Anxiety Levels and Sibling Relationship Quality of Adults with Siblings with Down Syndrome Compared to those of Adult Siblings of Typically Developing Individuals

Katie L. McCormack
University of Vermont, klmccorm@uvm.edu

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Anxiety Levels and Sibling Relationship Quality of Adults with Siblings with Down Syndrome

Compared to those of Adult Siblings of Typically Developing Individuals

Katie L. McCormack

University of Vermont
ADULT SIBLING RELATIONSHIPS AND ANXIETY IN DOWN SYNDROME

Abstract

This study examined anxiety levels and relationship quality of adult siblings of individuals with and without Down syndrome. Adult participants between the ages of 18 to 29 years of age with either a biologically related sibling with Down syndrome or a typically developing sibling were recruited via email through the University of Vermont, Down syndrome organizations and programs and Special Olympics organizations within the Northeast. Qualified individuals completed Riggio’s *Lifespan Sibling Relationship Scale* and Speilberger’s *State-Trait Anxiety Inventory* online. Data were calculated using SPSS. The results showed that siblings of individuals with Down syndrome have lower anxiety levels than siblings of typically developing individuals. These findings indicate that having a sibling with Down syndrome does not warrant elevated concern of increased anxiety of the typically developing sibling. Similarly, relationship quality was not significantly different between both groups, indicating that having a sibling with Down syndrome does not have an adverse effect on the sibling relationship. Future research should attend to a larger, nationally representative sample, as well as expand comparison variables between sibling groups, including sociability and peer relationships.
Anxiety Levels and Sibling Relationship Quality of Adults with Siblings with Down Syndrome Compared to those of Adult Siblings of Typically Developing Individuals

**Introduction to Problem**

Most children with disabilities, including those with mental disorders, intellectual disabilities or developmental delays, are offered accommodations and services. While assistance is provided to individuals with these conditions, their typically developing siblings are often overlooked. McHale and Gamble (1989) found that every child who has a sibling with a disability experiences life differently from their peers who do not and this experience affects many facets of his or her development. Although little research has been done on siblings of individuals with Down syndrome, several studies have found that siblings of children with a range of developmental disabilities have higher anxiety than those without siblings with disabilities (Barnett & Hunter, 2012; McHale & Gamble, 1989). With the occurrence of Down syndrome being 8.27 out of 10,000 in the general U.S. population, many of whom are born to families with other children, it is important to understand the impact, if any, on the sibling (Presson et al., 2013). For example, a higher likelihood of anxiety found among the individuals who have a sibling with Down syndrome could imply that the sibling relationship has a deeper impact that requires attention.

**Significance**

There has been much research regarding the interactions between children with disabilities and their typically developing siblings (Barnett & Hunter, 2012; McHale & Gamble, 1989), the behavioral characteristics of siblings of children with Autism Spectrum Disorder
ADULT SIBLING RELATIONSHIPS AND ANXIETY IN DOWN SYNDROME

(Kaminsky & Dewey, 2001) and parent perception of their children’s behavior (Sanders & Morgan, 1997). However, there has been little research regarding adult anxiety levels and sibling interaction among adult siblings of individuals with Down syndrome.

Anxiety

Investigating the anxiety levels among people of different life situations is important because anxiety has wide implications for quality of life. Anxiety affects communication skills, reactions to difficult situations, and coping mechanisms (Mendlowicz & Stein, 2000), characteristics important to ensuring quality of life. There are tools for coping with anxiety, but many people do not receive the help they need because there is a lack of understanding of their condition and the need to attend to the consequences of increased anxiety prior to their occurrence. Research suggests that siblings of children with anxiety disorders also have clinical mental health diagnoses and behavioral issues. Sibling difficulties, however, are often overlooked in the context of their sibling’s more immediate anxiety issues and needs (Dia & Harrington, 2006). If a relationship exists between having a sibling with Down syndrome and higher levels of anxiety in adulthood, anxiety prevention methods could be better provided for during childhood. This thesis seeks to determine if having a sibling with Down syndrome impacts the anxiety levels of individuals with this experience.

Sibling Interaction

The quality of sibling relationships is also important to examine, because siblings spend the most time together than with any other family member. The more time spent with someone, the more influence each individual has on the other (Bank & Kahn, 1975). Notably, most sibling relationship research has been carried out with typically developing siblings. Thus, it is important to examine sibling interaction among siblings of different populations including
ADULT SIBLING RELATIONSHIPS AND ANXIETY IN DOWN SYNDROME

individuals with Down syndrome. Having a sibling with Down syndrome is a unique life experience that differs from the life experiences of individuals who only have typically developing siblings.

Anxiety and Sibling Relationship

Research regarding anxiety and the quality of sibling relationships has been limited and confined. Thus far, research among children has suggested that siblings of individuals with Autism Spectrum Disorder (ASD) have greater anxiety within their relationship than do siblings of individuals with Down syndrome (Pollard, McNarama, Freedman & Kotchick, 2013). The quality of the sibling relationship may be the source of anxiety. However, there has been little comparison of siblings of individuals with ASD or Down syndrome with siblings of typically developing individuals. For the little research that does exist, it has been found that adult siblings of individuals with Down syndrome purport to have good quality sibling relationships compared to siblings of individuals with ASD (Orsmond & Seltzer, 2007).

Purpose of this Study

This study explored the anxiety levels and relationship quality of adult siblings of individuals with Down syndrome, compared to the anxiety levels of adult siblings of typically developing individuals. Gathering data from the adult sibling provides perspective into the relationship of having a sibling with Down syndrome. Further, relationship quality is an important factor that impacts anxiety. Since previous studies have shown varying relationships in the anxiety levels of siblings of individuals with Down syndrome compared to siblings without a brother or sister with this condition, it was important to determine the long-term impact, if any. A definition of key terms can be found in Appendix G.
ADULT SIBLING RELATIONSHIPS AND ANXIETY IN DOWN SYNDROME

Research Questions

Questions

1) Do adult siblings of individuals with Down syndrome exhibit higher levels of anxiety than adult siblings of typically developing individuals?

2) Do siblings of individuals with Down syndrome have a higher quality sibling relationship than individuals with typically developing siblings?

Review of Literature

Anxiety disorders affect about 18% of American adults in a given year, proving to be the most common among mental disorders (Kessler, Chiu, Demler, & Walters, 2005). Anxiety disorders develop from a plethora of genetic and environmental factors. One of the leading environmental factors is life experiences (Hettema, Prescott, Myers, Neale, & Kendler, 2005). As such, it is important to investigate different life experiences that may act as a source of anxiety.

This study investigated the presence of anxiety in adult siblings of individuals with Down syndrome, compared to adult siblings of typically-developing individuals. It was hypothesized that siblings of individuals with developmental disabilities have higher levels of anxiety than siblings of typically developing individuals. Researchers suggest that siblings spend the greatest amount of time together within the family unit, and therefore influence control over each other (Bank & Kahn, 1975). Due to the strong effect a sibling relationship has on an individual, and the impact that life experience has on an individual’s anxiety, it is important to examine sibling relationship quality in addition to overall anxiety level.

Down syndrome arises from an extra chromosome on all or part of chromosome 21. Physiologically, individuals with Down syndrome have higher risks for congenital cataracts,
congenital heart disease, anomalies in the gastrointestinal tract, seizures, visual impairment, hearing impairment, thyroid dysfunction, skeletal anomalies and sleep apnea (Lott & McCory, 1992). Socially, individuals with Down syndrome can flourish just as much as typically developing individuals. The level of socialization hinges on the same types of variables that affect all individuals’ development, including family experiences, individual characteristics, and community life (Lott & McCory, 1992).

Currently, there is little research on sibling relationships solely involving individuals with Down syndrome; although, several studies reviewed included individuals with Autism Spectrum Disorder (ASD) and other disabilities (Kaminsky & Dewey, 2001; McHale & Gamble, 1989; Orsmond & Seltzer, 2007; Pollard et al., 2013). In addition, there are no studies that have specifically examined the relationship between anxiety and having a sibling with a disability. Thus far, notable studies involving sibling relationships have found correlations between anxiety and internalizing behaviors, particularly related to relationship roles. Findings, however, have been equivocal. For example, a study investigating sibling relationship and anxiety sources (Cuskelly & Gunn, 2003) found that sisters did not take on more caregiving than brothers regardless of if their siblings had Down syndrome. These results contrasted with an earlier study that found sisters of children with disabilities, in fact, spent more time performing caregiving activities (McHale & Gamble, 1989). Thus, there is ambiguity not only concerning the source of anxiety, but also the gender of siblings who act as caregivers.

Other studies have found more consistent evidence of overall better sibling relationship quality for siblings of individuals with Down syndrome versus siblings of individuals with ASD (Kaminsky & Dewey 2001; Orsmond & Seltzer, 2007; Pollard et al. 2013). Again, because there is a paucity of research in this area, there is much ambiguity as to the kinds of relationships that
can be inferred. Although siblings of individuals with Down syndrome are found to have a better quality relationship with their sibling, it has been observed that they have increased internalizing behavior and anxiety (Holsen, 1999; McHale & Gamble, 1989). In an attempt to make sense of the conflicting research, Pollard and colleagues (2013) reviewed several past studies related to sibling relationships and anxiety which focused on the relationships of children with siblings who have disabilities. From these studies, Pollard and colleagues (2013) hypothesized that siblings of individuals with Down syndrome would report higher levels of relationship quality and lower levels of anxiety compared to siblings of individuals with ASD. The results yielded no significant differences in anxiety between the two groups; however, Pollard et al. (2013) only surveyed children. Children do not readily comprehend anxiety and in fact, only one article that Pollard et al. (2013) reviewed considered the adult sibling perspective.

The lack of literature regarding sibling relationships among adults who have siblings with disabilities is disconcerting, as research has shown that life experiences within childhood can sometimes have a devastating effect on adulthood (Felitti et al., 1998). This is not to imply that growing up with a sibling who has a disability is an adverse life experience, but rather, to emphasize the impact of childhood experiences, whether positively or negatively, on adult livelihood.

This literature review addresses each of the components relevant to this study and is organized into two sections: (1) a description of anxiety including a discussion of the role of genetics and the impact on families, and (2) a review of sibling relationships in families of children with disabilities, specifically those families with children who have mental health disorders, Down syndrome and ASD. The literature was reviewed using the University of Vermont’s Bailey-Howe Library online catalogue, and from there using an ancestry approach
ADULT SIBLING RELATIONSHIPS AND ANXIETY IN DOWN SYNDROME

once a related article was discovered. Due to the rarity of literature written about siblings, Down syndrome and anxiety, there was no limitation concerning the timing of the studies. Many studies reviewed date back over twenty years as there have been few recent studies. At the end of each section, the relevance of the literature to the research reported in this thesis is discussed.

Anxiety

Prevalence. Anxiety is a difficult concept to define, but can be considered a state of lasting tension and continuous expectation of danger in some form (Wolman & Stricker, 1994). Researchers have uncovered that anxiety disorders have a genetic basis (Hettema, Neale, & Kendler, 2001; Marks, 1986). In particular, anxiety disorders are more common in first-degree relatives of individuals diagnosed with an anxiety disorder than individuals who were not diagnosed (Tuma & Maser, 1985). Even still, anxiety is a complex issue that cannot be tied to any one particular gene, or separated from environmental factors. In past studies, there has been great difficulty in distinguishing the precise role of genetic factors in relation to anxiety. More likely, anxiety stems from a combination of genetic and environmental factors (Wolman & Stricker, 1994). However, simply knowing the origins of anxiety does not imply that all who suffer from it are aware of the condition. In fact, only about a fourth of individuals with anxiety disorders were found to have received treatment for their disorder (Tuma & Maser, 1985).

With anxiety disorders being the most common mental health problem in children and adolescents, Dia and Harrington (2006) investigated the impact of having a sibling with an anxiety disorder. To participate in the study, the family needed to have one child diagnosed with an anxiety disorder who had a sibling between the ages of six and eighteen. There was no restriction as to whether the sibling had been diagnosed with an anxiety disorder. In fact, 12% of the siblings had been diagnosed with an anxiety disorder by a mental health professional, and
ADULT SIBLING RELATIONSHIPS AND ANXIETY IN DOWN SYNDROME

over half of the siblings who had not been diagnosed had at least one elevated internalizing or externalizing scaled score. These elevated scores were consistent with the scores of children who are generally referred to mental health professionals for emotional and behavioral concerns. Although these findings do not show causality, they do suggest that children with anxiety disorders are more likely to have siblings who also have signs of anxiety or are diagnosed with anxiety disorders (Dia & Harrington, 2006). Similarly, it is equally important to look at the impact that individuals with other disabilities or disorders have on their typically developing siblings, to determine if the typically developing sibling is adversely affected.

**Measurements of anxiety.** Measurements of anxiety used in sibling research have largely been children’s scales as most research in the field has examined sibling relationships in children. A couple of studies have used the *Child Behavior Checklist (CBCL)*, a caregiver informant measure of 120 items designed for six through eighteen year olds (Dia & Harrington, 2006; Shivers, Deisenroth, & Lounds, 2013). One of the strengths of the CBCL is that its scores are based on a normative sample, meaning that certain behaviors are assessed as normal, clinical or borderline (Dia & Harrington, 2006). The CBCL has shown good reliability, with test-retest reliability ranging from .82 to .95, Cronbach’s alpha ranging from .75 to .90 within the six subscales (Aschenbrand, Angelosante, & Kendall, 2005). However, the CBCL is better used as a broad indicator of anxiety rather than a diagnosis for a specific type of anxiety (Aschenbrand et al., 2005; Nakamura, Ebetsuti, Bernstein, & Chorpita, 2009).

When measuring adult anxiety, it is not sufficient to use scales created for children. All of the measurements used thus far to study children and sibling anxiety have incorporated parental reports, because children do not readily grasp the concepts of stress and anxiety. None of the
studies relied solely on child reports. Thus, it was necessary to identify anxiety measurement tools appropriate for adults for the proposed study.

In determining adult anxiety measurements, special attention was given to McDowell’s *Measuring Health* (2006), a book that reviews and compares the most reliable and frequently used anxiety scales. After reviewing the purposes of each scale, two particular scales were most relevant to the purpose of this study; the *Beck Anxiety Inventory* (BAI), and the *State-Trait Anxiety Inventory* (STAI). The BAI is a shorter 21 item self-questionnaire, while the STAI is a 40 item self-questionnaire. The difference in length is due to the type of anxiety being measured. Although the BAI is shorter than the STAI, the STAI distinguishes between state and trait anxiety whereas the BAI focuses solely on state anxiety. State anxiety is the temporary anxiety experienced in certain situations, and trait anxiety indicates anxiety that has been persistent over time. Since this study is investigating sibling relationships and anxiety, it is necessary to know whether individuals experience trait anxiety. The internal consistency of the STAI falls within .86 and .95. Similarly, for the BAI the internal consistency falls within .90 and .94. Both have been widely used with college students, psychiatric patients, and adults within a given community. The BAI is particularly useful to distinguish between anxiety and depression, and is the most precise tool for measuring the said difference. However, for this study, it was more important to use a tool that would measure trait anxiety, with stable scores regardless of how stressed the participant feels during the particular testing time. The STAI does just this, and shows stable trait scores regardless of the presence of stressfulness (McDowell, 2006). The BAI, being only a state score, would be influenced too much by the present stress conditions of the individual. Thus, the STAI was the best anxiety measurement tool for this particular study.
**Impact on siblings.** Research regarding how having a sibling with Down syndrome influences a child’s anxiety has been limited with inconsistent findings. Holsen (1999) found that although siblings of children with Down syndrome did not show elevated problems in psychosocial functioning, they did show higher rates of internalizing behavior on the CBCL. Similarly, McHale and Gamble (1989) reported that girls with siblings with disabilities performed more poorly in almost every area of psychological well-being. In contrast, Pollard et al. (2013) found no differences in overall anxiety levels of siblings of children with ASD or Down syndrome. These are the only three studies found that have specifically investigated the anxiety of siblings of children with Down syndrome, all with contrasting results. This paucity in the current research reinforces the need for additional investigation in this area.

**Sibling Relationships**

**Siblings of children with disabilities.** One of the earlier, landmark studies that explored sibling relationships of individuals who had siblings with disabilities was conducted by McHale and Gamble (1989). This study set the stage for future studies by investigating broadly if differences existed between siblings of children with an array of disabilities and without disabilities in regards to daily activities, psychological well-being, and family processes that meditate well-being. At the time when the study took place, little information was known about the daily activities of siblings of children with disabilities that may have instigated emotional and behavioral problems. Using a multi-modal test method of telephone calls and home interviews, the researchers gathered the information over a period of two years, making the study longitudinal, in addition to cross-sectional. McHale and Gamble (1989) concluded that children with siblings with disabilities reported spending more time in caregiving activities, and that female siblings in particular tested poorly in almost all areas of psychological well-being.
However, although female siblings scores were in higher ranges than normal, they did not reach clinical cut offs, meaning that the results were not seen as indicating pathology. Thus, there is a need for more research in the area of examining sibling relationships.

**Siblings of children with mental health disorders.** Subsequent research has been conducted from the perspective of siblings of individuals with mental health problems, including anxiety disorders. Although limited, this research is more recent as siblings of children with mental health difficulties have been typically overlooked by both researchers and health agencies. Barnett and Hunter (2012) investigated if siblings of children with mental health problems had different behavior, quality of life, and self-concept from reported population norms. Barnett and Hunter reported typically developing siblings in families with children with mental health disorders had higher rates of mental health problems, lower quality of life and lived in poorly functioning families. These results are consistent with those of Dia and Harrington (2006) who found that over half the siblings of children with an anxiety disorder had at least one elevated anxiety scale score. The Dia and Harrington (2006) study was exploratory, being the first to specifically look at the functioning of siblings of children with an anxiety disorder. As anxiety appears to have a familial basis, it is likely genetics play a large part in determining an individual’s anxiety. However, because siblings are so influential on each other, the source of anxiety does not necessary only result from shared genetics.

**Siblings of children with ASD.** Several studies have compared the relationships between siblings of individuals with Down syndrome, siblings of individuals with ASD and siblings of typically developing individuals (Cuskelly & Gunn, 2003; Cuskelly & Gunn, 2006; Holsen, 1999; Kaminsky & Dewey, 2001; Orsmond & Seltzer, 2007; Pollard et al., 2013). The importance of these comparisons was to gauge if there were particular factors within sibling
relationships that contributed to overall relationship quality and personal well-being. Two studies in particular, led by Kaminsky and Dewey (2001) and Pollard et al. (2013), researched sibling relationship quality and intimacy within sibling dyads including a child with Down syndrome or ASD, respectively.

Although Kaminsky and Dewey (2001) and Pollard et al. (2013) used different sibling relationship measurements, the sibling domain of the *Network of Relationships Inventory* and the *Sibling Relationship Questionnaire Revised*, both yielded similar results in that siblings of children with ASD reported less intimacy and lower relationship quality with their sibling than did siblings of children with Down syndrome.

Pollard and colleagues (2013) provided an important follow-up as they examined anxiety as a source for the differences in the sibling relationship quality and intimacy yielded by Kaminsky and Dewey (2001). Building on the knowledge that siblings of children with ASD show significant, negative, differences in sibling relationship quality compared to siblings of children with Down syndrome, Pollard et al. (2013) did not find significant differences in anxiety among the siblings of the two groups. However, Pollard et al. (2013) did find that sibling relationship quality acted as a moderator of anxiety. Negatively perceived sibling relationship quality was related to higher levels of anxiety, more evident in siblings of children with ASD than siblings of children with Down syndrome.

A major point of divergence between Pollard et al. (2013) and Kaminsky and Dewey (2001) was in the study design. Kaminsky and Dewey (2001) anticipated the variability of individuals with ASD and required an age match of the typically developing sibling dyads to the sibling dyads of individuals with ASD and Down syndrome. In the Pollard et al. (2013) study, there was no comparison group of typically developing sibling dyads, the group of individuals
ADULT SIBLING RELATIONSHIPS AND ANXIETY IN DOWN SYNDROME

with ASD was twice as large as the group of individuals with Down syndrome and the assessment tool was administered online, so there was no way of ensuring the exact diagnosis of the individuals with ASD. Orsmond and Seltzer (2007) also followed up on the Kaminsky and Dewey (2001) study by examining the adult sibling relationship quality and intimacy of siblings of individuals with ASD and Down syndrome, respectively. This was the first study to examine sibling relationships in adulthood when a sibling had ASD or Down syndrome. The findings of the study suggested that the same behaviors and relationships observed in childhood were also observed in adulthood; siblings of individuals with ASD continue to have less intimate sibling relationships compared to siblings of individuals with Down syndrome.

Adult sibling relationships are important to research in that many adult siblings of individuals with disabilities become the primary caregiver of their sibling later in life. Kaminsky and Dewey’s (2001) findings on children sibling relationships were affirmed such that siblings of adults with ASD spend less time with and have a less intimate relationship than siblings of adults with Down syndrome. As with Pollard et al.’s (2013) study, however, Orsmond and Seltzer (2007) did not compare the siblings of adults with ASD and Down syndrome to siblings of typically developing adults. Still, the results suggest that there are differences between sibling relationships when an individual has ASD versus Down syndrome. The differences may be subtle, but they suggest that having a sibling with Down syndrome is an entirely different experience for an individual than having a sibling with ASD.

**Siblings of children with Down syndrome.** Few studies have been conducted which solely compare siblings of children with Down syndrome to siblings of typically developing children. With the occurrence of Down syndrome being 8.27 out of 10,000 in the general U.S. population, the siblings of these individuals are an important and significant number to be
ADULT SIBLING RELATIONSHIPS AND ANXIETY IN DOWN SYNDROME

studied further (Presson et al., 2013). An early study by Riper (2000) examined relationships among several variables that impact the well-being in siblings of children with Down syndrome. Rather than focus on sibling relationships, Riper emphasized how different variables within the family affect the sibling of the child with Down syndrome. The major finding of the study was that the presence of a child with Down syndrome did not have a negative effect on the sibling or family, and could even enhance the family’s development in areas such as understanding, compassion and appreciation for others.

This was further confirmed by two later studies by Cuskelly and Gunn (2003; 2006) which found that sibling relationships of dyads with a child with Down syndrome did not differ greatly from other typical sibling dyads, and that having a sibling with Down syndrome did not appear to have a negative impact on problem behaviors or self-perceptions.

Although, the two studies by Cuskelly and Gunn (2003; 2006) investigated sibling relationships and quality of relationships, they did not measure specific qualities in siblings such as anxiety. These two studies suggest that having a sibling with Down syndrome does not necessarily impact the sibling relationship compared to having a sibling with a more debilitating disability. However, the studies do not give insight into how the sibling’s condition may affect a child’s internalizing behaviors, including anxiety, or how the condition may affect the adult later in life.

Measurements of relationship quality. Sibling relationships are a relatively new field of study, and the repertoire of tools used to measure sibling relationship is limited. A recent study by Buist, Dekovic and Prinzie (2013) was particularly useful in uncovering the different methods available for measuring sibling relationship quality. Buist et al.’s meta-analysis examined 34 previous studies that measured sibling relationship quality, and found the most frequently used
tools were the *Sibling Relationship Questionnaire* (SRQ; Furman & Buhrmester, 1985), the *Sibling Relationship Inventory* (SRI; Stocker & McHale, 1992) and the *Sibling Inventory of Differential Experience* (SIDE; Daniels & Plomin, 1985).

The SRQ pioneered sibling relationship measurements, as it was the first of its kind to develop a framework for assessing specific relationship qualities. This questionnaire focuses on warmth/closeness, relative power/status, conflict and rivalry. With 51 questions, the researchers originally administered the questionnaire to a pool of participants in the fifth and sixth grade (Furman & Buhrmester, 1985). Subsequent use of the SRQ has been among children between the ages of 8 and 16, albeit with a shortened version (Richmond, Stocker, & Rienks, 2005; Stocker, Burwell, & Briggs, 2002). Evaluation of the SRQ revealed good construct validity and high internal reliability (Derkman, Scholte, Van der Veld, & Engels, 2010).

The SIDE was created around the same time as the SRQ, but differs in that it was intended to measure and compare environmental experience for each individual sibling rather than qualities within the sibling relationship. The SIDE has eleven scales with 73 items that assess experience in four domains; sibling interaction, parental treatment, peer characteristics, and events specific to the sibling. The scale has been used on siblings who are within 12 to 28 years of age. Test-retest reliability measured around .84. The SIDE is a useful tool in uncovering the source of personality differences between siblings and understanding just how different the sibling experience is within any given family (Daniels & Plomin, 1985).

The SRI is very similar to the SRQ, and in fact uses the same four part classification system which includes affection, hostility, rivalry and power/symmetry (Stocker & McHale, 1992). Unlike the SRQ, there are only seventeen questions. The researchers focused on birth order and rather than using an inter-rater method of data collection, opted to test both children in
the sibling dyad on their perception of their sibling as well as themselves. All the scales except for power/symmetry showed high internal consistency between .74 and .84 (Stocker & McHale, 1992). The SRI was intended to measure sibling relationships in children, and is essentially a modified successor to the SRQ.

Another follow up to the SRQ is the *Adult Sibling Relationship Questionnaire*, which aimed to examine adult sibling relationships (ASRQ; Stocker, Lanthier, & Furman, 1997). The ASRQ is an 81 item questionnaire that measures the same content as the SRQ; warmth, conflict and rivalry. This questionnaire focuses on the adult sibling relationship as it stands in the present time, with no content incorporating childhood experiences. Test-retest reliability was high over a two week period, along with high internal consistency around .96. The ASRQ is one of the few measurements developed to measure quality of adult sibling relationships.

One of the newest tools that measures the quality of adult sibling relationships is the *Lifespan Sibling Relationship Scale* (LSRS; Riggio, 2000). As the name implies, the LSRS incorporates information from the sibling relationship throughout the lifespan, beginning in childhood up to the present. No other scale has been developed that does so. The LSRS is a self-report scale that measures three categories: frequency and positivity of behavior towards sibling; affect towards sibling; and, beliefs about siblings and the sibling relationship. The scale is comparably shorter than other sibling relationship scales, with 48 questions that are divided into 6 subscales that measure emotion, beliefs, and behavioral interactions with the sibling as a child and adult, respectively. The scale has generally been used with college students between the ages of 18 and 24. The results have indicated a high internal consistency; Cronbach’s alpha equaled .96 for total scale score (Riggio, 2000). Due to the incorporation of childhood and adult relationship factors, the LRSR was the best sibling relationship measurement tool for this study.
ADULT SIBLING RELATIONSHIPS AND ANXIETY IN DOWN SYNDROME

Summary

With the limited and inconsistent results reported in the literature, the effect of having a sibling with Down syndrome remains unclear. The research thus far has hypothesized that siblings of individuals with Down syndrome should show higher levels of anxiety, yet the limited findings have proven otherwise (Holsen, 1999). Most research has focused on the sibling relationship between the child with Down syndrome and the typically developing child, as a moderator for anxiety (Cuskelly & Gunn, 2003; Kaminsky & Dewey, 2001; Orsmond & Seltzer, 2007; Pollard et al. 2013). In almost all the research, both sibling relationships and anxiety have been measured by parental input, as children do not cognitively understand concepts such as anxiety (Barnett & Hunter, 2012; Cuskelly & Gunn, 2006; Dia & Harrington, 2006; Holsen, 1999; Kaminsky & Dewey, 2001; McHale & Gamble, 1989; Pollard et al. 2013).

It is difficult to measure all aspects that contribute to one’s psychological well-being, and specifically anxiety, when you are a sibling of an individual with Down syndrome. However, it is important to examine if such a relationship suggests increased levels of anxiety, in order to offer better resources and treatments for individuals with anxiety. The rarity of research examining adult sibling relationship quality, adult siblings of individuals with Down syndrome, and corresponding anxiety levels in the presence of ambiguous research regarding children suggests a notable gap in the current research. An examination of these relationships in adult populations is likely to be more consistent as adults are able to comprehend the necessary concepts required for self-reports of anxiety and sibling relationship. It is important to look at anxiety levels within the adult sibling population, as it facilitates better understanding of the extent to which having a sibling with Down syndrome affects an individual over the course of their life.
Methods

Design

This was a descriptive survey study addressing anxiety levels and sibling relationship quality of adult siblings of individuals with Down syndrome compared with anxiety levels and sibling relationship quality adult siblings of typically developing individuals. Two questionnaires were administered to measure anxiety and sibling relationship, respectively. The *State Trait Anxiety Inventory* (STAI) (see Appendix A) measured siblings’ state and trait anxiety. The *Lifespan Sibling Relationship Scale* (LSRS) (see Appendix B) measured the quality of the sibling relationship. Both surveys were administered via online survey systems. Group comparisons were conducted between the responses of adult siblings of individuals with and without Down syndrome.

Ethical Considerations

Individuals were recruited by email and social media through Down syndrome organizations within the Northeast (see Appendix C), as well as through the University of Vermont. Permission was received from the Institutional Review Board (see Appendix D).

Participants were fully informed of the purpose of the study in the introduction to the survey (see Appendix E). Any participant who chose not to participate after initially agreeing to do so was able to withdraw before the beginning or completion of the survey, and their survey data was not included in the data analysis. Once surveys were complete, the participant could not revoke their participation, due to anonymity. The Principal Investigator (PI) monitored the completion of the surveys and confirmed those participants who dropped out.
ADULT SIBLING RELATIONSHIPS AND ANXIETY IN DOWN SYNDROME

Participants

A sample size of 60 siblings of individuals with Down syndrome, and 80-100 siblings of individuals without Down syndrome was desired. A higher number of siblings was expected for the latter group, since having siblings with Down syndrome is less common. Participants were between the ages of 18 and 29 years old. A limit of one hundred participants who were siblings of typically-developing individuals was placed on the first survey website, LimeSurvey©, to prevent all the licenses for the second survey from being used by the predominant group.

Initially, a greater number of siblings of individuals without Down syndrome was desired to match sibling relationship age and gender to the test group. However, due to the fewer number of overall participants, this was abandoned in favor of contrasting the two groups using the available data from all participants.

There were 61 participants in total. Forty-three participants completed both the LSRS and STAI, five participants completed only the LSRS, and 13 participants did not complete either survey. Of the participants who completed both surveys, fifteen had a sibling with Down syndrome, and twenty-eight did not. The 43 participants who completed both surveys and the five participants who completed only the LSRS were included in data analysis.

The identifiers in this study were age, gender and educational level of the participant and age and gender of the participant’s sibling, which were necessary for group comparison and identifying statistical correlation or lack thereof. The mean age of participants with siblings with Down syndrome was 22.59 years, and for participants without was 21.06 years. Complete demographic data can be viewed in Table 1. The last three digits of the participant’s phone number and the middle initial of the participant were also collected on both surveys in order to
ADULT SIBLING RELATIONSHIPS AND ANXIETY IN DOWN SYNDROME

link the participant’s responses. All information was accessible only to the PI, via a password protected laptop.

Measures

State Trait Anxiety Inventory. This self-report measure evaluates state and trait anxiety, including temporary anxiety and general anxious tendencies. There are forty questions, twenty of which measure state or situational anxiety (the temporary anxiety experienced in certain situations), and twenty of which assess trait or underlying anxiety (anxiety that has persisted for a long duration of time). The STAI has high internal consistency, with a Cronbach’s alpha of .95 on the state scale and .91 on the trait scale within the general population. The content covers five of the eight domains of generalized anxiety disorder identified in the DSM-IV (McDowell, 2006). With the numerous similarities between anxiety and depression, the STAI does not distinguish them as strongly as other scales, such as the Beck Anxiety Inventory, but it does differentiate both state and trait anxiety which were important to the current study. The STAI has been used with a variety of participants, including healthy patients, students, adults, military personal, and inmates. Initially, it was designed specifically for high school and college students. Currently, it is the most frequently used tool for measuring anxiety (McDowell, 2006).

Lifespan Sibling Relationship Scale. The Lifespan Sibling Relationship Scale (LSRS) is a self-report scale, measuring three facets of sibling relationship: frequency and positivity of behavior towards sibling; affect towards sibling; and, beliefs about sibling and sibling relationship. There are 48 questions which are further divided into 6 subscales measuring emotion, beliefs, and behavioral interactions with sibling as a child and adult. This scale is especially novel in that it focuses on individual attitudes toward adult sibling relationships, by incorporating attitudes of the sibling relationship in childhood. The scale has generally been used
with college students between the ages of 18 and 24. The results have shown high internal consistency with a Cronbach’s alpha of .96 and a test-retest coefficient of .91 (Riggio, 2000).

**Procedures**

Participants either received recruitment emails or were directed to notices on social media sites including Facebook™ and Twitter™ inviting eligible persons to participate in this study (see Appendix F). Participants provided implied consent by initiating the survey. Individuals who were interested had access to the first survey, the LSRS, which was administered through LimeSurvey©. At the beginning of the survey, individuals were informed of the purpose of the survey, as well as requirements, confidentiality and anonymity. After completing the LSRS, participants were directed to the second survey, the STAI, which was administered through MindGarden’s© survey system (mindgarden.com). Once participants concluded both surveys, their participation in the study was complete. The PI monitored the responses of both surveys, and all incomplete surveys were deleted during data analysis. Thirteen incomplete surveys were discarded before data analysis. All surveys were anonymous. Data was analyzed for descriptive and inferential statistics using the statistical software, SPSS.

**Results**

**Statistics and Data Analysis**

This study examined the anxiety levels and relationship quality of adult siblings of individuals with Down syndrome, compared to the anxiety levels of adult siblings of typically developing individuals. Overall, there were forty eight participants. Five of these participants did not complete the STAI, but were included in statistical analysis to compare their effect on the statistical significance. Specifically, there were fifteen adult siblings of individuals with Down syndrome who participated fully; four males and eleven females. Additionally, there were twenty
eight siblings of typically developing individuals who participated fully; four males and twenty-four females. All participants were between the ages of 18 and 29. Specific demographic information on all participants can be viewed in Table 1.

Inferential statistics were completed to compare the relationship between having a sibling with Down syndrome and having a typically developing sibling, with regards to mean score on both the STAI and LSRS. Data analysis was completed separately for the two surveys. Data were entered into SPSS and the total scores for each survey were calculated. The LSRS was scored and coded using a five point Likert scale, while the STAI was scored automatically using Mindgarden’s© Transform System. After the data was entered, two \( t \)-tests were applied, which determined group comparisons and the significance of findings between siblings of individuals with Down syndrome, and siblings of typically developing individuals. A correlation test was also used to determine whether there was a significant correlation between anxiety and sibling relationship scores.

**Anxiety and Sibling Relationship Quality**

Mean scores were first compared to see the initial differences between the two groups of siblings. A higher mean score for relationship quality indicated a closer relationship. A higher mean score for both state and trait anxiety indicated higher levels of anxiety. Mean comparisons showed that participants who have siblings with Down syndrome had overall higher sibling relationship scores and lower state and trait anxiety scores. The mean scores of participants with siblings with Down syndrome were 191.18 in relationship quality, 34.53 in state-anxiety, and 38.00 in trait-anxiety. In comparison, the mean scores of participants with typically developing siblings were 173.48 in relationship quality, 39.81 in state-anxiety, and 45.93 in trait-anxiety.
ADULT SIBLING RELATIONSHIPS AND ANXIETY IN DOWN SYNDROME

This information is displayed in Table 2 and includes normative score comparisons. These scores included the five participants who did not take the STAI. When these five participants were not included, the mean scores changed only slightly, and the same trends remained.

Insert Table 2 here

Two separate, independent t-tests were used to determine the significance of the trends found in the mean scores. The first t-test only included the forty-three participants who completed both surveys. The p-values comparing sibling groups were .085 for sibling relationship quality, .205 for state-anxiety, and .036 for trait-anxiety. These values indicate that only trait-anxiety was statistically significant.

A second t-test which included the five participants who had only responded to the LSRS was used to investigate if there would be a change in the p-value for relationship quality. Of these five participants, two had siblings with Down syndrome and three did not. When these participants were included, the p-value was .046. This value indicates that those five additional participants were enough to reach statistical significance for relationship quality.

No significant correlations were found between having a sibling with Down syndrome as compared to having a sibling without Down syndrome, for either sibling relationship quality and anxiety level. For siblings of individuals with Down syndrome, the correlation between relationship quality and state-anxiety was -.19, and was -.206 between relationship quality and trait-anxiety. For siblings of typically developing individuals, the correlation between relationship quality and state-anxiety was -.306, and was -.069 between relationship quality and trait-anxiety.
This study sought to investigate the effects of having a sibling with Down syndrome in adulthood, specifically regarding anxiety levels and sibling relationship quality. Although mean scores indicated that siblings of individuals with Down syndrome had higher sibling relationship qualities and lower state and trait anxiety scores, significance was only found for trait-anxiety.

Trait-anxiety is defined as underlying anxiety, the tendency to experience anxiety on a daily basis and can be considered anxiety that has persisted for a long period of time (McDowell, 2006). The literature does not provide information about having a sibling with Down syndrome and corresponding anxiety levels. In the past, studies have found that sibling relationship quality is a moderator of anxiety (Cuskelley & Gunn, 2003; Kaminsky & Dewey, 2001; Orsmond & Seltzer, 2007; Pollard et al. 2013). This study did not support that finding; there was no correlation between sibling relationship quality and anxiety levels. However, the second t-test that included the five participants who only took the LSRS showed there was significance between having a sibling with Down syndrome and having a higher sibling relationship quality. While relationship quality cannot be used to explain the significance of lower trait-anxiety in adult siblings of individuals with Down syndrome, speculations can be made.

There are no indications from this study as to what could cause lower trait-anxiety in siblings of individuals with Down syndrome, and the following discussion is merely speculation. Since a marginally significant relationship of .085 was found between having a sibling with Down syndrome, and having a closer sibling relationship, perhaps these individuals were more embedded or integrated in their sibling’s lives growing up. These individuals could have had greater access to the culture of disability and organizations such as the Special Olympics, which could have provided them with a better way of coping with uncommon social situations or
anxiety-provoking situations. In addition, growing up with a sibling with Down syndrome could have provided these individuals with a different perspective and outlook on anxiety. Perhaps “typical” anxiety-provoking situations throughout the day affected these individuals to a lesser extent because of their experience with their sibling.

Although the original premise of this study was that the identification of anxiety level and relationship quality was important to determine any potential need for support or intervention, these results suggest, in fact, that siblings of individuals with Down syndrome do not have increased anxiety levels and may have stronger quality sibling relationships than those individuals without siblings with Down syndrome. This requires a greater examination of what supports relationship quality that may moderate anxiety levels often found in siblings of individuals with other disabilities.

**Limitations and Future Research**

There were a number of limitations to this study. First, both groups were small in size, especially siblings of individuals with Down syndrome. As discussed, by including just five more participants in the relationship quality analysis, significance was established. Sample size should be increased if possible, as it would provide more evidence for significance, or lack thereof, among all the domains. Second, the demographic information in this study did not include race, ethnicity, or area of origin, and participants were recruited through organizations within the northeast. It would be important to include greater diversity in race, ethnicity and area of residence to investigate similarities and differences among siblings representing greater diversity. Further, with a larger sample size, researchers could investigate gender differences in both the participant and their sibling.
ADULT SIBLING RELATIONSHIPS AND ANXIETY IN DOWN SYNDROME

Only one moderator, sibling relationship quality, was used as a potential influence on state or trait anxiety. Although there were no correlations found between relationship quality and state and trait anxiety in this study, it would beneficial to include other factors that might correlate with anxiety. These factors could provide evidence of variables that affect anxiety levels.

**Conclusion**

Since siblings of individuals with Down syndrome have significantly lower trait-anxiety compared to siblings of typically developing individuals, there is no elevated concern that these siblings experience higher anxiety. Similarly, relationship quality was not significantly different between both groups of siblings, indicating that having a sibling with Down syndrome does not have an adverse effect on the sibling relationship. It appears that having a sibling with Down syndrome is not detrimental to an individual’s anxiety level or relationship quality. Indeed, having a sibling with Down syndrome might even be considered beneficial to an individual.
ADULT SIBLING RELATIONSHIPS AND ANXIETY IN DOWN SYNDROME

References


ADULT SIBLING RELATIONSHIPS AND ANXIETY IN DOWN SYNDROME


ADULT SIBLING RELATIONSHIPS AND ANXIETY IN DOWN SYNDROME


ADULT SIBLING RELATIONSHIPS AND ANXIETY IN DOWN SYNDROME


Appendix A: State Trait Anxiety Inventory

The State Trait Anxiety Inventory by Charles D. Spielberger, Ph.D.

For use by Katie McCormack only. Received from Mind Garden, Inc. on August 12, 2014

SELF-EVALUATION QUESTIONNAIRE
STAI Form Y-1

Please provide the following information:
Name ______________________ Date ______________ S ______
Age ______________________ Gender (Circle) M F T ______

A number of statements which people have used to describe themselves are given below. Read each statement and then blacken the appropriate circle to the right of the statement to indicate how you feel right now, that is, at this moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feelings best.

1. I feel calm ................................................................. 1 2 3 4
2. I feel secure .............................................................. 1 2 3 4
3. I am tense ................................................................. 1 2 3 4
4. I feel strained ........................................................... 1 2 3 4
5. I feel at ease ............................................................ 1 2 3 4
6. I feel upset .............................................................. 1 2 3 4
7. I am presently worrying over possible misfortunes ........ 1 2 3 4
8. I feel satisfied ........................................................... 1 2 3 4
9. I feel frightened ......................................................... 1 2 3 4
10. I feel comfortable ..................................................... 1 2 3 4
11. I feel self-confident .................................................. 1 2 3 4
12. I feel nervous .......................................................... 1 2 3 4
13. I am jittery ............................................................... 1 2 3 4
14. I feel indecisive ......................................................... 1 2 3 4
15. I am relaxed ............................................................ 1 2 3 4
16. I feel content .......................................................... 1 2 3 4
17. I am worried ........................................................... 1 2 3 4
18. I feel confused .......................................................... 1 2 3 4
19. I feel steady ............................................................ 1 2 3 4
20. I feel pleasant .......................................................... 1 2 3 4

STAI - Adult Instrument © 1968, 1977 Charles D. Spielberger. All rights reserved in all media. Published by Mind Garden, Inc., www.mindgarden.com
ADULT SIBLING RELATIONSHIPS AND ANXIETY IN DOWN SYNDROME

For use by Katie McCormack only. Received from Mind Garden, Inc. on August 12, 2014

SELF-EVALUATION QUESTIONNAIRE
STAI Form Y-2

Name___________________________________________________________ Date__________

DIRECTIONS
A number of statements which people have used to describe themselves are given below. Read each statement and then blacken in the appropriate circle to the right of the statement to indicate you generally feel.

21. I feel pleasant.............................................................. 1  2  3  4
22. I feel nervous and restless.............................................. 1  2  3  4
23. I feel satisfied with myself.............................................. 1  2  3  4
24. I wish I could be as happy as others seem to be............... 1  2  3  4
25. I feel like a failure.......................................................... 1  2  3  4
26. I feel rested................................................................. 1  2  3  4
27. I am “calm, cool, and collected”....................................... 1  2  3  4
28. I feel that difficulties are piling up so that I cannot overcome them........ 1  2  3  4
29. I worry too much over something that really doesn’t matter...... 1  2  3  4
30. I am happy................................................................. 1  2  3  4
31. I have disturbing thoughts.............................................. 1  2  3  4
32. I lack self-confidence................................................... 1  2  3  4
33. I feel secure................................................................. 1  2  3  4
34. I make decisions easily.................................................. 1  2  3  4
35. I feel inadequate............................................................ 1  2  3  4
36. I am content.............................................................. 1  2  3  4
37. Some unimportant thought runs through my mind and bothers me........ 1  2  3  4
38. I take disappointments so keenly that I can’t put them out of my mind.... 1  2  3  4
39. I am a steady person...................................................... 1  2  3  4
40. I get in a state of tension or turmoil as I think over my recent concerns and interests........ 1  2  3  4

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Appendix B: Lifespan Sibling Relationship Survey

The Lifespan Sibling Relationship Survey by Heidi R. Riggio, Ph.D.

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.
Appendix C: Recruited Organizations

- University of Vermont (http://www.uvm.edu/)
- Champlain Valley Down Syndrome Organization (http://cvdsg.org/)
- New Hampshire Special Olympics (http://www.sonh.org/)
- Massachusetts General Down syndrome Program
  (www.massgeneral.org/downsyndrome)
Appendix D: IRB Approval Notices

Memorandum

TO: Katie McCormack
FROM: Gale Weld
DATE: 24-Jun-2014
SUBJECT: CHRBSS: 14-494
       Anxiety Levels of Adult Siblings of Individuals with Downs Syndrome Compared to Those of Adult Siblings of Typically Developing Individuals

Attached is a signed assurance form which certifies this application has been reviewed and approved.

This project has been approved for waiver of documentation of informed consent and, if applicable, individual authorization for disclosure of protected health information.

As the Principal Investigator of this approved protocol you have specific responsibilities. Please refer to the Research Manual, Section 9. Submission of Materials After Initial Approval is Obtained and Section 10. Investigator Responsibilities to review these responsibilities and obtain further guidance.

cc: Patricia Prelock
Protection of Human Subjects Assurance

Title: Anxiety Levels of Adult Siblings of Individuals with Down Syndrome Compared to Those of Adult Siblings of Typically Developing Individuals
Principal Investigator: Katie McCormack,
Institution: University of Vermont and State Agricultural College, Burlington, VT 05405

This institution has an approved assurance of compliance on file with the Department of Health and Human Services which covers this activity.

University of Vermont and State Agricultural College: FWA 00000723 Expiration Date: Nov 12, 2018
Fletcher Allen Health Care, Inc.: FWA 00000727 Expiration Date: Feb 20, 2018
IRB number 00000486

Certification of IRB Review

This activity has been reviewed and approved by an IRB in accordance with the requirements of 45 CFR 46, including its relevant Subparts; and, when applicable, with the requirements of 21 CFR 50 and 21 CFR 56.

Date of approval JUN 20 2014 Date of expiration JUN 19 2015

IRB Review Type: Expedited review

Institutional Signature/Date: ___________________________ 6/20/14
Name and Title of Official: Sara Barry, MPH, Associate Chair,
Committee on Human Research in the Behavioral Sciences
Appendix E: Survey Cover Letter

The purpose of this research study is to compare the anxiety levels of adult siblings of individuals with Down syndrome to adult siblings of typically developing individuals. Dr. Patricia Prelock from the University of Vermont (UVM) is a Co-Investigator and is supervising this study.

*The research is being conducted by a student in the Department of Communication Sciences & Disorders at the University of Vermont.*

Gathering data from the adult sibling gives perspective into the relationship of having a sibling with Down syndrome. Relationship quality is an important factor that impacts anxiety. Since previous studies are limited and have shown varying correlations of higher anxiety levels in siblings of individuals with Down syndrome compared to siblings without a brother or sister with Down syndrome, it is important to determine the long term impact, if any.

If you take part in this study, you will be asked to complete two surveys which examine anxiety and sibling relationship quality, respectively. The questions on the anxiety survey assess both short term anxiety (state anxiety), and anxiety that has existed for a longer duration (trait anxiety). The questions on the sibling relationship scale assess current and retrospective relationship qualities such as closeness and affection. All questions on both surveys must be completed in order to take part in the study. Both surveys will be answered in one sitting, with the total time of about twenty minutes.

Before starting the survey, please remember to keep your sibling with Down syndrome in mind when responding or, if you have only typically developing siblings, to keep only one of them in mind when responding.

*A note on privacy*

This survey is anonymous. The record of your survey responses does not contain any identifying information about you, unless a specific survey question explicitly asked for it. If you used an identifying token to access this survey, please rest assured that this token will not be stored together with your responses. It is managed in a separate database and will only be updated to indicate whether you did (or did not) complete this survey. There is no way of matching identification tokens with survey responses.
Appendix F: Recruitment Email

SUBJECT: Down Syndrome Sibling Relationship and Anxiety Study

I am an Honor’s College student at the University of Vermont in the College of Nursing and Health Sciences. I am seeking young adult participants for a research study investigating anxiety in siblings of individuals with Down syndrome and siblings of typically developing individuals. You must be between the ages of 18-29. You must have either a biologically related sibling with Down syndrome, or a typically developing biological sibling. You will be asked to complete two online surveys measuring anxiety and sibling relationship quality. Approximate completion time is about twenty minutes. Responses will be stored on a password protected laptop that only the principal investigator has access to. If you are interested in learning more and/or participating in this research study please proceed to <insert link>.

My honors thesis advisor is Dr. Patricia A. Prelock, Dean of the College of Nursing and Health Sciences. For more information, please contact: <insert email>.

Thank you for considering participating in this study! Katie
Appendix G: Key Terms

Definition of Key Terms

Anxiety- “a feeling of worry, nervousness, or unease, typically about an imminent event or something with an uncertain outcome” (Oxford’s dictionary.com, n.d.)

Autism Spectrum Disorder- “a developmental disability that can cause significant social, communication and behavioral challenges” (Centers for Disease Control and Prevention [CDC], 2014)

Down syndrome- “a genetic condition in which a person has 47 chromosomes instead of the usual 46.” (MedlinePlus, 2013)

Sibling- “one of two or more individuals having one common parent” (Merriam-Webster.com, n.d.)

Typically developing individual- an individual who develops skills and behaviors in a predictable and consistent sequence
Table 1
Demographic Characteristics

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Overall</th>
<th>N</th>
<th>(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Participant Gender</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>9</td>
<td>18.80%</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>39</td>
<td>81.30%</td>
<td></td>
</tr>
<tr>
<td><strong>Participant Highest Level of Education Completed</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>High School</td>
<td>7</td>
<td>14.60%</td>
<td></td>
</tr>
<tr>
<td>Some Post-Secondary</td>
<td>26</td>
<td>54.20%</td>
<td></td>
</tr>
<tr>
<td>Bachelor's Degree</td>
<td>10</td>
<td>20.80%</td>
<td></td>
</tr>
<tr>
<td>Post-Graduate Degree</td>
<td>5</td>
<td>10.40%</td>
<td></td>
</tr>
<tr>
<td><strong>Participant Sibling’s Gender</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>29</td>
<td>60.40%</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>19</td>
<td>39.60%</td>
<td></td>
</tr>
<tr>
<td><strong>Does Your Sibling Have Down Syndrome?</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>17</td>
<td>35.40%</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>31</td>
<td>64.60%</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Range</th>
<th>Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Participant Age</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>With a sibling with Down syndrome</td>
<td>18-28 years</td>
<td>22.59 years</td>
</tr>
<tr>
<td>Without a sibling with Down syndrome</td>
<td>18-29 years</td>
<td>21.60 years</td>
</tr>
<tr>
<td><strong>Age of Participant’s Sibling</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Has Down syndrome</td>
<td>2-38 years</td>
<td>21.29 years</td>
</tr>
<tr>
<td>Does not have Down syndrome</td>
<td>14-32 years</td>
<td>20.61 years</td>
</tr>
</tbody>
</table>

*Includes the five participants who did not complete the STAI
Table 2
Mean Sibling Relationship and Anxiety Scores of Siblings

<table>
<thead>
<tr>
<th>Does your sibling have Down syndrome?</th>
<th>Mean Score</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Relationship Quality</td>
<td>State-Anxiety</td>
<td>Trait-Anxiety</td>
</tr>
<tr>
<td>No</td>
<td>173.48</td>
<td>39.18</td>
<td>45.93</td>
</tr>
<tr>
<td>Yes</td>
<td>191.18</td>
<td>34.53</td>
<td>38.00</td>
</tr>
<tr>
<td>Normative Score*</td>
<td>164.80</td>
<td>36.54 (male)</td>
<td>35.55 (male)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>36.17 (female)</td>
<td>36.15 (female)</td>
</tr>
</tbody>
</table>

*Normative scores were taken from the original studies.