in resolving, and what factors influence their perceptions of uncertainty.

Across studies, parents identify key areas where a diagnosis would have a positive impact: labels, causes, prognosis, treatment, social support, and acceptance of the condition (Rosenthal, *et al*, 2001 and Madeo, *et al*, 2012). Quantitative investigations of factors associated with parental uncertainty have found that perceived control and optimism are negatively associated with uncertainty while perceived disease severity is positively associated (Madeo, *et al*, 2012). While this research identifies states associated with perceived uncertainty, very little research has been conducted in how personality traits may modify the relationship between appraisals of uncertainty and adaptation. Parents' tolerance for uncertainty and resilience likely affect how they appraise the uncertainty of not having a diagnosis, but this has yet to be studied. Since parents of children with undiagnosed medical conditions must cope with persistent uncertainty, it is important to understand the relationships among uncertainty appraisals, personality traits, coping efficacy and coping as this information could inform the development of interventions that could be assessed for their success in facilitating parental adaptation.

Uncertainty is often described as a multi-domain construct that affects many aspects of one's quality of life. Cohen (1993) proposed the Spread of Uncertainty Theory to explain parental behavior under circumstances of sustained uncertainty. The theory identified five domains of uncertainty describing the origin of the uncertainty. Existential uncertainty stems from questions of the child's survival and quality of life. The second domain, etiological uncertainty, focuses on why their child was affected. Treatment uncertainty, the third domain, is concerned with choosing between different treatment options. The fourth domain, situational uncertainty, originates from the added layer of being in unfamiliar hospitals and working with new physicians and staff. Lastly,

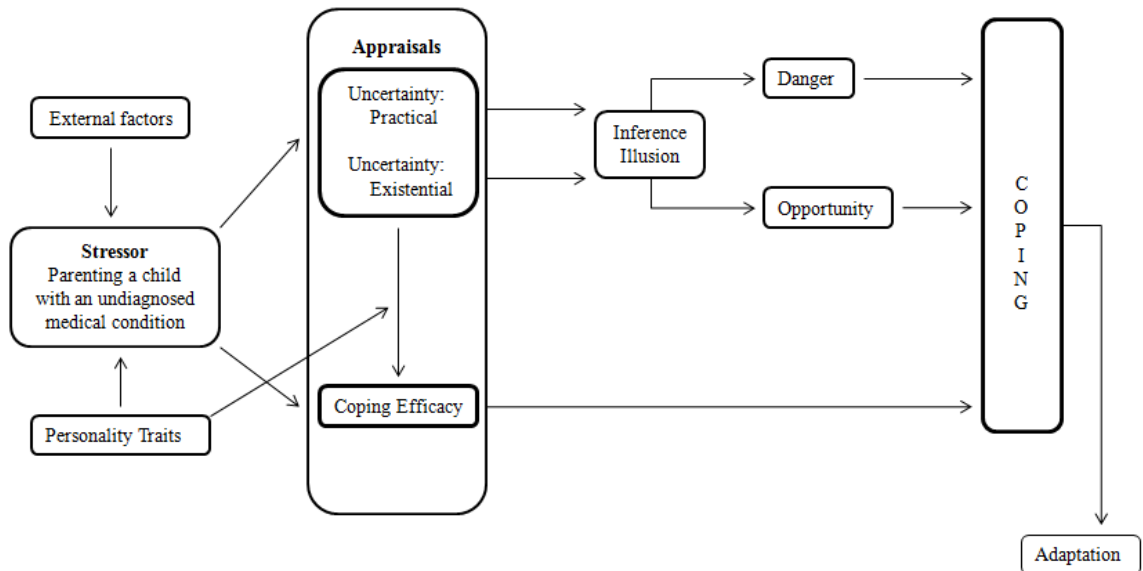
biographical uncertainty focuses on the personal consequences the child's illness has for the parents. Mishel's Perceived Uncertainty in Illness Model also proposes that there are multiple domains of uncertainty. Specifically Mishel posits that there are eight dimensions: vagueness, lack of clarity, ambiguity, unpredictability, inconsistency, probability, multiple meanings and lack of information (1981). More recently an expanded taxonomy was proposed to characterize uncertainty and synthesize the diverse theoretical literature from many different fields, including communication, decision science, health services, and psychology (Han, *et al*, 2011).

Han and colleagues propose an integrative taxonomy of uncertainty which characterizes the uncertainty present in health care according to its source, issue and locus (Han, *et al*, 2011). In this model, uncertainty is defined as "the subjective perception of ignorance". Possible sources of uncertainty include probability, ambiguity and complexity. Issues of uncertainty are categorized as scientific, practical and personal and are defined by the concerns to which they pertain. Finally, the locus of uncertainty is either the patient or clinician. This taxonomy acknowledges uncertainty as a multidimensional concept which includes distinct domains. It is theorized that each of these domains of uncertainty may be related to different outcomes, such as coping, and appraisals, such as coping efficacy. The current study, using the newly developed Parental Uncertainty of Children's Health Scale, explores each of the sources of uncertainty and scientific and personal domains as they relate to the parent's experiences of raising a child with an undiagnosed medical condition.

Conceptual Framework

This study aims to explore the relationships between personality traits, uncertainty, coping efficacy and coping as informed by Lazarus and Folkman's Transactional Model of Stress and Coping (1984) and Mishel's Perceived Uncertainty in Illness Model (1981). The theories related to this conceptual framework (see Figure 1) will be discussed in this section and research related to the specific relationships will be addressed in the following section.

Figure 1: Proposed Conceptual Framework



The process of coping with a stressor or health threat is dynamic and influenced by personal and environmental characteristics and the appraisals made of the threat (Folkman & Greer, 2000). The Transactional Model of Stress and Coping (TMSC) theorizes that when faced with the stress of parenting a child with a medical condition, one cognitively appraises the situation to determine the relevance of what is happening (primary appraisal) and then what one can do about the stressful event (secondary

appraisal). It is important to consider that the circumstances surrounding the health threat change over time, such as during periods of crisis versus stable management, and therefore coping efficacy, coping and adaptation are likely to reflect these changes. Each of these concepts will be explained and described in the following sections. Thus, coping and adaptation are not stable states of being; they are ever changing and are affected by changes in the threat, appraisal, and coping efficacy. In our model, changes in the threat, or stressor, will result in changes in appraisals of uncertainty and coping efficacy. It is hypothesized that appraisals of uncertainty affect perceptions of coping efficacy and that each of these appraisals directly affect coping.

Mishel's Perceived Uncertainty in Illness Theory is similar to the TMSC in that it posits that a cognitive appraisal of a stressor leads to choice and use of a coping strategy. In this theory, uncertainty is viewed as a neutral construct and is evaluated by the individual to determine if it is a threat or an opportunity for personal growth (1981). As such, it is an appraisal made about the stressor that inhibits the formation of a cognitive structure that in turn hampers the individual's ability to appraise the situation. Mishel proposes that an individual faced with uncertainty struggles to determine the relevance of the stressor and so is unable to adequately appraise the situation further.

Additionally, while research has explored the various appraisals individuals make about health-related stressors and measured how those appraisals affect adaptation, very little research has been done on whether personality traits and individual differences, such as tolerance for uncertainty, resilience and optimism, may affect appraisals and whether or not the stressor is perceived as harmful and challenging. In this study we have defined the stressor as parenting a child with an undiagnosed medical condition. We aim

to better understand the relationship between coping efficacy and coping and hypothesize that coping efficacy mediates the relationship between appraisals of uncertainty and coping as parents' perceived ability to cope with uncertainty affects their ways of coping.

Coping Efficacy

Coping efficacy, also known as coping self-efficacy, is an individual's perceptions of their ability to cope; in other words, it is one's belief that he or she can or cannot successfully and effectively cope with a given situation. In our conceptual model, coping efficacy is a secondary appraisal that affects coping and ultimately adaptation. Coping efficacy has been studied as a multi-dimensional concept in professional caregivers of individuals with behavior problems and learning disabilities (Cudré-Mauroux, 2010). In this study of professional caregivers, it was suggested that coping self-efficacy affects not only the stress levels of the caregivers but also their interactions with their patients. Cudré-Mauroux found that during the interactions with patients, caregivers' coping self-efficacy was altered by transactional factors such as the environment and most significantly by the caregivers' perceived competency in handling the situation. Interactions where caregivers felt more competent and reported greater coping self-efficacy were more likely to result in the desired goal, which was often a behavior change. These data suggest that higher coping self-efficacy may result in better adaptation, as individuals feel more able to achieve their goals even in stressful situations.

The relationships between personality traits, coping self-efficacy and ways of coping have not been previously studied.

Personality Traits and Uncertainty

Previous research has demonstrated that while some parents continue to search for answers to become more certain about their child's diagnosis and/or prognosis, other parents are content to stop seeking (Rosenthal, *et al*, 2001). These parents frequently state that not having certainty allows for more possibility, or, in other words, they come to appraise uncertainty as an opportunity; their child is not limited by a label. It remains unknown what distinguishes these parents from one another and whether it is inherent personality traits that affect the appraisal of and coping with uncertainty.

Tolerance for Uncertainty

Tolerance for uncertainty is more commonly referred to as an intolerance of uncertainty or "the tendency of an individual to consider the possibility of a negative event occurring unacceptable, irrespective of the probability of occurrence" (Carleton, *et al*, 2009). Intolerance for uncertainty has been identified as an individual difference involved in excessive worry and state anxiety. Individuals with an intolerance for uncertainty frequently interpret ambiguous information as threatening because they are unable to predict the likelihood of a negative event occurring. Tolerance for uncertainty has been studied in undergraduate populations, medical students, residents, and practiced physicians as it relates to anxiety disorders; it has yet to be studied in parents of undiagnosed or ill children (Geller, *et al*, 1993). Studies of individuals with anxiety disorders have suggested that tolerance for uncertainty is fundamental to worry and anxiety levels and greatly affects appraisals made by individuals in stressful situations; individuals who have a higher intolerance for uncertainty have been found to interpret physical symptoms, such as heart palpitations, as more severe than individuals with a

lower intolerance for uncertainty. This research would suggest that tolerance for uncertainty is likely to affect parents' appraisals of uncertainty and likely their coping efficacy.

Resilience

Resiliency is often defined as the ability to maintain or regain positive levels of functioning despite adversity. Wagnild proposes five characteristics of resilience: (1) perseverance, "a willingness to continue the struggle to reconstruct one's life" in the midst of adversity, (2) equanimity, "sitting loose and taking what comes," (3) meaningfulness, "realization that life has a purpose" or that there is something worth living for, (4) self-reliance, a belief in oneself, and (5) existential aloneness, "the realization that each person is unique" and that some experiences cannot be shared (2009). Resiliency has been measured in many different populations and across many ethnicities and found to be positively correlated with spiritual growth, health promoting lifestyle practices, psychological well-being and negatively correlated with depression, anxiety, and obsessive compulsive behavior (Wagnild, 2009).

In families of children with Duchenne Muscular Dystrophy, "family hardiness", a measure of family resilience, was correlated with better parental health and higher levels of family adaptation (Chen & Clark, 2010). Resilience has not yet been studied in parents of children with undiagnosed medical conditions but it is likely that a more resilient parent will be more likely to view uncertainty as an opportunity for personal growth and will have a higher level of coping efficacy than a less resilient parent. In this study we will explore whether parents who identify themselves to be high on the trait of resilience have different appraisals about uncertainty than parents who do not identify themselves

as resilient and the extent to which the trait of resilience might affect the relationship between perceptions of uncertainty and parents' assessments about the efficacy of their attempts at coping.

Optimism

Studies among mothers of children experiencing a health threat have found that dispositional optimism, the tendency of an individual to expect positive outcomes in life, is protective against poor mental and physical health (Ekas, *et al*, 2010). In a previous study with parents of children with undiagnosed medical conditions, greater dispositional optimism was associated with greater coping efficacy, higher self-esteem, higher social integration, and higher spirituality scores (Madeo, *et al*, under review). Positive effects of optimism on coping efficacy were found to be greater among parents who perceive less uncertainty, suggesting that optimism may moderate the relationship between perceived uncertainty and coping efficacy. More broadly, this study suggests that greater optimism is correlated with better coping and adaptation. The present study will further explore how dispositional optimism affects perceived uncertainty levels and coping efficacy.

Coping

Coping is a dynamic cognitive and behavioral process where strategies are implemented to reduce, master, or tolerate a stressor after it has been appraised (Folkman *et al*, 1986). Coping strategies are often categorized as either emotion-focused or problem-focused. Emotion-focused coping strategies are used to manage emotional distress caused by the stressor and are considered most appropriate when there is little a person can do to change the outcome of the stressor (Folkman *et al*, 1991). Conversely, problem-focused coping strategies are used to change the environment or stressor that is

causing the distress. Coping strategies are considered relatively stable and are not easily altered by brief interventions, although more intensive interventions can help individuals develop and utilize new strategies. However, research suggests that most individuals tend to use both problem-focused and emotion-focused coping strategies and their effectiveness often depends on how closely they “match” the stressor.

Coping is a widely studied outcome measure and the literature is abundant. Research has demonstrated that fathers of children with recently diagnosed cancer used more emotion-focused coping strategies in the face of higher uncertainty (Sterken, 1996). LaMontagne and Pawlak, who studied how parents of children in pediatric intensive care units coped, found that parents used a combination of both problem and emotion-focused strategies (1990). They asked parents to identify their predominant stressor and found that coping strategies involving seeking social support were most often used by these parents, regardless of the predominant stressor. In this study coping is measured as an outcome, following appraisals of uncertainty and coping efficacy. Better understanding of how these and other variables effect types of coping strategies will help in the future development of interventions aimed at facilitating coping and adaptation during times of uncertainty.

The purpose of this study is to explore the uncertainty parents of children with undiagnosed medical conditions perceive, to understand how these perceptions of uncertainty affect coping efficacy, and to explore what factors, such as personality traits, affect perceptions of uncertainty.

Significance of Study

This study will make a contribution to the literature by describing the uncertainty present when raising a child with an undiagnosed medical condition and its importance to parents. Additionally it will provide information that has not, to our knowledge, been reported, including the relationships between perceptions of uncertainty, coping efficacy, tolerance of uncertainty, optimism and resilience. Understanding these conceptual relationships will inform the development of future intervention studies aimed at mitigating uncertainty and facilitating effective coping.

Information gleaned from this study is of particular importance to genetic professionals. Genetic counselors often work in clinics where children with undiagnosed conditions are being evaluated and thus are in a position to offer counseling to parents struggling with uncertainty. With the onset of clinical sequencing the scope of uncertainty is anticipated to expand making it important for genetic counselors and genetic professionals to understand the potential negative impact perceptions of uncertainty may have on adaptation to genomic sequencing information.

SPECIFIC AIMS & HYPOTHESES

The purpose of this study was to understand the uncertainty among parents of children with undiagnosed medical conditions, what factors contribute to perceptions of uncertainty and how this uncertainty affects coping efficacy.

Aim 1: To assess the reliability, convergent and divergent validity of the newly developed Parental Uncertainty of Children's Health Scale among parents of children with undiagnosed medical conditions.

Aim 2: To assess the dimensions of perceived uncertainty and their relative importance among parents of children with undiagnosed medical conditions.

Aim 3: To assess and explore potential mechanisms of the association between uncertainty and coping efficacy among parents of children with undiagnosed medical conditions.

Hypothesis 3.1: Lower levels of overall perceived uncertainty will be associated with higher coping efficacy.

Hypothesis 3.2: Coping efficacy will mediate the relationship between uncertainty and problem-focused and emotion-focused coping.

Aim 4: To determine whether tolerance for uncertainty, resilience, and optimism moderate the relationship between uncertainty and coping efficacy.

Hypothesis 4.1: Tolerance of uncertainty influences the association between uncertainty and coping efficacy.

Hypothesis 4.2: Resilience influences the association between uncertainty and coping efficacy.

Hypothesis 4.3: Optimism influences the association between uncertainty and coping efficacy.

METHODS

Study Population

Individuals 18 years or older who self-reported as having a child with a medical condition that had not been diagnosed were eligible to participate in this study.

Individuals of all socioeconomic, religious, and ethnic backgrounds were included.

Online recruitment strategies allowed individuals from many geographic locations throughout the United States to participate in the study. The sample size calculation indicated that 240 participants were needed to have 80% power to detect the effect of a key independent variable explaining a small-to-medium effect size (Cohen, 1988) of at least 3% of total variance in coping efficacy.

Recruitment Strategies

Participants for this study were recruited from national online support and advocacy groups for individuals and parents of children with an undiagnosed medical condition: Syndromes without a Name-USA (SWAN-USA), U.R. Our Hope, and In Need of a Diagnosis. Leaders of these organizations were contacted by the researcher (EM) and were asked to distribute the study announcement (Appendix A) through their websites, email listservs, and online message boards. Parents were told they were eligible to participate in this study if they had a child with a medical condition that had not been diagnosed and involved at least two parts of the body. The parent may or may not have a label for the ways their child's body is affected but they should not have a label for their child's overall condition.

Procedures

This study involved a one-time self-administered survey. Interested individuals were instructed to either access the electronic version of the survey through SurveyMonkey, a secured Internet site, or to contact the researcher for a paper copy of the survey. The first page viewed on the survey website was the study notice (Appendix B) that provided an overview and description of the study to ensure that participants were eligible and able to provide consent. Participants provided consent by checking a box on the first page of the survey and were asked not to provide names on the survey so that anonymity would be maintained. This protected the confidentiality of the participants.

Participants were instructed that they could withdraw from the study at any time, up until their submission of the survey, that they could skip any question(s) and that they could discontinue taking the survey at any time. Participants were not asked to provide any identifiable information on the survey. Studies were collected from June 21, 2013 through November 22, 2013.

This study was approved by the National Human Genome Research Institute's Institutional Review Board (Protocol # 13-HG-N162).

Study Design

This mixed methods study used a cross-sectional research design assessing quantitative assessments of key domains and qualitative assessments of uncertainty. Validated scales were used to assess coping efficacy, ways of coping, tolerance for uncertainty, resilience and optimism. The uncertainty scale used in this survey, Parental Uncertainty of Children's Health Scale (PUCHS) was developed for use in this study and had not been validated. The scale was piloted among five parents of children with

undiagnosed multiple congenital anomalies known to BBB and changes were made as needed to clarify the meaning of several items and to clarify prompts. Content validity interviews with these parents revealed that items were understood as they were intended and several minor revisions were made to improve clarity of the items. The entire survey took approximately 15-20 minutes to complete.

Study Instrument

The survey (Appendix C) included scales to assess perceptions of uncertainty, coping efficacy, coping strategies and traits of tolerance for uncertainty, resilience and optimism. In addition, it included questions about demographics, the time at which first concerns were noted, and characteristics of the child's medical conditions.

Parental Uncertainty of Children's Health Scale

The Parental Uncertainty of Children's Health Scale (PUCHS) was used to measure parents' perceptions of uncertainty about their child's undiagnosed medical condition and the uncertainty's relative importance. The PUCHS is a 28-item scale designed to assess uncertainty related to their child's undiagnosed condition. There are 14 items about perceptions of uncertainty; each is followed by a question assessing the importance of certainty related to that item. Each uncertainty item on the PUCHS represents uncertainty by a 5-point Likert-format scale ranging from -2 (strongly disagree) to 2 (strongly agree). Each importance item on the PUCHS represents importance by a 5-point Likert-format scale ranging from 1 (unimportant) to 5 (most important). Final averaged uncertainty scores, weighted by importance, can range from -2 to 2 with higher scores indicating greater uncertainty. Scores on either end of the range (-2, 2) represent an individual with little uncertainty that is important and high

uncertainty that is important, respectively. The reliability coefficient of the scale was calculated as 0.79 in this study.

Additional qualitative, and one quantitative question measuring degrees of emotions felt, follow the PUCHS.

Coping Self-Efficacy Scale

The Coping Self-Efficacy Scale was used to assess coping efficacy (Chesney, *et al*, 2006). This scale measures a person's perceived ability to cope effectively with life challenges. It consists of 26 items following a prompt (e.g. "When things aren't going well for you, or when you're having problems, how confident or certain are you that you can...") and is scored on a 7-point Likert-format scale ranging from 1 (not confident at all) to 7 (completely confident). This scale has previously been shown to be valid and reliable (Cronbach's $\alpha = 0.80-0.91$). Cronbach's alpha was calculated as 0.94 in this study.

The Coping Self-Efficacy Scale has been shown to have three distinct factors of coping efficacy. The first, **Use of Problem-Focused Coping**, are responses that assess confidence in one's ability to change problematic aspects of stressful events. It consists of 12 items (questions: 2,3,4,5,6,7,8,9,13,14, 20,25,26) and scores range from 12 to 84. The second factor, **Stopping Unpleasant Emotions and Thoughts**, assesses confidence in one's ability to manage emotional responses to stressful events. This factor consists of 9 items (questions: 1,10,11,12,15,19,21,22,23) and scores range from 9 to 63. The final factor, **Getting Support from Friends and Families**, combines confidence in one's ability to use both problem and emotion focused coping but remains distinct from both. It consists of 5 items (questions: 4,16,17,18,24) and scores range from 5 to 35. The

reliability coefficients for the three sub-scales are 0.91, 0.88, and 0.85 as calculated in this study. Each sub-scale may be evaluated independently of the others, or may be combined and evaluated as a total coping self-efficacy score.

Ways of Coping Checklist-Revised

The Ways of Coping Checklist-Revised (WCC-R) was used to assess coping (Vitaliano, *et al*, 1985). The WCC-R, a revision of the Lazarus and Folkman's original (WCCL) (1980), includes 42 items loading on five factors (problem-focused, wishful thinking, seeks social support, blamed self, and avoidance coping). Respondents were prompted to think about how they are coping with parenting a child with an undiagnosed medical condition. Parents estimated the frequency with which they use particular coping strategies in dealing with their child's undiagnosed medical condition on a 4-point Likert-scale ranging from 0 (never) to 3 (regularly). This scale has been shown to be valid and reliable ($\alpha = 0.73-0.88$) (Vitaliano, *et al*, 1985).

This scale allows for the assessment of both problem-focused coping and emotion-focused coping by combining sub-scales. By combining the blamed self, wishful thinking, and avoidance sub-scales a total "emotion-focused" coping score is calculated (Zakowski, *et al*, 2001). The problem-focused scale is as designed.

Tolerance of Uncertainty

The Tolerance for Ambiguity (TFA) scale developed by Geller was used to assess the trait, tolerance of uncertainty (Geller, *et al*, 1993). The scale consists of 7 statements and asks participants to choose how characteristic the statement is of them. It is scored on a 5-point Likert-format scale with answers ranging from 0 (not at all characteristic of me)

to 5 (very characteristic of me). Higher scores indicated a greater tolerance for uncertainty. The scale's reliability was calculated as 0.80 in this study.

Optimism

The Life-Orientation Test-Revised (LOT-R) was used to measure a participant's optimism (Scheier *et al.*, 1994). LOT-R is a ten item measure in which four items (questions: 2,5,6,8) are filler. Items are scored on a 5-point Likert-format scale ranging from 1 (strongly disagree) to 5 (strongly agree). Three items are reverse scored (questions: 3,7,9) and higher final scores represent higher optimism. The scale's reliability was calculated as 0.81 in this study.

Resilience

The 14-item Resilience Scale was used to measure an individual's resilience (Wagnild & Young, 1993). The scale includes 14 items measured on a 5-point Likert-format scale ranging from 1 (strongly disagree) to 5 (strongly agree) with higher scores indicating greater resilience. The scale's reliability was calculated as 0.88 in this study.

Qualitative Questions

Qualitative questions were included to learn more about parents' perceptions of uncertainty from raising a child with an undiagnosed medical condition.

- Please describe one or two effects that uncertainty about your child's symptoms or medical condition has had on your life.
- In what ways do you feel certain about your child's symptoms or medical condition?
- In what ways do you feel uncertain about your child's symptoms or medical condition?

- Please describe the features of your child’s symptoms or medical condition.
Which of your child’s daily activities are affected by his or her symptoms or conditions?

Additional Questions

Additional quantitative questions were included to account for possible confounding variables associated with raising a child with an undiagnosed condition, perceptions of uncertainty and coping efficacy.

- On a scale from “1” (not very severe) to “7” (very severe), how severe do you feel your child’s symptoms or medical condition is?
- What is your relationship to your child?
- How old are you?
- How many children do you have?
- How many of your children have undiagnosed medical conditions?
- Where does your child with an undiagnosed medical condition fall in the birth order of your children?
- How old is your child now?
- How old was your child when his or her condition first came to your attention?
- Is your child male or female?

RESULTS

Recruitment

During the recruitment period from June 21st to November 22nd 2013, 159 individuals started the online survey. All participants answered the survey electronically as there were no requests for a paper version. A response rate cannot be calculated because the total number of individuals who had access to the web link but chose not to complete the survey is unknown.

Approximately 40% of the surveys (n = 65) were incomplete. In the majority of these incomplete surveys, participants did not answer the survey beyond agreeing to participate and responding to the eligibility questions. This suggests that once they read the eligibility requirements, they determined they were ineligible. A total of 94 completed surveys were included in the data analysis.

Individuals were allowed to skip any question(s). Missing values were imputed for each scale if the answered questions showed a consistent pattern. The number of imputed scores differs across scales by the total number of questions; the PUCHS allows for only 3 answers to be imputed, coping self efficacy allowed 5 answers to be calculated, ways of coping checklist-revised allowed for 8 answers to be imputed, tolerance of uncertainty allows only 1 answer to be imputed, the optimism scale allows for up to 2 answers to be imputed, and the resilience scale allows for as many as 3 answers to be imputed. As such, the sample sizes for the scales vary, depending on each measure's tolerance of missing values.

Demographics of Participants and Children in the Sample

The mean age of participants in the study was 38.6 years (± 8.4). Respondents were predominantly female and Caucasian. The majority of participants (94%) were biological mothers of the child with an undiagnosed medical condition. Additionally, most respondents were married (76.6%). The mean age of the children in the sample was 8.0 years (± 5.2), with a range from 0.5 years to 24 years. There were slightly more daughters than sons in the sample, 57.6% and 42.4% respectively. Table 1 summarizes the characteristics of the sample.

Table 1: Demographic Characteristics of Study Population

Demographic Characteristic		%
N = 94		
Race*	White	94.7
	Asian	4.3
	Black or African American	1.1
	Native Hawaiian or Other Pacific Islander	1.1
	American Indian or Alaska Native	1.1
Ethnicity	Not Hispanic or Latino	88.3
	Hispanic or Latino	4.3
Current Marital Status	Single/Never Married	10.6
	Married	76.6
	Separated/Divorced	8.5
Highest Level of Education	High School/GED	5.3
	Technical School	5.3
	Some College	26.6
	Completed College	35.1
	Post-Graduate	23.7
Annual Household Income	Under \$30,000	12.8
	\$30,000 - \$50,000	18.1
	\$50,001 - \$70,000	26.6
	\$70,001 - \$100,000	16.0
	\$100,001 - \$250,000	19.1
	Above \$250,000	3.2
Relationship to Child	Biological Mother	92.6
	Biological Father	1.1
	Adoptive Mother	4.3
	Adoptive Father	1.1
Gender of Child	Male	42.4
	Female	57.6
Age of Child when Concern First Identified	Prenatally – Birth	24.5
	Delivery – 2 years of age	55.3
	> 2 years of age	11.7
Current Age of Child	< 4 years of age	26.7
	4 – 10 years of age	47.7
	11 – 18 years of age	20.9
	> 18 years of age	4.7

*Percentage does not equal 100% as participants were allowed to choose more than one response.

Remaining percentages may not equal 100% as a result of missing data.

Data Analysis

Data were analyzed using SPSS 21.0 (Statistical Package for the Social Sciences) software. Descriptive statistics, including mean, range and standard deviations, were calculated for all continuous variables and frequencies were calculated for categorical variables. Bivariate analysis was used to explore the relationships between uncertainty and coping efficacy and each independent variable as a preliminary step for hypothesis testing; it was used to identify significant relationships and possible confounding variables. Any variables that resulted in a p-value ≤ 0.05 by bivariate analysis were considered statistically significant, and considered as candidates for inclusion in a multivariate regression model.

The role of uncertainty and three personality traits were tested for their contributions to the variance in coping efficacy, one outcome variable. A second analysis tested the degree to which the variance in coping (as measured by the Ways of Coping) was explained by uncertainty and coping efficacy. Some of the demographic variables with multiple response categories were dichotomized before multivariate analyses were performed due to small sample sizes in each sub-group. These included relation to child (biologic mother versus not biologic mother), marital status (currently married versus currently unmarried), level of education completed (completed college versus not completed college), and ethnicity (Caucasian versus not Caucasian).

Multivariate regression modeling was used to test for the association of one covariate on the outcome measure while controlling for other covariates that may have acted as modifiers.

Additionally, hypothesized mediation and moderation analyses were completed. Moderation analysis was used to determine if the relationship between uncertainty and coping efficacy was moderated by personality traits. Mediation analysis was used to determine if coping efficacy mediates the relationship between uncertainty and coping. These relationships were deemed significant if they resulted in a p-value ≤ 0.05 .

Parental Uncertainty of Children's Health Scale

Factor Analysis

The Parental Uncertainty of Children's Health Scale (PUCHS) was created with seven dimensions of uncertainty intended: Diagnostic, Medical Management, Future, Reproductive, Family, Social and Existential. Each of these dimensions was measured using two items that assessed perceptions of uncertainty followed by two questions about their importance. The internal consistency of the PUCHS was $\alpha = 0.79$.

The exploratory factor analysis suggests that there are *five* (rather than seven) distinct dimensions of uncertainty identified by the PUCHS (Figure 1). The factor analysis was performed using both weighted uncertainty scores and unweighted uncertainty scores for each of the fourteen questions; both of these analyses revealed the same five factors. The first dimension, **Medical Management**, consists of seven items (questions 1-5, 9 & 10), and is a combination of the original domains labeled: Diagnostic, Medical Management, Future, and Family. The second dimension, **Future**, consists of one item (question 6) from the original Future domain. The third dimension, **Reproductive**, consists of two items (questions 7 & 8), the fourth dimension, **Social**, consists of two items (questions 11 & 12), and the fifth dimension, **Existential**, consists of two items (questions 13 & 14). As the future domain consisted of only one item, and

was thus insufficient to represent a factor, it was removed from the scale and the scoring was adjusted accordingly. Internal consistency coefficients were calculated for each of the remaining four subscales; medical management, reproductive, social, and existential, and were 0.84, 0.62, 0.81 and 0.94, respectively. Each sub-scale may be evaluated independently of the others, or may be combined and evaluated as a total uncertainty score. This study analyzed the entire PUCHS as a total weighted uncertainty score and also evaluated each sub-scale independently.

Table 2: Factor Loadings of Parental Uncertainty of Children’s Health Scale

	Component of Uncertainty			
	Medical Management	Social	Existential	Reproductive
1) ...with no clear understanding of my child's limitations	.769	-.111	.084	-.066
2) ...unsure how to think about my child's condition	.772	.244	.097	-.078
3) ...insufficiently prepared to participate in treatment decisions for my child	.684	.243	-.011	.129
4) ...unsure where to go for treatment of my child's condition	.682	.425	-.020	.183
5)...unsure of whether my child is expected to have a normal lifespan	.527	.014	.174	.084
6)...anticipating my child may do better than anyone has predicted	-.145	.002	-.139	.008
7)...lacking information to make decisions about having more children	.056	-.070	-.043	.862
8)...unsure what to tell relatives about risks to their children	.168	.251	.066	.782
9)...ill-prepared to make decisions for my family not knowing what the future may hold for my child	.777	-.034	.133	.309
10)...less able to address my family's concerns about my child	.549	.231	.209	.243
11)...struggling to find parents in a similar situation	.178	.868	.035	.020
12)...without support from parents going through similar experiences	.110	.889	.133	.106
13)...uncertain about the meaning of my child's life	.103	.099	.944	-.002
14)...questioning the purpose of my child's life	.138	.059	.957	.023

Highlighted values indicate which factor (or component) the item is part of. The factor loadings represent factor analysis of the weighted uncertainty scores and are identical to those calculated using unweighted uncertainty scores.

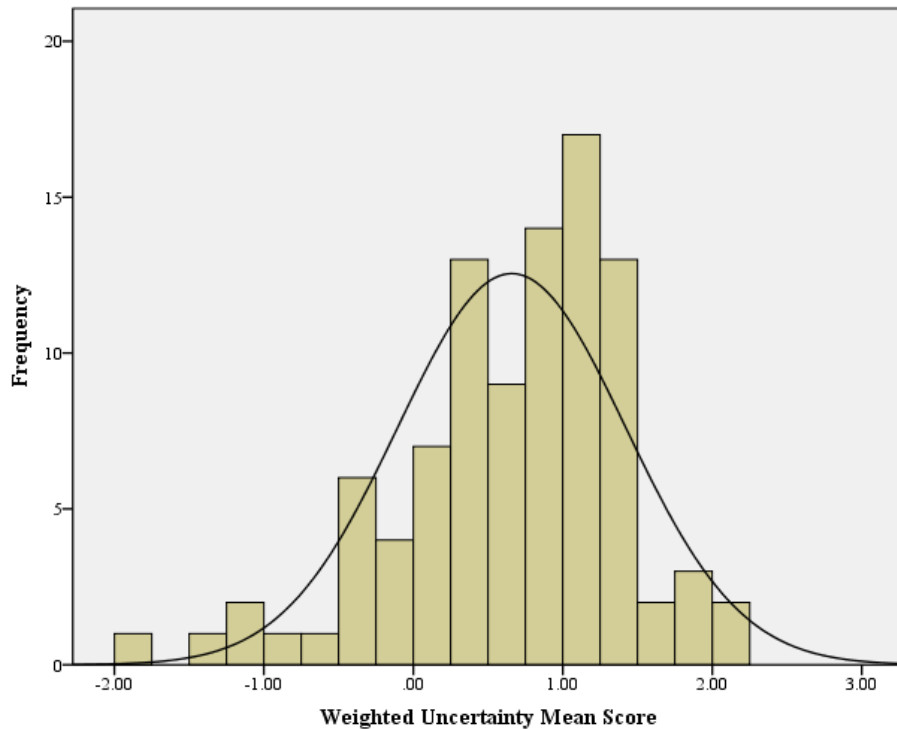
Weighted Uncertainty

The Parental Uncertainty of Children's Health Scale (PUCHS) was used to assess parents' perceptions of uncertainty and the related importance of resolving the uncertainty. Total weighted uncertainty scores were calculated by uncertainty scores weighted by their importance using the formula in Figure 2. An overall mean weighted score was calculated for each participant. Higher scores indicate an individual perceives more uncertainty about areas of importance to them related to their child's undiagnosed medical condition (possible range is -2 to 2). Scores for average weighted uncertainty ranged from -2.00 to 2.00 and the mean was 0.66 ± 0.76 .

Figure 2: Total Weighted Uncertainty Formula

$$\text{Total Weighted Uncertainty} = \frac{(\text{Uncertainty}_1 \times \text{Importance}_1) + (\text{Uncertainty}_2 \times \text{Importance}_2) + \dots + (\text{Uncertainty}_{14} \times \text{Importance}_{14})}{\text{Importance}_1 + \text{Importance}_2 + \dots + \text{Importance}_{14}}$$

Figure 3: Histogram of Parental Uncertainty of Children’s Health Average Weighted Scores



The results from the PUCHS reveal that parents of a child with an undiagnosed medical condition exhibit greater uncertainty than certainty about areas of their child’s undiagnosed condition that are important to them. The skewed distribution suggests that the majority of parents of children with undiagnosed medical conditions perceive uncertainty that is important to them. The variability in their perceptions of uncertainty allows an opportunity to test factors that may be related to degree of weighted uncertainty.

Dimensions of Perceived Uncertainty

The first aim of the study was to explore the dimensions of perceived uncertainty and their relative importance among parents of children with undiagnosed medical

conditions. As previously described, there were four distinct dimensions of uncertainty identified in the PUCHS: medical management, reproductive, social, and existential.

Medical Management Uncertainty

Uncertainty related to medical management was assessed by seven items which asked about uncertainty related to treatment decisions, lifespan expectations, familial concerns and decisions, and understanding of their child's limitations. Participant's weighted uncertainty scores ranged from -1.75 to 2.00, and the mean was 0.80 ± 0.83 .

Correlation analysis found that medical management uncertainty was significantly negatively associated with coping efficacy ($P_C = -0.338$, $p < 0.01$) and optimism ($P_C = -0.254$, $p < 0.01$). Medical management uncertainty was also positively associated with emotion-focused coping ($P_C = 0.274$, $p < 0.01$). Additionally, medical management uncertainty was significantly positively associated with the number of children the parent had with an undiagnosed medical condition ($P_C = 0.196$, $p < 0.05$).

Reproductive Uncertainty

Uncertainty about reproductive risks was assessed by two items which asked participants about uncertainty associated with making decisions about having more children and discussions with relatives about risks to their children. The weighted uncertainty scores ranged from -2.00 to 2.00, and the mean was 0.54 ± 1.20 .

Correlation analysis found that reproductive uncertainty was significantly positively associated with tolerance of uncertainty ($P_C = 0.188$, $p < 0.05$) and emotion-focused coping ($P_C = 0.259$, $p < 0.01$). Additionally, reproductive uncertainty was significantly negatively associated race ($P_C = -0.192$, $p < 0.05$) and relationship to child ($P_C = -0.304$, $p < 0.01$). These results indicate that higher reproductive uncertainty was

perceived when parents were Caucasian and the biological mother. Lastly, reproductive uncertainty was found to be significantly positively associated with the number of children the parent had with an undiagnosed medical condition ($P_C = 0.245$, $p < 0.01$).

Social Uncertainty

Social uncertainty was assessed by two items which asked participants about uncertainty in finding support and parents in similar situations. The weighted uncertainty scores ranged from -1.56 to 2.00, and the mean was 1.24 ± 0.98 .

Correlation analysis found that social uncertainty was significantly negatively associated with coping efficacy ($P_C = -0.243$, $p < 0.01$) and optimism ($P_C = -0.210$, $p < 0.05$). Additionally, social uncertainty was significantly positively associated with emotion-focused coping ($P_C = 0.264$, $p < 0.01$). Social uncertainty was not significantly associated with any of the socio-demographic variables.

Existential Uncertainty

Participants were asked about the meaning and purpose of their child's life in two items used to assess existential uncertainty associated with not having a diagnosis for their child's medical condition. The weighted uncertainty scores ranged from -2.00 to 2.00, and the mean was -1.08 ± 1.16 .

Correlation analysis of existential uncertainty and key variables demonstrated that it was significantly negatively associated with coping efficacy ($P_C = -0.397$, $p < 0.01$), problem-focused coping ($P_C = -0.243$, $p < 0.01$), optimism ($P_C = -0.365$, $p < 0.01$), and resilience ($P_C = -0.244$, $p < 0.01$). Additionally, existential uncertainty was significantly positively associated with marriage status ($P_C = 0.175$, $p < 0.05$), relationship to child ($P_C = 0.245$, $p < 0.01$), the age of the parent ($P_C = 0.252$, $p < 0.01$), and the number of children

the parent has ($P_C = 0.192$, $p < 0.05$). Existential uncertainty was also significantly negatively associated with ethnicity ($P_C = -0.230$, $p < 0.05$). Interpreting these dichotomized variables indicates that parent's perceive more existential uncertainty when they are not married, not the biological mother, and are Hispanic.

Table 3: Pearson's Correlations among Factors of Uncertainty and Key Variables

	Coping Efficacy	Problem-Focused Coping	Emotion-Focused Coping	Tolerance of Uncertainty	Optimism	Resilience
Medical Management	-0.338** 94	-0.135 92	0.274** 92	0.152 93	-0.254** 93	-0.142 93
Reproductive	0.049 94	0.068 92	0.259** 92	0.188* 93	-0.171 93	-0.136 93
Social	-0.243** 94	-0.124 92	0.264** 92	0.151 93	-0.210* 93	-0.134 93
Existential	-0.397** 94	-0.243** 92	0.229* 92	-0.011 93	-0.365** 93	-0.244** 93

The top number in each box represents the Pearson Correlation coefficient, the bottom number is 'N' for the scale on the survey.

*Correlation is significant at the 0.05 level (1-tailed)

** Correlation is significant at the 0.01 level (1-tailed)

Importance of a Diagnosis

Participants answered a question about how important having a diagnosis was to them at this point in time. Participants' answers ranged from 1.00 to 5.00, and the mean was 4.36 ± 0.89 . This suggests that for parents of children with an undiagnosed medical condition having a diagnosis is perceived to be of great importance.

Bivariate analysis found that the importance of a diagnosis was significantly positively associated with perceived weighted uncertainty ($P_C = 0.410$, $p < 0.01$). It was also found to be significantly negatively associated with optimism ($P_C = -0.318$, $p < 0.01$) and resilience ($P_C = -0.196$, $p < 0.05$).

Coping Self-Efficacy Scale

Table 4 shows the mean scores and standard deviations for the participants' responses to the Coping Self-Efficacy Scale. Each sub-scale should be interpreted as an individual's confidence in their ability to cope in that specific manner, e.g., "confidence in one's ability to use problem-focused coping". Higher scores indicate greater confidence in one's ability to cope effectively.

Table 4: Average Scores on the Coping Self-Efficacy Scale

	Mean \pm SD	Range of Study Sample	Range of Possible Scores
Total Coping Self-Efficacy	3.83 \pm 1.04	(1.35 – 6.08)	(1 – 7)
Problem-Focused Coping	4.14 \pm 1.08	(1.31 – 6.54)	(1 – 7)
Stopping Unpleasant Emotions & Thoughts	3.63 \pm 1.11	(1.11 – 5.78)	(1 – 7)
Getting Support from Friends & Families	3.49 \pm 1.44	(1.20 – 6.60)	(1 – 7)

Ways of Coping Checklist-Revised

Table 5 shows the mean scores and standard deviations for the participants' responses to the Ways of Coping Checklist-Revised. Higher scores indicate more frequent use of the coping strategy. As summarized in the table below, the most commonly used coping strategy among study participants was problem-focused coping, followed by seeking social support, wishful thinking, blaming oneself, and avoidance.

Table 5: Average Scores on the Ways of Coping Checklist-Revised

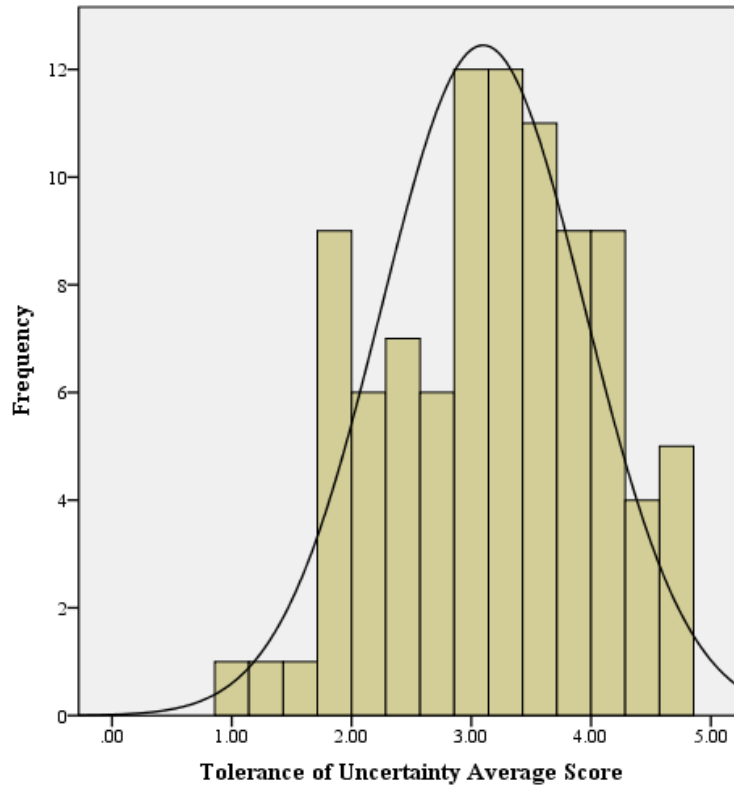
	Mean \pm SD	Range of Study Sample	Range of Possible Scores
Total Ways of Coping	1.99 \pm 0.28	1.12 - 2.74	(0 - 3)
Problem-Focused	2.34 \pm 0.35	1.33 - 3.0	(0 - 3)
Wishful Thinking	1.94 \pm 0.65	0.13 - 3.0	(0 - 3)
Seeks Social Support	2.17 \pm 0.62	0.00 - 3.0	(0 - 3)
Blamed Self	1.55 \pm 0.73	0.00 - 3.0	(0 - 3)
Avoidance	1.46 \pm 0.49	0.20 - 2.70	(0 - 3)
Emotion-Focused*	1.65 \pm 0.48	0.43 - 2.67	(0 - 3)

*Emotion-Focused Coping = Wishful Thinking + Blamed Self + Avoidance

Tolerance of Uncertainty

Participants' tolerance for uncertainty was assessed using the Tolerance for Ambiguity Scale (Cronbach's alpha = 0.80). Higher scores indicate individuals with greater tolerance for uncertainty (possible range = 1-5). Scores ranged from 1.0 to 4.71, and the mean was 3.10 ± 0.85 (Figure 4).

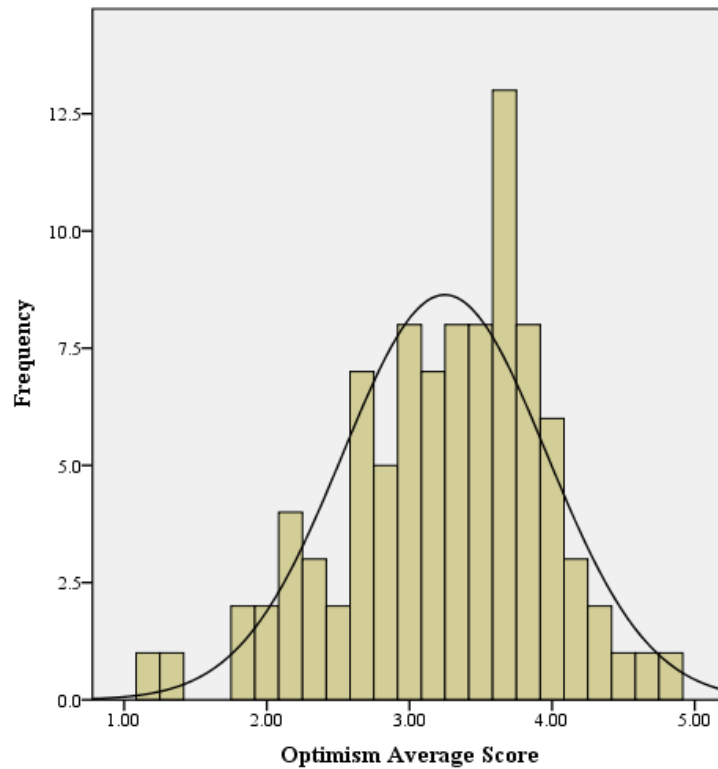
Figure 4: Histogram of Tolerance of Uncertainty Average Scores



Optimism

The LOT-R was used to assess participants' optimism (Cronbach's alpha = 0.81). Higher scores indicate more optimistic individuals (possible range = 1-5). Scores ranged from 1.17 to 4.83, and the mean was 3.25 ± 0.72 (Figure 5).

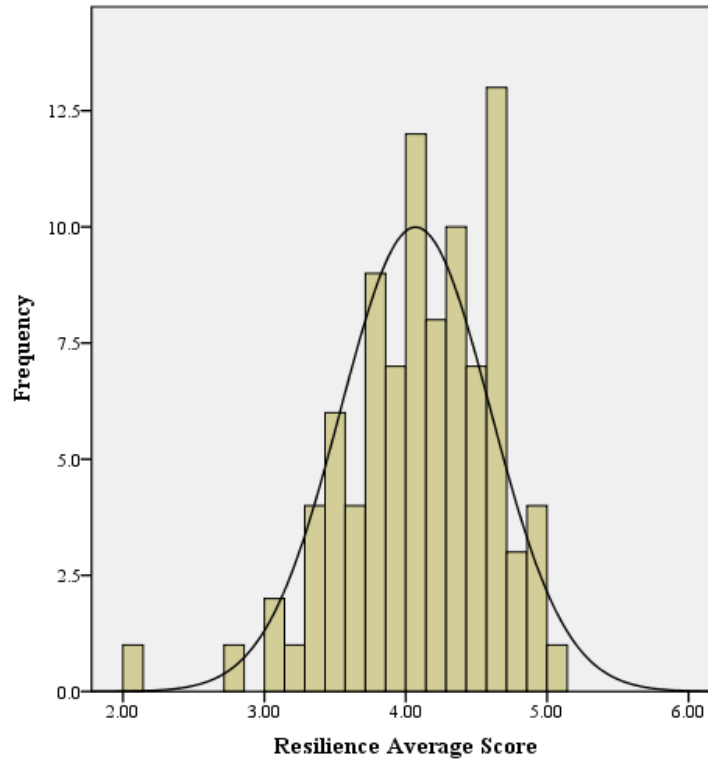
Figure 5: Histogram of Optimism Average Scores



Resilience

Participants' resiliency was measured using the 14-item resilience scale (Cronbach's alpha = 0.88). Higher scores indicate more resilient individuals (possible range 1-5). Scores ranged from 2.07 to 5.00, and the mean was 4.07 ± 0.53 (Figure 6).

Figure 6: Histogram of Resilience Average Scores



Correlations between Key Variables as Framed by the Conceptual Model

Using the conceptual model (Figure 1) as a framework for understanding relationships among key variables, bivariate analysis was performed to determine the strength and significance of predicted relationships. There is little evidence to guide hypotheses about how personality traits affect key variables in the model. As such, they were tested against each key variable. Correlation analysis was used to determine which key and socio-demographic variables should be entered into the multivariate regression model. Variables that had a significant correlation ($p < 0.05$) were candidates for inclusion in the multivariate regression model. Specific hypotheses about these relationships were explored.

Table 6: Pearson's Correlations among Key Variables

	Uncertainty	Coping Efficacy	Problem-Focused Coping	Emotion-Focused Coping	Tolerance of Uncertainty	Optimism	Resilience
Uncertainty	1.000 93	-0.382** 94	-0.154 92	0.288* 93	0.152 93	-0.318** 93	-0.196* 93
Coping Efficacy		1.000 94	0.522** 92	-0.243** 92	-0.124 93	0.489** 93	0.432** 93
Problem-Focused Coping			1.000 92	-0.116 92	-0.026 92	0.391** 92	0.571** 92
Emotion-Focused Coping				1.000 92	0.417** 92	-0.443** 92	-0.449** 92
Tolerance of Uncertainty					1.000 93	-0.167 93	-0.265** 93
Optimism						1.000 93	0.585** 93
Resilience							1.000 94

The top number in each box represents the Pearson Correlation coefficient, the bottom number is of participants who completed the scale on the survey.

*Correlation is significant at the 0.05 level (1-tailed)

** Correlation is significant at the 0.01 level (1-tailed)

Uncertainty

Uncertainty was hypothesized (Hypothesis 3.1) to be associated with coping efficacy, and coping. Correlation analysis demonstrated that perceived weighted uncertainty was significantly negatively correlated with coping efficacy ($P_C = -0.382$, $p < 0.01$). Perceived weighted uncertainty was also significantly negatively associated with optimism ($P_C = -0.318$, $p < 0.01$), and resilience ($P_C = -0.196$, $p < 0.01$). Additionally, perceived weighted uncertainty was significantly positively associated with emotion-focused coping, a sub-scale of the WCC-R ($P_C = 0.288$, $p < 0.01$) (Table 6).

Correlation analysis among perceived weighted uncertainty and socio-demographics found a significant positive association between the number of children a parent had with an undiagnosed medical condition and perceived weighted uncertainty ($P_C = 0.197$, $p < 0.05$). Just over a fifth (21.9 %) of parents in the study had more than one child with an undiagnosed medical condition. No other socio-demographic variables were significantly associated with uncertainty.

Simple linear regression of each significant predictor variable ($p < 0.05$) on uncertainty resulted in similar relationships; however the relationships with resilience and the number of children with an undiagnosed medical condition did not remain significant. The final regression model predicting perceived uncertainty included only optimism (Table 7). A multivariate linear regression model was not calculated as only one variable was found to be a significant predictor of perceived weighted uncertainty.

Table 7: Regression Modeling with Perceived Weighted Uncertainty as Dependent Variable

	P _C Coefficient	SLR β Coefficient (SE)
Optimism	-0.318**	-0.313 (0.098)**
Resilience	-0.196**	-0.260 (0.137)
Number of Children with an Undiagnosed Medical Condition	0.197*	0.197 (.102)

* Indicates a significant association with perceived weighted uncertainty (p <0.05)

** Indicates a significant association with perceived weighted uncertainty (p <0.01)

SLR = Simple Linear Regression; unstandardized β coefficient used

SE = Standard Error

Coping Efficacy

The conceptual model predicts that coping efficacy, a secondary appraisal, is related to uncertainty, and determines choice of coping strategies. As previously stated, coping efficacy was found to be significantly negatively associated with perceptions of uncertainty. Preliminary correlation analysis also showed that coping efficacy was significantly positively associated with: problem-focused coping, a sub-scale of the WCC-R, ($P_C = 0.522$, $p < 0.01$), optimism ($P_C = 0.489$, $p < 0.01$), and resilience ($P_C = 0.432$, $p < 0.01$). Coping efficacy was also found to be significantly negatively associated with emotion-focused coping, the second sub-scale of WCC-R ($P_C = -0.243$, $p < 0.01$).

Correlation analysis found no significant relationships among coping efficacy and socio-demographic variables of the participants. The final regression model predicting coping efficacy includes perceived weighted uncertainty, optimism and resilience (Table 8).

Hypothesis 3.1 predicted that lower levels of perceived uncertainty would be associated with greater coping efficacy. This hypothesis was supported by our data (Table 8). Figure 7 is a scatter plot graph that shows the negative relationship between perceived uncertainty and coping efficacy. Multiple linear regression analysis was used to adjust for potential confounding variables and perceived uncertainty remained a significant predictor of coping efficacy, even when accounting for the relationships of coping efficacy and uncertainty with the traits of optimism and resilience.

Table 8: Multivariate Regression with Coping Efficacy as Dependent Variable

	P _C Coefficient	SLR β Coefficient (SE)	MLR β Coefficient (SE)
Perceived Weighted Uncertainty	-0.382**	-0.566 (0.141)**	-0.400 (0.134)**
Optimism	0.489**	0.710 (0.133)**	0.400 (0.160)*
Resilience	0.432**	0.846 (0.185)**	0.426 (0.208)*

* Indicates a significant association with perceived weighted uncertainty (p <0.05)

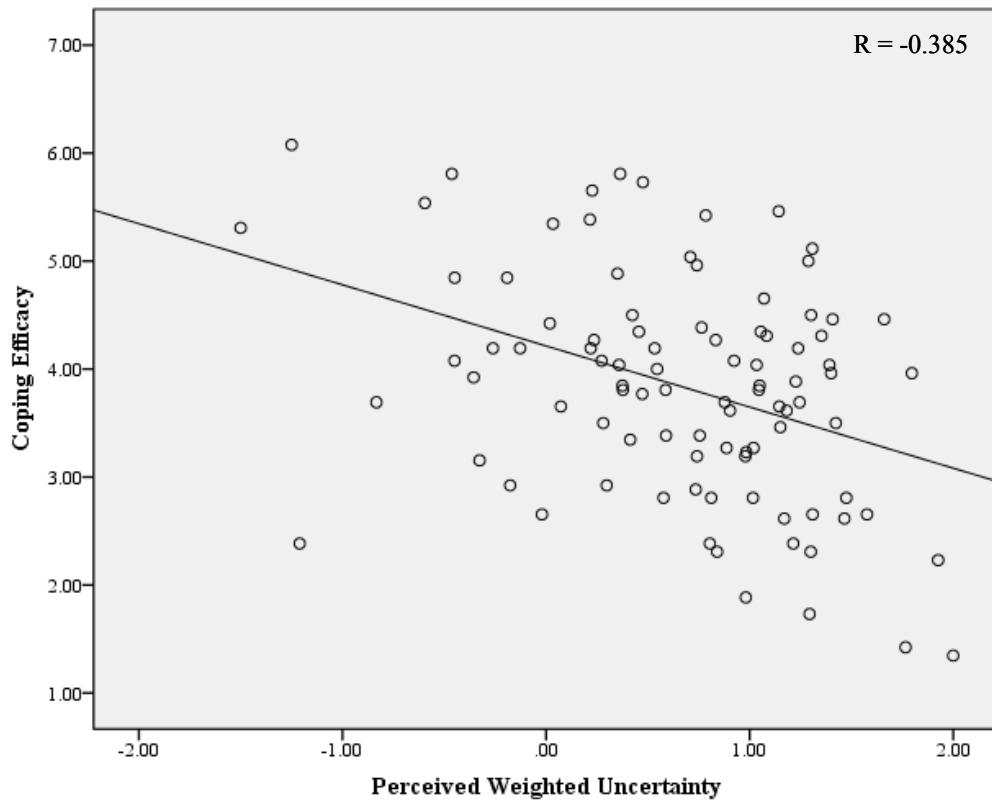
** Indicates a significant association with perceived weighted uncertainty (p <0.01)

SLR = Simple Linear Regression; unstandardized β coefficient used

MLR = Multiple Linear Regression; unstandardized β coefficient used

SE = Standard Error

Figure 7: Scatterplot of Uncertainty on Coping Efficacy



Coping

The conceptual model predicts that uncertainty and coping efficacy determine use of coping strategies. Each of the sub-scales of coping, emotion-focused and problem-focused, were analyzed independently (Tables 9 and 10). Correlation analysis found no significant relationships among problem-focused coping and socio-demographic variables of the participants. Emotion-focused coping, however, was found to be significantly negatively associated with the age of the parent ($P_C = -0.213$, $p < 0.05$). The final regression model predicting problem-focused coping includes coping efficacy and resilience (Table 9). The final regression model predicting emotion-focused coping includes resilience and tolerance of uncertainty (Table 10).

Table 9: Multivariate Regression with Problem-Focused Coping as Dependent Variable

	P _C Coefficient	SLR β Coefficient (SE)	MLR β Coefficient (SE)
Coping Efficacy	0.522**	0.176 (0.030)**	0.118 (0.032)**
Optimism	0.391**	0.191 (0.047)**	-0.018 (0.051)
Resilience	0.571**	0.376 (0.057)**	0.291 (0.067) **

Table 10: Multivariate Regression with Emotion-Focused Coping as Dependent Variable

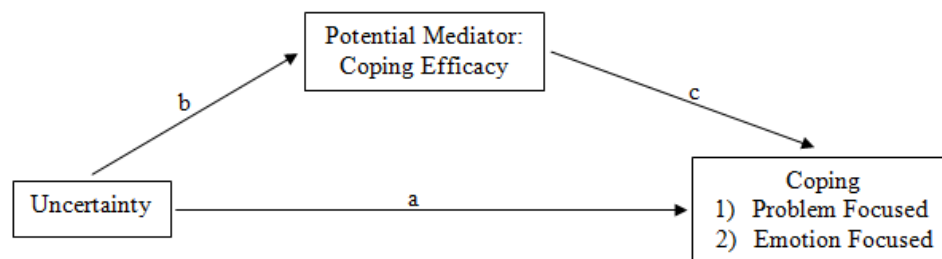
	P _C Coefficient	SLR β Coefficient (SE)	MLR β Coefficient (SE)
Perceived Weighted Uncertainty	0.288*	0.196 (0.069)**	0.107 (0.065)
Coping Efficacy	-0.243**	-0.122 (0.047)*	0.027 (0.049)
Optimism	-0.443**	-0.296 (0.063)**	-0.149 (0.077)
Resilience	-0.449**	-0.405 (0.085)**	-0.206 (0.100)*
Tolerance of Uncertainty	0.417**	0.237 (0.054)**	0.154 (0.053)**
Parent's Age	-0.213*	-0.012 (0.006)*	-0.006 (0.005)

* Indicates a significant association with perceived weighted uncertainty (p <0.05)
 ** Indicates a significant association with perceived weighted uncertainty (p <0.01)
 SLR = Simple Linear Regression; unstandardized β coefficient used
 MLR = Multiple Linear Regression; unstandardized β coefficient used
 SE = Standard Error
 Bolded variables indicate variables remaining in final model

Mediation Analysis

Hypothesis 3.2 was that coping efficacy mediated the relationship between perceived uncertainty and coping, as measured by the WCC-R. To test this hypothesis, a series of analyses were performed (Figure 8). The first analysis regressed perceived uncertainty on total coping (“a”). Perceived uncertainty was not shown to be significantly associated with total coping, suggesting that there was not a significant relationship to be mediated. Additionally, perceptions of uncertainty were not found to be significantly associated with problem-focused coping or emotion-focused coping once confounding variables were accounted for (Tables 9 and 10). In the multivariate regression model for emotion-focused coping, perceived weighted uncertainty was a candidate for inclusion in the multivariate linear regression model but was not found to be statistically significant. These analyses suggest that there is not a significant relationship between perceived uncertainty and coping that is mediated by coping efficacy.

Figure 8: Coping Efficacy Mediation Analysis



Personality Traits

Individuals who were more optimistic and resilient had lower levels of perceived uncertainty ($P_C = -0.318$, $p < 0.01$ and $P_C = -0.196$, $p < 0.05$, respectively). Tolerance of uncertainty was not found to be significantly associated with perceived uncertainty ($P_C = 0.152$, $p = 0.073$). In a multivariate analysis, only optimism remained a significant predictor of perceived uncertainty and accounted for 10 percent of the variance in perceived uncertainty ($R^2 = 0.101$).

Individuals who were more optimistic and resilient also showed greater coping efficacy ($P_C = 0.489$ and $P_C = 0.432$, $p < 0.01$). Tolerance of uncertainty was not significantly correlated with coping efficacy ($P_C = -0.124$, $p = 0.118$). In a multivariate analysis, optimism and resilience were significantly associated with coping efficacy when controlling for uncertainty, and together explained 27 percent of the variance in coping efficacy ($R^2 = 0.271$).

Moderation Analysis

The fourth aim of the study was to explore the relationship of personality traits on perceptions of uncertainty and coping efficacy by testing whether personality traits moderate the relationship between perceived uncertainty and coping efficacy (*hypotheses 4.1-4.3*). A series of analyses were performed (Figure 9) to test each personality trait independently.

To determine whether tolerance of uncertainty moderated the relationship, perceived uncertainty and tolerance of uncertainty were regressed on coping efficacy. Perceived uncertainty and tolerance of uncertainty were found to be significantly associated with coping efficacy, $F(2,90) = 8.93$ ($p < 0.01$). The second analysis included

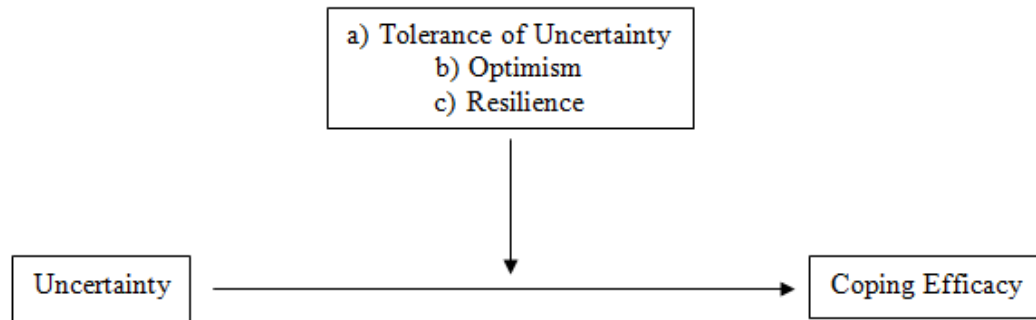
an interaction term (tolerance of uncertainty x uncertainty) regressed on coping efficacy. This model was also significant $F(3,89) = 5.89$ ($p < 0.01$). Including an interaction term did not change the amount of variance explained in coping efficacy and the interaction term was not found to be significant ($p > 0.05$). These analyses suggest that tolerance of uncertainty does not moderate the relationship between perceived uncertainty and coping efficacy.

To test whether optimism moderates the relationship between uncertainty and coping efficacy, similar regression analysis was performed. The first analysis regressed uncertainty and optimism on coping efficacy and found a significant relationship, $F(2,90) = 19.90$ ($p < 0.01$). The second analysis regressed uncertainty, optimism and an interaction term (optimism x uncertainty) on coping efficacy. This analysis also found a significant relationship among the variables, $F(3,89) = 14.27$ ($p < 0.01$). While the inclusion of the interaction term changed the amount of variance explained in coping efficacy, the effect was not statistically significant (R^2 change = 0.018, $p = 0.125$) and the interaction term was not statistically significant ($p > 0.05$).

Next, the same steps were taken to determine if resilience moderated the relationship between uncertainty and coping efficacy. The first analysis regressing uncertainty and resilience on coping efficacy found a significant relationship, $F(2,90) = 18.48$ ($p < 0.01$). The second analysis included an interaction term (resilience x uncertainty) regressed on coping efficacy and the model was also significant, $F(3,89) = 9.64$ ($p < 0.01$), however the interaction term was not found to be significant ($p > 0.05$). Including this interaction term did not change the amount of variance explained in coping

efficacy, meaning resilience did not moderate the relationship between perceived uncertainty and coping efficacy.

Figure 9: Personality Trait Moderation Analysis



As optimism was found to be a significant predictor of coping efficacy, it was also tested as a moderator between coping efficacy and coping. A series of analyses were performed, similar to those above, for each coping strategy, emotion and problem-focused, independently.

The moderation analysis of optimism and coping efficacy and problem-focused coping included resilience as an independent variable in each of the regression models. The first analysis regressed optimism and coping efficacy on problem focused coping and found a significant relationship, $F(3,88) = 21.33$ ($p < 0.01$). The second analysis included an interaction term (coping efficacy x optimism) and also demonstrated a significant relationship, $F(4,87) = 15.87$ ($p < 0.01$). However, the interaction term was not found to be statistically significant ($p > 0.05$). The addition of the interaction term resulted in a small, insignificant change in the variance of problem-focused coping explained (R^2 change = 0.001, $p = 0.728$). This suggests that optimism does not moderate the relationship between coping efficacy and problem-focused coping.

The moderation analysis of optimism on coping efficacy and coping efficacy on emotion-focused coping included perceived uncertainty, resilience and tolerance of uncertainty as independent variables in each of the regression models. The first analysis regressed optimism and coping efficacy on emotion-focused coping and found a significant relationship $F(5,86) = 9.58$ ($p < 0.01$). The second analysis included an interaction term (coping efficacy x optimism) and also demonstrated a significant relationship $F(6,85) = 8.81$ ($p < 0.01$). The addition of an interaction term increased the amount of variance explained in emotion-focused coping but not significantly (R^2 change = 0.026, $p = 0.064$).

It is possible that these personality traits do moderate the relationship between perceived uncertainty and coping efficacy and that this study lacked the power to detect these at a significant level as a result of a small sample size. This is particularly relevant in the analyses of optimism as a moderator of the relationships between uncertainty and coping efficacy, and coping efficacy and emotion-focused coping. In each of these analyses, including an interaction term with optimism increased the amount of variance explained though not at significant levels. Further research is needed to better characterize these possible relationships.

Qualitative Data

Initial thematic analysis of the open-ended questions revealed themes consistent with dimensions of uncertainty identified through the PUCHS.

Effects Uncertainty has had on Parents' Life

When asked to describe the effects uncertainty about their child's medical condition has on their life, parents' reported topics such as reproductive concerns, psychological well-being, social support, financial concerns, future planning, and concerns about death and quality of life. More broadly, answers fell into one of two categories; parents either reported ways the uncertainty has affected their own life or ways the uncertainty has affected the lives of people around them, their children in particular. Parents identified ways the uncertainty has affected decisions in their own life about job location, financial planning and communication with physicians, family members and the community at large. The answers reported suggest that uncertainty has wide reaching effects on parents and that each parent experiences these effects differently.

093- It effects my life in all aspects. I never know what to expect or how to feel. I am always expecting the worse possible outcome because I have seen only struggle with little hope. I am left fighting even when others feel it's ok to give up.

090- My constant worry and also the lack of understanding from other family members.

088- All consuming. Life altering. Unknown answers leave you seeking everywhere for truths for your child's life.

083- ... We do not belong to a specific community.

065- Getting my daughter to understand why her body is acting this way.

030- We are really struggling with planning for her future. We don't know if she will always need support, ..., if she'll be able to work or have her own family.

027- Takes much time away from enjoyment of life for all family members.

023- I spend all of my free time researching. It has completely consumed our families' whole life.

017- ... We are no longer able to live the life we hoped to provide for our children.

Some parents identified positive effects this uncertainty has had on their lives, reinforcing the notion that uncertainty is not inherently negative. The vast majority of these parents stated increased belief in God, a stronger faith, or a greater appreciation for life and their children.

040- Increased faith and trust in God to take care of our family. Increased appreciation for individual differences in all people and the beauty that arises from those differences.

054- When she first became disabled, they gave us a bunch of diagnoses and some of them were fatal and that's so devastating. But "not-knowing" gave me a sense of peace-especially because she's getting better.

057- I choose to look at my situation, although having been very difficult, still a blessing and a treasure to have my child.

Feelings of Certainty

When asked to describe ways in which they felt certain about their child's medical condition, parents' answers focus both on positive and negative areas of certainty. They describe being certain in ways they have made progress such as crossing possibilities off the list, getting adequate treatment for their current situation, and making it as far as they have. Additionally, many parents stated that they are certain of their faith, that there is a purpose for their lives, and that positive things have come from their experience. On the other hand, parents also expressed that they are certain of the severity of their child's medical condition, that it is grim, that it is likely to get worse and not

better, and that it will be the cause of their child's death. Interestingly, some parents very clearly stated they were certain of the value of a diagnosis and that it is worth pursuing.

090- I do not believe there is a cure. I believe she will die prematurely. I do believe that every life has a purpose. My daughter has been through hell and back. But has the best attitude.

084- That they exist and I am not crazy

082- We will do whatever we need to help her live the best life possible

075- I am certain that we will deal with things as they come in a fruitful way. I am certain that he will keep his faith in Jesus Christ as Savior no matter how bad things get day to day.

066- Still greatly loved and appreciated

054- I know what his symptoms are and I know that we are treating them. I know that the symptoms show a grim prognosis.

042- I feel certain that if we can get them to the right doctor who will listen to us they will get a diagnosis. I feel certain that if we can get a diagnosis we will be able to find a way to treat the conditions and allow them to have a successful happy life.

035- I know her well and think when we find an answer it will make a lot of sense when we can connect the dots. And she teaches me and has made us all better people.

032- We feel certain that his disabilities are severe and permanent

026- I feel certain my child will amaze everyone. I feel certain that she makes my whole family better people.

017- She is getting the treatment she needs based on her symptoms.

Feelings of Uncertainty

When asked to identify ways in which they felt uncertain about their child's medical condition, parent's answered with similar themes to those present in the PUCHS. Parents discussed uncertainty about medical management, such as the prognosis, type of

treatment they should consider, doctors they should visit, and what symptoms mattered for their child versus those others might consider normal of childhood.

091- I feel uncertain that treating her could hurt her or damage her more than her illness.

076- Whether or not he will be given the proper care by medical professionals

059- Prognosis and when to run to the ER vs. treat at home with nursing support

046- Not knowing what therapies may help the most.

041- I am always questioning every ache, pain, etc. she mentions

Parents also identified concerns about reproductive risks. Not only were parents concerned with risks to them for future children, but they were also concerned with risks for their child and their future family possibilities. The PUCHS does not ask specifically about reproductive risks for the affected child, but parents' answers suggest that this is an important concern.

083- certainly it can affect her future children

064- We do not know how the birth defects are connected or the risks of other family members having children with similar issues.

While the "future" domain of the PUCHS was not identified as a specific dimension after factor analysis, many parents identified uncertainty about the future. These concerns extended past uncertainty for the future of their child's medical condition and included concerns about the future of their family, their other children, and decisions they may have to make in the future.

090- How long will she live? Will she die a slow-painful death?

065- I wish there were expectations for the future

053- We do not know what to expect in the future or how this will affect his life/lifespan

050- Is there something ticking away in him that will end in a shorter life span.

033- We don't know what to expect as he ages

019- His life span, will he need to go into a group home or live with us, what will happen when his father and I are gone. Will his older sister be responsible for caring for him and how will that impact her life and future family?

One of the most mentioned areas of uncertainty was that of social uncertainty.

Social uncertainty is defined by the PUCHS as finding parents in similar situations and receiving support from them. However, in the open-ended questions many parents expanded on this and described uncertainty about how to communicate with physicians and the community. It seems that not knowing how to describe what is wrong with their child has inhibited parents from finding other parents and sources of support. Additionally, this difficulty in communicating what is going on with their child seems to leave parents feeling as though they aren't believed or that their concerns are not being taken seriously.

094- I don't always feel like I can explain what's happening to medical professionals or that they always believe me.

069- Because she looks "good" I do not always feel my concerns are being taken seriously. I worry that something is being missed...

054- I am uncertain where this is all stemming from. I do not believe that my child is the only one out there with this condition.

051- Concerned about how rare it is...

013- What would best treatment be or what has worked best for other children like her

Existential concerns about the meaning and purpose of their child's life were not reported in the open-ended questions. However, many parents reported the uncertainty associated with existential questions such as 'why' and whether they are spending the time they have in the best way.

087- The reasons why, how, who? Was this preventable? Was this inevitable? Can we stop it? Why can't genetics figure it out yet?

078- the WHY of his symptoms

043- I don't know how to help my children. ... I don't know how to help my children LIVE rather than survive!

039- Uncertain about her capabilities for change, about how hard to work to progress her, about what caused her to be so profoundly affected.

037- ...I don't understand the present

Interactions with Medical Professionals

Across all three qualitative questions participants identified difficulties and frustration interacting with medical professionals because of uncertainty. This effect of uncertainty was not addressed in the quantitative measures of the survey, but the recurrent answers mentioning this concern indicate the importance of how uncertainty impacts these parents' relationships with medical professionals. Participants spoke of losing faith in doctors, feeling unsupported and disbelief, and frustration about being left to make decisions physicians were unable to make.

094- I don't always feel like...medical professionals always believe me

076-Whether or not he will be given the proper care by medical professionals

071- That no doctor can help us

034- I also feel like the medical community tends to give up on us, or they brush us off

025- We now lack confidence in doctors

023- I feel uncertain because of conflicting information between various specialists

078- Difficulty communicating with medical professionals because of his needs and limitations

046- Trouble getting physicians to work with us

020- My other issue is with our medical team; my son has seen 17 doctors, has had nearly 100 tests performed with clear results, and no game plan for the future because his specialists cannot agree on the next step.

DISCUSSION

When individuals are faced with a stressful situation, such as being the parent of a child with an undiagnosed medical condition, Lazarus and Folkman propose that they will progress through a series of primary and secondary appraisals of their situation (1984). The appraisals represent initial efforts toward adapting to a stressful medical event. In the conceptual model (Figure 1), appraisals, including uncertainty and coping efficacy, personality traits, and coping, are posited to contribute to adaptation to the stressful event of raising a child with an undiagnosed medical condition.

Perceptions of Uncertainty

Uncertainty, a primary appraisal in the model, is a large part of illness experience and it has effects on coping and adaptation. Uncertainty is inevitable for parents raising a child with an undiagnosed medical condition and can arise from many different unknowns. In this population, uncertainty stemmed from four distinct domains, was perceived as important to resolve and was related to key process and outcome variables.

As predicted by the study's first hypothesis, parents who perceived more uncertainty had lower coping efficacy. In other words, parents with higher perceptions of uncertainty viewed themselves as less able to cope with their child's undiagnosed medical condition. Three of the four domains of uncertainty also demonstrated strong negative correlations with coping efficacy: medical management, social and existential uncertainty. This suggests that it is not only not knowing a diagnosis or having prognostic information that inhibits parents' confidence in coping, but their uncertainty about social support and meanings in life greatly also affect their coping efficacy. Patients and parents may benefit from conversations that focus not only on the lack of information available,

but also the sense of feeling alone and how it affects their perceptions of confidence and competence in managing the situation.

High levels of perceived uncertainty may leave parents feeling overwhelmed and as though they are unable to accomplish anything. Participant 014 speaks to this in her answer, *“I feel overwhelmed due to uncertainty in which directions to focus my efforts to help my child.”* She goes on to list all of the areas she tries to focus her efforts on and ends stating that all the uncertainty impacts her confidence and *“ability to mother my other children.”* Genetic counselors can work to help categorize the uncertainty, by dividing it into smaller, manageable pieces and by aiding parents in determining which areas are most important to them and how to prioritize their concerns. Additionally, as coping efficacy is a cognitive appraisal, working with parents to help them recognize the effect uncertainty has on their confidence may provide an opportunity to help change their appraisal by acknowledging previous successes in their coping with difficult stressors.

Dimensions of Uncertainty

Uncertainty related to medical management, including diagnosis, prognosis, and risk to relatives, was identified as the second most important domain of uncertainty to resolve. The positive correlation between medical management uncertainty and the number of children the parent had with an undiagnosed medical condition suggests that with increasing number of undiagnosed children, parents perceive more medical uncertainty even when asked to focus on a particular child. It seems that instead of providing guidance or a sense of “having been there before”, adding more children with undiagnosed conditions may amplify the perceptions of medical uncertainty.

Reproductive uncertainty, meaning the possible risks for future children and decisions about whether to have more children, was the only domain not significantly correlated with coping efficacy. This may be due to low sample size, but its wide range of scores and low importance suggest that parents of a child with an undiagnosed medical condition do not perceive much uncertainty about their reproductive risks and choices. It is also possible that uncertainty about reproductive choices and risks does not affect parent's perceptions of their ability to cope. Additionally this may be a reflection of the average age of our participants, 38.6 years, and that they are nearing the end or are past the child-bearing stage in their lives and are no longer concerned about reproductive risks. As evidenced by the qualitative data, some participants were concerned with the risk for their child's children; however this was a small number of parents. As the vast majority of children in the sample were less than 10 years of age, these few parents likely represent those with older children who have made it through their childhood and are now focused on their child's future adult life.

Participants who were not biological parents of the child perceived significantly less reproductive uncertainty, demonstrating an understanding of the concern for inherited medical conditions. Additionally, reproductive uncertainty was the only domain that had a significant relationship with tolerance for uncertainty; parents who were more tolerant of uncertainty perceived more reproductive uncertainty. This suggests that individuals who are more comfortable with uncertainty may be more willing or able to explore and identify uncertainty as it relates to reproduction.

Social uncertainty, related to finding parents in similar situations and support from these parents, was a domain in which parents perceived the most uncertainty. The

positive correlation between social uncertainty and emotion-focused coping suggests that parents who perceive more social uncertainty employ more emotion-focused coping skills. While the relationship between social uncertainty and problem-focused coping was not found to be significant, there was a trend toward a negative correlation. Comparing these two results, perhaps parents faced with more social uncertainty utilize emotion-focused coping because without a social group, without knowing parents in similar situations, they are unaware of what problems to tackle and therefore rely on emotion-focused methods. It is possible that knowing parents in similar situations and having support from these parents offers a road-map of sorts allowing new parents to benefit from their experiences.

These findings are supported by previous qualitative studies which have shown that parents of children with undiagnosed conditions struggle to find support and access to services (Lewis, *et al*, 2010, Rosenthal, *et al*, 2001, Yanes, 2013). In these studies parents stated they had particular difficulty accessing medical and educational services and wanted more help navigating healthcare and disability resources. The qualitative data from this study support these findings. Parents from the current study identified “*difficulty getting insurance to cover therapies*” and uncertainty about “*how to advocate for medical care*” as effects the uncertainty about their child’s medical condition had on them. Additionally, however, parents in this study emphasized the “*lack of support from others*” and demonstrated high uncertainty with respect to social support. It seems that while help navigating through the medical and disability system may be helpful, parents continue to seek and desire support from other parents in similar situations.

Existential uncertainty, knowing the meaning and purpose of your child's life, was the least important domain of uncertainty to resolve and participants showed the least amount of uncertainty within this domain. This suggests that regardless of the uncertainty, parents in the current study are able to find meaning and purpose in their child's life, so that this domain has far less importance. The negative correlation between existential uncertainty and optimism and resilience suggests that parents who perceive more existential uncertainty are less optimistic and resilient. As personality traits are stable, it is likely that optimistic and resilient individuals are more certain of the meaning and purpose of their child's life or less concerned with not knowing.

Existential uncertainty is negatively associated with problem-focused coping and positively associated with emotion-focused coping. As existential concerns are largely abstract and intangible, it follows that the most effective way of coping with these concerns is not through problem-focused coping, as there are not specific tasks to accomplish. Rather existential uncertainty is managed through the use of emotion-focused strategies, such as talking about these concerns and directing one's energy to managing the feelings these concerns provoke.

Coping Efficacy as a Mediator of Uncertainty and Coping

Coping efficacy is an appraisal of how confident a parent feels about their ability to cope with a child with an undiagnosed medical condition. Parents who had greater coping efficacy also reported higher levels of problem-focused coping. Because perceived uncertainty is negatively related to coping efficacy, it can be understood that more perceived uncertainty leads to lower levels of coping efficacy and less use of problem-focused coping even in the absence of a significant relationship between

uncertainty and coping. This presents opportunities for interventions that may lead to better coping and adaptation; genetic counselors can work to mitigate uncertainty while also working to increase coping efficacy by identifying ways parents have already coped effectively.

Specifically, counselors can work to mitigate social uncertainty by providing patients with contact information of parents in similar situations and support groups unique to their circumstances. Additionally, as many children have a unique set of medical conditions it may be helpful to work with parents to identify ways they can relate to other parents whose children differ from them with respect to their medical conditions. With such a specific collection of medical problems, it is unlikely to find a parent in an identical situation, instead parents may benefit from connecting with many parents who share different aspects of their experiences. Locating these sources of support may also help to increase parents' self-efficacy. Bandura has shown that seeing a person, similar to yourself, succeed can help to increase beliefs of self-efficacy (1994).

Coping efficacy may be improved by identifying ways in which parents feel confident and competent in their ability to handle the future and ways they have succeeded in managing the past. As coping efficacy is a cognitive appraisal it may be altered by brief interventions aimed at reframing a parent's perspective of their experience. Research has demonstrated that the most effective way to create a strong sense of self-efficacy is through "mastery experiences" (Bandura, 1994). As counselors we can work to help identify these experiences in which parents had to persevere through adversity and succeeded in order to create a stronger sense of coping self-efficacy.

In multivariate linear regression optimism was a significant predictor of coping efficacy. Parents who were more optimistic showed greater coping efficacy. Optimistic individuals have a greater tendency to expect positive outcomes and it is likely that this extends to perceptions of themselves including confidence in one's self. As personality traits are immutable, the relationship between optimism and coping efficacy demonstrates the importance of targeting interventions to parents who show less dispositional optimism. As health care resources are limited, it is necessary to target interventions to those who will benefit most. Our data suggest that optimistic parents show much higher coping efficacy than those who are less optimistic, suggesting that less optimistic individuals may benefit more from interventions geared at increasing coping efficacy.

Previous research findings suggest that individuals who have doubts about themselves and their capabilities are more likely to give up quickly or not try as hard in the face of obstacles (Bandura, 1994). It is possible then that individuals who are less optimistic, who are less likely to believe in success and a positive outcome, are more likely to give up quickly. Parents with a child with an undiagnosed medical condition face many obstacles which are important to overcome, such as developing effective coping strategies, giving up in the face of these struggles is likely to greatly affect parents' coping and adaptation. It is reasonable then, that less optimistic individuals will need more encouragement and reminders of previous success in the face of a new obstacle. As genetic counselors, working to increase coping self-efficacy in less optimistic individuals is likely to help prevent them from giving up when confronting a new challenge.

When accounting for the interaction of uncertainty and each of the three personality traits, the amount of variance in coping efficacy was decreased, although not statistically significantly. This suggests that levels of each personality trait may moderate the relationship of uncertainty and coping efficacy. In other words, there may be an interaction between uncertainty and each personality trait that helps explain the changes in coping efficacy for an individual. Given the limited power of this study to detect interactions between personality traits and uncertainty at a significant level, it remains an important area for future research.

Ways of Coping

After multivariate analysis, coping efficacy and resilience remained positive predictors of problem-focused coping. Parents who were more resilient and had greater coping efficacy demonstrated greater use of problem-focused coping. In other words, parents who have more confidence in their ability to cope with raising a child with an undiagnosed medical condition are more likely to employ problem-focused strategies. Parents demonstrated highest coping efficacy in the domain of problem-focused coping, suggesting that parents are selecting coping strategies based on how confident they feel in employing them.

Resilience and tolerance of uncertainty were predictors of emotion focused coping. Parents who had a higher tolerance for uncertainty and who were less resilient displayed higher levels of emotion-focused coping. It is possible that personality traits play a large role in determining what type of coping strategies a person utilizes, problem-focused versus emotion-focused, rather than determining how well a person will cope.

However, it is also reasonable that these data represent individuals choosing coping strategies that complement their personality and match the source of the stressor.

Qualitative Data

The qualitative data largely supported the newly developed PUCHS and the dimensions of uncertainty it captured. This suggests that the scale addresses aspects of uncertainty that are important and relevant to parents of children with undiagnosed medical conditions. These data also identified effects of uncertainty that were not asked about with the PUCHS and demonstrate an area for continued revision of the scale. Of particular importance is the repeated mention of frustration and difficulty communicating with medical professionals. Parents expressed exhaustion from repeated telling their child's story, anger at not having adequate ways of explaining their child's condition, and a loss of faith in the medical community. As genetic counselors, this is an important aspect to consider. Counselors are often able to help bridge the gap between families and the medical team. Parents of children with undiagnosed medical conditions likely need help creating a concise story that highlights the relevant information for physicians and a place to vent about their frustration with doctors. Genetic counselors can work to acknowledge these frustrations and help parents discover strategies for managing future doctor's visits thus mitigating some of the effects of uncertainty.

In the PUCHS, existential uncertainty is defined as uncertainty related to the meaning and purpose of the child's life. The qualitative data suggest there may be other aspects of existential uncertainty that are of importance to these parents. Specifically, parents mention low-feelings of worth as a parent and have concerns that they are not a good parent or have failed as a parent. Uncertainty about their child's medical condition

left participant 082 feeling “*unsure if we are doing the best we can for our son. It causes extreme guilt and ... a constant fear that I may be failing him as a parent.*” Similarly, participants report feeling that they “*always second guess myself as a parent.*” Previous qualitative data have found that parents report feelings of guilt and wanting to “be let off the hook” when the cause of their child’s medical condition is unknown (Rosenthal, *et al*, 2001). Guilt is common in genetic disorders but perhaps uncertainty compounds this sense of having failed or being to blame for the medical conditions. Further research can help to better understand feelings of guilt and failure as a parent, but it is clear that this is important to parents and worthy of discussion in genetic counseling sessions.

Clinical Implications

Findings from this study have implications for health care providers, such as genetic counselors, who work with parents during continued follow-up and evaluations when the diagnosis remains unknown. This study contributes to the understanding of how parents of children with undiagnosed medical conditions appraise the uncertainty and their coping efficacy revealing that most parents perceive uncertainty in areas that are important to them and on average feel only moderately confident in their ability to cope effectively. This is of particular importance because appraisals are one component of the Transactional Stress and Coping Model that health care providers are most able to change (Biesecker & Erby, 2008). Appraisals, by definition, are subjective, and differ across individuals and over time. As demonstrated by the data, perceptions of uncertainty are associated with coping efficacy and subsequently related to coping. Therefore, helping parents mitigate perceptions of uncertainty and increase appraisals of coping efficacy may lead to long term improvements in coping and adaptation.

Variation in levels of importance and uncertainty across the four domains offer genetic counselors the opportunity to help parents work through the uncertainty that is important to them. It will not always be possible to mitigate uncertainty related to lacking information, such as prognostic information or risks for relatives, but working with parents to alleviate other domains of uncertainty may prove important for long term adaptation. By targeting specific domains of uncertainty we may enhance coping efficacy, improving long term coping and adaptation. Additionally, realizing the widespread sources of uncertainty that arise from raising a child with an undiagnosed

medical condition will help health care providers such as genetic counselors create empathic connections better enabling us to work with these parents.

Parents in this study identified social uncertainty as the domain they felt most uncertain about. In other words, parents felt most uncertain about finding parents in similar situations and receiving support from these parents. Genetic counselors are in a unique position to help parents in alleviating some of this uncertainty by identifying potential sources of social support. This can be done either by providing information about support groups, such as the ones parents were recruited from, or by identifying families in similar circumstances and connecting them with one another.

As indicated by these results, personality traits affect perceptions of uncertainty, coping efficacy and coping strategies used. This offers health care providers an opportunity to target interventions to those individuals who will be best served. For example, interventions aimed at increasing coping efficacy are likely most helpful to individuals who identify as less optimistic, as those who are optimistic tend to have higher coping efficacy. These interventions may involve reframing parents' thoughts about their circumstances and their ability to manage, re-enforcing successes they have had in the past, or through identifying similar families who have made it through the same struggle. Similarly, personality traits may help predict what coping strategies individuals are most likely to utilize in the presence of a stressful event. The data suggest that resilient individuals are more likely to use problem-focused coping than they are to use emotion-focused coping strategies. It is possible then, that when problem-focused strategies are not appropriate for the situation, resilient individuals may need additional help identifying effective coping strategies. Given limited health care resources, it will

become increasingly important to target interventions to individuals who will receive the most benefit.

Study Limitations

While the data provided by these parents have clinical implications for health care providers, there are several limitations to the study. A cross-sectional study design does not allow for understanding causal relationships and the small sample size may prevent the finding of significant relationships among key variables. However, the study is strengthened by the use of a theoretically-grounded framework that facilitated the conceptual understanding of key variables and their relationships with one another which guided the study design and result interpretations.

Another potential limitation is the recruitment strategy. It is possible that parents of children with undiagnosed medical conditions who chose to participate in this study were different from those who chose not to participate. For instance, it is possible that parents who are involved in support and advocacy groups may perceive more uncertainty and have lower coping efficacy, than parents who are not members of these groups. Or, the opposite could be true. Additionally, this population is likely to over-capture parents who are still seeking information or a diagnosis and not those who have stopped looking for information; it is possible that these two groups have different perceptions of uncertainty. Lastly, the study population was largely non-Hispanic Caucasian, married, and the biological mother of the child meaning that the results of this study are not generalizable to a greater population of parents of children with an undiagnosed medical condition.

Areas for Future Research

The purpose of this study was to explore perceptions of uncertainty when a diagnosis is lacking. The Parental Uncertainty of Children's Health Scale, however, can be used to examine the uncertainty about a child's health regardless of a diagnosis. Additional studies using the new PUCH scale to examine uncertainty with and without a diagnosis will help to clarify the uncertainty that arises specifically from lacking a diagnosis. Comparing results across populations of parents of children with diagnosed conditions is an important next step in understanding uncertainty.

While this study is the first of its kind to include analysis of personality traits, only three traits were examined. Further analysis of personality traits is warranted to expand understanding of perceptions of uncertainty and what distinguishes a person who views it as an opportunity versus a threat. Of particular relevance to the existential uncertainty is how and whether spirituality and religion are involved in coping with this uncertainty.

To better understand the temporal relationship among the key variables included in this study and to understand uncertainty, perceptions of uncertainty, and coping as dynamic processes, longitudinal studies are needed. Additionally, in Lazarus and Folkman's Transactional Model of Stress and Coping, coping and adaptation are a continuous feedback process. Uncertainty and coping efficacy are also likely to feedback into this loop as they change over time.

Conclusion

This cross-sectional study of parents of children with undiagnosed medical conditions identified important relationships between appraisals, personality traits and coping efficacy. Specifically, this study highlighted the role of uncertainty and optimism in predicting coping efficacy. The majority of these parents perceive a great amount of uncertainty which they view as important to resolve. Further, this study identified that parents of children with undiagnosed medical conditions are most uncertain and interested in resolving uncertainty as it relates to social support and medical management. Problem-focused coping strategies were more frequently utilized by these parents, suggesting that they are working to change the stressor, perhaps by finding a diagnosis. This study also found that personality traits contribute to the type of coping strategies these parents employ. For instance, parents who are more resilient tend to use more problem-focused coping strategies than emotion-focused. Ultimately, these responses enhance health care providers' overall understanding of the significant impact of the uncertainty present when raising a child with an undiagnosed medical condition.

Appendix A: Study Announcement

Researchers at the National Institutes of Health and the Johns Hopkins University are seeking parents raising a child with an undiagnosed medical condition to participate in a study.

This study is being done to learn more about how parents perceive uncertainty and what factors affect this uncertainty when their child has a medical condition for which the cause remains unknown. We hope to gather more information in order to develop tools or approaches that can be used to assist parents who have a child with an undiagnosed medical condition.

We are looking for parents who have a child with a medical condition that has not been diagnosed and involves at least two parts of his or her body. You may or may not have a label for the ways your child's body is affected (for example mental retardation OR cleft lip) but you should not have a label for your child's overall condition.

The study consists of a survey that one parent completes. The survey should take 20-30 minutes.

For more information about the study or take the survey, please click here:
<https://www.surveymonkey.com/s/ParentalUncertainty>

Appendix B: Study Notice

Dear Parent,

You are invited to participate in a study conducted by researchers at the National Institutes of Health and the Johns Hopkins University.

Why is this study being done?

To learn more about how parents cope with the uncertainty of having a child with undiagnosed medical condition(s). We are interested in hearing from parents who may feel as though there is a lot of uncertainty and from parents who feel as though there is little uncertainty.

Who can take part in this study?

You must be 18 years of age or older and must be the parent, biological or adoptive, of a child with an undiagnosed medical condition(s). Please fill out only one survey per household.

What is involved in this study?

There is one survey that takes approximately 20-30 minutes to complete. It asks about your thoughts and feelings about your experience as a parent of a child with an undiagnosed medical condition(s) and about how you manage the uncertainty of lacking a diagnosis.

What are the risks of this study?

There are no known risks of taking part in this study. If at any point taking the survey makes you feel upset or anxious you may stop taking the survey. If the survey causes you to become upset or worried about yourself or your child, you can also contact the researchers (see below) and they will help direct you to the appropriate resources.

Are there benefits to taking part in this study?

You will not personally receive any benefits from taking part in this study. We hope to learn more about how parents manage any uncertainty that may be a part of raising a child with an undiagnosed medical condition and pass that understanding on to help parents in the future.

Do I have to participate?

No, you do not have to take part in this study if you do not want to. Your decision to take the survey will not have an effect on your child's healthcare or your participation in any support groups. If you begin the survey, you can choose to skip any question that you don't want to answer. You can also stop taking the survey at any time. If you finish the survey and then change your mind, we will not be able to delete your responses since the surveys are all anonymous.

Who else will know that I am in the study?

We do not ask for your name or contact information on this survey. If you provide us with your name by calling or writing us, we will not link your name with your responses. This study will not be part of any medical record. When we report our research results, it will be done with no identifiable information from individual participants.

How do I participate?

The survey can be found online at <https://www.surveymonkey.com/s/ParentalUncertainty>. If you prefer to complete a paper version of the survey, please contact Ellen Macnamara at macnamaraef@mail.nih.gov to receive the survey and a pre-addressed and stamped return envelope. Any contact information you give to the researchers in order to mail the survey will immediately be destroyed after it is mailed.

What do I do if I have questions or concerns about this study?

Please contact the researchers using the contact information provided below with any questions or concerns that you may have about your rights as a participant.

Thank you very much for your interest and time! We greatly appreciate your consideration in participating in this study.

Ellen Macnamara
Associate Investigator, JHU/NHGRI
Genetic Counseling Training Program
Program

macnamaraef@mail.nih.gov

Barbara Biesecker
Primary Investigator, JHU/NHGRI
Genetic Counseling Training

(301) 496-3979

barbarab@mail.nih.gov

Appendix C: Survey Instrument

Dear Parent,

Thank you for your interest in participating in this survey.

The goal of the study is to learn more about the uncertainty when a child has an undiagnosed medical condition. It is anonymous; no one will be able to link you to your responses.

This survey will take about 20-30 minutes to complete. Taking it is completely voluntary. You may choose not to take it or to stop taking it at any point. Only one parent per family should take this survey.

There are not known to be benefits to you from taking this survey. Some people find participating in surveys such as this one gratifying.

The risks are that the questions may cause you some sadness or anxiety. If you wish to contact someone about the survey, the investigators' contact information can be found below.

Your decision whether to take the survey will not have an effect on your child's healthcare or your participation in any support groups. If you finish the survey and submit it and then change your mind, we will not be able to delete your responses, as we will not be able to tie them to you.

The information you provide will be kept confidential and used for research purposes only. It will not be released to anyone other than the researchers of this study. A summary of the results will be provided to the groups that list the study for participants to read.

We have been studying uncertainty for a couple of years. You may have previously answered our survey on uncertainty and adapting to raising a child without a diagnosis. This survey is new and builds upon our past work to explore specific areas of uncertainty and how they affect coping. We would benefit greatly from your completion of this survey regardless of whether you completed the past one.

Contacts:

Ellen Macnamara
Research Fellow, JHU/NHGRI
Genetic Counseling Training Program
macnamaraef@mail.nih.gov

Barbara Biesecker, PhD, MS
Primary Investigator, JHU/NHGRI
(301) 496-3979
barbarab@mail.nih.gov

***Please check the box below if you have read and understand this information**

- I have read the introduction and understand the purpose and procedures.

Please check the responses that are true for you:

- I am 18 years old or older.
- I am the parent of a child with an undiagnosed medical condition(s).
- My child's undiagnosed medical condition affects at least two (2) parts of his or her body.
- My child's undiagnosed medical condition has remained undiagnosed for at least two (2) years.

If you checked all of the boxes above, you are eligible to complete this survey. Please complete every question on the survey.

If you did not check all of the boxes, you are not eligible to complete this survey. Thank you for your time and interest.

****Please follow the instructions at the beginning of each section. Thank you for your time and participation.****

SECTION A

Instructions: This section asks you about the uncertainty you feel about your child’s undiagnosed medical conditions.

If you have multiple children who have undiagnosed medical conditions that meet our criteria, please focus on your experiences with your oldest affected child while answering the following questions.

Please rank the degree to which you agree with the following statements:

Not having a diagnosis for my child’s condition leaves me...

	Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree
...with no clear understanding of my child’s limitations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...unsure how to think about my child’s condition	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please rank how important each is to you:

	Unimportant	Somewhat Unimportant	Neutral	Somewhat Important	Most Important
Having a clear understanding of my child’s limitations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Having a background against which to think about my child’s condition	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please rank the degree to which you agree with the following statements:

Not having a diagnosis for my child’s condition leaves me...

	Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree
...insufficiently prepared to participate in treatment decisions for my child	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...unsure where to go for treatment of my child’s condition	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please rank how important each is to you:

	Unimportant	Somewhat Unimportant	Neutral	Somewhat Important	Most Important
Being prepared to participate in treatment decisions for my child	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Knowing where to go for treatment of my child’s condition	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

SECTION A continued

Instructions: This section asks you about the uncertainty you feel about your child’s undiagnosed medical conditions.

If you have multiple children who have undiagnosed medical conditions that meet our criteria, please focus on your experiences with your oldest affected child while answering the following questions.

Please rank the degree to which you agree with the following statements:

Not having a diagnosis for my child’s condition leaves me...

	Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree
...unsure of whether my child is expected to have a normal lifespan	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...anticipating my child may do better than anyone has anticipated	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please rank how important each is to you:

	Unimportant	Somewhat Unimportant	Neutral	Somewhat Important	Most Important
Being sure that my child is expected to have a normal lifespan	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Anticipating that my child may do better than has been predicted	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please rank the degree to which you agree with the following statements:

Not having a diagnosis for my child’s condition leaves me...

	Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree
...lacking information to make decisions about having more children	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...unsure what to tell relatives about risks to their children	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please rank how important each is to you:

	Unimportant	Somewhat Unimportant	Neutral	Somewhat Important	Most Important
Having information to make decisions about having more children	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Knowing what to tell relatives about risks to their children	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

SECTION A continued

Instructions: This section asks you about the uncertainty you feel about your child’s undiagnosed medical conditions.

If you have multiple children who have undiagnosed medical conditions that meet our criteria, please focus on your experiences with your oldest affected child while answering the following questions.

Please rank the degree to which you agree with the following statements:

Not having a diagnosis for my child’s condition leaves me...

	Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree
...ill-prepared to make decisions for my family not knowing what the future may hold for my child	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...less able to address my family’s concerns about my child	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please rank how important each is to you:

	Unimportant	Somewhat Unimportant	Neutral	Somewhat Important	Most Important
Being able to make decisions for my family not knowing what the future may hold	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Addressing my family’s concerns about my child	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please rank the degree to which you agree with the following statements:

Not having a diagnosis for my child’s condition leaves me...

	Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree
...struggling to find parents in a similar situation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...without support from parents going through similar experiences	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please rank how important each is to you:

	Unimportant	Somewhat Unimportant	Neutral	Somewhat Important	Most Important
Finding parents in a similar situation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Having support from parents going through similar experiences	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

SECTION A continued

Instructions: This section asks you about the uncertainty you feel about your child’s undiagnosed medical conditions.

If you have multiple children who have undiagnosed medical conditions that meet our criteria, please focus on your experiences with your oldest affected child while answering the following questions.

Please rank the degree to which you agree with the following statements:

Not having a diagnosis for my child’s condition leaves me...

	Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree
...uncertain about the meaning of my child’s life	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...questioning the purpose of my child’s life	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please rank how important each is to you:

	Unimportant	Somewhat Unimportant	Neutral	Somewhat Important	Most Important
Having clarity about the meaning of my child’s life	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Understanding the purpose of my child’s life	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

SECTION A continued

Instructions: This section asks you about the uncertainty you feel about your child’s undiagnosed medical conditions.

If you have multiple children who have undiagnosed medical conditions that meet our criteria, please focus on your experiences with your oldest affected child while answering the following questions.

Please rank how important a diagnosis is to you right now:

Having a diagnosis for my child’s condition is...

- Unimportant
- Somewhat Unimportant
- Neutral
- Somewhat Important
- Most Important

Please rank the strength of each feeling you may have about not having a diagnosis for your child’s condition:

	Low	Somewhat Low	Neutral	Somewhat High	High
Frustrated	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Hopeful	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Unsatisfied	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Indifferent	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Motivated	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Grateful	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Resigned	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Angry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

SECTION A continued

This section asks you to elaborate on the uncertainty you feel about your child’s medical conditions.

If you have multiple children who have undiagnosed medical conditions that meet our criteria, please focus on your experiences with your oldest affected child while answering the following questions. Please answer each question.

Please describe one or two effects that uncertainty about your child’s symptoms or medical conditions has had on your life.

In what ways do you feel certain about your child’s symptoms or medical condition?

In what ways do you feel uncertain about your child’s symptoms or medical condition?

Please describe the features of your child’s symptoms or medical condition. Which of your child’s daily activities are affected by his or her symptoms or condition?

On a scale from “1” (not very severe) to “7” (very severe), how severe do you feel your child’s symptoms or medical condition is?

- 1 (not very severe)
- 2
- 3
- 4
- 5
- 6
- 7 (very severe)

SECTION B

This section asks you about your confidence in handling problems. For each of the following items choose the response that is most accurate for you. Please answer each item.

When things aren't going well for you, or when you're having problems, how confident or certain are you that you can:

	Not confident at all	A bit confident	Somewhat confident	Moderately confident	Quite confident	Highly confident	Completely confident
Keep from getting down in the dumps	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Talk positively to yourself	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sort out what can be changed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Get emotional support from friends and family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Find solutions to your most difficult problems	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Break an upsetting problem down into smaller parts	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Leave options open when things get stressful	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Make a plan of action and follow it when confronted with a problem	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Develop new hobbies or recreations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Take your mind off unpleasant thoughts	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Look for something good in a negative situation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Keep from feeling sad	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
See things from the other person's point of view during a heated argument	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

SECTION B continued

This section asks you about your confidence in handling problems. For each of the following items choose the response that is most accurate for you. Please answer each item.

When things aren't going well for you, or when you're having problems, how confident or certain are you that you can:

	Not confident at all	A bit confident	Somewhat confident	Moderately confident	Quite confident	Highly confident	Completely confident
Try other solutions to your problems if your first solutions don't work	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Stop yourself from being upset by unpleasant thoughts	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Make new friends	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Get friends to help you with the things you need	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Do something positive for yourself when you are feeling discouraged	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Make unpleasant thoughts go away	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Think about one part of the problem at a time	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Visualize a pleasant activity or place	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Keep yourself from feeling lonely	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Pray or meditate	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Get emotional support from community organizations or resources	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Stand your ground and fight for what you want	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Resist the impulse to act hastily when under pressure	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

SECTION C

This section asks how often you use different techniques to help you cope. You will find a sentence or phrase describing a behavior that you may or may not use. Please choose the answer that best corresponds with how often, if at all, you use that behavior to cope with raising a child with an undiagnosed medical condition. There are no right, wrong, or best answers.

If you have multiple children who have undiagnosed medical conditions that meet our criteria, please focus on your experiences with your oldest affected child while answering the following questions. Please answer each item.

I have used this behavior...

	Never	Rarely	Sometimes	Regularly
Bargained or compromised to get something positive from the situation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Concentrated on something good that could come out of the whole thing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Tried not to burn my bridges behind me but left things somewhat open	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Changed or grew as a person in a good way	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Made a plan of action and followed it	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Accepted the next best thing to what I wanted	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Came out of the experience better than I went in	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Tried not to act hastily	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Changed something so things would turn out all right	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Just took things one step at a time	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

SECTION C continued

This section asks how often you use different techniques to help you cope. You will find a sentence or phrase describing a behavior that you may or may not use. Please choose the answer that best corresponds with how often, if at all, you use that behavior to cope with raising a child with an undiagnosed medical condition. There are no right, wrong, or best answers.

If you have multiple children who have undiagnosed medical conditions that meet our criteria, please focus on your experiences with your oldest affected child while answering the following questions. Please answer each item.

I have used this behavior...

	Never	Rarely	Sometimes	Regularly
Known what had to be done, so I doubled my efforts and tried harder to make things work	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Come up with a couple of different solutions to the problem	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Accepted my strong feelings but didn't let them interfere with other things too much	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Changed something about myself so I could deal with the situation better	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Stood my ground and fought for what I wanted	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Talked to someone to find out about the problem	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Accepted sympathy and understanding from someone	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Got professional help and did what they recommended	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Talked to someone who could do something about the problem	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Asked someone I respected for advice and followed it	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Talked to someone about how I was feeling	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Blamed myself	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

SECTION C continued

This section asks how often you use different techniques to help you cope. You will find a sentence or phrase describing a behavior that you may or may not use. Please choose the answer that best corresponds with how often, if at all, you use that behavior to cope with raising a child with an undiagnosed medical condition. There are no right, wrong, or best answers.

If you have multiple children who have undiagnosed medical conditions that meet our criteria, please focus on your experiences with your oldest affected child while answering the following questions. Please answer each item.

I have used this behavior...

	Never	Rarely	Sometimes	Regularly
Criticized or lectured myself	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Realized that I brought on the problem	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Hoped a miracle would happen	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Wished I was a stronger person-more optimistic	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Wished that I could change what happened	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Wished that I could change the way I felt	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dreamed or imagined a better time or place than the one I was in	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Had fantasies or wishes about how things might turn out	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Thought about fantastic or unreal things	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Wished the situation would somehow go away	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

SECTION C continued

This section asks how often you use different techniques to help you cope. You will find a sentence or phrase describing a behavior that you may or may not use. Please choose the answer that best corresponds with how often, if at all, you use that behavior to cope with raising a child with an undiagnosed medical condition. There are no right, wrong, or best answers.

If you have multiple children who have undiagnosed medical conditions that meet our criteria, please focus on your experiences with your oldest affected child while answering the following questions. Please answer each item.

I have used this behavior...

	Never	Rarely	Sometimes	Regularly
Went on as if nothing had happened	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Felt bad that I couldn't avoid the problem	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Kept my feelings to myself	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Slept more than usual	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Gotten mad at what caused the condition	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Tried to forget the whole thing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Tried to make myself feel better by eating, drinking, smoking or taking medications	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Kept others from knowing I was going through a difficult time	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Avoided being with people	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Refused to believe it had happened	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Read or looked for information about research studies	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

SECTION D

The following section asks questions about characteristics of people.

Please rate each item on a scale from 1 (Not at all characteristic of me) to 5 (Very characteristic of me).

	Not at all characteristic of me	A bit	Neutral	Somewhat	Very characteristic of me
It really disturbs me when I am unable to follow another person's train of thought	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If I am uncertain about the responsibilities involved in a particular task, I get very anxious	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Before any important task, I must know how long it will take	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I don't like to work on a problem unless there is a possibility of getting a clear-cut and unambiguous answer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The best part of working on a jigsaw puzzle is putting in the last piece	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am often uncomfortable with people unless I feel that I can understand their behavior	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A good task is one in which what is to be done and how it is to be done are always clear	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

SECTION D continued

The following section asks questions about characteristics of people.

Please rate how strongly you agree with each statement as it describes you.

	Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree
In uncertain times, I usually expect the best	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
It's easy for me to relax	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If something can go wrong for me it will	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I'm always optimistic about my future	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I enjoy my friends a lot	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
It's important for me to keep busy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I hardly ever expect things to go my way	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I don't get upset too easily	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I rarely count on good things happening to me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Overall, I expect more good things to happen to me than bad	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

SECTION D continued

The following section asks questions about characteristics of people.

Please rate how strongly you agree with each statement as it describes you.

	Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree
I usually manage one way or another	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel proud that I have accomplished things in my life	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I usually take things in stride	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am friends with myself	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel that I can handle many things at a time	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am determined	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I can get through difficult times because I've experienced difficulty before	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have self-discipline	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I keep interested in things	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I can usually find something to laugh about	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My belief in myself gets me through hard times	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
In an emergency, I'm someone people can generally rely on	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My life has meaning	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When I'm in a difficult situation, I can usually find my way out of it	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

SECTION E

This section asks questions about you, your family and your child with undiagnosed medical conditions. Please select the choice that is most accurate for you.

What is your relationship to your child?

- Biological Mother
- Biological Father
- Adoptive Mother
- Adoptive Father
- Other (please specify) _____

How old are you?

How many children do you have?

How many of your children have undiagnosed medical conditions?

Where does your child with an undiagnosed medical condition fall in the birth order of your children?

- Oldest (First Child)
- Middle
- Youngest (Last Child)
- Other (please specify) _____

SECTION E continued

This section asks questions about you, your family and your child with undiagnosed medical conditions. Please select the choice that is most accurate for you.

If you have more than one affected child, please answer the next questions regarding your oldest affected child.

How old is your child now?

How old was your child when his or her condition first came to your attention?

Years old _____

Months old _____

Weeks Gestation _____

Is your child male or female?

- Male
- Female

How many body parts are affected by your child's undiagnosed medical conditions?

Please list and describe the undiagnosed medical conditions present in your child.

Is there anything else that you want us to know about that we have not asked?

This section asks about demographic information. Please select the answer that is most accurate for you.

What is your current marital status?

- Single/Never Married
- Married
- Separated/Divorced
- Widowed
- Other (please specify) _____

What is your highest level of education completed?

- Elementary/Junior High
- High School/GED
- Technical School
- Some College
- Completed College
- Post-graduate

What is your annual household income?

- Under \$30,000
- \$30,000 - \$50,000
- \$50,001 - \$70,000
- \$70,001 - \$100,000
- \$100,001 - \$250,000
- Above \$250,000

What is your ethnic background?

- Hispanic or Latino
- Not Hispanic or Latino

What is your racial background? (Choose all that apply)

- American Indian or Alaska Native
- Asian
- Black or African American
- Native Hawaiian or Other Pacific Islander
- White

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Yanes, Tatiane. “Living with Uncertainty: The Role of Hope, Social Support, and Illness Cognition in Raising a Child with an Undiagnosed Medical Condition.” MSc thesis to Griffith University, 2013.

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EDUCATION

Johns Hopkins University/National Institutes of Health May 2014
Genetic Counseling Training Program

University of Virginia May 2011
Majors: Biology and Cognitive Science
GPA: 3.39/4.0

GENETIC COUNSELING CLINICAL EXPERIENCE

Research

- National Institutes of Health, Bethesda, MD
 - National Human Genome Research Institute
 - National Eye Institute
 - Undiagnosed Disease Program, NHGRI

Pediatric

- University of Virginia Genetics, Charlottesville, VA

Cancer

- Georgetown University Hospital, Lombardi Comprehensive Cancer Center, Washington, DC

Prenatal

- MedStar Franklin Square Medical Center, Baltimore, MD
- Johns Hopkins Hospital, Baltimore, MD
- George Washington University MFA, Washington, DC

SCIENCE AND RESEARCH EXPERIENCE

University of Virginia Department of Cell Biology: Center for Research in
Contraceptive and Reproductive Health

Undergraduate Researcher (05/10-05/11)

- Trained in and performed protocols independently; gel electrophoresis, western blotting, IHC, tissue collection, processing and analysis
- Designed and carried out experiments under guidance of a post-doctoral fellow
- Analyzed and presented data to the Director and PhDs of the lab

Genetics and IVF Institute, Fairfax, VA

Intern in the Preimplantation Genetic Diagnosis Lab (05/09-08/09)

- Trained in and performed procedures; spreading, staining (FISH) and scoring of embryos, blood preparation and chromosomal analysis
- Observed genetic counseling sessions
- Observed egg and sperm retrieval procedures

PUBLICATIONS

- Pires, E.S, Hlavin, C.H, Macnamara, E.F., & et. al. (2013) SAS1B Protein (Ovastacin) Shows Temporal and Spatial Restriction to Oocytes in Several Eutherian Orders and Initiates Translation at the Primary to Secondary Follicle Transition. *Developmental Dynamics*, 242, 1405-1426.
- Turriff, A, Macnamara E, Levy HP, and Biesecker, BB. The Impact of Living with Klinefelter Syndrome: A Qualitative Exploration of Adolescents and Adults. (In preparation)

INTERPERSONAL RELATIONSHIPS and TEAM AND COMMUNITY BUILDING

University of Virginia Housing Division and Residence Life Office
Senior Resident (08/10-05/11)

- Established effective team of twelve Resident Advisors and promoted collaboration and cooperation among all members through staff meetings and group activities
- Developed and successfully balanced personal and professional relationships with Deans, professional staff, Resident Advisors and residents
- Collaborated with my twelve Resident Advisors to establish a safe, welcoming and enjoyable community for our 200+ freshman residents
- Utilized various communication styles to build effective relationships with students at varying developmental stages

Resident Advisor (08/08-05/09 and 08/09-05/10)

- Established an identity as a knowledgeable leader by interacting with students in a variety of settings
- Developed and delivered programs to support residents needs
- Established a safe and welcoming community by setting expectations as exemplified in personal action

CRISIS MANAGEMENT

University of Virginia Housing Division and Residence Life Office

- Responded quickly and confidently to ensure safety and well being of residents during crises
- Personalized my response to each student by drawing on training and knowledge base

Senior Resident (08/10-present)

- Oversee and advise on all major incidents that occur in the dorms
- Guide and enable Resident Advisors to effectively handle incidents that extend beyond their training

Resident Advisor (08/08-05/09 and 08/09-05/10)

- Responded to incidents that occurred throughout the academic year
- Trained to recognize and respond to at risk students, with regards to mental, emotional and physical health, in addition to aiding students in their transition to University life

HONORS AND AWARDS

Nominated to National Residence Hall Honorary Society (2010)

Letter of Commendation from the Residence Life Program at UVA (2009)

Phi Eta Sigma Honor Society Member (2008-present)

The National Scholars Honor Society Member (2008-present)