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Specific Worries in Siblings of Children with Down Syndrome

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Abstract

In this exploratory study, 13 children who had siblings with Down syndrome and 11 children with typically developing siblings were interviewed about general anxiety and specific worries concerning their sibling. Parents completed corresponding measures regarding the child participant's anxieties as well as a general measure of child behavior. Results indicated that siblings of children with Down syndrome had more sibling-specific worries and slightly heightened internalizing behavior as compared to controls. Parents of siblings with Down syndrome reported more worries than did the control parents.

Specific Worries in Siblings of Children with Down Syndrome

Families of children with special needs are often exposed to a variety of beneficial and difficult experiences. Possible positive impacts of such experiences include increased awareness and acceptance of persons with special characteristics, heightened academic performance, and altruism. On the other hand, extra stressors and variables within the family, including added responsibility, decreased parental attention, and the child's behavioral problems, may affect each member more negatively. These experiences may result in a constellation of unique life changes, coping mechanisms, and attitude responses for all family members, including typically developing siblings. Several researchers (Bagenholm & Gillberg, 1991; Begun, 1989; Cuskelly & Dadds, 1992; Gath, 1973; Gath & Gumley, 1984, 1987; Knott, Lewis, & Williams, 1995; McHale & Gamble, 1989; McHale, Sloan, & Simeonsson, 1986) have investigated possible differences between sibling dyads in which one sibling is developmentally delayed and those in which both siblings are developing typically. They have focused on many features of the exceptional experiences of siblings of children with developmental disabilities. Issues explored include sibling interaction patterns, emotional and behavioral problems, prosocial behavior and other child characteristics, and changes in family dynamics.

Recently, experts in the area have debated whether having a sibling with special needs has positive or negative effects on child development (Hannah & Midlarsky, 1985; Lobato, 1993). Possible influences on the typical sibling may

be “negative,” “positive,” or may lack a definite valence. Although the specific nature of pathways between the presence of a sibling with Down syndrome and the typically developing sibling's mental and emotional health remains unclear, several modes of influence can be hypothesized. For example, the possible impact of having a sibling with special needs may be moderated by variables such as parent responses, public reaction to the sibling with Down syndrome, and family conflict resulting from the addition of a child with a developmental disability. To date, contrasting findings have generated substantial empirical investigations; however, the need for information on these childhood relationships continues to increase for a number of reasons.

As just indicated, confusion exists over the specific nature of the experience of siblings. Both positive and negative descriptions of life with a sibling with Down syndrome have been reported. Moreover, most studies have concentrated on general responses to having a sibling with special needs, and there is little information specific to effects of having a sibling with Down syndrome. Additional research is needed to clarify such experiences. Further, with a better understanding of this unique experience, health care providers may be able to design more efficient and helpful support groups for siblings of children with special needs geared towards allowing children to have contact with other siblings like them. Finally, increased visibility of persons with Down syndrome, as a function of decreased institutionalization and increased practice of inclusion of developmentally disabled children, may affect sibling relationships and development differently than in the past.

In the proposed study, the analysis and specific worries of children with Down syndrome and their siblings will be explored and contrasted with the experiences of siblings of typically developing children. To provide background for the study's hypothesis and design, previous research on siblings with special needs will be reviewed. First, I will explore the possible effects of growing up with a sibling with Down syndrome, including social and emotional functioning of siblings, child responsibilities and parental expectations, and differences in sibling interaction patterns. Next, I will discuss the documented (though controversial) effects that may be dependent on intervening variables such as the child's ordinal position and gender. Finally, and more specific to the design of the current study, I will focus on the ways specific worries of these siblings may be categorized.

Social and Emotional Functioning of Siblings

Several influences on the sibling's social and emotional well being, both direct and indirect, have received attention in literature on this population. Most of these factors are considered negative, but positive influences are also reported. Externalizing behavior problems exhibited by siblings of children with Down syndrome have been reported by mothers and teachers (Cuskelly & Dadds, 1992; Gath, 1973; Gath & Gumley, 1987; McHale & Gamble, 1989). Deviancy in the form of conduct disorders, attention problems, and antisocial behavior on the part of the non-handicapped child has been attributed to the presence of a sibling with Down syndrome (Cuskelly & Dadds, 1992; Gath, 1973).

Additionally, internalizing problems, such as anxiety, resulting from interaction with the sibling may add to the child's challenges. For example, adult siblings report higher levels of subjective burden, defined as the level of perceived feelings of stress, pressure, and burden as a function of their part in taking care of their sibling with special needs (Greenberg, Kim, & Greenley, 1997). McHale and Gamble (1989) found that, compared to siblings of typically developing children, siblings of children with disabilities had significantly higher scores on anxiety, as measured by the Revised Children's Manifest Anxiety Scale. Additionally, mothers of these siblings report their non-handicapped children to be more susceptible to anxiety due to emotional problems and family situations (Gath & Gumley, 1987). For instance, some children worried about their sibling's future in reference to their ability to function on their own. This anxiety may be internalized, leading to internal turmoil. I will consider this point in more detail further on.

Some studies do not show clear patterns of negative outcomes. For example, Bagenholm and Gillberg (1991) found no significant differences between siblings of children with autism, mental retardation, and typical development on either self-concept or behavior toward the sibling. Further, research shows a pattern of better general academic attainment and positive attitude at school as perceived by teachers (Gath & Gumley, 1987).

Many of these studies comparing Down syndrome to control groups use natural group designs. Since researchers cannot randomly assign children to groups of interest, results are basically correlational in nature, showing

relationships between group membership and different variables. Also, many of the studies lack a control group of typical dyads. Causal interpretations cannot be drawn from correlational studies such as these due to the fact that such studies do not control for confounding variables or allow conclusions regarding direction of influence. Finally, multi-modal measurement was rarely used, with only one parent (usually the mother) serving as the only participant reporting on the child's behavior and functioning. Multi-modal data helps avoid bias resulting from child-only or parent-only measurement, which usually gives only one view of the topic at hand.

Sibling Responsibilities and Parental Expectations

Researchers have reported that siblings of children with handicaps appear to have significant increased responsibilities and parental expectations in both the school and home environments. For example, siblings may have increased responsibility in household chores, caregiving tasks, and experience higher parental expectations (Gath & Gumley, 1987; McHale & Gamble, 1989).

It is not clear, however, whether these increased responsibilities and expectations have positive or negative impacts on child development. Although most reports show negative outcomes in this area of functioning, some researchers have discovered positive effects. For example, siblings of children with handicaps are reported by mothers to be more accepting and supportive of their siblings (McHale, Sloan, & Simeonsson, 1986).

Sibling Interaction

Additionally, many researchers have focused on sibling roles and interaction in typical dyads and dyads involving a child with Down syndrome. Role asymmetries in which one sibling is strongly dominant over the handicapped child in managerial and teacher roles, are often seen in sibling dyads containing a developmentally delayed child (Abramovitch, Stanhope, Pepler, & Corter, 1987; Knott, Lewis, & Williams, 1995; Stoneman, Brody, Davis, & Corter, 1987). More specifically, Knott, Lewis, and Williams (1995) found that dyads that included a child with autism interact less than the Down syndrome dyads. However, in both dyads, the typical sibling initiated more caregiving interaction than did the sibling with Down syndrome or autism. Knott et al. concluded that role asymmetry was present in both groups.

Researchers have also found effects for perceptions of family roles within the population of families with a child with developmental disabilities. For instance, in a study comparing siblings of children with autism, mental retardation, or no cognitive or physical disability (McHale, Sloan, & Simeonsson, 1986), siblings of handicapped children reported having a less positive role in their family as compared to controls.

Although sibling roles may dictate behavior in certain situations, sibling interaction may vary depending on gender and ability to initiate contact, especially during play. Abramovitch et al. (1979, 1980) conducted a series of studies on sibling interaction of typically developing children. In their naturalistic observation they found that older females initiated more

interaction. This held for same- and mixed-sex dyads. Birth interval (between siblings) was not found to have a significant effect on sibling interaction (Abramovitch, Corter, & Lando, 1979; Abramovitch, Corter, & Pepler, 1980). Finally, they found that peer relations do not correspond with those of sibling dyads (Abramovitch, Corter, Pepler, & Stanhope, (1986).

In contrast to these findings on typically developing children, researchers have discovered different outcomes when considering the effect of birth interval on interaction for sibling dyads in which one sibling is developmentally disabled. In one study, typical siblings who were born first were reported to initiate less interaction prosocially than were the siblings of children with Down syndrome (Abramovitch et al.). Within the Down syndrome dyad, the older, typically developing sibling initiated more interaction (both prosocial and agonistic) than the child with Down syndrome. Compared with younger typical children, young siblings with Down syndrome imitated their older siblings with less frequency. McHale and Gamble (1989), in their comprehensive study, obtained similar results as measured multi-modally by the Sibling Inventory of Behavior (SIB), although parental report of sibling interaction for both mentally handicapped and matched controls showed similar ratings of the frequency of positive and negative interactions. Other research (i.e., Bagenholm & Gillberg, 1991) supports this evidence of decreased initiation by children with Down syndrome.

Ordinal Position and Gender as Intervening Variables

In addition, researchers have focused on identifying moderating risk factors present in the sibling's situation. Of particular interest have been the sibling's ordinal position and sex. Hannah and Midlarsky (1985) reported several instances in the research literature of a tendency for children who are older than their handicapped sibling to be more adversely affected. Specifically, McHale and Gamble (1989) found significant correlations between anxiety and age. That is, the older the sibling, the more anxiety they experienced. Additionally, the trend for female siblings to experience a more difficult adjustment has been reported. Further, a sex by ordinal position effect has been widely documented (Cuskelly & Dadds, 1992; Gath, 1973; Greenberg, Kim, & Greenley, 1997; McHale & Gamble, 1989). Specifically, researchers have found that older female siblings receive the most direct adverse effect due to increased time spent caregiving and doing household chores. Similarly, McHale and Gamble (1989) found significant correlations between anxiety and age. That is, the older the sibling, the more anxiety they experience. In contrast, Bagenholm and Gillberg (1991) failed to find a trend in birth order, although this may be due to cultural differences between Sweden and the United States.

Specific Worries

With increased responsibilities and a lower level of parental resources (i.e., attention, caregiving time), siblings of children with developmental

disabilities may experience negative psychological effects. One of the most prevalent emotional responses, anxiety, may go unreported due to its internalizing nature. Additionally, most of the information on anxiety pertains to the population of siblings of children with “disabilities,” failing to delineate those specific to siblings of children with Down syndrome. Likewise, research on this topic is usually based on clinical anecdotal reports and not empirical studies.

Although relatively little is known about the specific worries of siblings of children with disabilities, as mentioned earlier, some research has detected the presence of anxiety in this population. However, the majority of studies have relied on maternal report of worries, instead of interviewing the children themselves. Earlier research based on child self-report (McHale, Sloan, & Simeonsson, 1986) indicates trends in worries about anxiety-provoking conditions such as future concerns as well as feelings of embarrassment and rejection for siblings of children with mental retardation.

Despite the lack of information on the special anxieties of siblings of children with Down syndrome, clinical literature describes certain trends in interaction and family functioning that allow for inferences regarding the types of worries that may be experienced. Based on extensive review of clinical and research literature, Groh (1997) grouped these worries into four categories: Self Worries (i.e., anxiety about the child’s own well-being), Sibling Worries (i.e., anxiety about the disabled sibling’s well-being), Family Worries (i.e. anxiety about family functioning), and Social Worries (i.e., anxiety other effects on the

child). Each of these areas, specific to Down syndrome, is discussed in detail below. For this section, as well as further sections, the term “child” will refer to the target (typically developing) child, while the term “sibling” will refer to the child with Down syndrome, unless otherwise noted.

Self Worries: Anxiety about the Child’s Own Well-being

Some children might experience Self Worries, concerning the possible negative effects that the sibling might experience. Worries of this nature comprise the child’s lack of information about Down syndrome and anxiety about the sibling’s behavioral disturbances that may affect the child (i.e., breaking of the child’s personal belongings). These anxieties may cause a misunderstanding of the sibling or fears about implications for oneself (e.g., that the child could “catch” Down syndrome). Bagenholm and Gillberg (1991) reported that 67% of the children ages 5 to 20 whose siblings have mental retardation could not explain what was different about or wrong with their sibling. This may cause the child to worry that the cause of the disability is a mystery. Increased household responsibility may also cause anxiety in the child. Children with siblings with handicaps spend twice as much time performing caregiving tasks as children whose siblings are typically developing (McHale & Gamble, 1989).

Sibling Worries: Anxiety about the Disabled Sibling’s Well-being

Some children may have Sibling Worries about the sibling with Down syndrome. These include anxiety that the sibling with Down syndrome may not fit in socially because of their temper tantrums and stubborn behavior,

which may lead to lack of social relationships. Also, children might worry about the future of the sibling with Down syndrome (Bagenholm & Gillberg, 1991). Finally, young children may feel that they won't be able to communicate properly with their sibling. Children with Down syndrome often have speech problems, and some fail to speak at all.

Family Worries: Anxiety about Family Functioning

When a child with Down syndrome is born, families often experience great changes. Because of the extra needs of this new sibling, typically developing children may receive less parental attention. Family Worries about these parental resources may be felt by children. In some cases, these changes might be incorrectly credited to the parent loving the sibling with Down syndrome more. Correlations have been found between anxiety and parental differential treatment, maternal negativity, and caregiving tasks (McHale & Gamble, 1989). Also, young children may notice the differences in family life when a sibling has Down syndrome. Particularly, disruption of family outings might occur because of uncontrollable behavior of the sibling. These situations may cause undue worry in the child if issues are not discussed.

Social Worries: Anxiety about Social Relationships and Related Issues

When seen in public, children might also feel embarrassed around the sibling with Down syndrome, prompting other, more socially-associated worries. They may feel that their peer group does not accept their sibling. As they mature, children might become more aware of this and believe that people make derogatory remarks about their sibling. In addition, the child may feel

that the subject of Down syndrome is not to be discussed within the family, leading to anxiety and isolation.

When worries and issues fail to be addressed in family communication, anxieties may be further internalized by the child and ignored by the parent. As children with Down syndrome enroll in mainstream schooling, people become aware of their disabilities. The public must respond to the presence of those who are different. However, the reaction by peers and other figures in the child's life to the sibling with Down syndrome may be one of misunderstanding and negativity. Because research on the issues is outdated and little is known of recent adjustment of this population, more research is needed to explore the effects on children with siblings with Down syndrome.

Current Study

The current study seeks to assess these specific worries in children whose siblings have Down syndrome. This study is unique in its reliance on both child- and parent-report, as well as its attempt to focus on siblings of children with Down syndrome, instead of more general populations of siblings of children with mental retardation or other developmental disabilities. Finally, rather than exploring the entire sibling experience, I hope to specifically identify *worries* within this population. Specifically, I hypothesize that higher levels of general anxiety will be present in children whose siblings have Down syndrome as compared to siblings of typically developing children. Also, I anticipate higher levels of self-worries, sibling worries, family worries and social worries specific to siblings of children with Down syndrome. Next, I

hypothesize a small positive correlation between parental reports of sibling worries and child report of sibling worries in both groups. Finally I expect a difference between male and female children whose siblings have Down syndrome in that females will show more worries than males.

Method

Participants

Participants for this study were 24 children between the ages of 7 and 14 and one of their parents (see Table 1). Participants were recruited through flyers and letters distributed to local Down syndrome support groups, local schools and the local YMCA.

All participants, both parents and children, were of a white, non-Hispanic racial background. About half of the participants ($n = 13$, 7 male and 6 female) had a sibling with Down syndrome (DS group), while about half had a typically developing sibling (Typical group; $n = 11$, 6 male and 5 female). One participant was dropped from the study due to the fact that she was five years old and could not understand the meaning of the questions being asked. The Typical group did not differ from the DS group in proportion of boys and girls, $\chi^2(1) = .001$, $p = .97$, or age, $t(22) = 1.30$, $p = .21$.

All parents who participated in the study were biological parents of both the child participant and the target sibling. Slightly more fathers participated for the DS group, but not significantly so, $\chi^2(1) = 1.70$, $p = .19$. The mean education level for both DS parents ($M = 16.12$ years, $SD = 2.57$) and for Typical group parents ($M = 16.46$ years, $SD = 2.51$) was quite high.

All of the target siblings in the DS group, that is, the child on whom the Sibling Worries Survey was filled out, were diagnosed with Down syndrome and received special services from their schools. The Typical group target siblings had no diagnosed developmental disabilities and received no additional remedial educational services. Target siblings in the DS group (ages 1 to 15, $M=6.49$, $SD=3.69$) were significantly younger than target siblings in the Typical group (ages 1 to 18, $M=10.68$, $SD=4.53$), $t(22)=-2.50$, $p<.05$. All but one of the participating children in the DS group filled the Sibling Worries Survey out on a younger sibling with Down syndrome. Of the control group target siblings, 7 were older and only 4 were younger.

Measures

Child Measures. Child participants were interviewed using two inventories. The measures were presented in random order.

The Revised Children's Manifest Anxiety Scale (RCMAS; Reynolds & Richmond, 1978) was used to examine the level and types of persistent childhood worries. The scale consists of 37 items in a yes/no self-report format (e.g., "I feel that others do not like the way I do things: Yes / No "). Reliable age norms for the age group in question have been established for the RCMAS, as well as support for its construct validity (Reynolds, 1980). The total anxiety score will be used in data analysis.

The second measure was the Sibling Worries Survey (SWS), an inventory based on Groh's Autism Worries Survey (AWS; Groh, 1997). There has been little specific research done in this area, and no validated scales were found to

test this variable (specific worries) for this population (Down syndrome).

Therefore, this measure was modified from Groh to detect and identify the sibling worries associated with Down syndrome. This data will be used as part of a larger validation study of the Sibling Worries Survey.

The survey includes 47 closed-ended items. Major categories of worries correspond with the aforementioned specific worries in this population: (1) Self Worries, (2) Sibling Worries, (3) Family Worries, and (4) Social Worries.

Internal consistency and reliability was adequate for all four scales. Sample subscale items and Cronbach alpha values are presented in Table 2.

The survey questions have the following format: (1) a statement about a Down syndrome worry (e.g., “Some kids worry that they have to do more chores around the house because their brother has Down syndrome.”), (2) four simple line drawings of a child’s face (the gender of which matches the participant’s gender) corresponding to varying expressions of worry and labeled with the statements “This boy really worries”, “This boy kind of worries”, “This boy worries just a little bit”, and “This girl doesn’t worry” , and (3) appearance of the question “Which child are you most like?” (See Figure 1 for sample page.). If an answer was vague or the child was uncertain, the researcher asked the child to “tell me more” in order to clarify responses.

For typical controls, the Sibling Worries Survey was modified to account for the fact that 10 questions specifically mention Down syndrome. For example, item 11, “Some kids worry that they might also have Down syndrome” was rephrased as “Some kids worry that they might also have special

problems.” The SWS yields ten scores for each child; number and mean intensity of worries for each of the subscales as well as Total Worries. For this project, only the number of worries scores for Total Worries and subscales were used.

Parental Measures. Parents filled out corresponding versions of the RCMAS and SWS to assess their view of the participating child’s anxieties and worries. In addition parents completed the Child Behavior Checklist (CBCL; Achenbach & Edelbrock, 1983). A standardized inventory, the CBCL measures internalizing and externalizing behavior problems and social competency for children ages 2 to 18, providing norms for children of different ages and sexes. Validity of the CBCL has been well-established (Cohen, 1988; Edelbrock & Costello, 1988).

Procedure

Upon arrival at the research location, the parent and child participants met with the researcher to go over the purpose of the study. Confidentiality was explained and participants told that there are no right or wrong answers to questions in the research process. The researcher obtained informed consent from the parent and assent from the child. Permission was also obtained for videotaping the interview. The child participant then went through an interview with the researcher while the parent participant completed questionnaires. The researcher read each question to the child and recorded the response.

Following the data collection, the researcher, child, and parent met for debriefing procedures to address the participant's concerns, provide feedback, and explain follow-up procedures. References were given regarding further information on sibling resources. Additionally, parents received a copy of the consent form for their records. Compensation was provided in the form of small gifts for both the parent and child.

Results

Data Analysis

First the DS and Typical group scores on the measure of general anxiety (RCMAS) and on behavior (CBCL) were compared to national norms using one-sample t-tests. Next, using the t-test for independent samples, the DS and Typical groups were compared on general problem measures (RCMAS and CBCL).

In analyzing Sibling Worries Survey scores, three sets of planned comparisons were conducted: (1) comparisons of DS and Typical group based on child-report, (2) comparisons of DS and Typical groups based on parent-report, and (3) comparisons of the parent's tendency to overreport or underreport child's worries. Given the exploratory nature of this study and its small sample size the significance level was set at $p < .05$ for individual comparisons.

Finally, for exploratory purposes, we computed correlation coefficients to assess the relationship among SWS subscales in general and specifically, agreement between parent and child report. Further, differences between girls

and boys on the overall scores and subscale scores of the SWS were tested using independent sample t-tests.

Comparison to National Norms

Using one sample t-tests, participants in the DS group did not score significantly different in comparison to national norms ($M=50$, $SD=10$) on the measures of general anxiety, $t(12)=.17$, $p=.86$. Similarly, the Typical group did not differ significantly from national norms on the RCMAS, $t(10)=-1.39$, $p=.20$ (see Table 3 for means).

CBCL scores were compared to national norms to determine whether the sample differed from the national population. Neither the Typical group nor the DS group differed significantly on overall total number of problems, or on the CBCL externalizing subscale of behavior. The DS group CBCL internalizing scale was marginally higher than national norms, $t(10)=1.99$, $p=.08$. On the total competence scale, which tests such variables as social ability and activity in sports, the Typical group scored significantly higher compared to national norms, $t(9)=4.40$, $p<.01$, while the DS group scored marginally higher, $t(10)=2.05$, $p=.07$.

Down Syndrome versus Typical Group on General Measures

In order to determine whether the siblings of children with Down syndrome differed from siblings of typically developing children on the measure of general anxiety, child-reported scores on the RCMAS were analyzed using an independent sample t-test. The DS group did not report significantly more anxieties than the Typical group, $t(22)=1.18$, $p=.249$.

To explore behavior patterns, as measured by the parent-report CBCL, scores for the number of Total Problems, Total Competence, Externalizing Behavior and Internalizing Behavior, were compared for the two groups. None of the tests approached significance.

Sibling Worries Survey

Child Report. Using a t-test for independent samples, the total number of worries reported by children for the DS ($M=17.54$, $SD=10.13$) and Typical ($M=14.91$, $SD=7.74$) were compared. No significant difference was found between the groups in the overall number of worries endorsed, $t(22)=.70$, $p=.49$ (see Table 4).

As shown in Table 4, DS group siblings reported significantly more sibling related worries (i.e., Sibling-Focused Worries Subscale) than did Typical group siblings, $t(22)=2.17$, $p<.05$. In contrast, no significant differences on the other child-report SWS subscales were found for the two groups.

Parent Report. Although child participants in both groups reported about the same number of worries, parent-report measures show different results. Overall, parents of children with Down syndrome reported that their children have more worries than did parents of typically developing children. The DS group parent-reported mean on the Total Worries Score ($M=24.23$, $SD=12.91$) was significantly higher than the mean for the Typical group ($M=9.00$, $SD=8.0$), $t(22)=3.39$, $p<.01$ (see Table 5).

Parents of children with Down syndrome also reported more child worries than the control group on different subscales. Significant differences

were found on the Self Worries, $t(22)=3.26$, $p<.01$, Sibling Worries, $t(22)=4.26$, $p<.001$, and Social Worries, $t(22)=3.84$, $p<.001$, scales.

Difference Scores. In order to explore differences between parent and child report within each group on the Total Worries Score and subscales of the SWS, difference scores were compared. On the Total Worries Score, Typical group parents significantly underreported child worries relative to DS group parents, $t(22)=2.72$, $p<.05$ (for means see Table 6). A similar trend occurred for the difference scores on the Self Worries subscale, $t(22)=2.27$, $p<.05$, the Sibling Worries subscale, $t(22)=2.28$, $p<.05$, and the Social Worries subscale, $t(22)=3.77$, $p<.01$. Differences between the parent and child reports for the two groups on the Family Worries subscale approached significance, $t(22)=1.81$, $p=.08$. As shown in Figure 2, DS group parents had a tendency to overreport their children's worries, while Typical group parents tended to underestimate the number of child worries.

Correlational Analysis. Correlations among the subscales for both child-report and parent-report on the versions of the Sibling Worries Survey were calculated. Based on child-report, subscales were significantly correlated with one another, with correlations ranging from $r=.41$ to $r=.70$ (see Table 7). Parent-report subscales were also significantly correlated, ranging from $r=.67$ to $r=.90$ (see Table 8).

Child and parent agreement was also calculated for the total scale and each subscale. Between child- and parent-report, there was a marginally significant correlation on the Total Worries Score, $r=.39$, $p=.06$ and significant

correlations on both Sibling Worries, $r=.50$, $p<.05$, and Social Worries, $r=.64$, $p<.001$. Correlations between scores on the Self Worries, $r=.30$, $p=.16$, and Family Worries, $r=.16$, $p=.46$, subscales were not significant (see Table 9).

Gender Differences

The two groups, DS and T, were combined to determine whether male and female children report different numbers and kinds of worries. No significant differences were found between male and females on the SWS Total Worries score or on SWS subscales.

Discussion

The primary goal of this study was to determine whether siblings of children with Down syndrome have more sibling-associated worries than siblings of children who are typically developing. By using a multi-modal approach of measuring the actual child's worries as well as the parent's perception of the child's worries, it was hoped that a more valid view of these worries could be obtained. Overall, three major findings emerged, (1) siblings of children with Down syndrome did not exhibit significantly elevated problems in general psychosocial functioning, (2) by child-report, siblings of children with Down syndrome did not differ significantly from siblings of typically developing children in terms of sibling worries, (3) by parent report, siblings of children with Down syndrome had more worries than siblings of typically developing children, and (4) parents of children with Down syndrome overestimated the number of child worries, while parents of typically developing children underreported their child's worries.

In examining these, which indicate some significant differences between siblings of children with Down syndrome and typical controls, it is important to consider the results within the context of this study (these general indications will be considered in detail below). First of all, it is important to note that all of the families of children with Down syndrome in the sample were willing to come in for a study on worries of siblings of children with Down syndrome, are involved with local Down syndrome support groups, and many of the siblings themselves had taken part in sibshops. Thus, the parents were already attuned to possible worries of their non-disabled children, which may have increased their endorsement of child worries. Additionally, they were actively involved in informing themselves about Down syndrome through support groups. This involvement may make them more emotionally intact and available to the possibility of child worries. Finally, siblings who have take part in sibshops have already been given the chance to learn about Down syndrome and share any anxiety, thus decreasing the amount they realistically endorse.

Compared to national norms, the sample did not differ significantly on measures of overall general anxiety or of overall behavior problems. However, on the internalizing scale of the CBCL, children in the DS group had marginally higher scores. As shall be discussed later, the nature of internalizing problems (that they tend not to be shared or exhibited to others) may have caused children not to feel comfortable reporting the worries to researchers.

Encouraging possibilities were discovered in the area of total competence. While the Typical group children had significantly higher scores

than the national norm, children in the DS group also had higher, though not significant, scores. Such a finding could indicate that effects of having a sibling with Down syndrome exist are not necessarily negative.

Contrary to hypotheses, on a measure of general anxiety siblings of children with Down syndrome did not differ from siblings of typically developing children. This effect may be understood by examining the following reasons. First, there may truly be no difference in terms of general anxiety between the two groups. Secondly, the questionnaire may not have measured anxiety accurately for these children. For instance, although children are supposed to respond honestly to the questionnaire, such self-report may make it difficult for general internalized worries to be reported. In doing so, this difficulty may lead to consistent underreporting of anxiety on the child's behalf, although this is purely speculative considering that the RCMAS measure has been established to have validity and take underreport and overreport into account. The finding that children in the DS group failed to demonstrate significant differences from the Typical group participants on the CBCL overall score or on subscale scores, lends support to the hypothesis that siblings of children with Down syndrome are as well-adjusted as children without siblings with Down syndrome.

In considering the hypothesis that siblings of children with Down syndrome would report more specific worries than typical controls, we found interesting results. Although all DS siblings reported at least some specific worries, their number of worries, as compared to the Typical group, did not

differ significantly either for Total Worries or subscales of interest. There was a marginally significant trend, however, for these DS siblings to endorse significantly more worries associated with their disabled sibling (i.e., Sibling-Focused Worries subscale). This lack of pervasive group differences is similar to the finding of McHale et. al. (1986) for their Sibling Problems Questionnaire and Sibling Relationship Inventory both of which failed to show major differences between siblings of children with Mental Retardation, Autism, or typical development. I conclude that siblings of children with Down syndrome may have slightly more specifically sibling-related worries than children with typically developing siblings. Additional data is needed to confirm this hypothesis.

However, there may be alternative explanations for the lack of significant group differences in sibling-specific worries, although the reasons are complex and sometimes contradictory. For example, I hypothesized that children would experience higher levels of social worries due to their sibling's having Down syndrome. While people with Down syndrome are becoming a larger part of the community, due mostly to the recent laws passed on inclusive education, I anticipated that siblings would continue to experience anxiety about issues such as others staring at the child with Down syndrome, the child with Down syndrome misbehaving in public, or feeling as though they have to make excuses for their sibling. Yet, the heightened public awareness of people with Down syndrome may actually serve to decrease worries because the general

public has been exposed and is therefore more comfortable with interacting with special populations.

Additionally, because children with Down syndrome are no longer being institutionalized, their families have the opportunity to live with them on a daily basis. This setup may ease and increase communication about the sibling with Down syndrome, where in the past, families were limited to infrequent visits and sparse discussion of the institutionalized child.

Furthermore, increased access to sibshops and support group connections may serve to increase understanding and communication between parents and children, as well as giving children a supportive atmosphere to share their feelings with other children in the same situation as themselves. Due to the increase in communication — as a function of decreased institutionalizing, inclusive education, and supportive groups — siblings may harbor fewer worries specific to the child with Down syndrome, even when compared to siblings of typically developing children.

Further, in examining demographic variables in families of children with Down syndrome, it is apparent that several factors may contribute to the amount of worries a child may have. For instance, a more complex interaction of variables, such as gender, age, amount of communication in the family, parenting style, as well as how the parent perceives the limitations and “specialness” of the child with Down syndrome, may lead to different outcomes in terms of worries. In failing to control for all of these variables, these intricate interactions may be lost.

Parents of children in the DS group reported that their children have more worries than did parents of children in the Typical group. That is, parents of children with Down syndrome perceive their children as having a greater total number of worries, as well as more specific worries about themselves, their siblings, and social consequences of having a sibling with Down syndrome. This finding corresponds with results from similar studies based on parent-report of child anxiety (i.e., Gath and Gumley, 1987). Parents of Typical group children failed to endorse these worries to the same extent. In this way, the two groups differ as predicted.

Overall, DS parents exhibited a tendency to describe their children as having more worries than did their children themselves, while parents of typically developing children tended to report fewer worries than did their participating children. This group effect may indicate a number of possibilities. First of all, DS parents may have overestimated the number of worries of their participating child. As mentioned above, parents were willing to be questioned about possible child worries, which may increase the likelihood that they would endorse such worries. Additionally, they may have been more likely to endorse worries as a function of their novelty, that is, due to their hypersensitivity to worries and problems in general, as a function of dealing with having a child with Down syndrome. Conversely, siblings of children with Down syndrome may internalize their worries, resulting in lower self-report scores. As reported by McHale and Gamble (1989) and Gath and Gumley (1987), siblings of developmentally disabled children have higher anxiety scores, which is an

internalizing characteristic (although this was not found as strongly in this sample).

It is important, however, to note that the parents within the DS group may have been unlike each other. For example, a parent of a newborn may focus all of their attention on dealing with the newness of the condition, without thinking about the sibling's worries. Contrastingly, a parent with heightened sensitivity to their children's anxiety may overestimate the actual extent to which the child worries. Yet, because the correlation between parent and child report of total worries was marginally significant, parents may overestimate, *but still generally agree on*, the relative number of total worries experienced by their child. Furthermore, parent-child correlations on the Sibling Worries and Social Worries subscales were found to be significant, indicating possible agreement on specific groups of worries.

In contrast to prior research (i.e., Gath, 1973; Hannah & Midlarsky, 1985), female siblings of children with Down syndrome did not report more sibling-related worries than their male counterparts. Female siblings are sometimes required to perform caregiving tasks, possibly causing increased parental behavior and increased worries about the child with Down syndrome (Gath & Gumley, 1987). However, perhaps this sample is not subjected to these chores, or failed to express and endorse related worries.

There are some significant limitations to the current study. First, the small sample size may have limited the power to obtain significant results. Although recruitment of participants was extensive, the low frequency of Down

syndrome (as compared to typical development) limited participant availability. Second, some participants in the DS group came from the same family. Although their answering patterns were not identical, this confound may have affected the overall kinds and amounts of worries. Third, the DS group and the Typical group were not matched ideally, which may have led to improper balancing between age and gender. Although data were not analyzed to detect differences between older and younger siblings, literature has indicated that siblings who are older than the child with Down syndrome experience more worries than those who are younger than the target sibling (McHale & Gamble, 1989). This may be due to the additional role of caretaking in which the older sibling may be put, causing increased anxiety. Because most of the Typical group reported on worries about older siblings, while DS group reported on younger siblings, differences in ordinal position may have affected results.

Fourth, some families of children with Down syndrome may not have the same supportive resources, perhaps due to geographic location or the current availability of support services. Thus, it is possible that such parents may have overreported child worries in the DS group while their children may have underreported (or internalized) worries.

Further, variability on other characteristics within the sample may have affected findings. For instance, the age range of the sibling with Down syndrome was highly variable. However, worries of children whose siblings with Down syndrome were just recently born may greatly differ from those who have lived with their sibling for over ten years. The siblings of a newborn with

Down syndrome may have “initial” worries, including misunderstandings about Down syndrome, while “experienced” siblings may have greater anxiety about the future of a teenager with Down syndrome.

Additionally, as stated before, only some of the siblings had attended sibshops. Without the chance to voice concern in a supportive atmosphere, those who had not attend sibshops may endorse more worries or may have internalized more worries. Another complicated interaction may exist due to the child’s own coping style. An introverted child who overestimates the strength or presence of their worries may endorse different numbers and kinds of worries than one who is highly optimistic about their sibling, thus downplaying the importance and existence of anxiety. Thus, caution must be taken in generalizing information from group studies (like this one) of Down syndrome families to individuals.

Several clinical implications may be drawn from results of the current study. For instance, in working with families of children with Down syndrome, there exists a delicate balance between generalization of results and variability in families. It may be beneficial to enhance communication between family members, allowing sibling worries to be discussed openly and in a non-threatening environment so that better understanding between the child and parent may be achieved. If a misunderstanding cannot be cleared up, asking a professional or referencing a book may be useful. Ongoing communication about new worries may also be helpful.

As shown by the difference scores, parents vary in their tendency to either overreport or underreport their child's worries. In addition to aiding parent-child understanding, sensitivity to the parent's direction of report should be used in clinical applications. For instance, awareness of how parents estimate their child's anxiety is important for professionals working with parents. Specifically, information should not add excess anxiety to those parents who already worry (by saying that parents need to be highly attentive to their children's worries) nor demean or lessen the existence of possible worries (by telling them that parents overworry). In sum, report of significant findings, with regard to individual cases, should be used in the most appropriate manner.

Future researchers must endeavor to discover whether siblings of children with Down syndrome have similar levels of sibling worries as do siblings of typically developing children, or are differentially internalizing, and therefore not reporting, the worries they experience. Exploring resources in order to find a larger sample size and matching typical controls may increase the ability to find significant results and patterns. Additionally, researchers must pay close attention to variability throughout the families and within each family in detecting intervening variables, perhaps by regression analysis or path analysis. Finally, sensitivity to each family's background must be considered in applying results to clinical settings.

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Table 1

Participant Demographics

| <u>Group</u> | <u>Age Range</u> | <u>Age M (SD)</u> | <u>Gender</u> | <u>Ordinal Position</u> |
|------------------------------|------------------|-------------------|-------------------------|---|
| DOWN SYNDROME | | | | |
| Participating Child (n = 13) | 8-14 | 11.38 (2.00) | Male = 7 Female = 6 | Older than target sibling = 12 Younger than target sibling = 1 |
| Parent (n = 13) | | | Male = 4 Female = 9 | |
| Target Sibling | 1-15 | 6.49 (3.69) | | |
| TYPICAL | | | | |
| Participating Child (n = 11) | 7-13 | 10.38 (1.78) | Male = 6 Female = 5 | Older than target sibling = 4 Younger than target sibling = 7 |
| Parent (n = 11) | | | Male = 1 Female = 10 | |
| Target Sibling | 1-18 | 10.68 (4.53) | | |

Table 2

Sibling Worries Survey Subscales and Sample Items

| <u>Subscale</u> | <u>Sample Items</u> |
|--|--|
| <u>SELF</u> (10 items, child alpha=.79) parent alpha=.84) | <p>Some kids worry that their brother will break their things.</p> <p>Some kids worry that they don't understand what their brother feels.</p> <p>Some kids worry that they have to more chores around the house because their brother has Down syndrome.</p> <p>Some kids worry that they will have to take care of their brother when they are older.</p> |
| <u>SIBLING</u> (10 items, child alpha=.87) parent alpha=.93) | <p>Some kids worry that their brother will get lost.</p> <p>Some kids worry that their brother might get worse.</p> <p>Some kids worry that their brother won't ever talk or won't ever talk much.</p> <p>Some kids worry that their brother can't explain what is wrong with him.</p> |
| <u>FAMILY</u> (10 items, child alpha=.78) parent alpha=.93) | <p>Some kids worry that their parents don't love them as much as they love their brother.</p> <p>Some kids worry that their parents spend too much money on their brother and there won't be enough left over for them.</p> <p>Some kids worry that they can't talk to their parents about their brother.</p> <p>Some kids worry that their brother will mess up their family's plans.</p> |
| <u>SOCIAL</u> (10 items, child alpha=.87) parent alpha=.95) | <p>Some kids worry that other kids might tease them about their brother.</p> <p>Some kids worry that other kids think they are weird because of their brother.</p> <p>Some kids worry that people say bad things about their brother.</p> <p>Some kids worry that their brother will embarrass them in public.</p> |

Table 3

Overall Anxiety and Problems: Revised Children's Manifest Anxiety Scale
and Child Behavior Checklist vs. National Norms

| <u>Group</u> | <u>Measure</u> | <u>Sample M (SD)</u> | <u>Norm</u> | <u>t(22)</u> |
|------------------------|------------------|----------------------|-------------|------------------|
| Down Syndrome (n = 13) | | | | |
| | RCMAS | | | |
| | Total Anxiety | 50.46 (9.51) | 50 (10) | .17 |
| | CBCL | | | |
| | Total Problems | 51.27 (5.95) | 50 (10) | .71 |
| | Externalizing | 49.10 (6.03) | 50 (10) | -.47 |
| | Internalizing | 54.64 (7.72) | 50 (10) | 2.0 ^t |
| | Total Competence | 56.55 (10.56) | 50 (10) | 2.1 |
| Typical (n = 11) | | | | |
| | RCMAS | | | |
| | Total Anxiety | 45.64 (10.44) | 50 (10) | -1.4 |
| | CBCL | | | |
| | Total Problems | 47.55 (7.22) | 50 (10) | -1.1 |
| | Externalizing | 47.36 (8.35) | 50 (10) | -1.1 |
| | Internalizing | 50.36 (7.93) | 50 (10) | .15 |
| | Total Competence | 60.00 (7.2) | 50 (10) | 4.4* |

^t p<.10

* p<.01

Table 4

Total Number of Sibling Worries: Child-Report Down Syndrome vs. Typical

| <u>SWS Scales</u> | <u>Group</u> | <u>Mean Number of Worries Reported (SD)</u> | <u>t(22)</u> |
|----------------------------------|---------------|---|--------------|
| TOTAL WORRIES n = 47 | Down Syndrome | 17.54 (10.13) | .70 |
| | Typical | 14.91 (7.74) | |
| SELF WORRIES n = 10 | Down Syndrome | 5.08 (2.50) | .67 |
| | Typical | 4.56 (1.92) | |
| SIBLING WORRIES n = 10 | Down Syndrome | 5.46 (2.26) | 2.17* |
| | Typical | 3.45 (2.25) | |
| FAMILY WORRIES n = 10 | Down Syndrome | 1.85 (1.95) | -.69 |
| | Typical | 2.45 (2.38) | |
| SOCIAL WORRIES n = 10 | Down Syndrome | 4.31 (3.31) | .98 |
| | Typical | 3.18 (2.04) | |

* p<.05

Table 5

Total Number of Sibling Worries: Parent-Report Down Syndrome vs. Typical

| <u>SWS Scales</u> | <u>Group</u> | <u>Mean Number of Worries Reported (SD)</u> | <u>t(22)</u> |
|----------------------------------|---------------|---|--------------|
| TOTAL WORRIES n = 47 | Down Syndrome | 24.23 (12.91) | 4.0** |
| | Typical | 9.00 (7.99) | |
| SELF WORRIES n = 10 | Down Syndrome | 6.00 (2.94) | 3.3** |
| | Typical | 2.72 (1.68) | |
| SIBLING WORRIES n = 10 | Down Syndrome | 6.62 (3.15) | 4.3*** |
| | Typical | 1.91 (2.02) | |
| FAMILY WORRIES n = 10 | Down Syndrome | 4.77 (3.79) | 1.49 |
| | Typical | 2.73 (2.72) | |
| SOCIAL WORRIES n = 10 | Down Syndrome | 6.23 (3.77) | 3.8*** |
| | Typical | 1.45 (1.81) | |

* p<.05
** p<.01
*** p<.001

Table 6

Difference Scores for Parent and Child Report on the Sibling Worries Survey

| <u>SWS Scales</u> | <u>Group</u> | <u>Mean Difference Score</u> <u>(SD)</u> | <u>t(22)</u> |
|-------------------|---------------|---|--------------|
| TOTAL WORRIES | Down Syndrome | 6.69 (13.31) | 2.72* |
| | Typical | -5.91 (8.26) | |
| SELF WORRIES | Down Syndrome | .92 (3.50) | 2.27* |
| | Typical | -1.73 (1.79) | |
| SIBLING WORRIES | Down Syndrome | 1.15 (3.00) | 2.28* |
| | Typical | -1.55 (2.81) | |
| FAMILY WORRIES | Down Syndrome | 2.92 (3.80) | 1.81 |
| | Typical | .27 (3.29) | |
| SOCIAL WORRIES | Down Syndrome | 1.92 (3.01) | 3.8*** |
| | Typical | -1.73 (1.19) | |

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

Table 7

Correlations between Sibling Worries Survey Subscales Based on Child-Report

| <u>Subscales</u> | <u>Correlation r</u> | | | |
|------------------|----------------------|------------------------|-----------------------|-----------------------|
| | <u>Self Worries</u> | <u>Sibling Worries</u> | <u>Family Worries</u> | <u>Social Worries</u> |
| Self Worries | — | .47* | .67*** | .68*** |
| Sibling Worries | | — | .41* | .57** |
| Family Worries | | | — | .71*** |
| Social Worries | | | | — |

* p<.05

** p<.01

*** p<.001

Table 8

Correlations between Sibling Worries Survey Subscales Based on Parent-Report

| <u>Subscales</u> | <u>Correlation r</u> | | | |
|------------------|----------------------|------------------------|-----------------------|-----------------------|
| | <u>Self Worries</u> | <u>Sibling Worries</u> | <u>Family Worries</u> | <u>Social Worries</u> |
| Self Worries | — | .84*** | .67*** | .74*** |
| Sibling Worries | | — | .76*** | .90*** |
| Family Worries | | | — | .78*** |
| Social Worries | | | | — |

*** p<.001

Table 9

Correlations between Child- and Parent-Report on the Sibling Worries Survey Subscales

| <u>Subscales</u> | <u>Correlation r</u> | | | | |
|---------------------|----------------------|------------------------|-----------------------|-----------------------|----------------------------|
| | <u>Self Worries</u> | <u>Sibling Worries</u> | <u>Family Worries</u> | <u>Social Worries</u> | <u>Total Worries Score</u> |
| Self Worries | .30 | | | | |
| Sibling Worries | | .50* | | | |
| Family Worries | | | .16 | | |
| Social Worries | | | | .64** | |
| Total Worries Score | | | | | .39 |

* p<.05
** p<.01

Figure Caption

Figure 1. Sample page from the Sibling Worries Survey.

16. Some kids worry that they don't get enough attention from their parents because their brother needs so much attention.



This boy really worries.



This boy kind of worries.



This boy worries just a little bit.



This boy doesn't worry.

Which one are you most like?

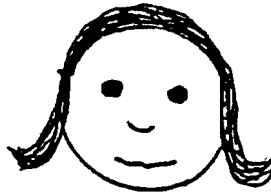
29. Some kids worry that their sister will misbehave in a public place.



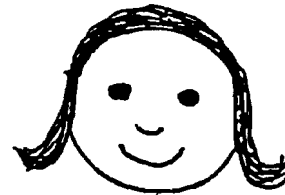
This girl really worries.



This girl kind of worries.



This girl worries just a little bit.



This girl doesn't worry.

Which one are you most like?

Figure Caption

Figure Caption

Figure 2. Mean number of worries reported by parents and children on the Sibling Worries Survey subscales.

