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My Child's Keeper: Child Vulnerability and Quality of Life on Parental Stress and Grit

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MY CHILD'S KEEPER: CHILD VULNERABILITY AND QUALITY OF LIFE
ON PARENTAL STRESS AND GRIT

by

Abigail Armstrong

A Thesis
Submitted to the Graduate School,
the College of Education and Human Sciences
and the School of Psychology
at The University of Southern Mississippi
in Partial Fulfillment of the Requirements
for the Degree of Master of Arts

Approved by:

Dr. Bonnie Nicholson, Committee Chair
Dr. Emily Yowell
Dr. Michael Madson

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ABSTRACT

There is a reciprocal relationship between parenting stress and child distress that has been well documented (e.g., Rechenberg, Grey & Sadler, 2017). These effects generalize to physical outcomes such that higher maternal depression has been associated with poorer child health-related quality of life (HRQOL; Jaser, Whittemore, Ambrosino, Lindemann, & Grey, 2008). In the same way that parental distress has been shown to affect the child, parental perceptions of child vulnerability in children with chronic illness has also been associated with negative outcomes, including child depressive symptoms (Mullins et al., 2004), increased health care use (Spurrier et al., 2000), and increased child anxiety (Anthony, Gil, & Schanberg, 2003). Further, few studies have considered positive variables which may be associated with positive HRQOL. One such factor is grit, or the tenacity to persevere (Duckworth, Peterson, Matthews, & Kelly, 2007). Given the role that stress may play in HRQOL, and the lack of research exploring correlates which guard against poor outcomes, the current study aimed to examine the mediating role of perceived child vulnerability within the relationship between parental stress, grit, and child HRQOL. A sample of 67 parents of children with Postural Orthostatic Tachycardia Syndrome (POTS) completed a basic demographic questionnaire, the Parental Stress Scale (Berry & Jones, 1995), the Child Vulnerability Scale (Forsyth, Horwitz, Leventhal, Burger, & Leaf, 1996), the Short Grit Scale (Duckworth & Quinn, 2009), and the Pediatric Quality of Life Inventory 4.0 (Varni, Seid, & Kurtin, 2001). Child vulnerability did not mediate the relationship between parental stress and HRQOL or grit and HRQOL.

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CHAPTER I – INTRODUCTION

The number of children in the United States with a chronic health condition has doubled from 12.8% in 1994 to 26.6% in 2006 (Journal of the American Medical Association, 2010).

Postural Orthostatic Tachycardia Syndrome (POTS) is a demanding chronic health condition that is estimated to impact between 1,000,000 and 3,000,000 of these Americans (Grubb, 2008). According to Grubb, Calkins, and Rowe (2005) POTS is characterized by a heart rate increase of 30+ beats per minute within 10 minutes of standing or a head-up tilt, in the absence of orthostatic hypotension. Patients with POTS are likely to report heart palpitations, fatigue, lightheadedness, an intolerance to physical exercise, nausea, diminished concentration, tremors, fainting, and near fainting episodes (Karas, Grubb, Boehm, & Kip, 2000). Symptoms can range in severity and interfere with normal daily activities such as, bathing, housework, and even eating. POTS typically co-occurs with a variety of other chronic conditions, which are listed in Table 1 (see Appendix A).

Similar to parents of children with other chronic illnesses (Mussatto, 2006), parents of children with POTS are exposed to a number of potential stressors because they have to maintain their regular parenting role while also caring for a child with a chronic health condition. This can include a number of daily tasks like monitoring the child's fluid and salt intake, ensuring they take their daily medication(s), wearing specialized compression stockings or other mobility aids, getting plenty of sleep, and pacing their activity levels throughout the day (KidsHealth, 2018). Compared to families with healthy children, families with chronically ill children have reported a series of

negative effects such as, high levels of stress (Hatton & Emerson, 2003; McIntyre, Blacher & Baker, 2002), low well-being (Baker, Blacher & Olsson, 2005; Blacher & McIntyre, 2006), negative feelings related to parenting (McIntyre, Blacher & Baker, 2002; Maes, Broekman, Dosen & Nauts, 2003), lower marital satisfaction (Stefl, 1983), and financial strain (Hunfeld, Perquin, Duivenvoorden, Hazebroek-Kampschreur, Passchier & van Suijlekom-Smit, 2001). These effects often impact children's emotional and physical health. For example, higher maternal depression was associated with poorer child health related quality of life (HRQOL; Jaser, Whittlemore, Ambrosino, Lindemann, & Grey, 2008) and parental stress was associated with stress symptoms in the child (Rechenberg, Grey & Sadler, 2017), as well as poorer child adjustment (Mullins, Fuemmeler, Hoff, Chaney, Van Pelt, & Ewing, 2004).

While parenting stress has been shown to impact child outcomes in both healthy and chronically ill children, the mechanisms that affect these relationships need additional investigation (Takeuchi, Williams, & Adair, 1991; Mullins et al., 2004; Streisand, Braniecki, Tercyak, & Kazak, 2001; Manuel, 2001). Further, the impacts of positive parenting variables (e.g., variables associated with resilience) are understudied in populations of chronically ill families. Therefore, the purpose of this study was to examine perceptions of child vulnerability as a mediator in the relationship between parenting factors (stress and grit) and child HRQOL.

Child Health-Related Quality of Life

According to the Office of Disease Prevention and Health Promotion (2014), HRQOL is a multi-dimensional concept that includes the mental, social, emotional, and physical functioning of a person with a chronic illness. HRQOL has been found to

contribute to well-being and may be associated with psychological distress often experienced by people who have a chronic illness. Ojelabbi, Graham, Haighton, and Ling (2017) suggest that psychological distress can exacerbate the symptoms of a chronic illness and worsen the course of the disease. Because it contributes to well-being, HRQOL is an important construct to consider when evaluating the effects of illness and health management (Ojelabi et al., 2017). Despite the clear impact on a person's prognosis, HRQOL is not given the attention it demands in the health management of chronic illness or supporting literature (Chakraborty & Chaudhury, 2015).

Varni, Limbers, and Burwinkle (2007) conducted a study comparing over 2,500 chronically ill children, clustered into 33 disease categories, to over 9,500 healthy children to investigate differences in HRQOL. Patients with diabetes, gastrointestinal conditions, cardiac conditions, asthma, obesity, end stage renal disease, psychiatric disorders, cancer, rheumatologic conditions, and cerebral palsy reported significantly worse overall HRQOL than healthy children. Similarly, both Wallandar and Varni (1998) and Varni and colleagues (2007) found that chronically ill children are likely to experience worse physical, social, emotional, and school functioning in comparison to healthy children. Further, for some health conditions (i.e., fibromyalgia) self-reported HRQOL and symptom scales may be the only indicators of disease activity and/or treatment effects (Acquadro et al., 2001; Willke, Burke, & Erickson, 2004; Shelman, Eisen, Burwinkle, & Varni, 2006).

A select few studies have examined the relationship between parental emotional distress and the child's HRQOL. Of these studies, higher parental stress (Moreira et al., 2013; Kazak & Barakat, 1997), higher maternal depression (Jaser et al., 2008), and higher

perceived child vulnerability (Hullmann, Wolfe-Christensen, Meyer, McNall-Knapp, & Mullins, 2010) were found to be related to lower HRQOL. If a relationship between family functioning and the child's HRQOL exists, it may be due to the parent's emotional distress in the same way that parental stress is related to stress symptoms in the child.

Some research has also examined how positive parenting qualities may be related to HRQOL for children with chronic illness. Parenting responsiveness was found to improve HRQOL in a sample of children with diabetes (Botello-Harbaum, Nansel, Haynie, Iannotti, & Simons-Morton, 2008). Aran, Shalev, Biran, and Gross-Tsur (2007) found that children that rated their parents as more supportive and accepting of them also reported high levels of HRQOL in a sample of children with cerebral palsy. Parents allowing their child more autonomy and independence, despite their disability, was also associated with higher levels of HRQOL. Parenting style also affected the child's HRQOL over and above, severity of illnesses, IQ, socioeconomic status, and anxiety level (Aran et al., 2007). Few studies have accounted for positive parenting variables associated with family functioning which may positively impact HRQOL. Therefore, a secondary aim of the current project was to consider grit, or the tenacity to persevere (Duckworth et al., 2007), as one possible mechanism that positively impacts HRQOL and which also may impact perceived child vulnerability.

It is important to note that most of this research has been conducted with families and children managing Type 1 Diabetes. Therefore, further research is needed to expand our understanding of the impact of parental stress on HRQOL in samples of children with other chronic illness.

Parental Stress

Parenting stress can be defined as stress directly related to the role of being a parent (Abidin, 1995). As previously stated, the child's chronic illness and associated medical responsibilities impact the entire family system. Once a child is diagnosed with a chronic illness, the parent must face the upsetting news of their child's diagnosis, the associated treatments, new daily responsibilities, and possibly even a shortened life expectancy (Cousino, & Hazen, 2013).

Parents usually take considerable responsibility for treatment management (Drotar, 2006). Caring for a child with a chronic illness becomes increasingly demanding, resulting in increased levels of parental stress (Cousino & Hazen, 2013; Moreira, Frontini, Bullinger, & Canavarro, 2013). A number of studies have found that parents of chronically ill children experience more stress than parents of healthy children that do not have to deal with these everyday stressors (i.e., Crist et al., 1994; Goldberg, Morris, Simmons, Fowler, & Levison, 1990; Quittner et al., 1998; Solomon & Breton, 1999; Powers et al., 2002).

Research suggests that parenting stress can affect the child physically or psychologically (Mullins et al., 2004; Streisand et al., 2001; Manuel, 2001). Parenting stress has the potential to interfere with the management of the child's chronic health condition (Streisand et al., 2001). For example, research examining parents of children with sickle cell disease found that higher parental stress at baseline was associated with greater disease severity and more frequent health care utilization one year later (Barakat et al., 2007), and greater disease severity and more routine and urgent health care utilization (Logan, Radcliffe, & Smith-Whitley, 2002). In research investigating

caregivers of children with asthma, lower parental stress was found to be linked to better prognosis and medication adherence (Celano, Klinnert, Holsey, & McQuaid 2011; DeMore, Adams, Wilson, & Hogan, 2005).

Mullins and colleagues (2004) quantified some of the effects of parental stress on a chronically ill child's psychological functioning. Specifically, parenting stress moderated the relationship between perceived vulnerability and depressive symptoms in children with diabetes. Manuel (2001) found that higher parental stress in caregivers of children with arthritis was related to greater family conflict and greater parental psychological distress.

Parents of children with chronic illness were likely to have higher levels of stress due to the increased amount of daily responsibilities they face (i.e., Crist et al., 1994; Goldberg, Morris, Simmons, Fowler, & Levison, 1990; Quittner et al., 1998; Solomon & Breton, 1999; Powers et al., 2002). Higher parental stress has been linked to greater disease severity (Barakat et al., 2007), parents perceiving their child as more vulnerable (Mullins et al., 2004) and lower HRQOL for the child (Moreira et al., 2013; Kazak & Barakat, 1997). However, there is still hope. Positive psychological traits and their impact on physical illnesses are beginning to be examined in the context of chronic illness (Park et al., 2016). One of these traits is grit.

Grit

Grit can best be defined as a commitment to long-term goals and the ability to persist despite any barriers (Duckworth, Peterson, Matthews, & Kelly, 2007). Individuals with higher levels of grit are more likely to strive for goals that take years to achieve, rather than seeking immediate satisfaction, which differentiates grit from the more short-

term characteristic known as conscientiousness (Duckworth et al., 2007). Grit has been associated with a number of important predictors of long-term success such as, graduating high school, college grade point average (GPA; Cross, 2014), academic retention (Duckworth et al., 2007), psychological well-being (Vainio & Daukantaite, 2016), and life satisfaction (Singh & Jha, 2008).

Grit has also been shown to be associated with variables similar to quality of life. For example, grit has been associated with healthy functioning and overall well-being (Hill, Burrow, & Bronk, 2016; Salles, Cohen, & Mueller, 2014; Sheridan, Boman, Mergler, & Furlong, 2015; Singh & Jha, 2008). Overall, grit has been further associated with variables that make up subjective well-being, such as, life satisfaction (Salles, Cohen, & Mueller, 2014), happiness (Vainio, & Daukantaité, 2016) and lower distress (Sing & Jha, 2008).

It is plausible to consider that having high levels of grit may also impact parenting tenacity and the ability to persist in caring for a chronically ill child. However, only one study thus far has investigated the relationship of grit with HRQOL (Sharkey et al., 2017). Sharkey and colleagues (2017) investigated the role of grit in college student health, more specifically, in relationship to health care management skills and HRQOL. Grit was found to be positively related to HRQOL and healthcare management skills in healthy college students. Furthering their research, Sharkey et al (2018) examined grit in a population of college students with a chronic medical condition. Higher grit was related to lower levels of depressed and anxious symptomology and was directly related to increased emotional wellbeing.

While studies have not specifically examined grit in relation to caring for a chronically ill child, traits similar to grit, such as resilience, have. Early research examining resilience suggests that higher resilience helps improve coping and emotional well-being, which may also lead to better self-care (Burton, Pakenham, & Brown 2010; Carver, 2005). Resilience has been found to impact one's ability to manage the difficult treatment and lifestyle requirements associated with diabetes (Yi-Frazier et al., 2010). Individual resilience may also promote healthy choices and positively impact quality of life, while reducing negative consequences, such as psychological distress in both caregivers and children (Eilertsen, Hjemdal, Le, Diseth, & Reinfjell, 2016; Fergus & Zimmerman, 2005; Folkman, 1997; Fraser & Pakenham, 2009; Kim & Knight, 2016; Miller et al., 2017; Rew & Horner, 2003).

Another similar trait that has been investigated is family hardiness. Family hardiness can be defined as the family's ability to work together to combat stressors and figure out solutions to a variety of problems (McCubbin, Thompson & McCubbin, 1996). Svavarsdottir, McCubbin and Kane (2000) found the hardiness was related to parents' overall well-being in a sample of parents of children with asthma. Further, in a cross-sectional research study that examined families that had children diagnosed with asthma from Iceland and the United States found that parents that scored low on depression measure and high on well-being measures also had higher hardiness (Svavarsdottir & Rayens, 2005).

Horton and Wallander (2001) have suggested that there is a lot of individual variation from parent to parent in the amount of distress they experience in parenting their chronically ill child. This suggests that simply having a child with a chronic illness

is not enough to cause a parent to have significant distress and instead the individual's disposition may play an important role in determining outcomes (Mednick et al., 2007). An important disposition that is very similar to grit and that may be a protective factor is called high-hope thinking (Horton & Wallander, 2001). Individuals with higher hope set higher goals for themselves and perceive they will be successful at achieving these goals, even when faced with obstacles. Horton and Wallander (2001) and Mednick et al. (2007) both found that mothers of children with chronic illness that had higher hope also had lower distress, despite facing their child's illness.

High hope is very similar to grit, in that they both involve a commitment to reach goals despite barriers. However, grit goes a step further than high-hope thinking. Compared to a person with high-hope thinking, a person with grit is more likely to persist despite any obstacles and consistently strive towards long-term goals (Duckworth et al., 2007). Grit has also been found to be positively related to HRQOL in a population of healthy college students (Sharkey et al., 2017). Considering the previous research, it is plausible to hypothesize that grit will be positively associated with higher rates of HRQOL in this population.

While there are some studies linking stress and grit to HRQOL, the mechanisms responsible for this relationship are less clear. One variable, perceived vulnerability, or the tendency to perceive a chronically ill child as more impaired than they are, may help explain these connections.

Perceived Vulnerability

Parental perceptions of child vulnerability are a set of cognitions that describe a parent's anxiety about their child's health (Green & Solnit, 1964). Parental perceptions of

vulnerability reflect the parent's attitudes or beliefs and may be distinct from actual capabilities of the child (Thomasgard & Metz, 1997). According to Thomasgard and Metz (1997), these perceptions also include the conscious and unconscious perceptions of fear related to the child's health. Research suggests that having a child with a chronic illness facilitates the development of feelings of perceived child vulnerability to subsequent illness, injury, or even death (Thomasgard, 1998). In this way, perceived vulnerability can be characterized as a fear-induced response to illness (Thomasgard & Metz, 1997), rather than a characterization of actual vulnerability.

Perceived child vulnerability has been shown to impact the adjustment of the child with a chronic illness (Lopez, Mullins, Wolfe-Christensen, & Bourdeau, 2008). Hullman, Wolfe-Christensen, Meyer, McNall-Knapp, and Mullins (2010) found that higher perceived child vulnerability was related to lower HRQOL in patients with cancer. Spurrier and colleagues (2000) found that parents of child with asthma that perceived their child as more vulnerable utilized more healthcare, such as giving their child preventive medication, taking their child to the physician for acute asthma care, and keeping their child home from school more frequently. Higher levels of both perceived child vulnerability and parental stress have been linked to child-reported depressive symptoms in children with diabetes (Mullins et al., 2004). In this same study, parental stress moderated the vulnerability-depression relationship and magnified the relationship between perceived child vulnerability and child-reported depressive symptoms (Mullins et al., 2004). Vance, Morse, Jenney, and Eiser (2001) found that parents of children with acute lymphoblastic leukemia who reported more parental stress related to their child's

illness and higher perceived child vulnerability also reported lower HRQOL for their children.

Higher perceived child vulnerability has been linked to lower HRQOL (Hullmann, Wolfe-Christensen, Meyer, McNall-Knapp, & Mullins, 2010) and higher parental stress (Mullins et al., 2004). Given the connection between perceived vulnerability and both parental stress and HRQOL, the current study proposes that perceived vulnerability may be one mechanism linking parental stress to HRQOL such that parents with higher levels of stress are more likely to perceive greater vulnerability in their chronically ill child and this may impact HRQOL. While no studies to date have investigated the relationship between grit and perceived vulnerability, it is plausible to consider that grit may be similarly related to perceived vulnerability and HRQOL.

The Current Study

HRQOL has been shown to impact disease progression and psychological outcomes in children (Ojelabbi, et al., 2017; Chakraborty & Chaudhury, 2015). Several predictors of HRQOL have been explored, and generally center around parenting as one salient predictor (Moreira et al., 2013; Kazak & Barakat, 1997; Jaser et al. 2008). Specifically, parenting stress is repeatedly shown to impact chronically ill children's outcomes (Moreira et al., 2013; Kazak & Barakat, 1997). Interestingly, only a few studies have investigated positive predictors of HRQOL (Sharkey et al., 2017). Specifically, one such study found preliminary evidence linking grit and HRQOL, however additional investigation with differing populations is necessary to understand this construct with parents of chronically ill children. Therefore, the current study investigated both

parenting stress and grit (a facet of resilience) as predictors of HRQOL in a sample of parents of children with POTS.

Perceived vulnerability is often associated with both parenting stress (Mullins et al., 2004), and lower HRQOL (Hullmann, Wolfe-Christensen, Meyer, McNall-Knapp, & Mullins, 2010). Therefore, the current study also investigated whether parenting stress and grit predicted HRQOL and whether perceived vulnerability mediated these relationships.

The study hypotheses were as follows:

H1: The significant inverse relationship between parental stress and child's health related quality of life will be mediated by perceived vulnerability.

H2: The relationship between grit and child's health related quality of life will be mediated by perceived vulnerability.

CHAPTER II – METHODS

Participants

Ninety-five participants initiated the survey link. Of these, 27 did not meet inclusion criteria (i.e., they were not the primary caregiver of a child or adolescent from 8 to 17 diagnosed with POTS and/or the child/adolescent they are reporting on did not receive a diagnosis at least 6 months prior to the study), so they were removed from analyses.

The final sample included 67 participants who were majority female (98.5%), with an average age of 44.85 years ($SD = 7.06$). Most were White/non-Hispanic parents (97.0%) and married (73.1%). For a more detailed description of participant's demographics, see Table 1.

Children consisted of 10 males (14.9%), 56 females (83.6%), and one transgender child (1.5%) with a mean age of 14.4 ($SD = 2.20$). The sample included 65 White/non-Hispanic children (97.0%) and two children who identified as other (3.0%). The mean severity of the children's POTS was 69.9 on a scale of 100 ($SD = 15.03$). Participants reported that 42 (62.7%) of these children have been diagnosed with other chronic conditions. 36 (53.7%) are currently being treated for these conditions. Participant answers to the survey indicated that ten of these children have been diagnosed with a learning disability (14.9%) and six are currently being treated for them (9.0%). Twenty-four (35.8%) of these children have been diagnosed with a mental health problem and nineteen (28.4%) of them are currently being treated for their mental health problem. Three (4.5%) of these children reported having behavioral problems in the past and one (1.5%) reported currently having behavioral problems.

Table 2. *Demographic Characteristics of the Sample*

Characteristic (Range)	<i>M</i>	<i>SD</i>
Participant age (25-58)	44.85	7.06
Child age (8-17)	14.40	2.20
	<i>N</i>	<i>%</i>
Participant Gender		
Male	1	1.5
Female	67	98.5
Participant Race		
White/non-Hispanic	66	98.5
Other Racial Groups	1	1.5
Marital Status		
Single, never married	2	3.0
Married	49	73.1
Living with partner	2	3.0
Widowed	2	3.0
Divorced	10	14.9
Separated	2	3.0
Education		
High school degree or equivalent	6	9.0
Some college	17	25.4
Associate degree	10	14.9
Bachelor's degree	13	19.4
Some graduate school	5	7.5
Master's degree	13	19.4
PhD	2	3.0
MD	1	1.5
Race of child		
White/non-Hispanic	65	97.0
Other	2	3.0
Gender of child		
Male	10	14.9
Female	56	83.6
Transgender	1	1.5
Characteristic (Range)	<i>M</i>	<i>SD</i>
Severity of POTS	69.90	15.03
	Yes	No
	<i>N (%)</i>	<i>N (%)</i>
Diagnosed with other chronic conditions?	42 (62.7)	25 (37.3)
Being treated for it?	36 (53.7)	6 (9.0)
Diagnosed with learning disability?	10 (14.9)	57 (85.1)
Being treated for it?	6 (9.0)	4 (6.0)
Diagnosed with a mental health problem?	24 (35.8)	43 (64.2)
Being treated for it?	19 (28.4)	6 (9.0)

Ever have any behavioral problems?	3 (4.5)	64 (95.5)
Currently have behavioral problems?	1 (1.5)	2 (3.0)

Procedure

This study was reviewed and approved by the University of Southern Mississippi’s Institutional Review Board Human Subjects Protection Review Committee (Appendix B). Parents of children with POTS were recruited online for participation using social media, and word of mouth recruitment. To participate in the study, participants needed to endorse being the primary caregiver of a child or adolescent from 8 to 17 diagnosed with POTS at least 6 months prior to participation. Participants completed an informed consent (Appendix C) and all other questionnaires through Qualtrics. The study took approximately 10 minutes to complete. Validity checks were included in the questionnaires prompting participants to respond in a specific way (i.e., Please select “Strongly Agree”). No participants had to be removed for answering both attention checks incorrectly.

Measures

Demographic Questionnaire. Participants were first asked to answer questions pertaining to the inclusion criteria for the study (i.e., will have to be the primary caregiver of a child or adolescent from 8 to 17 diagnosed with POTS and the child/adolescent they are reporting on will have to have received the diagnosis at least 6 months prior to the study). Previous research in chronic illness has required participants to be diagnosed 6 months prior to participating in the study (Moreria et al., 2013; Mednick et al., 2007; Anthony et al., 2011) and be aged 8-17 (Anthony et al., 2011; Cousins et al., 2015), which is why these criterion were chosen.

Participants were asked to report their age, race, ethnicity, gender, marital status, employment status, educational status, and household income, how many other children, if any are in the home, and if these other children had been diagnosed with any chronic health conditions. Participants will also be asked to report the age, race, ethnicity, gender, and age of diagnosis for their child. Additional questions regarding their medical condition are included, including any additional medical diagnoses their child has and then they were also asked to rate which medical condition they believe affects their child's life the most. See Appendix D for this measure.

Parental Stress Scale (PSS). Parental stress was measured using the Parental Stress Scale (PSS; Berry & Jones, 1995), an 18-item self-report measure assessing positive and negative components of parenthood. Participants were asked to rate their experiences with stress on a 5-point Likert scale (1=*Strongly Disagree* to 5=*Strongly Agree*) with eight positive items that are reverse scored. Items include things like “Caring for my child(ren) sometimes takes more time and energy than I have to give” and “The behavior of my child(ren) is often embarrassing or stressful to me.” With total scores ranging from 18-90, higher scores indicate higher levels of parental stress. Past literature has reported acceptable levels of internal consistency (Cronbach's $\alpha = .83$) and test-retest reliability ($r = .81$; Berry & Jones, 1995). Internal consistency for the PSS in the current study was acceptable ($\alpha = .87$).

Child Vulnerability Scale (CVS). Child vulnerability was assessed using the Child Vulnerability Scale (CVS; Forsyth et al., 1996), an eight-item measure, self-report measure assessing parent's perception of their child's vulnerability. Participants were asked to rate their perception of their child's vulnerability on a 4-point Likert scale (0=

Definitely False to 3= *Definitely True*) with higher scores indicating more perceived vulnerability. Items include statements such as, “I often check on my child at night to make sure s/he is okay” and “Sometimes I get concerned that my child doesn't look as healthy as s/he should.” With total scores ranging from 0 to 24, higher scores indicate more perceived vulnerability. Previous research has found the CVS to have acceptable internal consistency reliability (Cronbach's $\alpha = .74$; Forsyth et al., 1996) and test-retest reliability ($r = .84$; Thomasgard & Metz, 1997). Internal consistency for the CVS in the current study was acceptable ($\alpha = .79$).

Short Grit Scale (GRIT-S). Participant's grit was measured using the short grit scale (GRIT-S; Duckworth & Quinn, 2009), an 8-item self-report measure that evaluates two constructs of grit: perseverance and consistency of effort. Participants were asked to rate each item on a 5-point Likert scale (1 = *Not like me at all* to 5 = *Very much like me*).

Items include statements such as, “Setback don't discourage me” and “I am diligent.”

The grit score is calculated by adding up all of the points and then dividing by eight, with higher scores indicating higher levels of grit. Previous literature has found the GRIT-S to have acceptable reliability ($\alpha = .82$; Duckworth & Quinn, 2009; $\alpha = .77$; Eskreis-Winkler, Shulman, Beal, & Duckworth, 2014). Internal consistency for the GRIT-S in the current study was acceptable ($\alpha = .77$).

Pediatric Quality of Life Inventory 4.0, Parent-Proxy Report (PedsQL 4.0). Parental perception of child's quality of life was measured using the Pediatric Quality of Life Inventory 4.0 (PedsQL 4.0; Varni et al., 2001), a 23-item, self-report measure designed to assess health-related quality of life in both healthy populations and chronically ill populations. Participants were asked to rate their perception of their child's health related

quality of life on a 5-point scale (0 = *not at all a problem* to 4 = *almost always a problem*). Items include statements such as, “Hard to lift something heavy” and “Hard to take bath or shower,” and are reversed scored such that higher scores indicating higher quality of life. Scores can range from 0-100. The PedsQL 4.0 parent proxy-report has been found to have acceptable levels of internal consistency reliability (Cronbach’s $\alpha = .90-.95$; Varni et al., 2001). Internal consistency for the PedsQL 4.0 in the current study was acceptable ($\alpha = .90$).

CHAPTER III – RESULTS

Data Screening

Data from individuals with children aged 8-17, did not miss both attention checks, and completed at least 75% of the survey were included in analyses. Prior to analyses, data was screened for any missing data. Little's missing completely at random (MCAR) test was conducted to determine if values were likely missing at random (Little, 1988). Missing data points were determined to be missing at random and were replaced using estimated means imputation, which replaces the missing value with the mean of the available data (Beale & Little, 1975).

Preliminary Analyses

Diagnostics were also conducted to determine if there were any influential points. Studentized residual values were examined and points determined to be influential (i.e., points that increased or decreased by more than $\frac{1}{2} SD$ from their subsequent value) and one data point was removed. Data was also examined to determine if there were any leverage values or standardized DFFITS increasing or decreasing by 67%. Means, standard deviations, and correlations were also conducted to gain a better understanding of the basic relationship between the variables.

Homoscedasticity, normality of residuals, and multicollinearity were evaluated next. Homoscedasticity was evaluated by an inspection of the histogram of the predicted value and standardized residual of the dependent variable. To assess for multicollinearity, tolerance and VIF values were assessed. For the assumption to be met tolerance values must be more than 0.2 and VIF values have to be lower than ten. Both tolerance and VIF values were appropriate across all measures. Skewness and kurtosis were assessed by

calculating pseudo-z scores, which are calculated by dividing the kurtosis statistic by the associated standard error. The value should not exceed + or – 3. Values were appropriate across all measures.

Table 3. Means, standard deviations, and correlations of Study Measures (N = 68)

Measure	1	2	3	4	M	SD
1. PSS	—	.147	-.324**	-.403**	43.59	8.64
2. CVS		—	.057	-.259*	22.61	4.65
3. GRIT-S			—	.045	28.72	3.91
4. PedsQL				—	31.96	11.28

Note. PSS = Parental Stress Scale; CVS = Child Vulnerability Scale; GRIT-S = Short Grit Scale; PedsQL = Pediatric Quality of Life Inventory 4.0, Parent-Proxy Report

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

Multiple correlations and one-way ANOVAs were conducted to assess the potential effects of covariates on study variables. Bivariate correlations indicated that parent’s age, race, ethnicity, marital status, highest level of education, household income, number of other children in the home, child’s age, race, ethnicity, were not significantly related to parental stress, perceived vulnerability, grit, or child’s HRQOL. One-way ANOVAs revealed that there were significantly lower child vulnerability scores for children that had other chronic health conditions versus children that did not $F(20, 65) = 2.04, p < .05$, therefore, having more than one chronic health condition was included as a covariate.

Primary Analyses

To investigate the hypotheses a simple mediation analysis was performed using model 4 in PROCESS for SPSS. Parental stress significantly predicted HRQOL ($F_{(1, 65)} = 6.33, p < .01$), accounting for 16.5% of the variance. Child vulnerability also significantly predicted HRQOL ($F_{(1, 65)} = 4.59, p < .05$), accounting for 6.7% of the variance. Given that relationship between parental stress and HRQOL. Grit was not a significant predictor of HRQOL ($F_{(1, 65)} = .138, p = .69$), therefore a mediation model was not established.

Perceived vulnerability did not mediate the relationship between parental stress and HRQOL. As Figure 1 illustrates, the standardized regression coefficient between parental stress and HRQOL was statistically significant. The standardized regression coefficient between parental stress and perceived vulnerability was not statistically significant and neither was the standardized regression coefficient between perceived vulnerability and HRQOL. The standardized indirect effect was $(.078)(-.48) = -.037$. We tested the significance of this indirect effect using bootstrapping procedures.

Unstandardized indirect effects were computed for each of 10,000 bootstrapped samples, and the 95% confidence interval was computed by determining the indirect effects at the 2.5th and 97.5th percentiles. The bootstrapped unstandardized indirect effect was $-.037$, and the 95% confidence interval ranged from $-.13$ to $.04$. Thus, the indirect effect was not statistically significant.

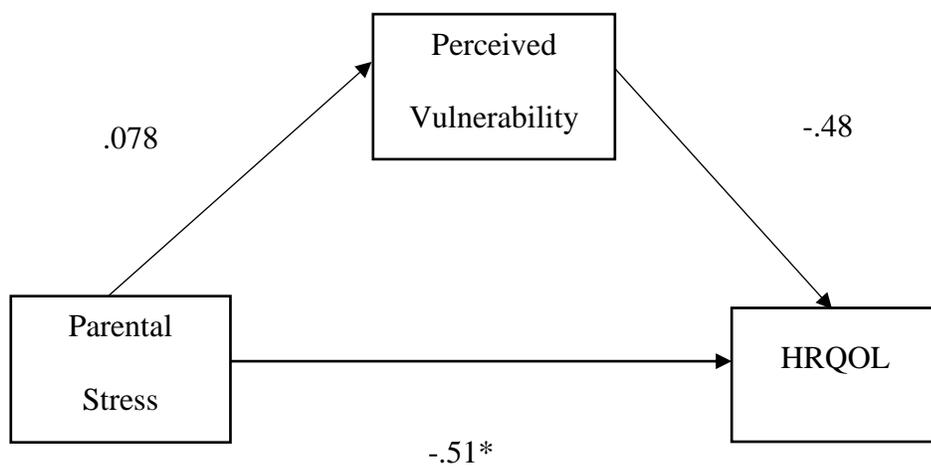


Figure 1. *Observed mediation model for the relationship between parental stress and HRQOL as mediated by perceived vulnerability.*

**p < .05*

CHAPTER IV – DISCUSSION

The purpose of the current study was to investigate whether perceived vulnerability mediated the relationship between parental stress and HRQOL and grit and HRQOL in a sample of parents of children with POTS. While parental stress significantly predicted HRQOL, perceived vulnerability did not mediate this relationship. Further, grit was not found to be a significant predictor of HRQOL, therefore a mediation model could not be established.

The first hypothesis posited the significant inverse relationship between parental stress and child's health related quality of life would be mediated by perceived vulnerability. Parental stress did significantly predict HRQOL, which is consistent with previous research that has linked parental stress and HRQOL (Moreira et al., 2013; Kazak & Barakat, 1997), and suggests that parents' distress can have some impact on children's experience with chronic illness. This is important because parents can work to cope with distress in a manner which may lead to more beneficial outcomes for chronically ill children. Child vulnerability also predicted HRQOL, which is also consistent with previous research that has linked child vulnerability and HRQOL (Hullmann, Wolfe-Christensen, Meyer, McNall-Knapp, & Mullins, 2010). Similarly, the more parents perceived their child as fragile or vulnerable, the more likely they would also be likely to report health-related lifestyle concerns. Contrary to our hypothesis however, perceived vulnerability did not mediate the relationship between parental stress and child's HRQOL. Overall, it appears that parental stress and child vulnerability do impact a child's HRQOL, but future studies will need to investigate other possible mechanisms to explain these relationships. Few studies have examined the relationship

between parental stress, perceived vulnerability, and HRQOL. While parental stress (Moreira et al., 2013; Kazak & Barakat, 1997) and perceived vulnerability (Hullmann, Wolfe-Christensen, Meyer, McNall-Knapp, & Mullins, 2010) were associated with lower HRQOL, perhaps this is not true for all chronic health conditions. Further, few studies have accounted for positive parenting variables associated with family functioning which may positively impact HRQOL. Positive parenting variables, such as parenting responsiveness, may better explain these relationships.

The second hypothesis posited that the relationship between grit and child's health-related quality of life would be mediated by perceived vulnerability. However, grit was not a significant predictor of HRQOL, so a mediation model could not be established. This is in contrast to the only other study that has examined the relationship between grit and HRQOL and found them to be related (Sharkey et al., 2017). However, this study was conducted with a sample of healthy college students. It is possible that grit does not significantly impact HRQOL for individuals with chronic health conditions. Further, few studies have examined the relationship between positive psychological traits and HRQOL. One variable that has been found to be associated with HRQOL is parenting style. Aran and colleagues (2007) found that parenting style positively affected the child's HRQOL over and above, severity of illnesses, IQ, socioeconomic status, and anxiety level.

Limitations

There are a few limitations that should be mentioned. While this is the first study to examine these variables in a sample of parents of children with POTS, the sample size was underpowered, which makes it more difficult to see the potential relationships

between variables. Another limitation is the survey was only published to online support groups for people that either have POTS or know someone with POTS. This only allows certain individuals to know about the study and makes it more likely that those who participated did so because they are passionate about the subject. For example, they may be more likely to complete the survey than someone in the general population who has a child with POTS and/or may be more likely to seek out information to help their child than others because they are already in support groups for those with POTS. This being said, results are likely not generalizable to all parents of children with POTS. Further, the severity of symptoms for this sample was relatively high, at almost 70 out of 100. This may not be representative of all children with POTS and also could have influenced parental stress, perceived vulnerability, and HRQOL. The sample was also predominantly White and female, which affects the generalizability of the findings to other races and genders.

This study also relied on self-report data, which has a variety of potential limitations, specifically recall bias. Recall bias can include a person forgetting an event entirely or remembers an event occurring in a different time-period than it actually did (Sudman & Bradburn, 1974). Furthermore, because this study was cross-sectional in nature, it can only provide information on how these specific variables are affecting parents of children with POTS at this point in time. Expanding on this limitation, it is not always appropriate to use mediation to examine cross-sectional data. While many researchers have used cross-sectional designs to test mediation, they have ignored any consideration of time, which plays an important role in mediation analysis. Overall, using mediation to examine cross-sectional data can result in biased estimates of mediation

parameters (Maxwell & Cole, 2007), so this should also be considered when interpreting results.

Areas for Future Research

To better understand the relationship between the variables in this study, future research may seek to explore these variables in a larger, more representative sample. Participants could be recruited from doctor's offices, POTS specialty clinics, online support groups, or in-person support groups. This would make the sample more generalizable and would also help increase sample size. Additionally, future research may seek to better understand the impact of having multiple chronic conditions has on both parents and the children. Having an additional chronic health condition is likely to cost more money and cause increased stress for the family; therefore, exploring this relationship may be important for future research. This sample also reported more severe symptoms, so future research may want to include efforts directed at recruiting or encouraging people with low or mild symptoms to also participate. Future research may seek to examine resilience, as opposed to grit, as POTS also requires difficult treatment and lifestyle changes. Resilience has been found to impact one's ability to manage the difficult treatment and lifestyle requirements associated with other chronic health conditions (Yi-Frazier at al., 2010), so this variable might be more appropriate for this sample due to the lifestyle changes an individual with POTS must make. Lastly, future research may also seek to examine the role of various covariates not examined in this study, such as parenting styles.

Conclusions

In conclusion, this is the first study to investigate parental stress, grit, perceived vulnerability, and HRQOL in a sample of parents of children with POTS. Contrary to the first hypothesis, perceived vulnerability did not mediate the relationship between parental stress and HRQOL. However, parental stress and perceived vulnerability did significantly predict HRQOL. This highlights the importance of how a parent's stress level and how vulnerable they perceive their child can impact their child's HRQOL. The second hypothesis, that perceived vulnerability would mediate the relationship between grit and HRQOL, was also not supported. Grit was not found to predict HRQOL. This may be due to the sample being underpowered or it may highlight the importance of investigating other positive variables that may be related to parental stress, perceived vulnerability, and HRQOL. The limitations of the current study including the small sample size, the survey only being published to online support groups for people with POTS or that know someone with POTS, the children's POTS severity level, the sample being predominantly White and female, and the cross-sectional nature of the study are important to remember when interpreting results. Future studies may seek to collect data from a variety of different locations, have a larger sample size, investigate the impact of having multiple chronic health conditions, and investigate the impact of covariates.

APPENDIX A – Common Conditions that Co-occur with POTS

Condition	Support
Chronic fatigue	Ocon, Messer, Medow & Stewart, 2012; Bagai, Song & Ling, 2011; Okamoto, Raj & Peltier, 2012
Fibromyalgia	Staud, 2008
Sleep disturbances	Bagai et al., 2011
Ehlers-Danlos syndrome Type III (mixed connective tissue disease)	Gazit, Nahir, Grahame & Jacob, 2003; Kanjwal, Saeed, Karabin, Kanjwal & Grubb, 2010
Chronic headaches and migraines	Thieben et al., 2007; Ojha, Chelimsky & Chelimsky, 2011; Mack, Johnson & Rowe, 2010
Type I Chiari malformation	Garland & Robertson, 2001

APPENDIX B – IRB Approval Letter

Office of
Research Integrity



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NOTICE OF INSTITUTIONAL REVIEW BOARD ACTION

The project below has been reviewed by The University of Southern Mississippi Institutional Review Board in accordance with Federal Drug Administration regulations (21 CFR 26, 111), Department of Health and Human Services regulations (45 CFR Part 46), and University Policy to ensure:

- The risks to subjects are minimized and reasonable in relation to the anticipated benefits.
- The selection of subjects is equitable.
- Informed consent is adequate and appropriately documented. Where appropriate, the research plan makes adequate provisions for monitoring the data collected to ensure the safety of the subjects.
- Where appropriate, there are adequate provisions to protect the privacy of subjects and to maintain the confidentiality of all data.
- Appropriate additional safeguards have been included to protect vulnerable subjects. Any unanticipated, serious, or continuing problems encountered involving risks to subjects must be reported immediately. Problems should be reported to ORI via the Incident template on Cayuse IRB.

The period of approval is twelve months. An application for renewal must be submitted for projects exceeding twelve months.

PROTOCOL NUMBER: IRB-19-337

PROJECT TITLE: MY CHILD'S KEEPER: CHILD VULNERABILITY AND GRIT ON PARENTAL STRESS AND QUALITY OF LIFE

SCHOOL/PROGRAM: School of Psychology, Psychology

RESEARCHER(S): Abigail Armstrong, Bonnie Nicholson

IRB COMMITTEE ACTION: Exempt

CATEGORY: Exempt

Category 2.(i). Research that only includes interactions involving educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures, or observation of public behavior (including visual or auditory recording). The information obtained is recorded by the investigator in such a manner that the identity of the human subjects cannot readily be ascertained, directly or through identifiers linked to the subjects.

APPROVED STARTING: July 30, 2019

Donald Sacco

Donald Sacco, Ph.D.
Institutional Review Board Chairperson

APPENDIX C – Informed Consent

ELECTRONIC INFORMED CONSENT

Project Title: My Child's Keeper: Child Vulnerability and Grit on Parental Stress and Quality of Life

Principal Investigator: Abigail Armstrong Phone: 901.287.1144 Email: abigail.armstrong@usm.edu

College: College of Education and Psychology Department: Psychology

PURPOSE: The present study seeks to better understand the relationship between child health-related quality of life, parental stress, perceived child vulnerability, and grit among parents of children with POTS.

DESCRIPTION OF STUDY: The present study will consist of completing several brief questionnaires on the Internet. Completion of the study should take approximately 15-30 minutes. Questions will be asked regarding your thoughts, feelings, and experiences.

BENEFITS: You will most likely not experience many benefits. However, the researchers hope this study will lead to a greater understanding of parenting, child health-related quality of life, and grit.

RISKS: The risks associated with your participation are minimal. You may find that a few questions may be difficult to answer or that you grow tired of answering questions. You may refuse to answer any question without penalty.

CONFIDENTIALITY: The records obtained from this study will be kept private. After the study is completed, a unique number will be assigned to your information. In any report that might be published using this data, no information will be included that will make it possible to identify any participant. Research records will be stored securely stored and only the researchers involved in this study will have access to the research records.

PARTICIPANT'S ASSURANCE: This project has been reviewed by the Institutional Review Board, which ensures that research projects involving human subjects follow federal regulations. Any questions or concerns about rights as a research participant should be directed to the Chair of the IRB at 601-266-5997. Participation in this project is completely voluntary, and participants may withdraw from this study at any time without penalty, prejudice, or loss of benefits. Any questions about the research should be directed to the Principal Investigator using the contact information provided in Project Information Section above.

Consent is hereby given to participate in this study.

APPENDIX D – Demographic Questionnaire

What is your age? _____

What is your race?

- White
- Black/African-American
- Asian-American
- Native American
- Native Hawaiian/Pacific Islander
- Other _____

What is your ethnicity?

- Hispanic
- Non-Hispanic

What is your gender?

- Female
- Male
- Transgender
- Other _____

What is your marital status?

- Single, never married
- Married or domestic partnership
- Widowed
- Divorced
- Separated

What is the highest level of education you have completed?

- Some high school education
- High school degree or equivalent (e.g., GED)
- Some college but no degree
- Associate's degree
- Bachelor's degree
- Some graduate education
- Master's degree
- PhD

Which of the following categories best describes your employment status?

- Part-time (less than 40 hours a week)

- Full-time (40 hours a week)
- Retired
- Disabled or unable to work

What is your total household income per year from all sources?

- \$0-\$24,999
- \$25,000-\$49,999
- \$50,000-\$74,999
- \$75,000-\$99,999
- \$100,000-\$124,999
- \$125,000-\$149,999
- \$150,000+

What is your religious affiliation?

- Atheism/Agnosticism
- Buddhism
- Christianity
- Hinduism
- Judaism
- Islam
- None
- Other (please specify) _____

How old is your child? _____

For the following questions, please select the child who you are currently filling the survey out in reference to (the child that has been diagnosed with POTS). Please respond to the following questions in reference to the one child you select.

What is your child's race?

- White
- Black/African-American
- Asian-American
- Native American
- Native Hawaiian/Pacific Islander
- Other _____

What is your child's ethnicity?

- Hispanic
- Non-Hispanic

What is this child's gender?

- Male
- Female
- Transgender
- Other _____

Has this child ever been diagnosed with a chronic health condition other than POTS?

- Yes
- No
- If yes: Is this child *currently* being treated for this chronic health condition?**
 - Yes
 - No

If yes, please describe the chronic health condition. _____

Has this child ever been diagnosed with a learning disability?

- Yes
- No
- If yes: Is this child *currently* being treated or receiving services for a learning disability?**
 - Yes
 - No

If yes, please describe the learning disability. _____

Has this child ever been diagnosed with a mental health condition?

- Yes
- No
- If yes: Is this child *currently* being treated for a mental health condition?**
 - Yes
 - No

If yes, please describe the mental health condition. _____

Has this child ever had behavioral problems?

- Yes
- No
- If yes: Does this child currently have behavioral problems?**
 - Yes
 - No

If yes: Please describe. _____

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