CHRONIC ILLNESS AND SIBLING RELATIONSHIPS IN CHILDHOOD: ASSOCIATIONS AMONG PARENTIFICATION, DIFFERENTIAL TREATMENT, AND COMMUNICATION

by

AMANDA B. COX

TRICIA WITTE, COMMITTEE CHAIR
SHERWOOD BURNS-NADER
THEODORE TOMENY

A THESIS

Submitted in partial fulfillment of the requirements
for the degree of Master of Science in the
Department of Human Development and Family Studies
in the Graduate School of
The University of Alabama

TUSCALOOSA, ALABAMA

2018

ABSTRACT

Using a retrospective survey design, adults who were raised with a chronically ill sibling were asked to report on levels of parentification, differential parenting, and communication/disclosure of the chronic illness during childhood and adolescence as well as the quality of their sibling relationship during childhood. Participants (N=107) were recruited via Amazon's Mechanical Turk (MTurk) and reported having a sibling with one of the following chronic illnesses: Cystic Fibrosis, Sickle-Cell Disease, Duchenne Muscular Dystrophy, Becker Muscular Dystrophy, or Hemophilia. A multiple regression examined whether sibling relationship scores could be predicted from sibling differential experiences with mother (Model 1a) and sibling differential experiences with father (Model 1b), with communication scores as a moderator. Results indicated that communication scores significantly predicted sibling relationship scores ($p < 0.05$) within both Model 1a and 1b. Additionally, sibling differential experiences with their father ($p = 0.0241$), but not mother ($p = 0.3273$), predicted sibling relationship scores. A multiple regression was performed to evaluate the degree to which sibling relationship scores could be predicted from parentification scores, with communication scores as a moderator (Model 2). Data analyses found that parentification scores were not predictive of sibling relationship scores. Communication scores significantly predicted relationship scores ($p < 0.05$), but the interaction (parentification score x communication score) was only marginally significant ($p = 0.0655$). These findings indicate that communication/disclosure of the chronic illness to the healthy sibling has important implications on the quality of the sibling relationship.

ACKNOWLEDGEMENTS

This thesis would not have been possible without the amazing support and guidance of Human Development and Family Studies Department here at the University of Alabama and Dr. Tricia H. Witte. I would also like to thank Dr. Sherwood Burns-Nader and Dr. Theodore Tomeny for their expertise, enthusiasm, and counsel through this project.

CONTENTS

LIST OF TABLES

LIST OF FIGURES

INTRODUCTION

Chronic illness is defined as a persistent condition or disease with incurable reoccurring symptoms that last longer than three months (American Academy of Pediatrics, 2017; Derouin & Jessee, 1996). Advances in medicine within in the last 20 years has greatly improved the outcomes for children with chronic diseases that were once considered untreatable and life-ending (Compas, Jaser, Dunn, & Rodriguez, 2012). Consequently, millions of children with chronic illness within the United States are now living longer than previously recorded (Waldboth, 2016).

Most research examining childhood chronic illness focuses on the ill child, while some studies also examine family dynamics, parents' perceptions of the ill child, and/or parental stress levels for certain forms if illness (e.g., childhood cancer) (O'Haver, 2010). Only a small proportion of studies have examined the impact of chronic illness on healthy siblings (O'Haver et al., 2010). It is unknown if healthy siblings experience parentification or perceive differential parenting during childhood and whether these experiences impact their relationship with the ill sibling. Furthermore, there is little concrete data on the impact of parental disclosure and communication about chronic illness on the healthy siblings' emotional and behavioral outcomes. Thus, the purpose of the present study was to investigate parentification, perceived differential parenting, and communication/disclosure of chronic illness as they relate to the quality of the relationship between healthy children and their chronically ill siblings.

LITERATURE REVIEW

Differential Treatment

Given the nature of childhood chronic illness, such as level of severity and complexity of the disease, dependence on family members and need for assistance may increase as the child ages. To meet the needs of the affected child, parents may be required to take on other responsibilities in addition to being the child's caretakers. Many parents will focus on the affected child and create a high level of dependency in that child (Murray, 2000a; Murray 2000b). Consequently, these parents may be unable to meet the healthy child's needs or may engage in differential parenting (Murray, 2000a; O'Haver, 2010).

Literature on the impact of differential parenting dates back to Sigmund Freund and Alfred Adler (Suitor et al., 2009). Both Freud and Adler postulated that children who were treated unfavorably were more likely to have decreased well-being, while children treated favorably were more likely to have increased well-being. Suitor et al. (2009) argues that theories of equity suggest that parental favoritism reduces the quality of sibling relationships, regardless of which child is favored, as the child who received more favoritism will experience guilt, while the child who experiences less attention will feel disappointment and anger. Suitor et al.'s (2009) study found that sibling closeness was lower when participants believed their mothers were currently closer/favored a specific child, regardless of whether the participant or another child was favored. Thus, theories of equity can be used to support research findings on the negative impact of differential parenting on siblings, even adult siblings, who perceive that their parents favor one child over the other, with the child who perceives inequity experiencing

discomfort, less closeness to their sibling, and greater conflict with their sibling (Suitor et al., 2009). Most of the research examining differential treatment has focused on healthy, typically-developing sibling pairs and has shown that adolescent's perception of parents' differential treatment is associated with maladjustment (Brody, Stoneman, & McCoy, 1992; Loeser, Whitemane, & McHale, 2016). However, studies examining differential treatment of children in families were a child has a chronic illness or condition have yielded conflicting findings on how healthy children perceive and respond to differential parenting and favoritism toward the sibling with a chronic illness. Healthy siblings' dissatisfaction with differential parenting, or parenting partiality, has been found to negatively impact their relationship with the ill sibling (Derouin & Jessee, 1996; Rivers & Stoneman, 2008). For example, Rivers & Stoneman (2008) found a relationship between healthy children's lack of understanding Autism Spectrum Disorder (ASD) and their negative perception of unfair differential parenting. Derouin and Jessee's (1996) examination of the healthy siblings' perception of family disruptions and self-esteem of healthy siblings of children with Cystic Fibrosis (CF) found that healthy children may harbor feelings of resentment and unhappiness when they perceive differential treatment.

Parentification

In 1997, Jurkovic first introduced "lost childhood" as a consequence of parentification, as it describes the experience of children who sacrificed their childhoods to assume the role of a parent and care for a sibling with an illness or disability, or taking over the parent's role in regard to other family responsibilities (e.g., taking care of other siblings who do not have an illness) so that their parents can better meet the needs of the sibling with an illness (Lamorey, 1999). Simply, parentification is a functional and/or emotional role reversal where the child assumes the roles and responsibilities of their parent (Hooper, 2007; Lamorey, 1999).

During the process of parentification, it is common for the parentified child to be emotionally available to his/her parents, while the parents remain unavailable to the child (Hooper, 2007). The parentified child's attempts at filling this emotional void can continue indefinitely, resulting in the parentified child's suppressing their own needs in order to meet the needs of their parents and sibling(s). Disturbances in the child's development can result in poor relationships, attachment issues, and poor differentiation of self from family of origin. Parentification can cause some siblings to become overburdened and internalize their sense of entity and self-worth as "little parents" (Lamorey, 1999).

Parentification of a sibling is likely to be a result of the disproportionate amount of parental attention (differential parenting) focused on the child with a chronic illness/condition, as parents become more involved with meeting the needs of sibling with a chronic illness, such as caregiving, teaching, training, and treatment activities (Lamorey, 1999). Sibling parentification may also be spurred by role confusion, guilt, anger, anxiety, and frustration, as well as sibling enmeshment and consistent behavioral patterns that reflect over-responsibility and caretaking (Lamorey, 1999). For example, in the case of pediatric cancer, families will likely redefine each person's role(s) within the family, with the healthy children taking over more roles (Hamama, Ronen, & Rahav, 2008). Taking on new roles can lead to feelings of the resentment towards the situation, parents, or affecting siblings, regardless if the new roles is imposed upon the healthy child or if they choose to take on new roles (Hamama, Ronen, & Rahav, 2008).

Communication

In the case of typically developing youth, Loeser, Whitemane, and McHale (2016) recommend that youth and parents engage in clear communication regarding the reasoning for differential treatment, as this can increase the likelihood of the adolescent perceiving the

treatment as fair, while mitigating sibling jealousy and maladjustment. However, there have been conflicting findings on the relationship between level of communication/disclosure of the illness and child outcomes in families where a child has a chronic illness (Derouin & Jessee, 1996; Plumridge et al., 2011). Differences in parents' communication and disclosure of information about the chronic illness is likely to vary by child (ill vs. healthy), disease severity, visibility of symptoms and/or disease traits, and transmission (Plumridge et al., 2011). In a study by O'Haver and colleagues (2010) examining risk and protective factors that affect the psychological adaptation of healthy siblings of a child with cystic fibrosis (CF), participants stated that they experienced little communication with the CF specialists. Similarly, only a small minority of parents reported that the healthy siblings had discussed CF at most doctor's appointment and very few of the participants (healthy siblings) reported having discussed the diagnosis of CF once with their parents.

Studies examining the relationship between differential treatment of typically developing children and communication found that in families where more disclosure occurred, the healthy children had better understanding of the chronic illness, their sibling, and their role in the family (Plumridge et al., 2011). Lobato & Kao (2002) examined the relationship between healthy siblings' level of knowledge of the chronic illness and their perception of sibling connectedness, as well as the use of an intervention (participation in camp) to increase level of knowledge. Overall, Lobato & Kao (2002) found that healthy siblings with greater knowledge of the chronic illness reported higher levels of sibling connectedness and had lower scores on negative adjustment scales. Similarly, Murray (2001) studied the impact of camp on self-concept of healthy siblings of children with cancer and found that the children whose families had more open communication scored higher on Personal Attribute Inventory for Children (PAIC), which

measures self-concept, and appeared to have less difficulty adapting (Murray, 2001). O'Toole et al.'s (2015) meta-analysis on chronic illness included several studies whose data indicated that communication and disclosure of the chronic illness with family members had positive consequences (e.g., communication as an effective coping strategy). Additionally, O'Toole et al. (2015) meta-analysis found no negative consequences reported by any of the studies included. In support of these findings, Plumridge et al. (2011) found that healthy children of families with less communication on their sibling's diagnosis were more likely to withdraw from the ill sibling and show higher levels of resentment towards their parents and siblings. Thus, communication may mitigate the healthy sibling's perception of unfair differential treatment and negative feelings towards their sibling who has chronic illness.

Sibling Relationship

Developmental psychologists believe that children learn social skills and appropriate interpersonal interactions through reciprocal relationships and experiences they have with older and younger siblings (Derouin & Jessee, 1996; Gorodzinsky et al, 2013). Sibling relationships can provide support throughout the individual's lifetime (Gorodzinsky et al, 2013). However, chronic illnesses and debilitating genetic conditions can result in changes to not only the patient-parent relationship, but the sibling relationship as well. These experiences can impact the siblings' relationship, potentially influencing the siblings' bond and interactions. For example, families of children with chronic illness, healthy siblings are likely to be potentially forgotten, disregarded, and neglected (Murray, 2000b), which can lead to feelings of resentment and jealousy (Ferraioli & Harris, 2009; Hamama, Ronen, & Rahav, 2008; Plumridge et al., 2011). Furthermore, healthy siblings' perceptions of parental favoritism toward their sibling with a chronic illness and feelings of rejection toward them have been associated with a more negative

sibling relationship (McHale, Sloan, & Simeonsson, 1986). In contrast, Malcolm et al. (2013) qualitative study on the impact of rare life-limiting conditions (LLCs), which are characterized by progressive and permanent physical and cognitive decline, on healthy siblings found that healthy siblings felt pride when caring for the affected child, rather than frustration or resentment. In addition, while healthy siblings reported experiencing social limitations and bullying due to their ill sibling's condition, all participants indicated feelings of protectiveness instead of embarrassment or resentment (Malcolm et al., 2013). Overall, there is conflicting and limited information on sibling's perception of their relationship with their sibling who has a diagnosis. Furthermore, there is little research on the impact of perceived differential treatment and parentification during childhood on the healthy sibling's perception of the sibling relationship and on the moderating role of communication/disclosure of the chronic illness.

METHODS

Hypotheses

Hypothesis 1: Communication levels will moderate the association between differential parenting and sibling relationship quality. With low levels of communication, there will be a negative association between differential parenting and sibling relationship quality.

Hypothesis 2: Communication levels will moderate the association between parentification and sibling relationship quality. With low levels of communication, there will be a negative association between parentification and sibling relationship quality.

Participants

Chronic illness is defined as a persistent condition/disease with reoccurring symptoms that last longer than 3-months (American Academy of Pediatrics, 2017). In this study, the following chronic conditions were chosen due to the relatively equal level of medical complexity related to acute and chronic care, require prolonged and/or frequent hospitalizations, and a predictable need for critical care interventions: Cystic Fibrosis (CF), Sickle-Cell Disease, Duchenne Muscular Dystrophy, Becker Muscular Dystrophy, Hemophilia. Furthermore, diseases that are curable (e.g. cancer) or are not one of the CDC's listed top ten leading causes of death for children (birth-18) (e.g. cancer, congenital anomalies, diabetes mellitus) were not chosen (CDC, 2017). In addition, participant age range was limited to 18-30 to reduce the flaws associated with long-term retrospective reporting. Furthermore, the age gap between participants and their siblings were limited to 6 years or fewer, as a means of ensuring that the participant and their sibling experienced the majority of each developmental stage at the same time.

Participants were recruited using Amazon's Mechanical Turk (MTurk), with location specification set to the United States. Of the 425 surveys submitted, 85 surveys were deleted because they had been viewed by potential participants but had not been started, and 25 surveys were deleted to because they were incomplete. Of the remaining 315 completed surveys, several were deleted because they failed to meet inclusion criteria. Inclusion criteria for participants were: 1) had a sibling diagnosed with one of the aforementioned chronic conditions, 2) they lived with a brother/sister who has a chronic illness for a minimum of 5-years during their childhood (birth – 18), 4) participants' age was between 18-30 years, and 5) the age gap between siblings was less than 7 years. Based on these inclusion criteria, 16 surveys were deleted because participants stated they did not have a sibling with a chronic illness, 105 surveys were discarded because participants reported having sibling with a chronic illness specified as "other" instead of one of the 5 conditions specified by the survey (Cystic Fibrosis, Sickle-Cell Disease, Duchenne Muscular Dystrophy, Becker Muscular Dystrophy, or Hemophilia), 71 surveys were discarded for not meeting the specified age criterion (i.e. age of participant exceeding 30 years), and 16 were discarded for not meeting the specified age gap between participant and sibling (e.g., age gap greater than or equal to 7 years).

Participants (n = 107) were 25.48 years old on average (SD = 3.3), with the majority of participants Caucasian (n = 67). Most participants were the oldest sibling in the family (n = 72). The ratio of sibling dyads are as follows: 39 pairs of male/male, 17 pairs of male/female, 24 pairs of female/male, and 25 pairs of female/female. The majority of participants had a sibling diagnosed with Cystic Fibrosis (n = 51), 24 participants had a sibling diagnosed with Hemophilia, 23 participants had a sibling diagnosed with Sickle Cell Disease (SCD), 7

participants had a sibling diagnosed with Duchene's Muscular Dystrophy, and 2 participants had a sibling diagnosed with Becker's Muscular Dystrophy.

Materials

Demographic Questionnaire. Participants completed a questionnaire (See Appendix M), which included questions on the participant's gender, age, birth order, as well as, their ill sibling's gender, age, birth order, and disease/condition. The questionnaire also included questions regarding parent marital status, parental level of education, parental job status, and household income.

Communication/Disclosure of Illness (CDI). A new questionnaire was developed to measure communication and disclosure of chronic illness information to the well-sibling (see Appendix N). The survey was created in collaboration with Dr. Sherwood Burns-Nader, an Assistant Professor at the University of Alabama's Department of Human Development and Family Studies. Dr. Burns-Nader's expertise is a Certified Child Life Specialist who has been certified by the Association of Child Life Professionals for 11 years and a preeminent scholar in the field.

The questionnaire is a 17-item self-report Likert scale, which includes statements related to: parental disclosure of sibling illness to the healthy child (e.g. Parents directly communicated information regarding sibling's illness/condition), questions about information gained from medical professionals (e.g. Doctor/nurse/medical professional directly communicated information regarding sibling's illness/condition), and questions pertaining to perceptions of open communication related to the sibling's diagnosis (e.g. My parents made it clear that I could discuss the topic of my sibling's chronic illness/condition with them whenever I felt the need). A reliability analysis was carried out on the CDI scale. Cronbach's alpha showed the questionnaire

to reach acceptable reliability ($\alpha = 0.93$). All items appeared to be worthy of retention, resulting in a decrease in the alpha coefficient if deleted. When summing items on this scale, missing data were substituted with the average score from the participants' answered questions, but only if participants completed at least 70% of the questionnaire (12 questions).

Parentification. Participants completed a modified version of Mika's (1987) Parentification Scale (PS; See Appendix O). The PS is a 30-item self-report assessment, designed to assess four types of parentification: child parenting his/her parent(s), child acting as a spouse to his/her parent, child parenting his/her siblings, and child taking on other roles generally taken by adults. Participants were asked to respond to the statements while recollecting their childhood. A composite score was calculated using the differential weights (Mika, 1987), with higher scores indicating higher levels of parentification. When creating composite scores, missing data were substituted with the average score from the participants' answered questions, but only if participants completed at least 70% of the questionnaire (21 questions).

Differential Treatment. The Sibling Inventory of Differential Experiences – Revised (SIDE-R; See Appendix P) was used to measure participants' perception of differential treatment by each parent toward themselves and their ill sibling. The SIDE-R is a 9-item self-report Likert scale, which requires participants to respond from 1 (Almost Never) to 4 (Almost Always) to statements regarding perception of parenting toward themselves (e.g. My mother/father has punished me for my misbehavior, My mother/father has shown an interest in the things I like to do) and toward their sibling (e.g. My mother/father has punished my brother/sister for his/her misbehavior, My mother/father has shown an interest in the things my brother/sister likes to do). The scale measures if differential parenting is perceived but does not specify if the parenting is

"positive" or "negative" in nature, as the scale does not apply differential weights depending on the type of differential treatment. Thus, the scale only measures if more or less attention was given to one or the other sibling. A discrepancy score was used to assess participants' perception of differential parenting, with negative scores indicating that the participant perceived more differential treatment towards themselves and positive scores indicating that the participant perceived more differential treatment towards their sibling with a chronic illness. Missing data was substituted with the average score from the participants' answered questions, but only if participants completed at least 88% of the questionnaire (8 questions) for each parent.

Sibling Relationship. Participants completed the Lifespan Sibling Relationship Scale (LSRS; Riggio, 2000; See Appendix Q). The LSRS is a self-report measure of sibling relationship quality and attitudes and provides an overall assessment of relationship quality by measuring affective, cognitive, and behavioral components of a sibling relationship (Riggio, 2000). The LSRS is composed of 48 items on a 5-point Likert scale from 1 (Strongly disagree) to 5 (Strongly agree) and higher scores indicate more positive attitudes about the sibling relationship. Only items that focused on participants' relationship with their sibling during childhood were used (24 items). Scores were summed to create a composite score, and missing data were substituted with the average score from the participants' answered questions, but only if participants completed at least 70% of the questionnaire (17 questions).

Procedure

University of Alabama's Institutional Review Board (IRB) approved of the study and all related amendments. A Qualtrics survey was disseminated by Amazon's Mechanical Turk (MTurk). The first page of the survey explained the premise of the study and was used as a means to gain implied consent (See Appendix A) Participants were paid $0.30 following

completion of the survey if they meet inclusion criteria. No identifying information was obtained, ensuring that responses remained anonymous.

RESULTS

Of the four independent variables (PS, SIDE-R Mother, SIDE-R Father, and CDI) only SIDE-R Father, $r(76) = 0.269$, $p = 0.017$, and CDI, $r(104) = 0.464$, $p < 0.001$, were significantly correlated to sibling relationship LSRS scores. Additionally, there was no significant correlation between PS scores and SIDE Scores (See Table 2). Multiple regression analyses were used to examine three conceptual models in SPSS 25 and Process 3.0 by Hayes (2017). Listwise deletions per analysis was used.

Model 1a and 1b. A multiple regression examined if sibling relationship scores (LSRS) could be predicted from differential parenting (SIDE-R) with mother (Model 1a) and with father (Model 1b), with communication scores (CDI) as a moderator. Model 1a included SIDE-R Mother Score, CDI, and the interaction (SIDE-R Mother Score x CDI) and was statistically significant, $n = 85$, $F(3, 81) = 8.76$, $p < 0.001$, $R^2 = 0.25$ (See Table 3). CDI was a statistically significant predictor of LSRS scores, $b = 0.4252$, $t(81) = 4.68$, $p < 0.001$, but SIDE-R Mother scores were not ($p = 0.3273$), and the interaction term was not ($p = 0.4488$) (See Table 4). This finding did not support the hypothesis; differential parenting with mother was not associated with the sibling relationship. However, level of communication predicted sibling relationship quality, such that higher levels communication/disclosure of chronic illness information to well-siblings predicted higher quality of their sibling relationship.

Model 1b included SIDE-R Father Score, CDI, and the interaction (SIDE-R Father Score x CDI) and was statistically significant, $n = 77$, $F(3, 73) = 9.94$, $p < 0.05$, $R^2 = 0.29$ (See Table 5). CDI scores, $b = 0.39$, $t(73) = 4.47$, $p < 0.001$, and SIDE-R Father, $b = 1.09$, $t(73) = 2.30$, $p =$

0.0241) were significant, but the interaction ($p = 0.1109$) was not (See Table 6). This finding indicates that father differential treatment does predict sibling relationship quality, with more differential treatment towards the sibling with a chronic illness by the father predicting higher sibling relationship quality scores. Additionally, level of communication predicted sibling relationship quality, such that higher levels communication/disclosure of chronic illness information to well-siblings predicted higher quality of their sibling relationship.

Model 2. A multiple regression examined if sibling relationship scores (LSRS) could be predicted by parentification scores (PS), with communication scores (CDI) as a moderator. Model 2 included PS, CDI, and the interaction (PS x CDI) and was statistically significant, $F(3,102) = 11.58$, $p < 0.05$, $R^2 = 0.25$ (See Table 7). However, PS was not a statistically significant predictor of LSRS scores, $b = -0.10$, $t(102) = -1.70$, $p = 0.0917$ (See Table 8). CDI was a statistically significant predictor of LSRS scores, $b = 0.44$, t (102) = 5.74, $p < 0.001$, such that higher levels communication/disclosure of chronic illness information to well-siblings predicted higher quality of their sibling relationship. The interaction, PS x CDI, was a marginally significant predictor of LSRS scores, $b = 0.0065$, $t(102) = 1.86$, $p = 0.0655$. In order to better understand the interaction, simple slopes were examined.

For low CDI scores, there was a significant negative association between PS and LSRS, $b = -0.23$, t (102) = -2.29, $p = 0.0241$, indicating that for those with less than average CDI scores, there was a 0.23 unit decrease to the total LSRS score for every 1-point increase in PS (See Figure 1). For both average and high CDI scores, however, there was no association between PS and LSRS ($b = 0.10$, $t(102) = -1.70$, $p = 0.0917$; $b = 0.02$, $t(102) = 0.23$, $p = 0.0819$). Overall, this finding indicates that for well siblings who receive less communication/disclosure of chronic illness regarding their sibling, parentification predicts poorer sibling relationship quality.

DISCUSSION

This study was conducted to fill the gap in the literature on the impact of childhood chronic illness on sibling relationships. Specifically, this cross-sectional survey study investigated the moderating role of communication and disclosure of chronic illness information on well-siblings' perceptions of parental differential treatment and parentification on the quality of the sibling relationship

Previous research has found that as family roles and responsibilities shift due to a diagnosis of childhood chronic illness, well-siblings are likely to experience differential parenting, such that the receive less attention (Derouin & Jessee, 1996; Murray, 2000a; Murray 2000b; O'Haver, 2010; Rivers & Stoneman, 2008), which can negatively impact on the quality of their relationship with the ill-sibling. In the present study, there was no predictive association between perception of differential parenting by the mother and sibling relationship quality, even with communication as a potential moderator. A predictive relationship between perception of differential parenting by the father and sibling relationship quality was found, however, such that more paternal parental attention towards the sibling with a chronic illness predicted higher sibling relationship quality. However, this study was unable to determine the nature (e.g. agreeableness vs. combativeness) and type (e.g. positive or negative) of paternal differential parenting towards the child with a chronic illness predicted. For example, if the differential treatment towards the sibling with a chronic illness consists of more positive differential treatment (e.g. praise, positive interactions), the father's attention may indirectly impact the well-sibling's perception of what is appropriate (i.e. how to play/interact with the sibling with a

chronic illness). This in turn, this may have fostered a sense of closeness and better sibling relationship. However, if the father's differential treatment towards the sibling with a chronic illness consists of more negative differential treatment (e.g. blaming the sibling for mistakes/problems), the well-sibling may have felt protective towards the sibling and a need to support and console them.

Parentification scores were not correlated with, nor did they predict, sibling relationship quality. However, there was marginally significant interaction between communication and parentification. This interaction indicated that parentification predicted poorer sibling relationship quality at low levels of communication, but not at average or high levels of communication. These findings suggest that good quality communication/disclosure of chronic illness information to well-siblings may buffer the effects of parentification on well-siblings' perception of the quality of their sibling relationship.

Overall, the significant contribution of communication in predicting sibling relationship quality, independently of parentification and differential parenting (i.e. as a main effect), suggests that level of communication is a critical determinant of sibling relationship quality, with higher quality the communication predicting better sibling relationship quality. This finding is not surprising, as the importance of communication and disclosure of illness to well-siblings on the well-sibling's ability to adapt has been well-documented (Murray, 2002; Wilkins & Woodgate, 2005), with findings indicating that the lack of communication can negatively impact well-siblings' relationships with their parents and sibling with a chronic illness (Plumridge et al., 2011; Sloper, 2000). This finding is further supported by Lobato & Kao's (2002) research, which found a positive relationship between the healthy sibling's level of knowledge of the

chronic illness and their perception of sibling connectedness; specifically, well-siblings with greater knowledge of the chronic illness reported higher levels of sibling connectedness.

Implications. Overall, these findings highlight the need for parents to communicate and disclose information regarding their child's chronic illness to their healthy child, as better communication and disclosure can help bolster adaptation and positive outcomes in the well-siblings, even despite the changing roles and parentification of the healthy child. Moreover, these findings support the efficacy of intervention strategies that focus on increasing communication and disclosure of chronic illness information to positively impact family relationships, as communication was found to be a statistically significant predictor of sibling relationship quality, regardless of other family dynamics (i.e. parentification and differential parenting). Lobato and Kao (2002) implemented an intervention program that consisted of six 90-minute group sessions, with two sessions focusing on improving well-sibling's knowledge and understanding of their sibling's disorder, two session managing well-siblings emotions with problem solving techniques, and one session focused on balancing the well-sibling's individual needs. The program included sibling and parent groups meant to enhance mutual understanding and perspective taking. The study found that this intervention program positively increased sibling connectedness from pre- to post-treatment, as well as from pre- to 3-month post-treatment. While the content is not specified, this intervention program shows that sibling relationship quality can be positively changed when the well-sibling is provided accurate information on their sibling's disorder and when well-sibling's and their parents engage in communication and perspective taking.

Limitations and Future Research. Use of retrospective analysis is a limitation of this study, as changes in participants' relationships with their parent(s) and sibling may have

impacted their recollection of their experiences during childhood. Thus, participant responses may not be accurate representations of their childhood experience. Another limitation of this study is that the scale that measured level communication and disclosure of chronic illness has not been validated, as it was created for this study. Future research should include validation of this scale, and/or a replication study should be conducted using a validated communication measure in order to determine if these findings are accurate. In addition, these participants were recruited from a large crowdsourcing platform (MTurk) with limited ability to screen for authentic participants who truly met inclusion criteria.

It is important to note that the interaction between SIDE-R Father Score x CDI (p = 0.1109) and PS scores (p = 0.0917) approached statistical significance. The lack of significance may be attributed to the small sample size (n = 77 and n = 107 respectively). Furthermore, since SIDE-R only measures perception of more or less differential treatment and does not specify the type of differential treatment (e.g. positive or negative attention), there is a lack of information regarding the type of differential treatment towards the participant and sibling with a chronic illness by the father predicts sibling relationship quality. A future study should examine if the nature of parental relationship (e.g. agreeable vs combative) and the type of differential treatment (e.g. positive vs. negative differential treatment) predicts sibling relationship quality within this population.

Additionally, small sample size and unequal groups across chronic illness, and participant sex and age, as well as the sex and age of the participants' siblings' limits between group analyses. Thus, future studies should use larger sample sizes and equally distribute participants across participant age and sex, sibling sex dyads, and chronic illness. Future studies should also examine the impact of sibling ER visits, short-term and long-term hospitalizations, as well as age

gap between the well-sibling and siblings with a chronic illness, in order to determine if the impact of such variables are correlated with or predict sibling relationship quality.

Conclusions. Previous research has found that communication and disclosure of chronic illness information to a well-sibling is a critical factor in enhancing family relationships and buffering the effects of parentification on the well-sibling. Siblings need accurate information regarding their sibling's chronic illness, as well as open communication on the topic, in order to maintain quality relationships with their sibling who has the chronic illness. Additionally, in situations where there is little communication and disclosure, the quality of the sibling relationship is likely to decline, particularly when the well-sibling is experiencing parentification.

REFERENCES

American Academy of Pediatrics. (2017). Chronic. Retrieved September 14, 2017, from https://www.healthychildren.org/English/health-issues/conditions/chronic/Pages/default.aspx

Brody, G. H., Stoneman, Z., & McCoy, J. K. (1992). Parental differential treatment of siblings and sibling differences in negative emotionality. *Journal of Marriage and Family, 54(3),* 643-651.

Cipolletta, S., Marchesin, V., & Benini, F. (2015). Family Functioning as a Constituent Aspect of a Child's Chronic Illness. *Journal of Pediatric Nursing, 30*(6). doi:10.1016/j.pedn.2015.01.024

Compas, B. E., Jaser, S. S., Dunn, M. J., & Rodriguez, E. M. (2012). Coping with Chronic Illness in Childhood and Adolescence. *Annual Review of Clinical Psychology, 8*(1), 455-480. doi:10.1146/annurev-clinpsy-032511-143108

CDC. (2017, March 2). 10 Leading Causes of Death by Age Group, United States - 2015. Retrieved from https://www.cdc.gov/injury/wisqars/LeadingCauses.html

Derouin, D., & Jessee, P. O. (1996). Impact of a chronic illness in childhood: Siblings' perceptions. *Issues in Comprehensive Pediatric Nursing, 19*(2), 135-147. doi:10.3109/01460869609038053

Ferraioli, S. J., & Harris, S. L. (2009). The Impact of Autism on Siblings. *Social Work in Mental Health, 8*(1), 41-53. doi:10.1080/15332980902932409Gorodzinsky, A. Y., Davies, W. H., Tran, S. T., Medrano, G. R., Bernacki, J. M., Burks, L. M., . . . Weisman, S. J. (2013). Adolescents' Perceptions of Family Dynamics When a Sibling Has Chronic Pain. *Children's Health Care, 42*(4), 333-352.

Gold, J. I., Treadwell, M., Weissman, L., & Vichinsky, E. (2011). The mediating effects of family functioning on psychosocial outcomes in healthy siblings of children with sickle cell disease. *Pediatric Blood & Cancer, 57*(6), 1055-1061. doi:10.1002/pbc.22933

Hamama, L., Ronen, T., & Rahav, G. (2008). Self-Control, Self-Efficacy, Role Overload, and Stress Responses among Siblings of Children with Cancer. *Health & Social Work, 33*(2), 121-132. doi:10.1093/hsw/33.2.121

Hooper, L. M. (2007). Expanding the Discussion Regarding Parentification and Its Varied Outcomes: Implications for Mental Health Research and Practice. *Journal of Mental Health Counseling, 29*(4), 322.

Hooper, L., Marotta, S., & Lanthier, R. (2008). Predictors of growth and distress following childhood parentification: a retrospective exploratory study. *Journal of Child & Family Studies, 17*(5), 693-705. doi:10.1007/s10826-007-9184-8

Jankowski, P. J., Hooper, L. M., Sandage, S. J., & Hannah, N. J. (2011). Parentification and mental health symptoms: Mediator effects of perceived unfairness and differentiation of self. *Journal of Family Therapy, 35*(1), 43-65. doi:10.1111/j.1467-6427.2011.00574.x

Jurkovic, G. J., Jessee, E. H., & Goglia, L. R. (1991). Treatment of parental children and their families: Conceptual and technical issues. *American Journal of Family Therapy, 19*, 302–314.

Lobato, D. J., & Kao, B. T. (2002). Integrated Sibling-Parent Group Intervention to Improve Sibling Knowledge and Adjustment to Chronic Illness and Disability. *Journal of Pediatric Psychology,* 27 (8), 711–716.

Lamorey, S. (1999). Parentification of siblings of children with disability or chronic disease. In N. D. Chase (Ed.), *Burdened children: Theory, research, and treatment of parentification* (pp. 75–91). Thousand Oaks, CA: Sage.

Maclean, W. E., Perrin, J. M., Gortmaker, S., & Pierre, C. B. (1992). Psychological Adjustment of Children with Asthma: Effects of Illness Severity and Recent Stressful Life Events. *Journal of Pediatric Psychology, 17*(2), 159-171. doi:10.1093/jpepsy/17.2.159

Malcolm, C., Gibson, F., Adams, S., Anderson, G., & Forbat, L. (2013). A relational understanding of sibling experiences of children with rare life-limiting conditions: Findings from a qualitative study. *Journal of Child Health Care, 18*(3), 230-240.

Mchale, S. M., Sloan, J., & Simeonsson, R. J. (1986). Sibling relationships or children with autistic, mentally retarded, and nonhandicapped brothers and sisters. *Journal of Autism and Developmental Disorders, 16*(4), 399-413. doi:10.1007/bf01531707v

McHale, S. M., Updegraff, K. A., Jackson-Newsom, J., Tucker, C. J., & Crouter, A. C. (2000). When does parents' differential treatment have negative implications for siblings? *Social Development, 9*, 149–172. doi:10.1111/1467-9507.00117.

Murray, J. S. (1999). Siblings of children with cancer: a review of the literature. *Journal of Pediatric Oncology Nursing,* 16, 25–34.

Murray, J. S. (2000a). Attachment theory and adjustment difficulties in siblings of children with cancer. *Issues in Mental Health Nursing,* 21, 149–169.

Murray, J. S. (2000b). Understanding sibling adaption to childhood cancer. *Issues in Comprehensive Pediatric Nursing, 23,* 39–47.

Murray, J. S. (2001). Self-concept of siblings of children with cancer. *Issues in Comprehensive Pediatric Nursing,24*(2), 85-94. doi:10.1080/01460860116709

Murray, J. S. (2002). A qualitative exploration of psychosocial support for siblings of children with cancer. *Journal of Pediatric Nursing, 17,* 327-337.

O'Haver, J., Moore, I. M., Insel, K. C., Reed, P. G., Melnyk, B. M., & Lavoie, M. (2010). Parental Perceptions of Risk and Protective Factors Associated with the Adaptation of Siblings of Children with Cystic Fibrosis. *Pediatric Nursing*, *36*(6), 284-291.

Plumridge, G., Metcalfe, A., Coad, J., & Gill, P. (2011). Parents' communication with siblings of children affected by an inherited genetic condition. *Journal of Genetic Counseling*, *20*(4), 374-383. doi:10.1007/s10897-011-9361-1

Rauer, A. J., & Volling, B. L. (2007). Differential parenting and sibling jealousy: Developmental correlates of young adults' romantic relationships. *Personal Relationships*, *14*(4), 495–511. http://doi.org/10.1111/j.1475-6811.2007.00168.x

R. Riggio, Heidi. (2000). Measuring Attitudes toward Adult Sibling Relationships: The Lifespan Sibling Relationship Scale. *Journal of Social and Personal Relationships*. *17*. 707-728. 10.1177/0265407500176001.

Shapiro, M. C., Henderson, C. M., Hutton, N., & Boss, R. D. (2017). Defining Pediatric Chronic Critical Illness for Clinical Care, Research, and Policy. *Hospital Pediatrics.* doi:10.1542/hpeds.2016-0107

Suitor, J. J., Sechrist, J., Plikuhn, M., Pardo, S. T., Gilligan, M., & Pillemer, K. (2009). The Role of Perceived Maternal Favoritism in Sibling Relations in Midlife. *Journal of Marriage and Family,71*(4), 1026-1038. doi:10.1111/j.1741-3737.2009.00650.x

Volling, B., & Belsky, J. (1992). The Contribution of Mother-Child and Father-Child Relationships to the Quality of Sibling Interaction: A Longitudinal Study. *Child Development, 63*(5), 1209-1222. doi:10.2307/1131528

Wolf, L., Fisman, S., Ellison, D., & Freeman, T. (1998). Effect of Sibling Perception of Differential Parental Treatment in Sibling Dyads With One Disabled Child. *Journal of the American Academy of Child & Adolescent Psychiatry,37*(12), 1317-1325. doi:10.1097/00004583-199812000-00016

APPENDIX A

Table 1

Participant Demographics

Variable	*n*	*%*
Race		
American Indian or Alaska Native	2	1.9
Asian	18	16.8
Black or African American	13	12.1
Native Hawaiian or Pacific Islander	1	0.9
White	67	62.6
Other	3	2.8
Decline to Answer	3	2.8
Sibling Chronic Illness		
Cystic Fibrosis	51	47.7
Hemophilia	24	22.4
Sickle Cell Disease	23	21.5
Duchene's Muscular Dystrophy	7	6.5
Becker's Muscular Dystrophy	2	1.9
Sibling Sex		
Male	63	58.9
Female	42	39.3
Decline to Answer	1	0.9
Missing	1	0.9
Parent Marital Status		
Married	84	78.5
Divorced	14	13.1
Other	5	4.7
Decline to Answer	4	3.7
Primary Household		
Single-Parent Household	32	29.9
2-Parent Household	75	70.1
Household Income		
Less than $25,000	13	12.1
$25,000 to $49,999	42	39.3
$50,000 to $74,999	29	27.1
$75,000 to $99,999	18	16.8
$100,000 or More	5	4.7

Mother Highest Level of Education		
Less than High School	5	4.7
Some High School	7	6.5
High School Degree or Equivalent	22	20.6
Some College	22	20.6
2-Year Degree	8	7.5
Technical/Vocational Degree/Certificate	4	3.7
Bachelor's Degree	28	26.2
Master's Degree	11	10.3
Doctoral or Professional Degree	0	0
Father Highest Level of Education		
Less than High School	2	1.9
Some High School	6	5.6
High School Degree or Equivalent	24	22.4
Some College	26	24.3
2-Year Degree	10	9.3
Technical/Vocational Degree/Certificate	7	6.5
Bachelor's Degree	19	17.8
Master's Degree	9	8.4
Doctoral or Professional Degree	4	3.7
Mother Employment Status		
Not Employed, Not Looking for Work	10	9.3
Not Employed, Looking for Work	5	4.7
Employed Full-Time (40+ Hours)	57	53.3
Employed Part-Time (Less than 30 Hours)	8	7.5
Working 2 or More Part-Time Jobs	3	2.8
In the Military	2	1.9
Disabled, Unable to Work	2	1.9
Homemaker	19	17.8
Student	1	0.9
Father Employment Status		
Not Employed, Not Looking for Work	4	3.7
Not Employed, Looking for Work	0	0
Employed Full-Time (40+ Hours)	80	74.8
Employed Part-Time (Less than 30 Hours)	6	6
Working 2 or More Part-Time Jobs	5	5
In the Military	4	4
Disabled, Unable to Work	2	2
Homemaker	2	2
Student	0	0
Other	3	2.8
Missing Data	1	0.9

APPENDIX B

Table 2

Correlation Coefficients (Spearman's Rho) Between Independent Variables (SIDE Differential Parenting Scores (Mother and Father), Communication/Disclosure of Chronic Illness Scale Score, Parentification Scale Score) and Dependent Variable (Lifespan Sibling Relationship Scale Score)

	1	2	3	4	5
SIDE Differential Parenting Mother Scores	-				
SIDE Differential Parenting Father Score	.374**	-			
Communication/Disclosure of Chronic Illness Scale Score	.048	.052	-		
Parentification Scale Score	.045	.040	.018	-	
Lifespan Sibling Relationship Scale Score	.192	.269*	.464**	-.104	-

Note. All independent variables were centered by their respective mean, ** $p < 0.01$ (2-Tailed), * $p < 0.05$ (2-Tailed).

APPENDIX C

Table 3

Multiple Regression Summary: Model 1a - SIDE Mother as Predictor of LSRS Score, with Communication as Moderation

R	R^2	F	df 1	Df 2	p
0.4950	0.2451	8.7646	3	81	0.000

APPENDIX D

Table 4

Multiple Regression: Model 1a - SIDE Mother as Predictor of LSRS Score, with Communication as Moderation

Variable	B	*SE*	*t*	*p*
Constant	82.7712	1.6675	49.6367	0.0000
SIDE Mother Score	0.5528	0.5609	0.9855	0.3273
Communication Score	0.4252	0.0909	4.677	0.0000
Interaction 1a	-0.0145	0.0191	-0.7612	0.4488

Note. Interaction 1a = SIDE Mother Score x CDI Score

APPENDIX E

Table 5

Multiple Regression Summary: Model 1b - SIDE Father as Predictor of LSRS Score, with Communication as Moderation

R	R^2	F	df 1	Df 2	p
0.5385	0.2900	9.9386	3	73	0.000

APPENDIX F

Table 6

Multiple Regression: Model 1b - SIDE Father as Predictor of LSRS Score, with Communication as Moderation

Variable	B	*SE*	*t*	*p*
Constant	83.0253	1.7756	46.7589	0.0000
SIDE Father Score	1.0948	0.4753	2.3031	0.0241
Communication Score	0.3940	0.0882	4.4673	0.0000
Interaction 1b	0.0439	0.0272	1.6139	0.1109

Note. Interaction 1b = SIDE Father Score x CDI Score

APPENDIX G

Table 7

Multiple Regression Summary: Model 2 – Parentification Score as Predictor of LSRS Score, with Communication as Moderation

R	R^2	F	df 1	Df 2	p
0.5041	0.2541	11.5829	3	102	0.000

APPENDIX H

Table 8

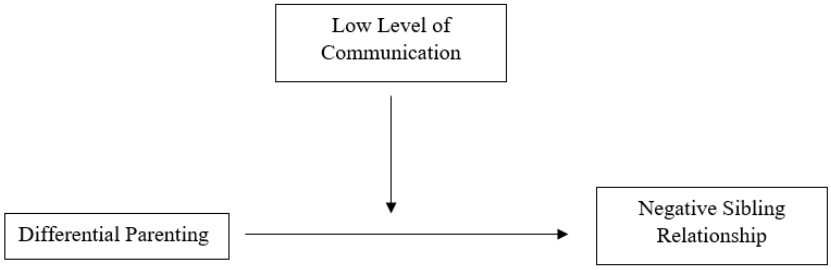
Multiple Regression: Model 2 – Parentification Score as Predictor of LSRS Score, with Communication as Moderation

Variable	B	*SE*	*t*	*p*
Constant	82.3091	1.3961	58.9563	0.0000
Parentification Score	-0.1040	0.0611	- 1.7024	0.0917
Communication Score	0.4413	0.0768	5.7427	0.0000
Interaction 2	0.0065	0.0035	1.8617	0.0655

Note. Interaction 2 = PS Score x CDI Score

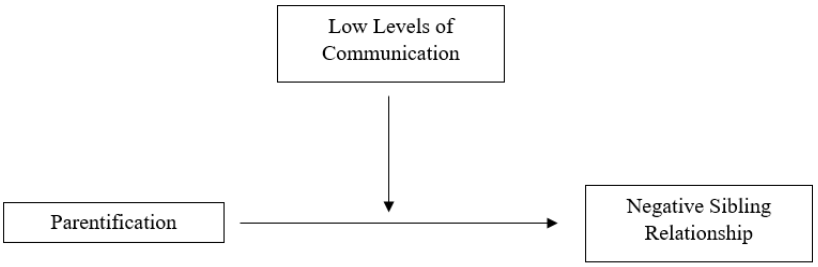
APPENDIX I

Model 1 (A & B): Theoretical Model of Differential Parenting and Sibling Relationship Quality, with Communication as A Moderator



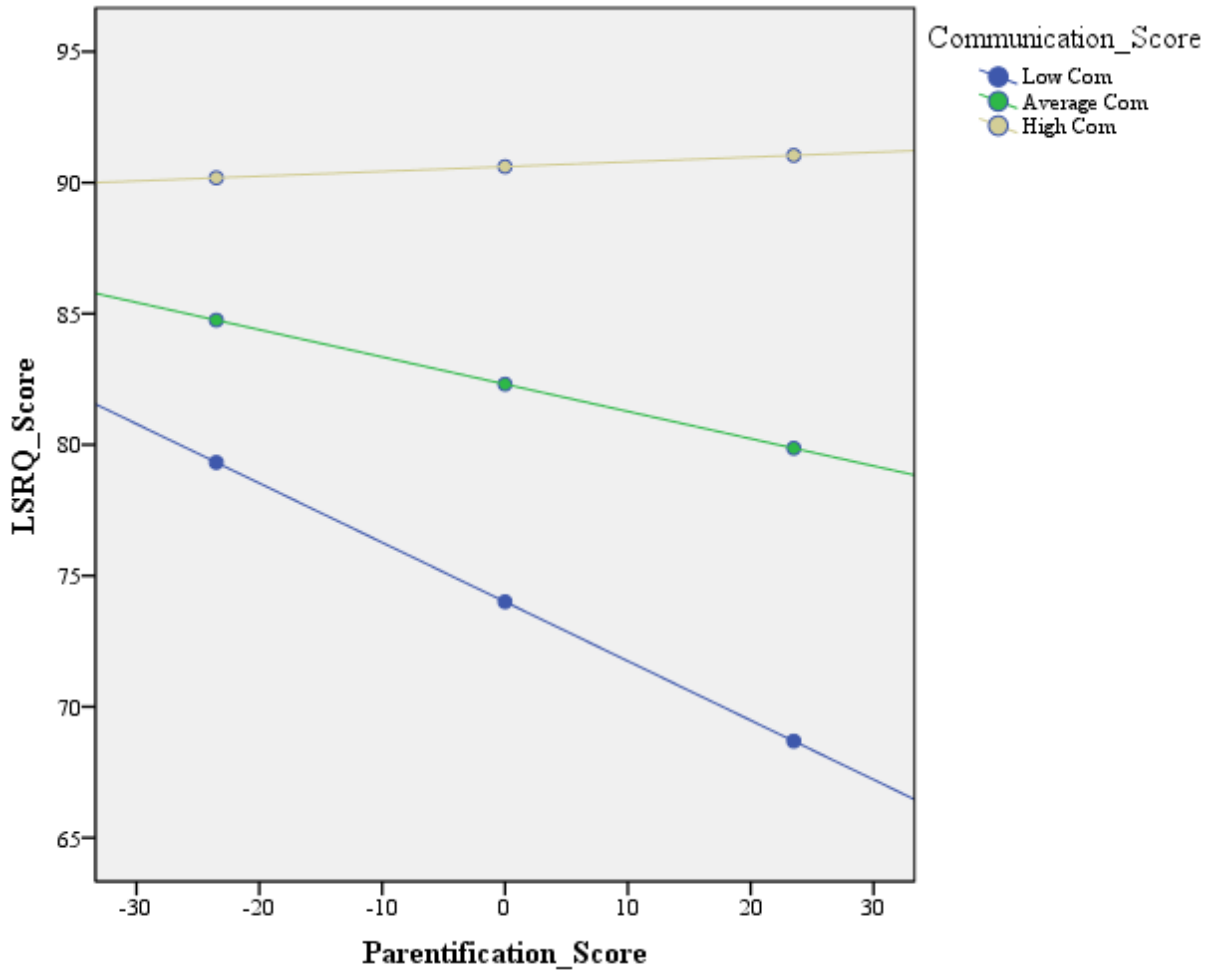
APPENDIX J

Model 2: Theoretical Model of Parentification and Sibling Relationship Quality, with Communication as A Moderator



APPENDIX K

Figure 1: Parentification As A Predictor of Sibling Relationship Quality, with Communication as A Moderator



APPENDIX L: Implied Consent and Information Sheet

Information Sheet for a Non-Medical Study
UNIVERSITY OF ALABAMA
HUMAN RESEARCH PROTECTION PROGRAM

Study Title: Siblings of Children with Chronic Illness

Researcher: Amanda Cox, Graduate Student at University of Alabama

What is this research study about? What is the investigator trying to learn? The purpose of the present study is to better understand the experiences individual had while living with a sibling with a chronic illness during their childhood.

What will I be asked to do in this research study? If you agree to be in this research study, you will be asked to complete an online survey. The survey will ask questions regarding your childhood experiences of living with a child with a chronic illness. Some questions may or may not make you uncomfortable while answering them. This survey asks questions about private information, so please complete the survey in a private setting and close the web browser upon completion to ensure others will not see your information.

How much time will I spend on this research study? This research study involves one online survey that should take approximately 30 minutes.

Will I be compensated financially for participating in this research study? Yes, you will receive 30 cents for participating in this study.

What are the risks (dangers or harms) to me if I am in this study? The main risk for participating in this study is that you may experience minor discomfort disclosing sensitive information. If you are not comfortable answering a particular question on the survey, you are free to skip the question.

What are the benefits (good things) that may happen if I am in this study? You may feel good knowing you are contributing to the body of literature on the impact of chronic illness on family dynamics.

How will my privacy and confidentiality be protected? This is an anonymous survey that you can take in a private setting on your own time.

What are my rights as a participant in this study? Taking part in this study is voluntary. It is your free choice to participate. You can refuse to be in the study with no penalty. Furthermore, if you start the study, you can skip any questions you feel uncomfortable answering or stop at any time. You will not receive any penalty for choosing to withdraw or choosing to not participate in this study. The University of Alabama Institutional Review Board (“the IRB”) is the committee that protects the rights of people in research studies. The IRB may review study

records from time to time to be sure that those involved in research studies are being treated fairly and that the study is being executed as planned.

Who do I call if I have questions or problems? If you have questions, concerns, or complaints about the study – either before you take it or after you are finished -- please email Tricia Witte, the Faculty Sponsor of Amanda Cox, at twitte@ches.ua.edu. If you have questions, concerns, or complaints about your rights as a person in this research study, call Ms. Tanta Myles, the Research Compliance Officer of the University, at 205-348- 8461 or toll-free at 1-877-820-3066. You may also ask questions, make suggestions, or file complaints and concerns through the IRB Outreach website at http://osp.ua.edu/site/PRCO_Welcome.html or email us at participantoutreach@bama.ua.edu. After you participate, you are encouraged to complete the survey for research participants that is online at the outreach website or you may ask the investigator for a copy of it and mail it to the UA Office for Research Compliance, Box 870127, 358 Rose Administration Building,Tuscaloosa, AL 35487-0127.

Can I print this form and keep it for my records? Yes, you may print this form and keep it for your records.

How do I agree to participate? If you would like to participate in this study, please proceed with the survey. If you do not want to participate, simply close this survey on your computer.

APPENDIX M: Demographic Questionnaire

Directions: Please fill in the blanks or circle/select the appropriate answers. This information will remain confidential and will only be used to better understand the participants in this study. There are no right or wrong answers, so please answer as honestly as possible.

Part I: Inclusion Criteria

1. Do/did you have a sibling (sister/brother) who had a chronic illness when you were growing up as a child (birth-18 years)?
    a. Yes
    b. No
2. What chronic illness/condition does your sibling have?
    a. Cystic Fibrosis
    b. Sickle-cell Anemia
    c. Duchenne Muscular Dystrophy
    d. Becker Muscular Dystrophy
    e. Hemophilia
    f. Other: _____
3. Did you live with your sibling who has a chronic illness for a minimum of 5 years during childhood (birth-18 years)?
    a. Yes
    b. No
4. Are you 5 years older than the child who has a chronic illness?
    a. Yes
    b. No
5. What is the age gap between you and your sibling with a chronic illness? (Please state the number of years apart you are in age to the sibling with a chronic illness)
    a. Sibling with a chronic illness is _____ years younger
6. Has your sibling passed away?
    a. Yes, how long ago did they pass away? _____
    b. No

Part II: Background Information

1. What is your age? _____
2. What is your sex?
    a. Male
    b. Female
3. What is your race?
    a. American Indian or Alaska Native
    b. Asian
    c. Black or African American
    d. Native Hawaiian or Pacific Islander
    e. White
    f. Other: _____
    g. Decline to Answer
4. What is your ethnicity?
    a. Hispanic or Latino or Spanish Origins
    b. Not Hispanic or Latino or Spanish origins
    c. Decline to Answer
5. Were you raised in the United States from at least age 5 and older?
    a. Yes
    b. No
6. What was your parent's marital status during your childhood
    a. Married
    b. Divorced
    c. Remarried
    d. Widowed/Widower
    e. Other: _____
    f. Decline to Answer
7. Did you primarily live in a single-parent household or a two-parent household during your childhood?
    a. Single-Parent Household
    b. 2-Parent Household
8. Please choose the income range best described your household income during your childhood.
    a. Less than $25,000
    b. $25,000 to $49,999
    c. $50,000 to $74,999
    d. $75,000 to $99,999
    e. $100,000 or more

9. Please choose the statement that best describes your parent(s) education level:

Mother	Father
a. Less than High School	a. Less than High School
b. Some High School	b. Some High School
c. High School Degree or Equivalent	c. High School Degree or Equivalent
d. Some College	d. Some College
e. 2-year Degree	e. 2-year Degree
f. Technical/Vocational Degree/Certificate	f. Technical/Vocational Degree/Certificate
g. Bachelor's Degree	g. Bachelor's Degree
h. Master's Degree	h. Master's Degree
i. Doctoral or Professional Degree	i. Doctoral or Professional Degree

10. Please choose the statement that best describes your parent(s) employment status:

Mother	Father
a. Not Employed, Not Looking for Work	a. Not Employed, Not Looking for Work
b. Not Employed, Looking for Work	b. Not Employed, Looking for Work
c. Employed Full-Time (40+ Hours)	c. Employed Full-Time (40+ Hours)
d. Employed Part-Time (< 30 Hours)	d. Employed Part-Time (< 30 Hours)
e. Working 2 or more Part-time Jobs	e. Working 2 or more Part-time Jobs
f. In the Military	f. In the Military
g. Disabled, Unable to Work	g. Disabled, Unable to Work
h. Homemaker	h. Homemaker
i. Student	i. Student
j. Other	j. Other

Part III: Sibling Information

1. How many siblings do you have?
    a. 1
    b. 2
    c. 3
    d. Other: _____
2. How many siblings were you raised with?
    a. 1
    b. 2
    c. 3
    d. Other: _____
3. What is your birth order?
    a. Oldest
    b. Middle
    c. Youngest
    d. Other: _____
4. What is the birth order of your sibling with a chronic illness?
    a. Oldest
    b. Middle
    c. Youngest
    d. Other: _____

5. What is the sex of your sibling with a chronic illness?
    a. Male
    b. Female
6. Which of the following best represents your relationship with your sibling with chronic illness?
    a. Biological Siblings
    b. Half-Siblings
    c. Step-Siblings
    d. Siblings through adoption
7. What is the sex of your sibling with a chronic illness?
    a. Male
    b. Female
    c. Other _____
    d. Decline to Answer
8. During your childhood, did you live primarily in the same household with the sibling who has chronic illness (more than 50% of the time, excluding hospitalizations)?
    a. Yes
    b. No

Part IV: Chronic Illness

1. Approximately how frequently did your sibling have short hospital stays (less than one week) for planned procedures or other issues (not including emergencies or ER visits)?
    a. Never
    b. Rarely
    c. Sometimes
    d. Often
    e. Frequently
2. Approximately how frequently did your sibling visit the Emergency Room (ER) for an emergency?
    a. Never
    b. Once or more per week
    c. A few times a month
    d. Once a month
    e. Once every few months
    f. Once a year
    g. Every few years
    h. Other _____
3. Did you go to the ER with your sibling?
    a. Never
    b. Rarely
    c. Sometimes
    d. Often
    e. Frequently
    f. Not Applicable

4. Was your sibling hospitalized for extended periods of time following an ER visit?
    a. Never
    b. Rarely
    c. Sometimes
    d. Often
    e. Frequently
5. When your sibling was hospitalized were you able to visit?
    a. Rarely
    b. Sometimes
    c. Often
    d. Frequently
    e. Always
    f. Not Applicable

APPENDIX N: Perception of Communication/Disclosure of Chronic Illness (CDI)

Instructions: Each item in this survey refers to a type of communication. For each of these, please write in the blanks the number that corresponds to the frequencies that best describe your experiences.

1=*strongly disagree,* 2=*disagree,* 3=*disagree somewhat*, 4=*neutral*, 5= *agree somewhat*, 6=*agree*, 7=*strongly agree*.

1. Parents directly communicated information regarding sibling's illness/condition. _____
2. Doctor/nurse/medical professional directly communicated information regarding sibling's illness/condition? _____
3. Parents indirectly communicated information regarding sibling's illness/condition. _____
4. Doctor/nurse/medical professional indirectly communicated information regarding sibling's illness/condition? _____
5. Parents communication of information regarding sibling's illness/condition was easy to understand. _____
6. I have had in-depth discussions with my parents about my sibling's condition. _____
7. I have had in-depth discussions with my parents about my risk (i.e. genetic or perceived risk). _____
8. I have had in-depth discussions with my parents about my emotions about my sibling's condition. _____
9. I have had in-depth discussions with my parents about changes to the family structure (e.g. environment) when my sibling was diagnosed. _____
10. My parents communicated the information more than my extended family did. _____
11. I have had in-depth discussions with my parents about resources and ways to cope (e.g. therapist, support group, more conversations with family). _____
12. My parents made it clear that I could discuss the topic of my sibling's chronic illness/condition with them whenever I felt the need. _____
13. I have had in-depth discussions with my mother/father when my sibling has to be hospitalized (e.g. treatment, emergency room visits, surgery). _____
14. My parents discussed how my sibling's life would change. _____
15. My extended family provided me with more information regarding my sibling's chronic illness/condition than my parents. _____
16. My parents explained why my sibling and myself were treated differently. _____
17. My parents regularly communicated a feeling of love for me after my sibling's diagnosis. _____

APPENDIX O: Parentification Scale (PS)

Instructions: Each item in this survey asks about a slightly different adult responsibility. For each of these, please write in the blanks the letter that corresponds to the frequencies that best describe how often you took on this responsibility: (a) before the age of 14, and (b) from ages 14 through 16.

1. I baby-sat for my younger siblings(s)
   before age 14: _____ from ages 14 through 16: _____
2. My parents were away for more than 24 hours, and I was the main person who assumed responsibility for my sibling(s)
   before age 14: _____ from ages 14 through 16: _____
3. I cleaned house for my family
   before age 14: _____ from ages 14 through 16: _____
4. I restored peace if conflicts developed between my parents
   before age 14: _____ from ages 14 through 16: _____
5. My parent(s) at times became physically ill, and I was responsible for taking care of them
   before age 14: _____ from ages 14 through 16: _____
6. I was the mediator or "go-between" when a conflict arose between my siblings
   before age 14: _____ from ages 14 through 16: _____
7. My parent(s) asked for my advice when making a decision about my sibling's misbehavior
   before age 14: _____ from ages 14 through 16: _____
8. One parent would come to me to discuss the other parent
   before age 14: _____ from ages 14 through 16: _____
9. I was responsible for deciding what action to take if one of my sibling(s) misbehaved, even when my parent(s) were present
   before age 14: _____ from ages 14 through 16: _____
10. My parent(s) sought my advice on adult matters
    before age 14: _____ from ages 14 through 16: _____
11. My parents would argue, and I would wind up on the side of one of them
    before age 14: _____ from ages 14 through 16: _____
12. I provided emotional support and/or comfort for my sibling(s)
    before age 14: _____ from ages 14 through 16: _____
13. I was responsible for dressing my sibling(s) or ensuring that he or she (they) got dressed
    before age 14: _____ from ages 14 through 16: _____

14. My parent(s) let me have a lot of influence when they were making important adult decisions
before age 14: _____ from ages 14 through 16: _____

15. My parent(s) discussed their financial issues and problems with me
before age 14: _____ from ages 14 through 16: _____

16. I did the dishes for members of my family
before age 14: _____ from ages 14 through 16: _____

17. When my sibling(s) had problems, I took a lot of responsibility for solving them
before age 14: _____ from ages 14 through 16: _____

18. I made dinner for members of my family
before age 14: _____ from ages 14 through 16: _____

19. I made rules, spoken or unspoken, for my sibling(s)
before age 14: _____ from ages 14 through 16: _____

20. My parent(s) shared intimate secrets (e.g., concerning relationships and/or sexual issues) with me
before age 14: _____ from ages 14 through 16: _____

21. When one of my siblings had a personal concern, they came to me for advice
before age 14: _____ from ages 14 through 16: _____

22. I was the mediator or "go-between" when a conflict arose between my parents
before age 14: _____ from ages 14 through 16: _____

23. My mother shared personal problems or concerns with me as if I were another adult
before age 14: _____ from ages 14 through 16: _____

24. I did the laundry for members of my family
before age 14: _____ from ages 14 through 16: _____

25. I was responsible for bathing my sibling(s)
before age 14: _____ from ages 14 through 16: _____

26. I consoled one or both of my parents when they were distressed
before age 14: _____ from ages 14 through 16: _____

27. My father shared personal problems or concerns with me as if I were another adult
before age 14: _____ from ages 14 through 16: _____

28. My sibling(s) came to me when they were having difficulties with our parent(s)
before age 14: _____ from ages 14 through 16: _____

29. I would decide what time my sibling(s) went to bed for the evening, even when my parent(s) were home
before age 14: _____ from ages 14 through 16: _____

30. One (or both) of my parents asked for my input (rather than my other parent's input) when making an important decision
before age 14: _____ from ages 14 through 16: _____

APPENDIX P: Sibling Inventory of Differential Experiences – Revised (SIDE-R)

Instructions: This questionnaire is designed to ask you about things that happen in families and about what life was like for you and your parents/guardians over the years when you were growing up and living at home. If your parents were divorced or if one died, answer the questions for the mother/guardian and father/guardian with whom you lived for the longest period of time. Each statement says something that is true in some families, and not true in other families. Please mark the circle which best represents your answer.

For the entire questionnaire, think about your experiences in your family over the years when you were growing up and living at home.

My Relationship with My Mother/Guardian Over the Years When I Was Growing Up And Living At Home

	Almost Never	Some-times	Often-	Almost Always
1. My mother/guardian has been strict with me.	1	2	3	4
2. My mother/guardian has been proud of the things I have done.	1	2	3	4
3. My mother/guardian enjoyed doing things with me	1	2	3	4
4. My mother/guardian has been sensitive to what I think and feel.	1	2	3	4
5. My mother/guardian has punished me for my misbehavior.	1	2	3	4
6. My mother/guardian has shown interest in the things I like to do.	1	2	3	4
7. My mother/guardian has blamed me for what another family member did.	1	2	3	4
8. My mother/guardian has tended to favor me.	1	2	3	4
9. My mother/guardian has disciplined me.	1	2	3	4

My Relationship with My Father/Guardian Over the Years When I Was Growing Up And Living At Home

	Almost Never	Some-times	Often-	Almost Always
1. My father/guardian has been strict with me.	1	2	3	4
2. My father/guardian has been proud of the things I have done.	1	2	3	4
3. My father/guardian enjoyed doing things with me	1	2	3	4
4. My father/guardian has been sensitive to what I think and feel.	1	2	3	4
5. My father/guardian has punished me for my misbehavior.	1	2	3	4
6. My father/guardian has shown interest in the things I like to do.	1	2	3	4
7. My father/guardian has blamed me for what another family member did.	1	2	3	4
8. My father/guardian has tended to favor me.	1	2	3	4
9. My father/guardian has disciplined me.	1	2	3	4

For this entire questionnaire, answer the questions for the sibling with chronic illness that you identified in the demographics questionnaire.

Sibling's Age: _____ Sibling is male/female (circle one)

Instructions: This questionnaire is designed to ask you about things that happen in families and about what life was like for your sibling who is closest in age to you and your parents/guardians over the years when you were growing up and living at home. If your parents were divorced or if one died, answer the questions for the mother/guardian and father/guardian with whom you lived for the longest period of time. Each statement says something that is true in some families, and not true in other families. Please circle the number that best represents your answer.

For the entire questionnaire, think about your sibling's experiences in your family over the years when you were growing up and living at home

My Sibling's Relationship with My Mother/Guardian Over the Years When I Was Growing Up And Living At Home

	Almost Never	**Some-times**	**Often-**	**Almost Always**
1. My mother/guardian has been strict with my brother or sister.	1	2	3	4
2. My mother/guardian has been proud of the things my brother/sister has done.	1	2	3	4
3. My mother/guardian enjoyed doing things with my brother/sister.	1	2	3	4
4. My mother/guardian has been sensitive to what my brother/sister thinks and feels.	1	2	3	4
5. My mother/guardian has punished my brother/sister for his/her misbehavior.	1	2	3	4
6. My mother/guardian has shown interest in the things my brother/sister likes to do.	1	2	3	4
7. My mother/guardian has blamed my brother/sister for what another family member did.	1	2	3	4
8. My mother/guardian has tended to favor my brother/sister.	1	2	3	4
9. My mother/guardian has disciplined my brother/sister.	1	2	3	4

My Sibling's Relationship with My Father/Guardian Over the Years When I Was Growing Up And Living At Home

	Almost Never	Some-times	Often-	Almost Always
1. My father/guardian has been strict with my brother or sister.	1	2	3	4
2. My father/guardian has been proud of the things my brother/sister has done.	1	2	3	4
3. My father/guardian enjoyed doing things with my brother/sister.	1	2	3	4
4. My father/guardian has been sensitive to what my brother/sister thinks and feels.	1	2	3	4
5. My father/guardian has punished my brother/sister for his/her misbehavior.	1	2	3	4
6. My father/guardian has shown interest in the things my brother/sister likes to do.	1	2	3	4
7. My father/guardian has blamed my brother/sister for what another family member did.	1	2	3	4
8. My father/guardian has tended to favor my brother/sister.	1	2	3	4
9. My father/guardian has disciplined my brother/sister.	1	2	3	4

APPENDIX Q: Lifespan Sibling Relationship Scale (LSRS)

Instructions: Each item in this scale refers to your relationship and feelings towards your sibling. For each statement, please write the number that corresponds to the frequencies that best describe your experiences.

1 = *strongly disagree,* 2 = *disagree,* 3 = *neither agree nor disagree*, 5 = *strongly agree*.

1. My sibling makes me happy.
2. My sibling's feelings are very important to me.
3. I enjoy my relationship with my sibling.
4. I am proud of my sibling.
5. My sibling and I have a lot of fun together.
6.* My sibling frequently makes me very angry.
7. I admire my sibling.
8. I like to spend time with my sibling.
9. I presently spend a lot of time with my sibling.
10. I call my sibling on the telephone frequently.
11. My sibling and I share secrets.
12. My sibling and I do a lot of things together.
13.* I never talk about my problems with my sibling.
14. My sibling and I borrow things from each other.
15. My sibling and I 'hang out' together.
16. My sibling talks to me about personal problems.
17. My sibling is a good friend.
18. My sibling is very important in my life.
19.* My sibling and I are not very close.
20. My sibling is one of my best friends.
21. My sibling and I have a lot in common.
22. I believe I am very important to my sibling.
23. I know that I am one of my sibling's best friends.
24. My sibling is proud of me.
25.* My sibling bothered me a lot when we were children.
26. I remember loving my sibling very much when I was a child.
27.* My sibling made me miserable when we were children.
28.* I was frequently angry at my sibling when we were children.
29. I was proud of my sibling when I was a child.

30. I enjoyed spending time with my sibling as a child.
31. I remember feeling very close to my sibling when we were children.
32. I remember having a lot of fun with my sibling when we were children.
33. My sibling and I often had the same friends as children.
34. My sibling and I shared secrets as children.
35. My sibling and I often helped each other as children.
36. My sibling looked after me (OR I looked after my sibling) when we were children.
37. My sibling and I often played together as children.
38.* My sibling and I did not spend a lot of time together when we were children.
39. My sibling and I spent time together after school as children.
40. I talked to my sibling about my problems when we were children.
41. My sibling and I were 'buddies' as children.
42.* My sibling did not like to play with me when we were children.
43. My sibling and I were very close when we were children.
44. My sibling and I were important to each other when we were children.
45. My sibling had an important and positive effect on my childhood.
46. My sibling knew everything about me when we were children.
47. My sibling and I liked all the same things when we were children.
48. My sibling and I had a lot in common as children.

Note. * Reverse scored item. Items 1–8 reflect Adult Affect; 9–16 reflect Adult Behavior; 17–24 reflect Adult Cognitions; 25–32 reflect Child Affect; 33–40 reflect Child Behavior; and 41–48 reflect Child Cognitions.

APPENDIX R: IRB Approval

THE UNIVERSITY OF ALABAMA | Office of the Vice President for Research & Economic Development
Office for Research Compliance

February 6, 2018

Amanda Cox
Department of Human Development & Family Studies
College of Human Environmental Sciences
The University of Alabama
Box 870311

Re: IRB # 18-OR-019-A "Parentification and Differential Treatment of Siblings of Children with Chronic Illness and the Impact on Sibling Relationship"

Dear Ms. Cox:

The University of Alabama Institutional Review Board has reviewed the revision to your previously approved expedited protocol. The board has approved the change in your protocol.

Please remember that your protocol will expire on January 18, 2019.

Should you need to submit any further correspondence regarding this proposal, please include the assigned IRB application number. Changes in this study cannot be initiated without IRB approval, except when necessary to eliminate apparent immediate hazards to participants.

Good luck with your research.

Sincerely,

[redacted]
Director & Research Compliance Officer
Office of Research Compliance

358 Rose Administration Building | Box 870127 | Tuscaloosa, AL 35487-0127
205-348-8461 | Fax 205-348-7189 | Toll Free 1-877-820-3066