ASSESSMENT OF HEALTH-RELATED QUALITY OF LIFE BETWEEN INFORMANTS AND PARENT-CHILD INFORMANT REPORT DISCREPANCIES WITH REGARD TO DOMAINS OF FUNCTIONING AMONG CHILDREN WITH FUNCTIONAL AND ORGANIC GASTROINTESTINAL DISORDERS

A Dissertation

by

VINCENT PHILLIP AGUIRRE

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Chair of Committee,	Robert W. Heffer
Co-Chair of Committee,	James W. Varni
Committee Members,	Sherecce A. Fields
	Leslie C. Morey
Head of Department,	Heather Lench

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ABSTRACT

Literature in Pediatric Health Psychology has traditionally had a focus in Health-Related Quality of Life (HRQOL) and HRQOL has been established as a standard measure to assess for functioning in children with pediatric chronic health conditions. In addition, a focus on Pediatric Gastrointestinal Disorders (GIDs) has emerged as a focus as well due to the high prevalence in children and the variety of ways they manifest. As assessment of HRQOL often includes child self-report and another informant report (e.g. parent proxy-report), a variety of previous research has taken interest in how well children and parents agree and disagree on HRQOL. Given parent-child agreement and disagreement/discrepancy has been shown to vary as related to domains of functioning, the present study assessed for levels of discrepancy as related to easily observed domains and domains less easily observed of HRQOL in a sample of children with GIDs. Findings support higher parent-child discrepancies for difficult to observe domains as compared to domains easily observed. Furthermore, additional analyses included assessment of discrepancy and average HRQOL as related to age, gender, and informant.

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CHAPTER I

INTRODUCTION

Health-Related Quality of Life

Health-related quality of life (HRQOL) is an essential health outcome for pediatric patients with gastrointestinal disorders (GIDs) in clinical trials or receiving health services (Food and Drug Administration, 2009; Varni et al., 2014). The current generally accepted definition of HRQOL incorporates a multidimensional construct (Eiser & Morse, 2001; Leidy, Revicki, & Genesté, 1999; Matza, Swensen, Flood, Secnik, & Leidy, 2004; Varni & Limbers, 2009) including, at a minimum, physical, psychological, and social functioning domains (Leidy et al., 1999; Varni & Limbers, 2009). Furthermore, patient reported outcomes (PROs), such as self-report of HRQOL, have grown in importance for use in measurement of efficacy outcomes of clinical trials (Patrick et al., 2007).

Although this definition has extensive support within pediatric psychology, a definition of HRQOL from Spieth and Harris (1995) offers a perspective more directly from the healthcare field. This perspective views HRQOL as "…the subjective and objective impact of dysfunction associated with an illness or injury, medical treatment, and healthcare policy (p. 176)." This definition is presented to introduce and provide a background for HRQOL from its origins in healthcare, because this is the context from which its conceptualization originates (Eiser & Morse, 2001). Eiser and Morse (2001) argue that a need to refine this concept came about from improvements in treatment of

illness due to improvements in modern medicine. Due to healthcare advances, death and critical conditions are less of a typical outcome for diseases, and fortunately, prevention and management of chronic health conditions are the norm (Eiser & Morse, 2001a; Spieth & Harris, 1996). A chronic health condition or chronic illness has been defined as a health problem that lasts three months or more, affects a child activities of daily living, and leaves a need for recurrent hospitalizations and regular health and medical care (Compas, Jaser, Dunn, and Rodriguez, 2012). Consideration of HRQOL is integral to the assessment of medical interventions and treatments (Eiser & Morse, 2001) and to an understanding of the increasing number of people living with and managing chronic health conditions (Harding, 2001).

HRQOL and Children with Chronic Health Conditions

Taking into consideration developmental variables and milestones necessary for adjustment unique to children and adolescents, assessing and understanding HRQOL is essential for youth during their progression through life (Hooper, Hynd, & Mattison, 2013). A plethora of literature aimed at understanding HRQOL in children with chronic health conditions has emerged over the past decade or more (Palermo, Long, Lewandowski, Drotar, Quittner, & Walker, 2008). For example, Varni, Limbers, and Burwinkle (2007a) assessed HRQOL using the Pediatric Quality of Life Inventory™ (PedsQL™) 4.0 Generic Core Scales in 2,500 pediatric patients affected by various chronic health conditions and 9,500 healthy comparison children. Results showed that children with asthma, diabetes, cancer, renal disease, gastrointestinal conditions, cardiac

disease, obesity, cerebral palsy, and rheumatology showed significantly lower rates of self-reported HRQOL relative to healthy children. Patients with cerebral palsy had the lowest self-reported HRQOL and children with diabetes had the highest self-reported HRQOL relative to all other children with chronic health conditions.

Ingresky et al. (2010) examined differences among 589 pediatric patients (ages 2 to 18 years) with obesity, eosinophilic gastrointestinal disorder, inflammatory bowel disease, epilepsy, diabetes, sickle cell disease, post-renal transplantation, and cystic fibrosis. Self-report and parent proxy-report forms of the PedsQL^{TM} 4.0 Generic Core Scales were completed to assess HRQOL. Results showed differences in HRQOL to be most prominent for parent proxy-report. Although several differences emerged across groups and subscales of HRQOL, pediatric patients with eosinophilic gastrointestinal and obesity had significantly lower parent proxy-reported HRQOL than all other diagnostic groups. Studies reviewed here represent only a small portion of findings related to HRQOL in children with chronic health conditions. Many other studies have investigated specific chronic health conditions in children and each usually included findings that these children have lower overall HRQOL relative to healthy comparison children. For example, chronic conditions studied have included cerebral palsy (Varni et al., 2005), irritable bowel syndrome (Varni et al., 2006), obesity (Halasi et al. 2018; Swallen, Reither, Haas, & Meier, 2005), thalassemia (Wan-Nor-Asyikeen, Zulkifli, & Zilfalil, 2017), spinal chord injury (Garma, Kelly, Daharsh, & Vogel, 2010) traumatic brain injury (Pagulayan et al., 2006; Erickson, Montague, & Gerstel 2010), asthma (Chen et al, 2007), cancer (Russell, Hudson, Long, & Phipps, 2006), low birth weight

(Rautava et al., 2009), celiac disease (Casellas et al., 2008), problems of sleep (Strine & Chapman, 2005, Duschenne Muscular Dystrophy (2010), sickle cell disease (Dale, Cochran, Roy, & Jernigan, 2011) and diabetes (Varni et al., 2017; Varni et al., 2018).

HRQOL and GIDs

Based on the literature reviewed here, pediatric chronic health conditions are generally debilitating not only within the physical symptoms and dysfunction specific to a particular disease, but across various facets in life, resulting in impairment in overall HRQOL. Gastrointestinal disorders/diseases (GID) are of particular interest when considering chronic health conditions due to their prevalence and the variety of ways in which they can manifest. A review by Peery et al. (2012) reported that about 60-70 million people in the United State are affected by GI disease, leading to 236,000 deaths yearly and 142 billion spent on cost of illness annually. For youth under age 20 years, one study found a prevalence of 43 per 100,000, and 28 per 100,000 for Crohn's disease and ulcerative colitis, respectively (Kappelman et al., 2007). This study also found prevalence for adults of 201 in 100,000, and 238 per 100,000 for Crohn's disease and ulcerative colitis, respectively.

Not only are GIDs pervasive, an elevated concern about GIDs also stems from the wide range in which they may present. For example, several different diagnosable GIDs are identified within two basic types: functional gastrointestinal disorders (FGID), and organic gastrointestinal diseases (OGID; see Costa, Mumolo, & Bellini, 2007 for a review). FGIDs (according to Rome III criteria) and OGIDs are differentiated based on

the conclusiveness of their medical origin. OGIDs are attributed to testable biochemical or structural abnormalities, whereas the medical etiology of FGIDs is unclear. Common FGIDs include functional constipation, functional abdominal pain, functional dyspepsia, and irritable bowel syndrome (Drossman et al., 2006). The prevalence of FGIDs has documented to be higher than FGIDs and range between 12% and 29% worldwide (Lewis, Palsson, Whitehead, Van Tilburg, 2016)

According to Banez and Cunningham (2009), common OGIDs include Crohn's disease (i.e., inflammation of the digestive track occurring anywhere from the mouth to the skin around the anus, co-occurring with mucosal inflammation), ulcerative colitis (i.e., inflammation of the colon affecting the inner lining of the mucosal wall), and indeterminate colitis (i.e., condition symptomatic of Crohn's disease and/or ulcerative colitis diagnosed as indeterminate colitis until a more specific diagnosis can be made).

Drossman et al., 2006 includes Rome III criteria for common FGIDs. However, Drossman and Hassler (2016) published and updated classification of FGIDs known as the Rome IV Criteria. In their review, Simren, Palsson, and Whitehead (2017), discussed that the updated Rome IV criteria took into account research and expertise from over 100 leading experts in gastroenterology. In addition, the authors explained that the Rome IV criteria is generally similar to Rome III criteria with the exception of four new diagnoses including: reflux hypersensivity, cannaboid hyperemesis syndrome/opiod-induced GI hyperalgesia. In addition, the Rome IV criteria continue to stipulate no specific laboratory findings used to diagnoses of FGIDs.

However, increased insight and speculation has been offered on the origin of FGIDs. For example, Simren, Palsson, and Whitehead (2017) discussed, "… growing recognition that multiple specific pathophysiological processes play a role in functional GI disorder, including imbalance between different types of gut bacteria, increase gut permeability, and altered immune function. Furthermore, the importance of neural and hormonal interaction between the brain and the gut in producing and modulating the symptoms of the disorders has been recognized" (p. 3). In other words, assumption of unknown organic etiology of FGIDs is decreasing with increased understanding and speculation of organic processes of the gut, brain, and endocrine systems contributing to symptoms. Moreover, Simren, Palsson, and Whitehead (2017) also discussed that a shift in perceptions of origins of FGIDs have influenced a gradual change in terminology, which is moving toward FGIDs being known as "Disorders of Gut and Brain Interaction." However, the term "Functional Gastrointestinal Disorders" continues to be largely used in recent publications as Rome IV is permeating into the literature.

Pediatric GIDs have emerged as a focus in the pediatric psychology literature (Hyman et al., 2006; Rasquin et al., 2006; Varni et al., 2014; Varni, Bendo, Denham, et al, 2015; Varni, Bendo, Nurko, et al., 2015; Varni, Bendo, Shulman, et al., 2015; Varni, Bendo, Franciosi et al., 2015; Varni, Nurko et al., 2015; Varni, Shulman et al., 2015; Walker et al., 2004; Walker et al., 2012), which can be attributed to their severity, pervasiveness, and the variety of forms (Drossman et al., 2006; Kappelman et al., 2007). Recent findings support specific GIDs and GID types (FGIDs vs OGIDs) vary on generic HRQOL, GID symptoms, level of worry, headaches, days missed in school, and

days in need of sick care (Varni et al., 2014; Varni, Bendo, Denham, et al, 2015; Varni, Bendo, Nurko, et al., 2015; Varni, Bendo, Shulman, et al., 2015; Varni, Bendo, Franciosi et al., 2015; Varni, Nurko et al., 2015; Varni, Shulman et al., 2015;). In addition, Greenley et al. (2013) showed children (ages 11 to18 years) with inflammatory bowel disease, including Crohn's disease and ulcerative colitis (OGIDs), and functional abdominal pain (a FGID), had impaired HRQOL. In addition, Varni, Shulman et al. (2015) found that children with irritable bowel syndrome and functional abdominal pain (FGIDs) self-reported lower HRQOL than healthy children. Moreover, other research has also revealed, according to parent-proxy report, that children with irritable bowel syndrome are more impaired in HRQOL relatively to healthy children, especially in school functioning (Kunz, Hommel, & Greenley, 2010). Evidence also showed that children with OGIDs and FGIDs have more impaired HRQOL compared to other chronic health conditions, including asthma and atopic dermatitis (Warschburger et al., 2014). Gumidyala and Greenley (2014) investigated various risk factors associated with GIDs and impaired HRQOL and Gumidyala and Greenley (2013) reviewed evidence that lower HRQOL in children with irritable bowel syndrome has been associated with female gender, family dysfunction, and symptoms of anxiety and depression.

Differences Between Informants

In the past, parent proxy-report was primarily utilized as a standard informant perspective of pediatric HRQOL (Upton, Lawford, & Eiser, 2008). However, evidence has shown that child self-report and parent-proxy report are not interchangeable (Upton,

Lawford, & Eiser, 2008) and that children can feasibly, reliably, and with validity provide self-report as young as age 5 years (Varni, Limbers, & Burwinkle, 2007b). The contemporary evidence-based view is that children, as self-report informants, know their internal experiences the best (Eiser & Varni, 2013). Therefore, parent-proxy report alone is not sufficient for understanding the HRQOL of children with chronic health conditions.

In the literature, an attempt has been made to better understand the perspectives of multiple informants (i.e., parents and children) regarding pediatric HRQOL and how they vary. A review by Upton, Lawford, and Eiser (2008) noted that, as a group, parents of children with chronic health conditions tend to underestimate their children's HRQOL relative to the children's perspective, and parents of healthy children tend to overestimate their children's HRQOL relative to the children's perspective. In addition, a variety of recent studies on pediatric chronic health conditions have also indicated that parents tend to rate their children as having lower HRQOL than the children do themselves and that age of the child might play a moderating role in the alignment of parent-child report of HRQOL (Bianchini, Fernandes, Silva, Nardo, & Carolino 2013; Kunz et al., 2010; I-Chan Huang, Shenkman, Leite, Knapp, Thompson, & Revicki, 2008; Lim, Velozo, & Bendixen, 2014; Yi-Frazier et al., 2016). There are a couple of studies that only found parent-child differences in reported pediatric HRQOL in the areas of psychosocial domains or social support, which suggests informant report differences might vary based on topic area (Vetter, Bridgewater, McGwin, 2012; Kontodimopoulous, Damianou, Stamatopoulou, Kalampokis, & Loukos, 2018). This

trend in the literature regarding variance in parent-child perspectives has led to the study of parent-child *agreement* (i.e., the extent to which reports are aligned; Upton, Lawford, & Eiser, 2008) regarding pediatric HRQOL, and the more recent development, understanding parent-child informant *discrepancy* (i.e., the extent to which informant reports are misaligned; De Los Reyes, et al, 2011).

Parent-Child Agreement

Although evidence is discussed regarding differences in parent-child agreement, Upton, Lawford, and Eiser (2008) explained these findings to be mixed, and, when measuring agreement through correlation (product moment or intraclass correlation), studies often find moderate to good agreement. Furthermore, agreement varying by domain or topic area is a common finding. For example, externalizing/more observable features, such as those related to physical functioning, often differ in level of agreement with regard to internalizing/less observable features, such as those measured in psychosocial domains, such as emotional and social (Upton, Lawford, & Eiser, 2008). Considering that studies find agreement typically ranges from moderate to good and variability of agreement (Cheng, Luh, Yang, Su, & Lin, 2015; Upton Lawford, & Eiser, 2008), it is evident that parent-child agreement is not perfect, especially given certain studies that provide indication of poor agreement (Upton, Lawford, & Eiser, 2008; Bray, Bundy, & Ryan, 2010).

A review by Upton, Lawford, and Eister, 2008 showed agreement as measured by pearon's *r* to range from 0.20 to 0.80 after considering several studies of pediatric

chronic health conditions regarding overall HRQOL and specific domains of HRQOL. For the most part, the pearson's *r* values were considered to be in moderate to high agreement range. Using the Intraclass Correlation Coefficient, Varni, Bendo, et al, 2014, found agreement (using disease specific GI HRQOL) for total HRQOL GI symptom score and domains to most generally range from 0.60 to 0.75, which can "good" agreement.

A review by Eiser and Varni (2013) discussed child and parent characteristics, which shed light on potential reasons and empirically supported reasons for differences in parent and child perspective on child HRQOL. The authors explained that younger children (i.e., toddler and younger) spend much more time with their parents than school-aged children, which may foster a greater agreement in parent-child perspectives. However, preschoolers' developmental level may make it difficult for them to speak about their emotional well-being. Therefore, they may not be able to self-report a perspective exactly parallel to parent proxy on this important facet of their HRQOL. In addition, Eiser and Varni (2013) noted that empirical literature supports that parents' well-being and functioning may affect their perception of their children's HRQOL in such a way that parents experiencing emotional distress (i.e., depression) are likely to report a more negative view of their child's HRQOL. Ultimately, these authors emphasized the overall limitations of a parent's perspective on his/her child's functioning. From the time of school age and through adolescence, children are away from their parents in very influential environments. These individual experiences away from parental supervision serve to create increasingly larger gaps in parent-child

perspectives of the child's social, emotional, and physical well-being. Even a healthy and thorough amount of communication between parent and child leaves out vital nuances that may never be fully understood by a parent.

Additionally, behavioral health, which can be an integral mechanism for influencing overall HRQOL, may be a mechanism for influencing parent-child agreement. Yeh and Weisz (2001) independently assessed parents and 381 children referred for outpatient behavioral health services. Agreement was examined between each child and his/her parent on target problems to be addressed in treatment. For 63% of parent-child dyads, not even one target problem was agreed upon. Even when target problems were grouped into general categories, one-third of dyads still did not agree on a single category. Furthermore, agreement was less for internalizing categories versus externalizing categories, as might be expected. Although this was a sample of children receiving outpatient behavioral health services, and not a sample of children coping with chronic health conditions, parallels can be made between the two in terms of informant agreement. HRQOL measures are often used to assess pediatric samples and this includes an evaluation of any emotional and psychosocial problems co-occurring with chronic health conditions. This is because emotional and psychosocial problems often do co-occur with chronic health conditions, and, essentially, these children experience problems with behavioral health, in addition to problems with physical health. Given the findings of Yeh and Weisz (2001), children experiencing behavioral health problems often do not agree with their parents on those problems. Perhaps, children with chronic health conditions, who also often experience psychosocial adjustment concerns related to

their chronic health condition, might have at least some notable disagreement with their parents about their functioning, as was evident in Yeh and Weisz (2001), which may influence parent-report and child self-report agreement. Furthermore, agreement might be influenced by parents' experience as well, as evidence suggests parents of children with chronic health conditions experience adjustment problems as well, leading to overall increased stress (Cousino & Hazen, 2013; Capitello, Fiorilli, Placidi, Vallone, Drago, Gentile, et al., 2016).

Whatever the reasons that parents and children do not completely agree when assessing pediatric HRQOL, much may be learned from this variance in perspectives. In fact, in discussing informant perspectives and child depression, Cole and Martin (2005) explained, "…a strength of parent-report may be that parents provide a broader and more stable picture of the child. A weakness is that parents may be relatively naïve about their child's internal state at any specific time. This combination of strengths and weaknesses suggests that parents may be better informants about more stable trait-like dimensions of depression than about less stable time specific dimensions" (p. 145). This point of view can be applied to informant perspectives on HRQOL, and provides one way in which researchers or clinicians can differentially value or apply informant reports for what each may have to offer. Davis, Nicolas, Waters, Cook, Gibbs, Gosch, and Ravens-Sieberer (2007) provided support to this speculation in a study including health children, which found that children were more likely than parents to self-report responses at extremes and base response on a recent specific event.

Parent-Child Discrepancy

Traditionally, differences across informants have been viewed as measurement error, but investigations into informant discrepancies have begun to consider varying informant ratings as an opportunity for a deeper understanding that values the unique perspectives on a child's functioning (Achenbach, 2011; De Los Reyes et al., 2011). Exploring differences in informant perspective can serve two purposes: (a) understanding the meaning behind differing perspectives or discrepancies across informants and (b) better understanding of functioning in children or various pediatric chronic health conditions (De Los Reyes et al., 2011). At the most basic level, parent child informant *discrepancy* is the value of differences between child self-report and parent-proxy report on a given measure. Discrepancy analysis makes use of a distribution of parent-child discrepancy values as a continuous variable for use in research. This is one approach that may evoke a deeper understanding of HRQOL in chronic pediatric health conditions by making statistical predictions through the use of informant discrepancies. The ability to associate certain variables with the degree to which parents and children are discrepant or misaligned, could greatly improve our understanding of chronic pediatric health conditions. For example, informant discrepancies have been used to predict behavioral concerns and various youth outcomes (De Los Reyes, 2011; De Los Reyes, Goodman, Kliewer, & Reid-Quinones, 2010). Beck, Hartos, and Simons-Morton (2006) showed that the level of disagreement (discrepancy) between teenagers and parents on appropriate driving conditions was positively associated with risky teen driving. In addition, Pelton and Forehand (2001) found that mother-teenager discrepancy in

perceptions of mother-teenager relationship was associated with both teenager internalizing problems and externalizing problems as rated by the mother. Also, Ferdinand, van der Ende, and Verhulst (2006) found that parent-child discrepancies in symptoms reporting predicted poor treatment outcome 3.4 years after outpatient behavioral health treatment for children and adolescents ages 11 to18 years. Moreover, Maurizi, Gershoff, and Aber (2012) found that discordance between adolescents and parents regarding parental practices predicted adolescent self-report of anxiety, conduct disorder symptoms, and quality of parent-adolescent relationship.

Comparing Agreement and Discrepancy Analysis

Assessment of agreement between informants has been thoroughly researched and established as a way to evaluate alignment of informant perspectives. However, this research has been limited due to the psychometric method of evaluation of agreement. As explained previously, agreement utilizes a correlation, which, in pediatric psychology research, is often the intraclass correlation coefficient (ICC; Upton, Lawford, & Eiser 2008). The ICC is used for its strength in informant comparison over other types of correlation, but, nevertheless, is bound by its parameters as a correlation. Correlations are usual for, but limited to, the examination of direction (indirect or direct correlation) and strength of association between two continuous variables, such as the report of two informants (Kramer & Feinstein, 1981). From this, the outcome is a single correlation coefficient describing the relationship between the two variables. However, this metric for examining alignment of parent-child perspective falls short of answering broad

theoretical questions about informant variance because: (a) no precisely objective method exists to report a statistical difference between groups (i.e., parent-child report group of children ages 5-7 years vs. parent-child report group of children ages 8-12 years) and (b) and no method exists to produce a distribution of correlations from a sample of parent-child dyads for use in regression models, or other statistical methods used to conceptualize broad theoretical frameworks.

As explained previously, discrepancy analysis allows for the production of an individual discrepancy value for each dyad in a sample allowing for a distribution of discrepancy values that can be used as a continuous discrepancy variable representing the level of discrepancy between informants for the measures or construct reported on (Sood et al. 2012). With a continuous discrepancy variable, statistical analyses can be conducted to evaluate differences between groups regarding informant discrepancy and to perform statistical predictions using a regression model. Moreover, a continuous discrepancy variable could lend itself to conceptualizing broad theoretical frameworks when applied to advanced statistical methods. Nevertheless, despite these differences in metrics for assessment, agreement and disagreement can be considered to be opposites that are "two sides of the same coin." Therefore, both agreement and discrepancy can be used in similar ways to add to our theoretical understanding for how informant reports compare.

Discrepancy Analysis and Pediatric GIDs

Discrepancy analysis should be applied to pediatric GID research for two important reasons. First, as mentioned previously, GIDs are receiving more attention in pediatric literature, due to their severity of impairment and variety of forms (Varni et al., 2014; Varni, Bendo, Denham, et al, 2015; Varni, Bendo, Nurko, et al., 2015; Varni, Bendo, Shulman, et al., 2015; Varni, Bendo, Franciosi et al., 2015; Varni, Nurko et al., 2015; Varni, Shulman et al., 2015; Drossman, 2016; Oudenhove, et al., 2016). Second, discrepancy analysis should be applied to pediatric GID research because internalizing symptoms of gastrointestinal nature are associated with a lower agreement between parents relative to externalizing symptoms (see review by Eiser and Varni, 2013). As children with GIDs experience a variety of GI symptoms that may not be observable enough for parents to yield complete concordance with their children, pediatric GID research could utilize discrepancy analysis, given the likelihood of misalignment in perspectives. More specifically, the likelihood for high parent-child discrepancy might be particularly likely for children with FGIDs relative to OGIDs, because they do not have documented biomedical causes and experience potentially a more unpredictable disorder process. Therefore, it seems reasonable to conclude that the nature of an FGID may yield *less* alignment in parent-child perspective.

Varni, Thissen et al. (2015) found in a general pediatric sample that parent-child informant discrepancies were lower for overt areas of functioning, such as physical functioning in the areas of upper extremities and mobility, and higher for subjective internal states, such as anxiety and depression Given that pediatric GIDs have a

relatively high prevalence in youth, are a growing focus in behavioral pediatric literature, and are associated with parent-child discrepancy, it would be advantageous to study informant discrepancies in a sample of children with GIDs. Moreover, considering the variance in level of parent-child informant discrepancies related to observable and less easily observed areas of functioning, it would be beneficial to compare parent-child discrepancies on domains of HRQOL and GID symptoms (observable and less observable) between GID type (FGID vs. OGID).

Scatter, Elevation, and Shape

With consideration to seminal literature beyond the pediatric psychology, informant reports can be assessed as consisting of three different components: scatter, elevation, and shape (Cronbach & Gleser, 1953). Elevation refers to the assessment of the "…mean of all scores for a given person" (p. 460). Comparing elevations between informant (e.g., child self-report and parent proxy-report) scores is equivalent to pediatric psychology literature related to assessing mean difference between child self-report and parent-proxy report regarding HRQOL. Scatter is "…the square root of the sum (i.e., sum of items for an informant) of squares of the spread of an individual's deviation scores about [its] own mean; that is, it is the standard deviation within the profile, multiplied by k (number of scores or items)" (p. 460). As explained by Cronbach and Gleser (1956), shape is "…the residual information in the score set after equating profiles for both elevation and scatter" (p. 460). In other words, after controlling for differences between informants (or raters), shape reveals the linear relationship between the raters. In pediatric psychology

literature, assessing for shape is most generally equivalent to assessing for "configual agreement" between informants. Discrepancy analysis between informants takes into account elevation, scatter, and shape, allowing for a global view of differences between informants.

Purpose and Rationale of the Present Study

Given the high potential for insight from differences in informant reports and the trend in the literature for a focus on pediatric GIDs, the present study investigated parent-child discrepancies and differences in elevations of HRQOL in pediatric GIDs. A few findings served as the main premise for the statistical models of the current study. As mentioned previously, Upton, Lawford, and Eiser (2008) found that parents and children (across chronic health conditions) tend to have higher *agreement* in reporting of HRQOL for observable domains, such as physical functioning, rather than for difficult to observe areas of functioning, such as emotional or social functioning. In addition, Varni, Thissen et al. (2015) found consistent evidence that parent-child informant *discrepancies* were lower for overt areas of functioning, such as areas of physical functioning, and higher for subjective internal states. Interestingly, using differential item function analysis, Jafari, Bagheri, Hasemi, and Shalileh (2013) provide support that parents and children interpret certain items of HRQOL (specifically studying the PedsQL^{TM} 4.0 Generic Core Scale) differently, especially items in the social subscale. These findings, considered together, show that parent's and children's perceptions of the children's functioning tend to be

more aligned considering more easily observable features, and less aligned when considering more difficult to observe features.

Furthermore, given the long history of evidence of mean differences between child self-report and parent proxy-report of HRQOL (Kunz et al., 2010; Lim, Velozo, & Bendixen, 2014; Upton, Lawford, and Eisert: Yi-Frazier et al., 2015), an examination of differences in elevations between informants provides an even wider view of informant report variances by providing an overall directional differences between informant reports regarding domains of HRQOL or GID symptoms. Comparison of discrepancy provides insight into amount of difference between informants, but comparison of elevations provides insight into a general perspective for which informant is reporting higher or lower functioning for increased insight to direction of difference. Given previous literature into mean differences of parent-child informant reports, we confidently expected that parent proxy-report would yield lower scores of HRQOL than child-report.

In addition, considering GID type and the demographic variables of age and gender with regard to variation in parent-child informant reports is beneficial and more comprehensive. Previous evidence suggests FGIDs have lower HRQOL than OGIDs, which may be due to the non-specificity in disease origin for FGIDs (Varni, Beno et al., 2015). This non-specificity might lead to a lack of agreement between informant, and, therefore, higher parent-child discrepancy for FGIDs relative to OGIDs.

In addition, evidence suggests that parent-child informant reports can vary by age. For example, in a pediatric sample, Varni, Burwinkle, Seid, and Skarr (2003) found

parent-child agreement to increase with child's age. Furthermore, in a sample of children with Type 1 and Type 2 Diabetes, parent-child discrepancies decreased with child's age (Yi-Frazier et al., 2016). A review by Upton, Lawford, and Eiser (2008), has described some mixed findings, explaining that one study found young children to have lower parent-child agreement relative to older ages, and another study found adolescents to have lower parent-child agreement relative to younger ages. In addition, another study found parent-child discrepancy lower for adolescents than for younger children with cancer (Parsons, Fairclough, Wang, & Hinds, 2012). Overall, developmental trends associated with agreement/discrepancy are likely, such that increased child age could be generally associated with higher agreement and lower discrepancy, which may speak to a difference in children's speech and cognitive abilities affecting agreement. In addition, one study found differences in HRQOL was lower for girls than for boys in a sample of overweight adolescents (Bianchini, Fernandes, Silva, Nardo, & Carolino 2013). Furthermore, a review by Gumidyala and Greenley (2013) discussed the finding that females were associated with higher HRQOL in a sample of children with irritable bowel syndrome. However, no other previous literature has demonstrated parent-child informant reports vary by gender for children, but, given this finding and possible developmental differences, it is reasonable to believe that pediatric patients with GIDs could have varying relationships with their parents (typically the primary caregiver is the mother) in part due to child's gender. Given this rationale, child gender was analyzed in the present study, as well.

Utilizing an established dataset of 600 parent-child dyads of children with at least one GID, the aim of this study was to investigate informant report variance between

specific domains of generic HRQOL and disease-specific HRQOL of GIDs, which will be referred to as GID symptoms domains. Item-level parent-child informant discrepancies of generic HRQOL domains (including physical, emotional, social, and school functioning), and GID symptoms domains (list of 14 domains in Figure 1) were calculated by adapting a statistical method for scatter of item differences between informants (Cronbach & Gleser, 1953). Parent-child item-level discrepancies and differences in elevation scores of HRQOL of informant reports were assessed with regard to HRQOL core scale domains and GID symptoms domains, with special interest in evaluating informant variance between easily observable domains and domains more difficult to observe. In addition, the between subject variables of GID type, child age, and gender were explored for main effects and interactions on item level parent-child discrepancy and average HRQOL.

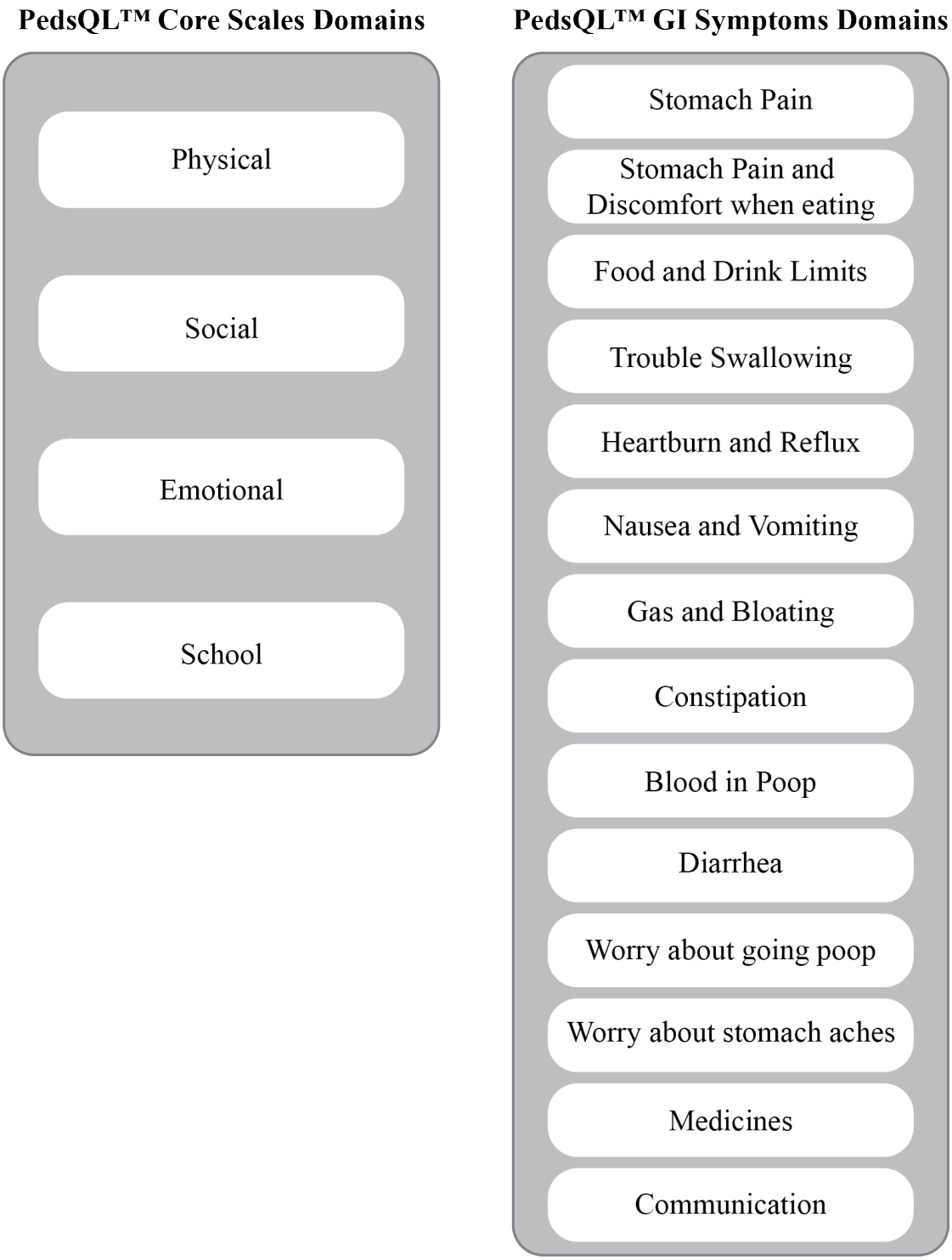

Figure 1. Domains of generic HRQOL (PedsQL™ 4.0 Core Scale Domains) and HRQOL (PedsQL™) GI Symptoms Domains

Hypotheses

1. Parent-Child Discrepancy
    a. Parent-child disrepancies for HRQOL domains (HRQOL Core Scales or GID symptoms) more difficult to observe (e.g., emotional and social domains) were expected to be higher than more easily observed domains (e.g., physical and school, see Figure 1, p. 23).
        i. Children with FGIDs will be higher in parent-child discrepancies than children with OGIDs.
        ii. Adolescents (13-18 years) will be lower in parent-child discrepancies relative to children (8-12 years) and young children (5-7 years).
        iii. Males will be higher in parent-child discrepancies than Females.
        iv. GID type, child age, and gender were expected to moderate the effect of HRQOL domains (HRQOL core scales domains, with four levels, see Figure1, p. 23; HRQOL GID symptoms domains, with 14 levels, see Figure 1, p. 23) on parent-child discrepancy of HRQOL core scales and GID symptoms.
2. Parent Child Average HRQOL (HRQOL core scales domains, with four levels, see Figure 1, p. 23)
    a. Child self-report was expected to be higher in HRQOL than parent-proxy report.
        i. Children with FGIDs will be lower in average HRQOL than children with OGIDs.

ii. Adolescents (13-18 years) will be lower in HRQOL relative to children (8-12 years) and young children (5-7 years).

iii. Males will be lower in average HRQL than Females.

iv. GI type, child age, and gender were expected to moderate the effect of HRQOL domain (core scales, with four levels, see Figure 1, p. 23; or GID symptoms, with 14 levels, see Figure 1, p. 23) on the difference between child self-report and parent proxy-report in average HRQOL.

CHAPTER II

METHOD

Participants

Pediatric patients (ages 5-18 years) and their parents were recruited from nine pediatric tertiary care GI clinical sites across the U.S. for the PedsQL™ Gastrointestinal Symptoms Module field test study (Varni et al., 2014). Patient participants had a physician-diagnosed GID (utilizing ICD-9-CM Diagnosis Codes and/or RomeIII criteria for FGIDs) for seven GID diagnostic groups including both FGIDs (i.e., functional constipation, functional abdominal pain, irritable bowel syndrome, functional dyspepsia) and OGIDs (i.e., Crohn's disease, ulcerative colitis, and gastroesophageal reflux disease). The diagnosis of a FGID or an OGID was made by each of the site investigators, who were board certified pediatric gastroenterologists. However, diagnoses were pre-existing to the present study and participants were aware of diagnoses at the time of participation of the present study. Results should be evaluated with this in mind. Diagnoses were based on current Rome III diagnostic criteria for FGIDs (Rasquin et al., 2006) and international standards for OGIDs (North American Society for Pediatric Gastroenterology, Hepatology, and Nutrition [NASPGHAN] and/or European Society for Pediatric Gastroenterology, Hepatology, and Nutrition [ESPGHAN] guidelines/consensus statements/reports).

Data collection for the present study was conducted as a part of the PedsQL™ Gastrointestinal Symptoms Module field test study, which took place between March

2011 and November 2013 (Varni et al., 2014). The current study reports statistical analyses of the data from the existing field test study database not previously conducted (Varni et al., 2014; Varni, Bendo, Denham, et al, 2015; Varni, Bendo, Nurko, et al., 2015; Varni, Bendo, Shulman, et al., 2015; Varni, Bendo, Franciosi et al., 2015; Varni, Nurko et al., 2015; Varni, Shulman et al., 2015;). Specifically, the calculations item level-discrepancies between GID types and GID types by child age groups have not been previously reported and are the focus of the current set of analyses.

A total of 600 families (600 parent/child dyads ages 5-18 years) were included in the present study. The average age of the 275 boys (45.80%) and 325 girls (54.20%) was 12.65 years (*SD* = 3.6). Table 2 (p. 27) Contains the child and parent-proxy participants' demographic characteristics for the GID groups.

Table 1. Descriptive Statistics of Sample

Youth (N = 600)	**Mean**	**Standard Deviation**	**Range**
Age *(in years)*	12.61	3.63	5.00 - 18.92
Gender		**Frequency**	**Percent Total**
Female		275	45.80
Male		325	54.20
Age Group			
5-7 Years		75	12.50
8-12 Years		229	38.20
13-18 Years		296	49.30

Table 1. Continued

Youth (N = 600)	Mean	Standard Deviation	Range
Ethnicity			
Black (Non-Hispanic)		51	8.50
Asian or Pacific Islander		10	1.70
Hispanic		60	10.00
American Indian/Alaskan Native		1	.20
White (Non-Hispanic)		454	75.70
Other		24	4.0
GI Disorder			
FGID		294	49.0
Chronic Constipation		124	20.7
Functional Abdominal Pain		116	19.30
Dyspepsia		14	2.30
Irritable Bowel Syndrome		40	6.70
OGID		306	51.00
Crohn's Disease		193	32.20
Ulcerative Colitis		65	11.20
Gastroesophageal Reflux Disease		43	7.20
Indeterminate Colitis		2	.30
Inflamatory Bowel		1	.20
Parents (*N* =596)			
Gender of Parents			
Female		529	88.17
Male		58	9.60
Other		7	1.17
Missing		6	1.00
Parent Education-Mother Proxy			
Less than high school graduate		38	6.33
High school graduate		80	13.30
Some college or certification course		148	24.70

Table 1. Continued

Youth (N = 600)	Mean	Standard Deviation	Range
College graduate		198	33.00
Graduate or professional degree		108	18.00
Missing		28	4.70
Parent Education-Father Proxy			
Less than high school graduate		51	.50
High school graduate		99	16.50
Some college or certification course		120	20.00
College graduate		148	24.70
Graduate or professional degree		103	17.20
Missing		79	13.20

Procedures

Written parental informed consent and child assent (when age appropriate) were obtained for these data during the field test study (Varni et al., 2014). The research protocol for the field test study was approved by the Institutional Review Board at each participating institution. Following initial identification by medical staff, eligible families were notified about the field test study, which varied across the nine sites, and included mailed recruitment letters, telephone contact, or in-person contact during outpatient clinic appointments. Data were collected across the nine sites by graduate and undergraduate students, nurses, research assistants, and clinical research coordinators following the online PedsQL™ administration guidelines (*www.pedsql.org*). Questionnaire administration was primarily conducted during clinic visits after the completion of the informed consent and assent forms.

Measures

PedsQL 4.0 Generic Core Scales

The 23-item PedsQL 4.0 Generic Core Scales encompasses four domains: Physical Functioning (8 items), Emotional Functioning (5 items), Social Functioning (5 items), and School Functioning (5 items; Varni et al. 2001). The Physical Health Summary Score is the same as the Physical Functioning Scale. To create the Psychosocial Health Summary Score, the mean is computed as the sum of the items divided by the number of items answered in the Emotional, Social, and School Functioning Scales. The scales use parallel child self-report and parent proxy report formats for children ages 5-18 years, and a parent proxy report format for children ages 2-4 years. The questions assess how much of a problem each item has been during the previous month. The age-appropriate PedsQL^{TM} forms for children and adolescents utilize a 5-point Likert scale ranging from 0 (never) to 4 (almost always) to signify nature of endorsement for each symptom described by each item. In addition, each parent proxy-report form utilized this same format for each age group. The PedsQL^{TM} form designated for young children uses a simplified 3-point Likert scale, with scoring including 0 (not at all a problem), 2 (sometimes a problem), 4 (a lot of a problem). The PedsQL^{TM} has been shown to have good reliability and validity with regard to psychometric performance (Varni et al., 2003; Varni, Seid, & Kurtin, 2001).

Items are reverse-scored and linearly trans- formed to a scale of 0-100, with higher scores indicating better HRQOL. Scale scores are computed as the sum of the items divided by the number of items answered (which accounts for missing data). If

more than 50% of the items in the scale are missing, then the scale score is not computed (Fairclough, 2002)

PedsQL™ Gastrointestinal Symptoms Module

The PedsQL™ Gastrointestinal Symptoms Scales encompass 14 individual domains: (a) Stomach Pain and Hurt Scale (6 items), (b) Stomach Discomfort When Eating Scale (5 items), (c) Food and Drink Limits Scale (6 items), (d) Trouble Swallowing Scale (3 items), (e) Heartburn and Reflux Scale (4 items), (f) Nausea and Vomiting Scale (4 items), (g) Gas and Bloating Scale (7 items), (h) Constipation Scale (14 items), (i) Blood in Poop Scale (2 items), and (j) Diarrhea Scale (7 items), (k) Worry About Going Poop Scale (5 items) and (l) Worry About Stomachaches Scale (2 items), (m) Medicines (4 items) , and (n) communication (5 items). The format, instructions, Likert response scale, and scoring method for the PedsQL™ Gastrointestinal Symptoms Scales are identical to the PedsQL™ 4.0 Generic Core Scales (Varni, Seid, & Kurtin, 2001), with higher scores indicating better HRQOL and hence lower symptoms (Varni et al. 2014). The Scales are comprised of parallel child self-report and parent proxy-report formats for children ages 5-18 years, and a parent proxy-report format for children ages 2-4 years. Child self-report forms are specific for ages 5-7 years, 8-12 years, and 13-18 years. For the purposes of the present study, only patient self-report scales are included given the focus on patient-reported outcomes. The instructions ask how much of a problem each item has been during the past one month. A 5-point response scale is utilized across child and adolescent self-report for ages 8-18 years (0 = never a problem;

1 = almost never a problem; 2 = sometimes a problem; 3 = often a problem; 4 = almost always a problem). To further increase the ease of use for young child self-report (ages 5-7), the response scale is reworded and simplified to a 3-point scale (0 = not at all a problem; 2 = sometimes a problem; 4 = a lot of a problem), and utilizes a faces scale adapted from the Pediatric Pain Questionnaire (Varni, Thompson, & Hanson, 1987).

Items are reverse-scored and linearly transformed to a 0-100 scale (0 = 100, 1 = 75, 2 = 50, 3 = 25, 4 = 0), so that lower scores demonstrate more (worse) gastrointestinal symptoms and hence lower (worse) gastrointestinal-specific HRQOL. Scale Scores are computed as the sum of the items divided by the number of items answered (this accounts for missing data). If more than 50% of the items in the scale are missing, the Scale Score is not computed (Fairclough, 2002). Although there are other strategies for imputing missing values, this computation is consistent with previous PedsQL™ peer-reviewed publications as well as other well-established HRQOL measures (Fairclough, 2002; Varni & Limbers, 2009).

PedsQL™ Family Information Form

Parents completed the PedsQL™ Family Information Form, which contains demographic information including the child's date of birth, gender, race/ethnicity, and parental education information (Varni et al., 2001).

Analyses

Calculation of Parent-Child Discrepancies

Item-level parent child informant discrepancies of HRQOL core scales and GID symptoms were calculated by adapting a statistical method for scatter to item differences between informants described in Cronbach & Gleser (1953). This procedure consists of first subtracting all items of the child self-report form from each corresponding item of the parent proxy-report form of the PedsQL™ 4.0 Generic Core Scales and the PedsQL™ Gastrointestinal Symptoms Scale. Next, the square value of each item difference was generated. Then, the sums of square item values were calculated within each domain. Furthermore, the square root of each sum of square items was calculated. Lastly, the resulting values for each domain were divided by the number of items to make each domain comparable to other domains. This produced a distribution of discrepancy value for each parent-child dyad.

Calculation of Elevation

For both child self-report and parent proxy-report, elevation was calculated for each domain. This was done by calculating the average for each domain (adding all items within each domain then dividing by number of items) for each informant (child self-report and parent-proxy report). This produced a distribution of elevation values for each domain for child self-report and parent proxy-report.

Statistical Methods

Two repeated measures ANOVAS were used to assess for the effects and interactions of the between subjects factors (GID type, child gender, child age) and within subject factors (HRQOL 4 core scale domains and 14 GID symptoms domains see Figure 1., p. 72 for the list of domains) on parent-child discrepancy of HRQOL and GID symptoms.

The first model was a 2 x 2 x 3 x 4 repeated measures ANOVA (see Figure 2, p. 35) used to test for possible effects and interactions of GID type (2 levels), child gender (2 levels), child age (3 levels), and HRQOL core scale domain (4 levels) on parent-child discrepancy of HRQOL of generic core scales. The second model was a 2 x 2 x 3 x 14 repeated measures ANOVA (see Figure 3, p. 36) used to test for possible effects and interactions of GID type (2 levels), child gender (2 levels), child age (3 levels), and GID symptoms domain (14 levels) on parent-child discrepancy of GID symptoms.

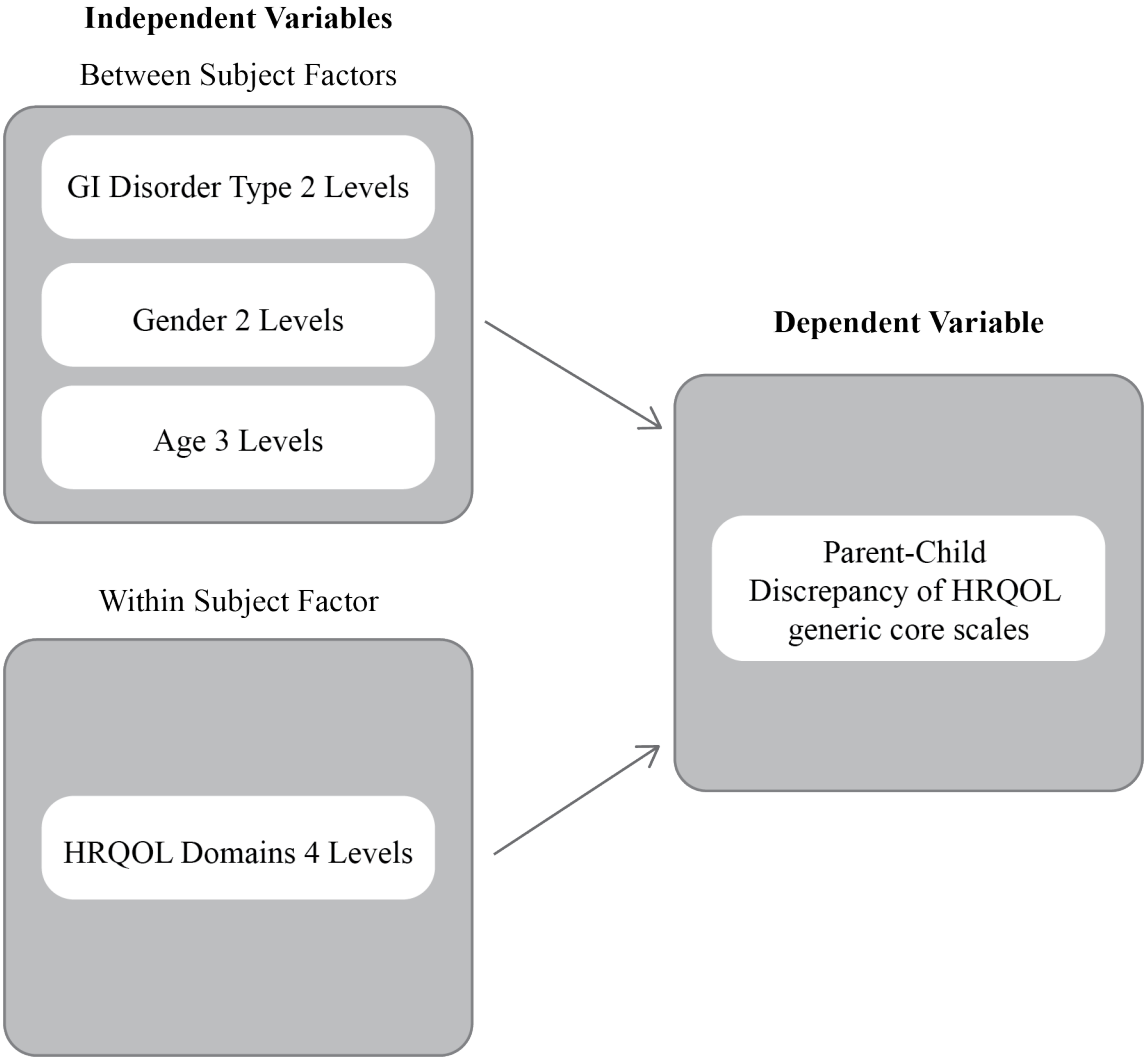

Figure 2. Statistical Model 1 examining potential main effects and interactions of Domains of HRQOL, GID Disorder Type, Gender, and Age on Parent-Child Discrepancy of HRQOL

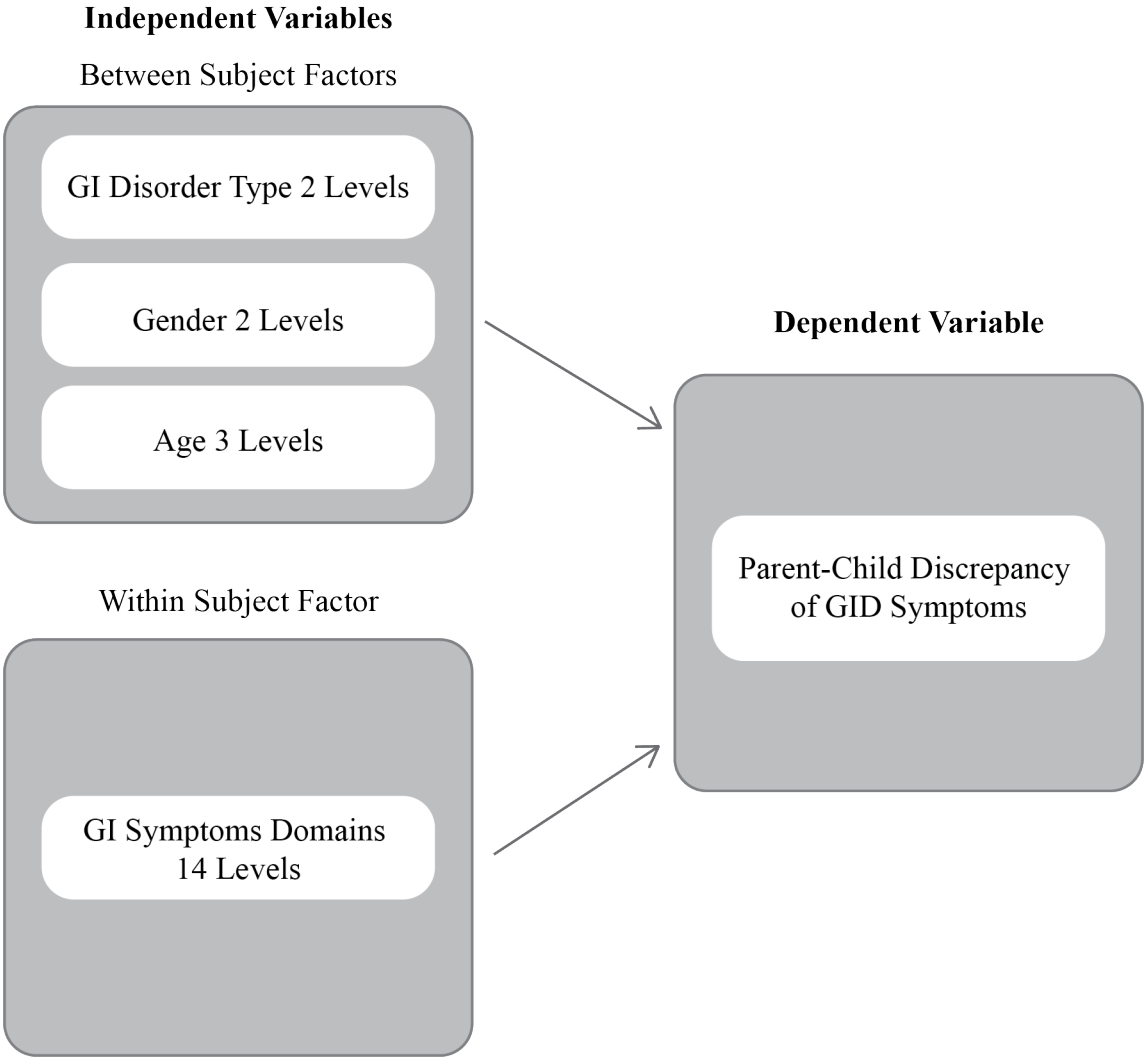

Figure 3. Statistical Model 2 examining potential main effects and interactions of Domains of HRQOL, GID Disorder Type, Gender, and Age on Parent-Child Discrepancy of HRQOL GI Symptoms

A third model compared informant (child self-report and parent proxy report) elevation between domains and informants. A 2x2x3x2x4 repeated measures ANOVA (see Figure 4, p. 37) was to used to test for the possible effects and interactions of GID type (2 levels), child gender (2 levels), child age (3 levels), HRQOL core scale domain (4 levels), and informant (2 levels) on average generic core scales HRQOL.

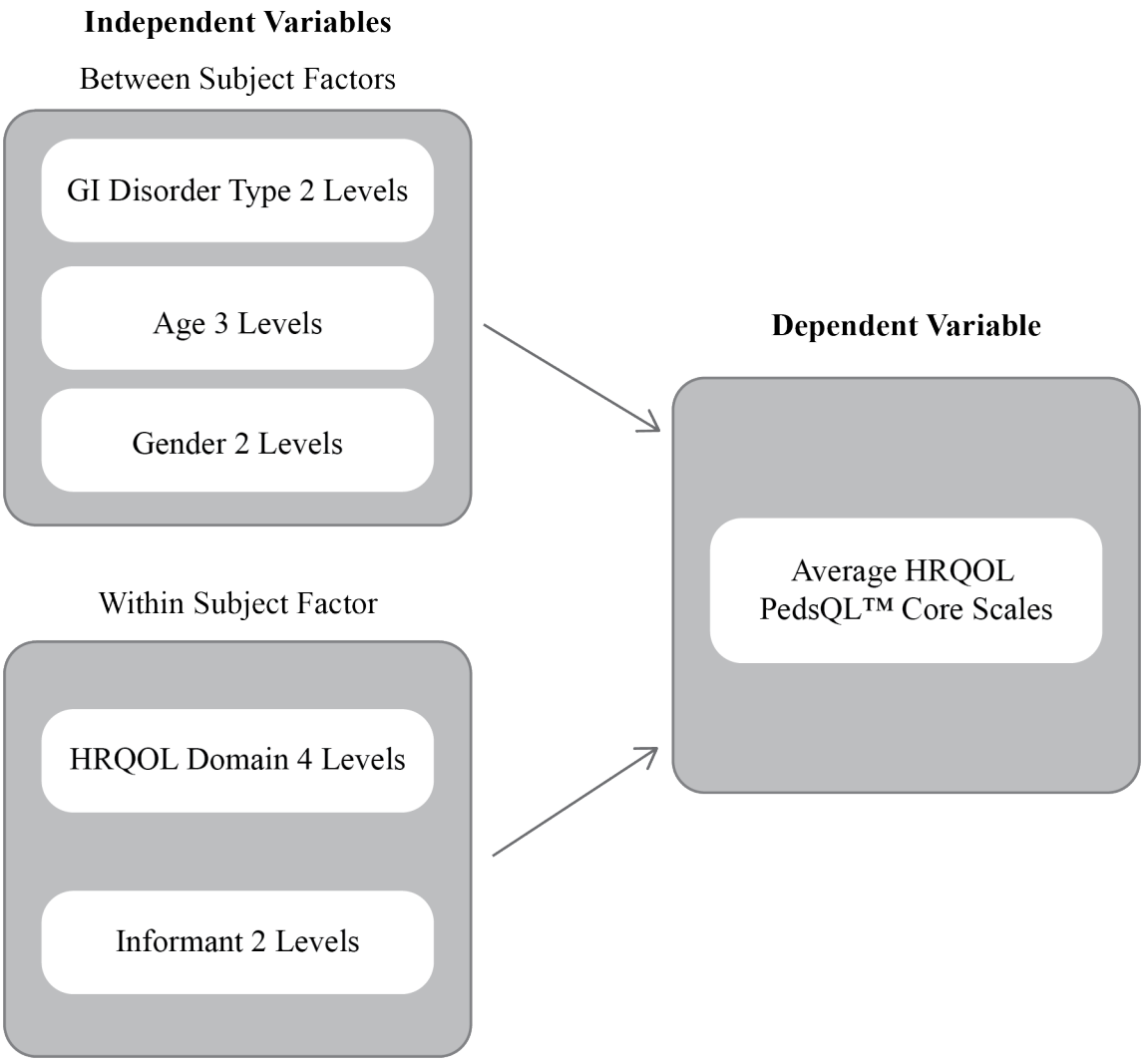

Figure 4. Statistical Model 3 examining potential main effects and interactions of Informant, Domains of HRQOL, GID Disorder Type, Gender, and Age on Average HRQOL

CHAPTER III

RESULTS

Parent-Child Discrepancy of PedsQL^{TM} Core Scales

Between-Subjects Effects and Interactions: GID Type, Child Gender, and Child Age. A main effect of GID type was found, F (1, 543) = 11.29, $p < .001$, $\eta^2 = .020$, such that parent-child discrepancy was higher for FGIDs (M = 11.88, SE = .33) than for OGIDs (M = 9.93, SE = .48). A main effect of child gender was found, F (1, 543) = 6.20, p = .001, $\eta^2 = .011$, such that parent-child discrepancy was higher for males (M = 11.63, SE = .43) than females (M = 10.18, SE = .39). No main effect of child age was found, F (2, 543) = 1.07, p = .43, $\eta^2 = .004$, such that parent-child discrepancy was similar for young children, children, and adolescents.

An interaction of child gender by child age emerged, F (2, 543) = 4.79, p = .01, η^2 = .017, such that parent-child discrepancy was higher for males (M = 13.40, SE = 1.09) than females (M = 9.65, SE = .99) in young children (5-7 years old). No other significant main effects or interactions were found.

Within-Subjects Effect and Interactions: HRQOL Core Scale Domains. A main effect of domains was found, F (3, 1,568.63) = 15.76, $p < .001$, $\eta^2 = .028$, such that emotional functioning (M = 12.03, SE = .42) and school functioning (M = 11.90, SE = .40) were higher in parent-child discrepancy than physical functioning (M = 9.36, SE = .33). Moreover, parent-child discrepancy was higher for emotional functioning (M = 12.03, SE = .42) than for social functioning (M = 10.34, SE = .46). In addition, school

functioning (M = 11.90, SE = .40) was higher in parent-child discrepancy than social functioning (M = 10.34, SE = .46). A listing of significant pairwise comparisons is presented in Table 3 (p. 39).

Table 2. Parent-Child Discrepancy of generic HRQOL separated by Domain, GID Type by Domain, Gender by Domain, Age by Domain, GID Type by Gender by Domain, GID Type by Age by Domain, and GID Type by Gender by Age by Domain

		Physical	**Emotional**	**Social**	**School**	**Differences**
	n	Mean (SE)	Mean (SE)	Mean (SE)	Mean (SE)	
						a<b***, a<d***
Domain	555	9.36 (.33)[a]	12.03 (.42)[b]	10.34 (.46)[c]	11.90 (.33)[d]	c<b**, c<d** a=c, b=d
GI Disorder Type						
Functional	271	9.89 (.37)	12.84 (.46)	11.94 (.51)	12.85 (.45)	
Organic	284	8.83 (.54)	11.20(.70)	8.73 (.76)	10.93 (.67)	
Child Gender						
Male	257	9.61 (.49)	12.34 (.62)	11.46 (8.12)	13.10 (.60)	
Female	298	9.12 (.44)	11.71 (.56)	9.21 (.61)	10.69 (.54)	
Child Age (in years)						
Young Child (5-7)	63	10.08 (.83)	12.91 (1.05)	10.64 (1.56)	12.47 (1.02)	
Child (8-12)	213	9.03 (.38)	11.46 (.48)	9.81 (.48)	11.28 (.46)	
Adolescent (13-18)	279	8.98 (.37)	11.70 (.47)	10.55 (.52)	11.91 (.46)	
GID Type x Gender						
Functional						
Male	102	10.08 (.58)	13.22 (.74)	13.08 (.81)	13.62 (.72)	
Female	169	9.70 (.44)	12.48 (.56)	10.80 (.62)	12.08 (.55)	

Table 2. Continued

		Physical	Emotional	Social	School	Differences
Organic						
Male	155	9.14 (.78)	11.46 (1.00)	9.85 (1.10)	12.58 (.96)	
Female	129	8.53 (.76)	10.94 (.96)	7.62 (1.06)	9.28 (.93)	
GID Type x Age (in years)						
Functional						
Young Child (5-7)	50	10.24 (.76)	14.08 (.96)	13.53 (1.06)	13.37 (.93)	
Child (8-12)	124	9.90 (.48)	12.83 (.61)	11.16 (.67)	12.53 (.59)	
Adolescent(13-18)	97	9.53 (.63)	11.63 (.80)	11.12 (.88)	12.65 (.78)	
Organic						
Young Child (5-7)	13	9.93 (1.47)	11.74 (1.87)	7.75 (2.06)	11.57 (1.81)	
Child (8-12)	89	8.15 (.58)	10.09 (.74)	8.46 (.81)	10.03 (.72)	
Adolescent (13-18)	182	8.42 (.39)	11.76 (.50)	9.99 (.54)	11.18 (.48)	
GID Type x Gender x Age						
Functional						
Male						
Young Child (5-7)	21	10.18 (1.15)	14.90 (1.47)	14.54 (1.62)	14.56 (1.42)	
Child (8-12)	58	10.74 (.69)	13.63 (.88)	12.95 (.97)	13.87 (.86)	
Adolescent (13-18)	23	9.32 (1.10)	11.14 (1.40)	11.75 (1.54)	12.43 (1.36)	
Female						
Young Child (5-7)	29	10.30 (.98)	13.27 (1.25)	12.53 (1.37)	12.18 (1.21)	
Child (8-12)	66	9.06 (.65)	12.03 (.83)	9.38 (.91)	11.20 (.80)	
Adolescent (13-18)	74	9.75 (.61)	12.13 (.78)	10.48 (.86)	12.86 (.76)	
Organic						
Male						
Young Child (5-7)	6	12.46 (2.16)	13.66 (2.74)	11.73 (3.02)	15.20 (2.66)	
Child (8-12)	56	7.40 (.71)	10.20 (.90)	8.33 (.99)	11.29 (.87)	
Adolescent (13-18)	93	7.57 (.54)	10.54 (.70)	9.48 (.77)	11.23 (.68)	

Table 2. Continued

		Physical	Emotional	Social	School	Differences
Female						
Young Child (5-7)	7	7.40 (2.00)	9.83 (2.54)	3.77 (2.80)	7.94 (2.47)	
Child (8-12)	33	8.90 (.92)	10.00 (1.17)	8.60 (1.29)	8.78 (1.14)	
Adolescent (13-18)	89	9.27 (.56)	12.99 (.72)	10.50 (.78)	11.13 (.70)	

*$p < 0.05$, **p < 0.01, ***$p < .001$

No significant interactions emerged between domain and any combination of between subject variables (i.e., child age, child gender, and GID type).

Table 3. Parent-Child Discrepancy of GID symptoms separated by Domain, GID Type by Domain, Gender by Domain, Age by Domain, GID Type by Gender by Domain, GID Type by Age by Domain, and GID Type by Gender by Age by Domain

		A1	**B2**	**C3**	**D4**	**E5**	**F6**	**G7**	**H8**	**I9**	**J10**	**K11**	**L12**	**M13**	**N14**
	n	Mean (SE)	Mean (SE)	Mean (SE)	Mean (SE)	Mean (SE)	Mean (SE)	Mean (SE)	Mean (SE)	Mean (SE)	Mean (SE)	Mean (SE)	Mean (SE)	Mean (SE)	Mean (SE)
Domain	544	7.74 (.24)	11.86 (.43)	10.41 (.44)	7.74 (.55)	10.92 (.49)	9.35 (.47)	10.59 (.31)	7.28 (.22)	8.40 (.71)	8.29 (.34)	10.43 (.42)	18.12 (. 90)	11.97 (.53)	15.62 (.53)
GI Disorder Type															
Functional	263	7.87 (.28)	11.92 (.49)	10.95 (.5)	8.32 (.63)	11.7 (.57)	9.9 (.55)	10.94 (.36)	7.89 (.25)	6.79 (.81)	9.5 (0.4)	11.78 (0.48)	19.47 (1.05)	12.3 (.61)	16.66 (.61)
Organic	281	7.61 (.39)	11.79 (.7)	9.87 (.71)	7.16 (.89)	10.14 (.80)	8.8 (.77)	10.25 (.51)	6.67 (.36)	10.02 (1.15)	7.07 (.56)	9.09 (.68)	16.76 (1.48)	11.64 (0.86)	14.59 (.86)
Child Gender															
Male	257	7.77 (.34)	11.4 (.61)	10.09 (.62)	8.25 (.78)	11.55 (.70)	8.83 (.67)	10.58 (.44)	7.51 (.31)	8.13 (1.00)	9 (0.49)	10.79 (.59)	18.81 (1.29)	11.32 (.75)	15.74 (.75)
Female	298	7.71 (.34)	12.31 (.60)	10.74 (.61)	7.23 (.77)	10.30 (.69)	9.87 (.67)	10.61 (.44)	7.05 (.31)	8.68 (.99)	7.56 (.48)	10.08 (.59)	17.42 (1.27)	12.62 (.74)	15.51 (.74)
Child Age (in years)															
Young Child (5-7)	65	9.23 (.60)	13.31 (1.06)	10.15 (1.08)	11.07 (1.36)	12.39 (1.22)	10.73 (1.18)	11.65 (.77)	8.22 (.55)	10.03 (1.75)	9.62 (.85)	11.94 (1.03)	20.35 (2.25)	11.69 (1.31)	18.56 (1.31)
Child (8-12)	209	7.3 (.28)	10.9 (.50)	10.24 (.51)	6.29 (.63)	9.88 (.57)	8.68 (.55)	9.97 (.36)	6.94 (.26)	7.03 (.82)	7.44 (.40)	9.59 (0.48)	17.69 (1.05)	12.66 (0.61)	13.14 (0.61)
Adolescent (13-18)	270	6.69 (.29)	11.35 (.52)	10.85 (.53)	5.86 (.66)	10.49 (.60)	8.65 (.57)	10.16 (.38)	6.69 (.27)	8.15 (.86)	7.79 (.42)	9.77 (.51)	16.31 (1.10)	11.55 (0.64)	15.16 (0.64)

Table 3. Continued

		A1	B2	C3	D4	E5	F6	G7	H8	I9	J10	K11	L12	M13	N14
GID Type x Gender															
Functional															
Male	93	8.14 (.45)	11.51 (.80)	10 .5 7 (.8 2)	7.69 (1.02)	12.45 (.92)	9.02 (.89)	11.43 (.58)	8.18 (.41)	6.44 (1.32)	9.95 (.64)	12.5 (.78)	19.66 (1.7)	12.18 (.98)	17.94 (.99)
Female	170	7.6 (.33)	12.33 (.58)	11.34 (.59)	8.95 (.74)	10.95 (.66)	10.79 (.64)	10.45 (.42)	7.61 (.30)	7.14 (.95)	9.05 (.46)	11.06 (.56)	19.28 (1.22)	12.42 (.71)	15.37 (.71)
Organic															
Male	151	7.41 (.51)	11.29 (.91)	9.6 (.93)	8.81 (1.17)	10.64 (1.05)	8.65 (1.01)	9.73 (.66)	6.84 (.47)	9.83 (1.51)	8.05 (.73)	9.07 (.89)	17.95 (1.93)	10.46 (1.12)	13.53 (1.13)
Female	130	7.82 (.60)	12.30 (1.05)	10.13 (1.08)	5.51 (1.35)	9.65 (1.21)	8.94 (1.17)	10.76 (0.77)	6.5 (0.54)	10.22 (1.74)	6.08 (0.84)	9.1 (1.03)	15.57 (2.24)	12.82 (1.3)	15.64 (1.31)
GID Type x Age															
Functional															
Young Child (5-7)	51	9.56 (.56)	12.1 (.99)	11.36 (1.01)	10.85 (1.26)	12.5 (1.14)	10.6 (1.1)	12.35 (.72)	9.11 (.51)	7.4 (1.63)	11.51 (.79)	13.95 (.96)	22.47 (2.1)	12.19 (1.22)	19.53 (1.22)
Child (8-12)	121	7.46 (.36)	11.66 (.64)	10.54 (.65)	7.33 (.81)	11.18 (.73)	10.16 (.71)	9.94 (.46)	7.49 (.33)	6.03 (1.05)	8.85 (.51)	11.07 (.62)	18.98 (1.35)	12.71 (.78)	13.74 (0.79)
Adolescent (13-18)	91	6.6 (.51)	11.99 (.89)	10.97 (.92)	6.79 (1.15)	11.42 (1.03)	8.95 (.99)	10.53 (.65)	7.09 (.46)	6.93 (1.48)	8.14 (.72)	10.32 (.87)	16.97 (1.9)	12 (1.10)	16.7 (1.11)

Table 3. Continued

		A1	B2	C3	D4	E5	F6	G7	H8	I9	J10	K11	L12	M13	N14
Organic															
Young Child (5-7)	14	8.91 (1.06)	14.52 (1.87)	8.94 (1.92)	11.30 (2.4)	12.29 (2.16)	10.85 (2.08)	10.95 (1.36)	7.32 (0.97)	12.66 (3.1)	7.72 (1.5)	9.92 (1.83)	18.23 (3.98)	11.2 (2.31)	17.59 (2.32)
Child (8-12)	88	7.15 (0.43)	10.14 (0.76)	9.93 (0.78)	5.25 (0.97)	8.58 (0.88)	7.20 (0.84)	10.00 (0.55)	6.4 (0.39)	8.03 (1.26)	6.03 (0.61)	8.12 (0.74)	16.4 (1.61)	12.61 (0.94)	12.54 (0.94)
Adolescent (13-18)	179	6.78 (0.29)	10.71 (0.52)	10.73 (0.53)	4.93 (0.66)	9.57 (0.6)	8.34 (0.58)	9.79 (0.38)	6.29 (0.27)	9.37 (0.86)	7.44 (0.42)	9.22 (0.51)	15.65 (1.10)	11.11 (0.64)	13.62 (0.64)
GID Type x Gender x Age															
Functional															
Male															
Young Child (5-7)	21	10.10 (0.86)	11.42 (1.51)	11.13 (1.55)	10.14 (1.94)	14.00 (1.75)	8.86 (1.68)	12.9 (1.10)	9.44 (0.78)	5.75 (2.51)	11.2 (1.21)	15.19 (1.48)	25.75 (3.21)	11.17 (1.87)	19.97 (1.88)
Child (8-12)	53	7.62 (0.54)	11.17 (0.95)	10.83 (0.97)	7.53 (1.22)	12.04 (1.1)	10.62 (1.06)	10.76 (0.69)	8.16 (0.49)	7.21 (1.58)	10.02 (0.76)	11.72 (0.93)	18.05 (2.02)	12.84 (1.17)	14.63 (1.18)
Adolescent (13-18)	19	6.7 (0.9)	11.93 (1.59)	9.75 (1.63)	5.41 (2.04)	11.31 (1.84)	7.57 (1.77)	10.64 (1.16)	6.94 (.82)	6.35 (2.63)	8.65 (1.28)	10.58 (1.55)	15.18 (3.38)	12.53 (1.96)	19.24 (1.97)
Female															
Young Child (5-7)	30	9.02 (.72)	12.78 (1.27)	11.59 (1.30)	11.55 (1.62)	11.01 (1.46)	12.34 (1.41)	11.81 (.92)	8.78 (.65)	9.05 (2.10)	11.83 (1.02)	12.71 (1.24)	19.19 (2.69)	13.21 (1.56)	19.10 (1.57)

Table 3. Continued

		A1	B2	C3	D4	E5	F6	G7	H8	I9	J10	K11	L12	M13	N14
Child (8-12)	68	7.29 (.48)	12.16 (.84)	10.25 (.86)	7.14 (1.08)	10.32 (.97)	9.7 (.94)	9.11 (.61)	6.81 (.44)	4.85 (1.39)	7.68 (.68)	10.41 (.82)	19.9 (1.79)	12.58 (1.04)	12.84 (1.04)
Adolescent (13-18)	72														
Organic		6.51 (.46)	12.05 (.82)	12.18 (.84)	8.16 (1.05)	11.53 (.94)	10.32 (.91)	10.43 (.60)	7.23 (.42)	7.51 (1.35)	7.63 (.66)	10.06 (.80)	18.76 (1.74)	11.47 (1.01)	14.17 (1.01)
Male															
Young Child (5-7)	8	9.48 (1.39)	15.73 (2.45)	10.5 (2.51)	16.46 (3.14)	14.88 (2.83)	13.06 (2.73)	10.25 (1.79)	8.13 (1.27)	11.96 (4.06)	10.6 (1.97)	11.11 (2.39)	24.31 (5.21)	9.04 (3.02)	16.68 (3.04)
Child (8-12)	54	6.75 (.53)	8.91 (.94)	8.55 (.97)	5.59 (1.21)	8.5 (1.09)	6.03 (1.05)	9.72 (.69)	6.27 (.49)	8.94 (1.56)	6.09 (.76)	7.58 (.92)	15.13 (2.00)	11.95 (1.16)	11.8 (1.17)
Adolescent (13-18)	89	6.00 (.42)	9.22 (.74)	9.75 (.75)	4.37 (.94)	8.56 (.85)	6.86 (.82)	9.23 (.54)	6.11 (.38)	8.57 (1.22)	7.44 (.59)	8.52 (.72)	14.42 (1.56)	10.37 (.91)	12.1 (.91)
Female															
Young Child (5-7)	6	8.33 (1.6)	13.31 (2.83)	7.37 (2.9)	6.13 (3.63)	9.70 (3.27)	8.64 (3.15)	11.65 (2.06)	6.51 (1.46)	13.36 (4.69)	4.85 (2.27)	8.74 (2.76)	12.14 (6.01)	13.36 (3.49)	18.51 (3.51)
Child (8-12)	34	7.55 (.67)	11.37 (1.19)	11.31 (1.22)	4.9 (1.52)	8.65 (1.37)	8.36 (1.32)	10.28 (.87)	6.52 (.62)	7.12 (1.97)	5.96 (.95)	8.66 (1.16)	17.67 (2.53)	13.26 (1.47)	13.28 (1.48)
Adolescent (13-18)	90	7.56 (.41)	12.21 (.73)	11.71 (.75)	5.49 (.94)	10.59 (.84)	9.83 (.81)	10.36 (.53)	6.46 (.38)	10.18 (1.21)	7.44 (.59)	9.92 (.71)	16.88 (1.55)	11.84 (.90)	15.13 (.91)

*$p < 0.05$, **p < 0.01, ***$p < .001$

Stomach Pain and Hurt[A1], Stomach Discomfort When Eating[B2], Food and Drink Limits[C3], Trouble Swallowing[D4], Heartburn and Reflux[E5], Nausea and Vomiting[F6], Gas and Bloating[G7], Constipation[H8], Blood in Poop[I9], Diarrhea[J10], Worry About Going Poop[K11], Worry About Stomach Aches[L12], Medicine[M13], Communication[N14]

Parent-Child Discrepancy of PedsQL™ GI Symptoms Scales

Between-Subjects Effects and Interactions: GID Type, Child Gender, and Child Age. A main effect of GID type was found, F (1, 532) = 4.30, p = .039, η^2 = .008, such that parent-child discrepancy was higher for FGIDs (M = 11.14, SE = .29) than for OGIDs (M = 10.10, SE = .41). A main effect of child age was found, F (2, 532) = 5.50, p = .004, η^2 = .02, such that young children (ages 5-7 years; M = 12.06, SE = .62) were higher in parent-child discrepancy than children (ages 8-12 years; M = 9.83, SE = .29) and adolescents (ages13-18 years; M = 9.96, SE = .30), which were similar in parent-child discrepancy. No other significant main effects or interactions were found.

Within-Subjects Effect and Interactions: HRQOL GID Symptoms Domains. A main effect of GID symptoms domains was found, F (7.47, 3,973.05) = 47.55, p < .001, η^2 = .082. Results of all pairwise comparisons of GI symptoms are listed on Table 5 (p. 48).

An interaction of GID symptoms domains and GID type emerged, F (7.47, 3,973.05) = 2.76, p = .001, η^2 = .005, such that differences between GID symptoms domains varied based on GID type. Therefore, listings of pairwise comparisons between GID symptoms domains separated by GID types were generated. Results of all pairwise

comparisons of GID symptoms domains within FGIDs are presented on Table 6 (p. 49). Results of all pairwise comparison within OGIDs are presented on Table 7 (p. 51). No other significant main effects or interactions were found.

Table 4. Pairwise comparisons of GID symptoms domains

	A1	**B2**	**C3**	**D4**	**E5**	**F6**	**G7**	**H8**	**I9**	**J10**	**K11**	**L12**	**M13**	**N14**
Mean (SE)	7.74 (.24)	11.86 (.43)	10.41 (.44)	7.74 (.55)	10.92 (.49)	9.35 (.47)	10.59 (.31)	7.28 (.22)	8.40 (.71)	8.29 (.34)	10.43 (.42)	18.12 (.90)	11.97 (.53)	15.62 (.53)
Stomach Pain and Hurt[A1]														
Stomach Discomfort When Eating[B2]	A<B *p*<.001													
Food and Drink Limits[C3]	A<C *p*<.001	B>C *p*=006												
Trouble Swallowing[D4]		B>D *p*<.001	C>D *p*<.001											
Heartburn and Reflux[E5]				D<E *p*<.001										
Nausea and Vomiting[F6]	A<F *p*=.001	B>F *p*<.001		D<F *p*<.01	E>F *p*=.004									
Gas and Bloating[G7]	A<G *p*<.001	B>G *p*<.001		D<G *p*<.001		F<G *p*=.02								
Constipation[H8]		B>H *p*<.001	C>H *p*<.001		E>H *p*<.001	F>H *p*<.001	G>H *p*<.001							
Blood in Poop[I9]		B>I *p*<.001	C>I *p*=.01		E>I *p*=.002		G>I *p*=.002							
Diarrhea[J10]		B>J *p*<.001	C>J *p*<.001		E>J *p*<.001	F>J *p*=.04	G>J *p*<.001	H<J *p*=.002						

Table 4. Continued

	A1	B2	C3	D4	E5	F6	G7	H8	I9	J10	K11	L12	M13	N14
Worry About Going Poop[K11]	A<K *p*<.001	B>K *p*=.006		D<K *p*<.001				H<K *p*<.001	I<K *p*=006	J<K *p*<.001				
Worry About Stomach Aches[L12]	A<L *p*<.001	B<L *p*<.001	C<L *p*<.001	D<L *p*<.001	E<L *p*<.001	F<L *p*<.001	G<L *p*<.001	H<L *p*<.001	I<L *p*<.001	J<L *p*<.001	K<L *p*<.001			
Medicine[M13]	A<M *p*<.001		C<M *p*<.008	D<M *p*<.001		F<M *p*<.001		H<M *p*<.001	I<M *p*<.001	J<M *p*<.001	K<M *p*=.008	L>M *p*<.001		
Communication[N14]	A<N *p*<.001	B<N *p*<.001	C<N *p*<.001	D<N *p*<.001	E>N *p*<.001	F<N *p*<.001	G<N *p*<.001	H<N *p*<.001	I<N *p*<.001	J<N *p*<.001	K<N *p*<.001	L>N *p*=.01	M<N *p*<.001	

Table 5. Pairwise comparisons of GID symptoms domains for FGIDs

	A1	B2	C3	D4	E5	F6	G7	H8	I9	J10	K11	L12	M13	N14
Mean (SE)	7.87 (.28)	11.892 (.42)	10.41 (.44)	8.32 (.63)	11.70 (.57)	9.90 (.55)	10.94 (.36)	7.90 (.25)	6.79 (.81)	11.78 (.48)	10.43 (.42)	19.47 (1.04)	12.30 (.61)	16.66 (.61)
Stomach Pain and Hurt[A1]														
Stomach Discomfort When Eating[B2]	A<B *p*<.001													
Food and Drink Limits[C3]	A<C *p*<.001													

Table 5. Continued

	A1	B2	C3	D4	E5	F6	G7	H8	I9	J10	K11	L12	M13	N14
Trouble Swallowing[D4]		B>D *p*<.001	C>D *p*<.001											
Heartburn and Reflux[E5]	A<E *p*<.001			D<E *p*<.001										
Nausea and Vomiting[F6]	A<F *p*=.001	B>F *p*=.001		D<F *p*=.02	E>F *p*=.004									
Gas and Bloating[G7]	A<G *p*<.001			D<G *p*<.001										
Constipation[H8]		B>H *p*<.001	C>H *p*<.001		E>H *p*<.001	F>H *p*<.001	G>H *p*<.001							
Blood in Poop[I9]		B>I *p*<.001	C>I *p*<.001		E>I *p*<.001	F>I *p*=.001	G>I *p*<.001							
Diarrhea[J10]	A<K *p*<.001	B>J *p*<.001	C<10 *p*=.01		E>J *p*<.001		G>J *p*=.002	H<J *p*<.001	I<J *p*=.001					
Worry About Going Poop[K11]	A<K *p*<.001			D<K *p*<.001		F>K *p*=.003		H<K *p*<.001	I<K *p*=.001	J>K *p*<.001				
Worry About Stomach Aches[L12]	A<L *p*<.001	B<L *p*<.001	C<L *p*<.001	D<L *p*<.001	E<L *p*<.001	F<L *p*<.001	G<L *p*<.001	H<L *p*<.001	I<L *p*<.001	J<L *p*<.001	K<L *p*<.001			
Medicine[M13]	A<M *p*<.001		C<M *p*=.049	D<M *p*<.001		F<M *p*=.001	G<M *p*=.03	H<M *p*<.001	I<M *p*<.001	J<M *p*<.001		L>M *p*<.001		
Communication[N14]	A<N *p*<.001	B<N *p*<.001	C<N *p*<.001	D<N *p*<.001	E>N *p*<.001	F<N *p*<.001	G<N *p*<.001	H<N *p*<.001	I<N *p*<.001	J<N *p*<.001	K<N *p*<.001	L>N *p*=01	M<N *p*<.001	

Table 6. Pairwise comparisons of GID symptoms domains for OGIDs

	A1	B2	C3	D4	E5	F6	G7	H8	I9	J10	K11	L12	M13	N14
Mean (SE)	7.61 (.39)	11.79 (.70)	9.87 (.71)	7.16 (.90)	10.14 (.80)	8.80 (.77)	10.25 (.51)	6.67 (.36)	10.02 (1.15)	7.07 (.56)	9.09 (.68)	16.76 (1.48)	11.64 (.86)	14.59 (.86)
Stomach Pain and Hurt[A1]														
Stomach Discomfort When Eating[B2]	A<B p<.001													
Food and Drink Limits[C3]	A<C p<.001													
Trouble Swallowing[D4]		B>D p<.001	C>D p=.004											
Heartburn and Reflux[E5]	A<E p<.001			D<E p=.002										
Nausea and Vomiting[F6]		B>F p=.001												
Gas and Bloating[G7]	A<G p<.001	B>G p=.03		D<G p=.001										
Constipation[H8]	A>H p=.048	B>H p<.001	C>H p=.001		E>H p<.001	F>H p=.01	G>H p<.001							
Blood in Poop[I9]	A<I p=.04					F>I p=.001		H<I p=.002						
Diarrhea[J10]	A<K p<.001	B>J p<.001	C>J p=.001		E>J p<.001	F<J p=.04	G>J p<.001		I<J p=.008					
Worry About Going Poop[K11]	A<K p=.03	B>K p=.001						H<K p<.001		J<K p=.002				

Table 6. Continued

	A1	B2	C3	D4	E5	F6	G7	H8	I9	J10	K11	L12	M13	N14
Worry About Stomach Aches[L12]	A<L *p*<.001	B<L *p*<.001	C<L *p*<.001	D<L *p*<.001	E<L *p*<.001	F<L *p*<.001	G<L *p*<.001	H<L *p*<.001	I<L *p*<.001	J<L *p*<.001	K<L *p*<.001			
Medicine[M13]	A<M *p*<.001			D<M *p*<.001		F<M *p*=.01		H<M *p*<.001		J<M *p*<.001	K<M *p*=01	L>M *p*<.001		
Communication[N14]	A<N *p*<.001	B<N *p*=.006	C<N *p*<.001	D<N *p*<.001	E<N *p*<.001	F<N *p*<.001	G<N *p*<.001	H<N *p*<.001	I<N *p*=.001	J<N *p*<.001	K<N *p*<.001	X	M<N *p*=.001	

HRQOL Core Scale Elevation Comparisons

Between-Subjects Effects and Interactions: GID Type, Child Gender, and Child Age. All analyses in this section controlled for informant (child self-report vs. parent proxy-report) and other between-subjects variables in the model. A main effect of GID type was found, F (1, 546) = 17.24, $p < .001$, $\eta^2 < .001$, such that HRQOL was lower for FGIDs (M = 69.48, SE = .29) than for OGIDs (M = 77.10, SE = 1.51). No main effects of child gender or child age were found.

An interaction of child gender and child age emerged, F (2, 546) = 5.16, $p = .01$, $\eta^2 < .019$, such that the differences in child age varied by child gender. For female children, HRQOL was reported higher in young children (ages 5-7 years; M = 80.86, SE = 3.19) and children (ages 8-12 years old; M = 74.01, SE = 1.61) relative to adolescents (ages13-18 years; M = 69.27, SE = 1.19). HRQOL was similar between age groups for male children.

Within-Subjects Effects and Interactions: Informant and HRQOL Core Scale Domains. A main effect of HRQOL core scale domains was found, F (2.88, 1,571.04) = 81.97, $p < .001$, $\eta^2 = .013$, such that social functioning (M = 81.15, SE = 1.01) was reported higher than physical functioning (M = 76.16, SE = 1.07), emotional functioning (M = 69.78, SE = 1.19), and school functioning (M = 66.07, SE = 1.19). Physical functioning was reported higher than emotional functioning and school functioning. Emotional functioning was reported higher than school functioning. A listing of significant pairwise comparisons for the main effects of HRQOL domain is presented in Table 8 (p. 54)

An interaction between HRQOL core scale domains and child age emerged, F (7.76, 1,571.04) = 81.97, $p < .001$, $\eta^2 = .013$. An interaction among HRQOL core scale domains, child gender, and child age also emerged, F (5.76, 1,571.04) = 2.66, $p < .02$, $\eta^2 = .01$. A listing of significant pairwise comparisons for the interactions of HRQOL core scale domains, child gender, and child age is presented in Table 8 (p. 54).

Table 7. Average generic HRQOL separated by Domain, GID Type by Domain, Gender by Domain, Age by Domain, GID Type by Gender by Domain, GID Type by Age by Domain, Gender by Age by Domain, and GID Type by Gender by Age by Domain

		Physicala	**Emotionalb**	**Socialc**	**Schoold**	**Differences**
	n	Mean (SE)	Mean (SE)	Mean (SE)	Mean (SE)	
Domain	1,116	76.16 (1.07)	69.78 (1.19)	81.15 (1.01)	66.07 (1.19)	d<b<a<c***
GI Disorder Type						
Functional	570	72.51 (1.22)	66.13 (1.36)	77.66 (1.15)	61.62 (1.35)	
Organic	284	79.81 (1.76)	73.43 (1.97)	84.63 (1.66)	70.52 (1.95)	
Gender						
Male	257	75.63 (1.56)	69.27 (1.74)	79.12 (1.47)	63.43 (1.73)	
Female	298	76.7 (1.47)	70.29 (1.64)	83.17 (1.38)	68.71 (1.63)	
Age						
Young Child (5-7)	63	78.85 (2.69)[a]	73.48 (3)	81.28 (2.53)	71.36 (2.98)	
Child (8-12)	213	75.36 (1.25)[b]	68.82 (1.4)	79.63 (1.18)	65.28 (1.39)	
Adolescent (13-18)	279	74.28 (1.25)[c]	67.03 (1.39)	82.52 (1.17)	61.56 (1.38)	
Differences		a>c**				
GI Type x Gender						
Functional						
Male	102	71.91 (1.94)	64.93 (2.17)	74.09 (1.83)	58.77 (2.16)	
Female	169	73.11 (1.48)	67.32(1.65)	81.23 (1.39)	64.46 (1.64)	

Table 7. Continued

		Physicala	Emotionalb	Socialc	Schoold	Differences
Organic						
Male	155	79.34 (2.45)	73.61 (2.73)	84.15 (2.30)	68.08 (2.71)	
Female	129	80.29 (2.54)	73.25 (2.83)	85.11 (2.38)	72.95 (2.81)	
GI Type x Age						
Functional						
Young Child (5-7)	50	76.65 (2.54)	72.14 (2.83)	77.78 (2.39)	69.69 (2.82)	
Child (8-12)	124	71.27 (1.58)	65.15 (1.77)	75.63 (1.49)	58.72 (1.76)	
Adolescent (13-18)	97	69.62 (2.12)	61.09 (2.36)	79.58 (1.99)	56.44 (2.35)	
Organic						
Young Child (5-7)	13	81.04 (4.74)	74.82 (5.28)	84.78 (4.45)	73.04 (5.25)	
Child (8-12)	89	79.44 (1.94)	72.49 (2.17)	83.64 (1.83)	71.83 (2.16)	
Adolescent (13-18)	182	78.95 (1.31)	72.98 (1.47)	85.47 (1.24)	66.68 (1.46)	
Gender x Age						
Male						
Young Child (5-7)	50	75.39 (3.87)[a]	67.26 (4.31)	78.54 (3.63)	65.3 (4.29)[a]	
Child (8-12)	124	73.53 (1.66)[b]	68.81(1.85)	77.54 (1.56)	62.24 (1.84)[b]	
Adolescent (13-18)	97	77.96 (2.06)[c]	71.73(2.3)	81.28 (1.94)	62.74(2.29)c	
Female						
Young Child (5-7)	13	82.3 (3.73)[d]	79.7 (4.16)	84.02 (3.51)	77.43 (4.14)[d]	
Child (8-12)	89	77.18 (1.88)[e]	68.83 (2.1)	81.73 (1.77)	68.32 (2.08)[e]	
Adolescent (13-18)	182	70.61 (1.39)[f]	62.33 (1.56)	83.77 (1.31)	60.39 (1.55)[f]	
Differences		d>f***			d>f**, e>f**	

Table 7. Continued

		Physicala	Emotionalb	Socialc	Schoold	Differences
GI Type x Gender x Age						
Functional						
Male						
Young Child (5-7)	21	74.85 (3.87)	67.38 (4.31)	75.66 (3.63)	65.24 (4.29)	
Child (8-12)	58	67.4 (2.33)	62.95 (2.6)	70.08 (2.19)	53.9 (2.58)	
Adolescent (13-18)	23	73.5 (3.69)	64.46 (4.12)	76.55 (3.47)	57.17 (4.1)	
Female						
Young Child (5-7)	29	78.45 (3.29)	76.9 (3.67)	79.91(3.09)	74.14 (3.65)	
Child (8-12)	66	75.15 (2.15)	67.35 (2.4)	81.19 (2.02)	63.55 (2.38)	
Adolescent (13-18)	74	65.74 (2.06)	57.72 (2.3)	82.6 (1.94)	55.71 (2.28)	
Organic						
Male						
Young Child (5-7)	6	75.93 (6.7)	67.14 (7.47)	81.43 (6.3)	65.36 (7.43)	
Child (8-12)	56	79.66 (2.37)	74.68 (2.64)	85 (2.23)	70.58 (2.63)	
Adolescent (13-18)	93	82.42 (1.84)	79.01 (2.05)	86.01 (1.73)	68.31 (2.04)	
Female						
Young Child (5-7)	7	86.16 (6.7)	82.5 (7.47)	88.13 (6.3)	80.71 (7.43)	
Child (8-12)	33	79.21 (3.08)	70.3 (3.44)	82.27 (2.9)	73.09 (3.42)	
Adolescent (13-18)	89	75.49 (1.88)	66.95 (2.1)	84.93 (1.77)	65.06 (2.08)	

*$p < 0.05$, **p < 0.01, ***$p < .001$ based on

A main effect of informants was found, F (1, 1, 546) = 8.58, p = .004, η^2 = .02, such that child self-report (M = 74.56, SE = .95) was higher in HRQOL than parent proxy-report (M = 72.01, SE = 1.08). An interaction between informants and child gender emerged, F (1, 1, 546) = 4.06, p = .04, η^2 = .007, such that females (M = 74.32, SE = 1.48) were higher than males (M = 69.71, SE = 1.57) in HRQOL for parent proxy-report. An interaction between informants and HRQOL domains also emerged, F (2.96, 1614.50) = 4.43, p = .004, η^2 = .008, such that differences between domains depended on informant. Further, an interaction among informants, HRQOL domains, and child age, F (5.91, 1614.50) = 2.43, p = .03, η^2 = .009, such that differences between HRQOL core scale domains depended on informant and child age. A list of all significant pairwise comparisons regarding informants is present in Table 9 (p. 58). In addition, a list of all Pearson Correlation values, means, standard deviations of average HRQOL Core Scale Domains and Discrepancy by Informant is present in table 10 (p.61).

Table 8. Average generic HRQOL separated by Informant, Informant by Gender, Domain, Domain by Informant, Age by Domain by Informant

Informant	**n**	**Mean (SE)**				**Differences**
Child Self-Report	558	74.56 (.95)[a]				
Parent Proxy-Report	558	72.01 (1.08)[b]				
Differences		a>b				
Informant by Gender						
Male						
Child Self-Report	258	74.01(1.38)[a]				
Parent Proxy-Report	258	69.71(1.57)[b]				
Female						
Child Self-Report	300	75.11(1.3)[c]				
Parent Proxy-Report	300	74.32(1.48)[d]				
Differences		d<b				
Domain		**Physical[a]**	**Emotional[b]**	**Social[c]**	**School[d]**	
	n	Mean (SE)	Mean (SE)	Mean (SE)	Mean (SE)	
Domain x Informant						
Child Self-Report	558	77.77[a1] (1.10)	71.95[b1] (1.30)	82.48[c1] (1.07)	66.04[d1] (1.26)	d<b<a<c***

Table 8. Continued

Informant	n	Mean (SE)				Differences
Parent Proxy- Report	558	74.55[a2] (1.3)	67.6[b2] (1.4)	79.81[c2] (1.23)	66.1[d2] (1.38)	a>b***, a<c,*** a>d***, b<c***, c>d***
Differences		a1>a2**	b1>b2**	c1>c2**		
Age x Domain x Informant						
Child Self-Report						
Young Child (5-7)	64	79.38a1 (2.75)	75.63b1 (3.27)	80.84[c1] (2.69)	70.26[d1] (3.16)	a1>d1**, c1>d1***,
Child (8-12)	215	77.64a2 (1.28)	71.42b2 (1.53)	81.08[c2] (1.26)	66.77[d2] (1.48)	a2>b2***, a2<c2**, a2>d2***, b2<c2*** b2>d2**, c2>d2***
Adolescent (13-18)	279	76.29a3 (1.27)	68.81b3 (1.52)	85.52[c3] (1.25)	61.1[d3] (1.47)	d3<b3<a3<c3***
Differences between Age groups within Child Self-Report				c2>c3*	d1>b2**, d1>d3**, d2>d3**	
Parent Proxy-Report						
Young Child (5-7)		78.31a4 (3.26)	71.33b4 (3.51)	81.72c4 (3.08)	72.47[4] (3.46)	a4>b4*, b4<c4**, c4>d4**

Table 8. Continued

Informant	n	Mean (SE)				Differences
Child (8-12)		73.07a5 (1.52)	66.22b5 (1.64)	78.19c5 (1.44)	63.79[d5] (1.61)	a5>b5***, a5<c5***, a5<d5***, a5>d5***, b5<c5***, c5>d55***
Adolescent (13-18)		72.27a6 (1.51)	65.25b6 (1.63)	79.52c6 (1.43)	62.03[d6] (1.6)	a6>b6***, a6<c6***, a6<d6***, a6>d6***, b6<c6***, c6>d6***
Differences between Age groups within Parent Proxy-Report					a2>b2*, a2>c2**	
Differences between informants within Age groups and Domains		a2>a5***, a3>a6**	b2>b5***, b3>b6**	c2>c5*, c3>c6**	d2>d5*	

Table 9. Pearson Correlation Values and Means and Standard Deviations of Average HRQOL Core Scale Domains and Discrepancy by Informant

Domain	Correlation Between Informants	Child Self-Report Mean (SD)	Parent Proxy-Report Mean (SD)	Discrepancy Score Mean (SD)
Physical	.62	76.86 (18.79)	73.71 (22.07)	9.10 (5.34)
Emotional	.60	70.72 (22.67)	66.82 (23.71)	11.93 (6.77)
Social	.54	83.37 (88.30)	79.95 (22.66)	10.33 (7.52)
School	.63	64.17 (21.71)	64.64 (23.66)	11.78 (6.62)

Note: All correlations are significant at $p<.001$

CHAPTER IV

SUMMARY

The purpose of the present study was to investigate variance in parent-child discrepancy with regard to HRQOL core scale domains and GID symptoms domains. We proposed that HRQOL domains more difficult to observe by parent informants would be higher in parent-child discrepancy than domains more easily observed by parent informants. Controlling for GID type, child gender, child age, and with consideration to the four HRQOL core scale domains of functioning (i.e., physical, emotional, social, and school) examined in the present study, emotional functioning and school functioning were similar in parent-child discrepancy. However, emotional functioning and school functioning were higher in parent-child discrepancy than physical functioning and social functioning, which were similar in parent-child discrepancy.

An assumption is that emotional functioning may be the most difficult domain to observe and understand for parent informants, because the internal experience of emotional functioning for children is likely very subjective and nuanced. For this reason, it makes sense that emotional functioning yielded one of the highest quantities of parent-child discrepancy relative to other HRQOL core scale domains. Moreover, physical functioning yielded the lowest parent-child discrepancy, because abilities in areas of physical functioning are likely easier to observe and keep track of for parent informants. However, the difference between social functioning and school functioning with regard to parent-child discrepancy is less clear. Both social functioning and school functioning

assess aspects in abilities that occur within parent supervision, which may influence lower parent-child discrepancy, and, outside of parent supervision, which may influence higher parent-child discrepancy. Taking this into consideration, one might expect similar parent-child discrepancy. However, given the differences in parent-child discrepancy, which ultimately yielded lower discrepancy for social functioning than school functioning, reasons for a better alignment in perspective regarding social abilities might be related to natural environment providing a more variety of opportunities for a parent to observe social functioning. Social functioning may be observed in the home with social interactions among family members and friends, on sports teams, or when a child is involved in any community activity. However, school functioning, for the most part, might only be observed in school or at home when it is time for homework. This is further complicated by an item of school functioning, which specifically asks about paying attention in class. Parents likely receive only indirect information through summaries of the child's school performance from report cards, teacher reports, and the children themselves. With that said, parents likely do not directly observe much detail in school.

This finding showing HRQOL core scale domains more difficult to observe having lower parent-children discrepancy than HRQOL core scale domains more easily observed was also consistent in results comparing GID symptoms domains. Controlling for GID type, child age, and gender, the four types of GID symptoms domains highest in parent-child discrepancy were Stomach Pain and Discomfort when Eating, Worry about Bowel Movements (pooping), Medicine (functioning in medication compliance), and

Communication (communication of experience with presenting GI problems). Considering overall pairwise comparisons, these four GID symptoms domains were most consistently higher in parent-child discrepancy than most other GID symptoms domains. Stomach Pain and Discomfort when Eating and Worry about Bowl Movements are reasonable to understand as GID symptoms domains less easily observed by informants and require a an open interpretation of the child's internal experience, which makes higher parent-child informant discrepancy for these GID symptoms domains expected. However, the GID symptoms domains of Medicine and Communication have the potential to be viewed by each informant objectively in practical circumstances allowing one to reasonable expect lower parent-child discrepancy for these GID symptoms domains. Nonetheless, items within each of these GID symptoms domains are presented with a large subjective component, and, therefore, influenced by internal experience, which seems to highly influence parent-child discrepancy. For example, these items may include: "it is hard for me (my child) to swallow medicines" and "it is hard for me (my child) to explain my (his/her) illness to other people." For items like these, parent-proxy report might be based in objective performance. Do the children perform these tasks and how well do they seem to perform these tasks? However, child self-report is left widely open to subjective internal experience and could be interpreted as asking how hard or difficult a task is, rather than if they *can* perform these tasks. For this reason, it seems rational to understand how the GID symptoms domains of Medicines and Communication yielded high parent-child discrepancy. Four GID symptoms domains with the lowest levels of parent-child discrepancies are Stomach

Pain and Hurts, Trouble Swallowing, Constipation, and Blood in Poop. It is reasonable to speculate that each of these GID symptoms domains are easily observed, except for Stomach Pain and Hurt, because feeling pain and hurt is a subjective internal experience. However, items within this GID symptoms domain are presented such that that the informant is asked how often stomach pain, hurt, and aching occurs. The questions of frequency are objective and easier to understand among informants, rather than the degree to which something feels difficult. Given frequency seems to be a large component evaluated regarding Stomach Pain and Hurt, this GID symptoms domain is likely more easily observed by informants.

Taken together, differences in HRQOL domains of functioning generally support the hypothesis of the current study that easily observable HRQOL domains are lower in parent-child discrepancy than HRQOL domains more difficult to observe. These findings are consistent with Upton, Lawford, and Eister (2008), which found higher parent-child agreement for physical functioning in relation to social functioning and emotional functioning. Furthermore, these findings are also consistent with the results of Varni, Thissen et al. (2015), indicating parent-child informant discrepancies were lower for overt areas of HRQOL functioning, such as areas of physical functioning, and higher for subjective internal states.

Consistent across types of domains (HRQOL domains vs. GID symptoms domains), children with FGIDs were higher in parent-child discrepancy than children with OGIDs. These findings are robust given they are significant after controlling for child age, child gender, and HRQOL domains (Generic Core and GI symptoms).

Another interesting finding and further support for the significance of GID types in how informant reports vary, is the interaction of GID type and GID symptoms domains on parent-child discrepancy. In other words, this indicates that differences in parent-child discrepancy between GID symptom domains depend on GID type. However, given the 14 GID symptoms domains, which yield 91 unique comparisons between GID symptoms domains, several different outcomes between pairwise comparisons emerged that are inconsistent between GID types. Despite this, more outcomes of pairwise comparisons between GID symptom domains were similar than not for FGIDs compared to OGIDs. Overall, GID symptom domains for FGIDs showed a trend for higher parent-child discrepancy than OGIDs. In addition, consistent across GID types, more easily observed GID symptoms domains are lower in parent-child discrepancy than domains more difficult to observe. These findings are expressed in detail in Tables 4 and 5. Overall these findings support differences between GID symptom domains to be consistent across GID types, but with GID symptoms domains having overall higher parent-child discrepancy for FGIDs than OGIDs. These findings further support the significance of higher parent-child discrepancy for FGIDs relative to OGIDs.

With regard to parent-child discrepancy, child age and child gender were also considered with regard to variance in informant reporting and hypothesized as possible moderators of the effects of HRQOL generic core scale domains and GID symptoms domains on parent-child discrepancy. Controlling for HRQOL generic core scale domain, child gender, and GID Type, no variance existed in age group (ages 5-7, 8-12, and 13-18 years) regarding parent-child discrepancy of generic HRQOL. However, with

regard to child gender, controlling for HRQOL generic core scale domain, child age, and GID type, males were higher in parent-child discrepancy of generic HRQOL than females. This suggests a greater misalignment of general perspective between boys and their parents than for girls and their parents. Given this finding, it seems reasonable to speculate that the gender difference could be related to possible developmental differences in verbal communication patterns between genders or natural gender differences in inclination toward openness regarding functioning. Lesser developed verbal abilities for boys compared to girls would likely lead to a difference in alignment of perspectives between the two genders, as less detail or sophisticated information would be shared by boys. Furthermore, the same effect would also occur if this result was due to a natural difference in motivation/desire to share about details in functioning that is lower for boys than for girls.

Controlling for GID symptoms domains, child gender, and GID type, there was meaningful variance in age group (ages 5-7, 8-12, and 13-18 years) regarding parent-child discrepancy of GID symptoms, such that young children (ages 5-7 years) were higher in parent-child discrepancy than children (ages 8-12 years) and adolescents (ages 13-18 years, which were similar in parent-child discrepancy. Overall, previous research shows mixed findings regarding variance of parent-child perspectives in informant reporting based on child age. However, the findings of the present study are consistent with Varni, Burwinkle, Seid, and Skarr (2003) and Yi-Frazier et al. (2015), which found parent-child agreement increased with child age and parent-child discrepancy decreased with child age, respectively. This is similar to the present study's findings of parent-child

discrepancy decreasing with child age. Controlling for GID symptoms domains, child age, and GID type, no gender difference was found between males and females with regard to parent-child discrepancy of GID symptoms.

To broaden the investigation of the present study and yield information in regard to individual informants, this present study compared elevations (averages) in generic HRQOL with regard to informants (child self-report and parent proxy-report), HRQOL core scale domain (etc. physical, emotional, social, school) GID type, child gender, and child age. Average HRQOL between GID types was previously investigated in Varni, Bendo, Nurko et al. (2015), and FGIDs were lower in HRQOL than OGIDs for child self-report and parent proxy-report. However, the present study advances this finding by providing analyses, which statistically control for variance accounted for by informants, in addition to HRQOL core scale domains, child gender, and child age. Controlling for informant, HRQOL core scale domain, child gender, and child age, HRQOL was lower for FGIDs than OGIDs. Furthermore, within the same model, controlling for the same variables, no differences emerged in child gender or age groups. However, although no main effect of child age or child gender were found, an interaction of child gender and child age was found, which, showed within females, HRQOL was reported higher in young children (ages 5-7 years) and children (ages 8-12 years) relative to adolescents (ages 13-18 years). In contrast, HRQOL was similar between child age groups within males).

Furthermore, controlling for HRQOL core scale domain, GID Type, child gender, and child age, a main effect of informant was found, such that parent proxy-

report was lower in HRQOL than child self-report. Furthermore, although no main effect of gender emerged, an interaction of informant and gender was found, such that within parent proxy report, boys were lower in HRQOL than females. Furthermore, controlling for informant, GID type, child gender, and child age, differences between domains emerged, such that social functioning was reported highest in HRQOL and higher relative to physical functioning, emotional functioning, and school functioning. Physical functioning was reported higher in HRQOL than emotional functioning and school functioning. Emotional functioning was reported higher in HRQOL than school functioning.

Additionally, interactions emerged for HRQOL core scale domain by child age, HRQOL core scale domain by child gender by child age, HRQOL core scale domain by informant, and child age by HRQOL core scale domain by informant. All of these findings provide nuances and detailed information regarding differences in average HRQOL moderated by these variables.

Conclusions

Two findings regarding variance in informant reports from the present study were the most robust and consistent across all statistical models performed. These findings include differences in informant reports due to GID type and differences in informant reports between GID symptoms domains more easy to observe and domains less easily observed. For GID types (FGIDs vs OGIDs), this further solidifies support regarding differences in their nature. Regarding the present study, differences in nature between

GID types leads to overall differences in perceptions of informants. Given this finding, it seems reasonable to conclude that the lack of specific knowledge of the etiology of FGIDs (pending application of Rome IV updated guidelines and insights) sets a different pattern of perceptions of HRQOL core scales and GID symptoms between informants relative to OGIDs.

In addition, it is interesting that the presence of an FGID as a primary diagnosis leads to higher parent-child discrepancy and a lower average HRQOL, which implies more impairment in functioning related to HRQOL. Given this, it is noteworthy to link these findings and begin to speculate how this implies that misaligned perspectives are associated with lower HRQOL.

However, one might consider that it is purely the nature of FGIDs that accounts most for the lower HRQOL for FGIDs relative to OGIDs, with problems in misaligned perspectives (parent-child discrepancy) between parents and children having a minimal and non-significant effect. In addition, this notion is supported, as findings of the present study found lower HRQOL for FGIDs than OGIDs even after controlling for differences between informant reports.

In contrast, through considering evidence yielded by comparing HRQOL core scale domains, one can see that this view would be limited. This is because after controlling for GID type, the domains of generic HRQOL highest in parent-child discrepancy are also the domains of HRQOL associated with the lowest reported HRQOL. This is consistent across informants and remains consistent when controlling for informants. Taken together, emotional functioning and school functioning yielded

higher parent-child discrepancy than physical functioning and social functioning. Furthermore, interestingly, emotional functioning and school functioning are more impaired in HRQOL than physical functioning and social functioning. Again, these findings are controlling for variance accounted for by GID type, which suggests that regardless of specific knowledge of disease origin, these HRQOL core scale domains (e.g. emotional and school) yielded the lowest levels of functioning and are areas in which parents and children are most misaligned in perspectives of functioning. For this reason, it is evident that higher parent-child discrepancy is associated with lower functioning (e.g. emotional and school) in areas most difficult for informants to observe. Considering implications towards GID Types, children with FGIDs might be experiencing their most significant problems in areas difficult to observe, resulting in lower HRQOL relative to OGIDs. This inference is also true when considering GID symptom domains.

Limitations of the Present Study

Multiple limitations of the present study may be considered. First, the standards used to determine diagnoses of FGIDs based on Rome III criteria recently updated. However, this limitation is minimal, given the diagnostic criteria are similar between Rome III and Rome IV criteria for the common FGIDs considered in the present study. Furthermore, not all possible GIDs were able to be included in the study (e.g., Celiac Disease), which may limit generalizability of findings to all children with GIDs. In addition, a participant's categorization in a specific GID type was based solely off of their primary

diagnosis and primary diagnoses were made by board certified gastroenterologists judging predominant symptoms. With that said, one should keep in mind the heterogeneity within GID types, because participants might exhibit symptoms that are characteristic of other GIDs or conditions outside of primary diagnosis. This should also be considered when generalizing findings regarding GID type to all children with GIDs. Also, a single agreed upon standard or most popular statistical method for calculating item-level parent-child discrepancies does not exist, which could make it difficult to compare the findings of the present study to other studies that have evaluated parent-child discrepancy, and, more specifically, parent-child item-level discrepancy.

Future Research Directions and Implications for Evidence-Based Practice

Findings from the current study suggest that children with FGIDs are more impaired in HRQOL relative to children with OGIDs and are more discrepant between informants in reporting of HRQOL relative to children with OGIDs. This evidence is sufficient to re-think and modify the type of evidence-based practices used to treat these pediatric chronic health conditions. Such modifications should commence with efforts to reduce the level of discrepancy among informants and provide a better understanding among informants about a child's health condition and functioning as it relates to generic HRQOL. Generic HRQOL concerns developmentally critical areas of functioning for every child, and it is seems logical to believe that improving parent's and child's understanding of each other's perspective should cultivate a situation in which is it easier to improve a child's physical, social, emotional, and school functioning, especially for

domains that are mostly subjective and difficult for informants to observe. Less misalignment or disagreement between parents and children should reduce the "mysteriousness" or "nonspecificity" of FGIDs, and help parents and their child better express to health service providers the intensity, frequency, and quality of target issues globally affecting the child's functioning. This should create better odds in being able to effectively address quality improvement for health services and maintenance of chronic health condition in everyday life.

Lastly, given findings of the present study, it can be concluded that the domains usually yielding lowest HRQOL for children with GIDs are also the same HRQOL domains parent and children are the least aligned in perspectives. These accentuate the need for more research into HRQOL for other pediatric chronic health condition to investigate if the same pattern is present. Furthermore, a better understanding regarding the directionality between more impaired HRQOL and higher parent-child discrepancy is needed. In other words, more research should be conducted examining statistical predictions to provide more insight for clarification as to whether impaired HRQOL leads to higher parent-child discrepancy or higher-parent child discrepancy leads to more impaired HRQOL.

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