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Having a Brother or Sister with Down Syndrome: Perspectives from Siblings

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Abstract

This study asks brothers and sisters about their feelings and perceptions toward their sibling with Down syndrome. We analyzed valid and reliable surveys from 822 brothers and sisters whose families were on the mailing lists of six non-profit Down syndrome organizations around the country. More than 96% of brothers/sisters that responded to the survey indicated that they had affection toward their sibling with Down syndrome; and 94% of older siblings expressed feelings of pride. Less than 10% felt embarrassed, and less than 5% expressed a desire to trade their sibling in for another brother or sister without Down syndrome. Among older siblings, 88% felt that they were better people because of their siblings with Down syndrome, and more than 90% plan to remain involved in their sibling's lives as they become adults. The vast majority of brothers and sisters describe their relationship with their sibling with Down syndrome as positive and enriching.

Keywords

Down syndrome; trisomy 21; siblings; brother; sister; prenatal diagnosis; attitudes

INTRODUCTION

When expectant parents receive a prenatal diagnosis of Down syndrome (DS), they often ask: what impact will such a child will have on my other sons and daughters? Researchers from the Netherlands surveyed 71 women who had terminated a pregnancy based on prenatal findings of DS, and 73% of them decided that the "burden" would be "too heavy for [their] other child[ren]" [Korenromp et al., 2007]. Consensus and Study Groups maintain that all expectant couples should receive accurate, nonjudgmental, and current information about DS during counseling sessions [American College of Obstretricians and Gynecologists et al., 2009; Skotko et al., 2009b; Skotko et al., 2009a], but the literature on sibling impact has been noticeably slim [Skotko and Levine, 2006].

Having a brother or sister with DS may, in fact, have benefits, according to some research. When siblings of persons with DS were compared to matched controls, they reported more empathy and kindness toward their brothers and sisters [Cuskelly and Gunn, 2003] and less conflict and more warmth in their relationship [Fisman et al., 2000]. In comparison to

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having a sibling with autism, adult brothers and sisters of people with DS feel more understanding, trust, and respect for their siblings[Hodapp and Urbano, 2007], describing their sibling relationship as more positive [Hodapp and Urbano, 2007; Orsmond and Seltzer, 2007] and less likely to impact their relationship with their parents [Orsmond and Seltzer, 2007]. Children who have siblings with DS also have been observed to interact more with their brothers and sisters when compared to their counterparts who have siblings with autism [Knott et al., 1995].

Other researchers have observed similarities—rather than differences—between those siblings who have brothers and sisters with DS and those who do not. Parents of children with DS reported that their siblings had no more behavioral problems than those of matched controls [Cuskelly et al., 1998], and, in other studies, parents did not report any significant differences in siblings' social competence [Van Riper, 2000; Cuskelly and Gunn, 2006; Kaminsky and Dewey, 2002; Rodrigue et al., 1993]. Brothers and sisters reported that they had just as much self-worth and self-competence as compared to matched controls, leading the authors to conclude "that brothers and sisters of a child with DS do not seem to be penalized in their opportunities to participate in a normal childhood" [Cuskelly and Gunn, 2006].

As siblings age, many assume more caregiving roles in comparison to matched controls [Cuskelly and Gunn, 2003]; although, this action is not universal [Cunningham, 1996]. For those siblings who do take on additional responsibilities, they typically view this involvement as a positive engagement and not as a burden [Cuskelly and Gunn, 2003]. Further, brothers have also been found to assume just as much responsibility as sisters, when a sibling has DS [Cuskelly and Gunn, 2003; Cuskelly and Gunn, 1993].

To date, no large quantitative studies have been done to characterize the collective feelings and perceptions of brothers and sisters who have siblings with DS. Within small study samples, they have been compared to controls and other populations, but they have not been asked directly: what is it like to have a sibling with DS? Through this study, we seek to gather their answers to this central question so that expectant parents—and their healthcare providers—can have more comprehensive information to aid in informed decision making.

MATERIALS AND METHODS

Participants

This study was nested in a larger cross-cultural, epidemiologic research project on family attitudes toward persons with DS. (Attitudinal perspectives from parents and self-advocates will be published separately.) The project was approved as protocol H-26552 by the Institutional Review Board of Boston University Medical Center.

Ten siblings, recruited by the lead authors, participated in focus group testing of the preliminary survey instruments. For the validity and reliability testing of the questionnaires, we invited all 300 families associated with the Down Syndrome Society of Rhode Island to participate. Because there is no national registry of individuals who have DS in the United States, the final survey instruments were distributed to all of the 4,924 family members of 6 nonprofit DS organizations, chosen for their size, cultural compositions, and geographic distribution throughout the United States: Down Syndrome Association of Atlanta (757 members), Massachusetts Down Syndrome Congress (1,143 members), Mile High Down Syndrome Association (Denver, CO) (877 members), Triangle Down Syndrome Network (Raleigh, NC) (280 members), Down Syndrome Association of Central Texas (371 members), and Down Syndrome Association of Los Angeles (1,574 members).

Survey Instrument

Phase I: Piloting—As we could not identify a pre-existing survey instrument that collected our desired information, we created a 3-page questionnaire for brothers and sisters, ages 9–11, and a separate 4-page questionnaire for brother and sisters, ages 12 and older (published in Appendix online). Our questionnaires were informed by previous research [Skotko and Levine, 2006] with direct input from participant representatives. The surveys gathered both quantitative and qualitative information, using open-ended questions and a series of Likert statements. The questionnaire for the younger siblings used a scale of 1 to 4 (with "1" being "yes"; "2" being "most of the time"; "3" being "once in a while"; and "4" being "no"), as Likert scales have been shown to be the best measure when surveying children [van Laerhoven et al., 2004]. The questionnaire for the older siblings used a scale of 1 to 7 (with "7" indicating strong agreement and "1" indicating strong disagreement). The questions measured feelings toward their brother or sister with DS in addition to the impact such a sibling was having on their lives. As optional measures, brothers and sisters were asked to report sociodemographic information. To satisfy the charge of incorporating qualitative research on genetic conditions [Bernhardt, 2008], we asked for siblings to answer open-ended questions on life lessons learned from their brother or sister with DS in addition to any advice that they would have for expectant parents. Through unique identifier numbers assigned to each family, we further linked parental reports about the following aspects of the sibling with DS: birth order, functional skills, health condition, and educational challenges.

In two separate focus group sessions that each met twice, the research tools were edited for wording clarity by 5 siblings, ages 9–11, and 5 siblings, ages 12 and older, who had a brother or sister with DS.

Phase II: Validity & Reliability Testing—The revised questionnaires were then distributed to all families of the Down Syndrome Society of Rhode Island for validity and reliability testing. Those who responded to the first mailing received an identical questionnaire 4 weeks later for test-retest reliability. In total, we received 40 responses from siblings ages 12 and older, and 45% of these respondents completed the second mailing. Eleven responses were received siblings ages 9–11, and 45% of the respondents completed the second mailing.

Construct validity was determined by measuring discriminant validity on the first mailing, which was defined *a priori* as a Pearson's correlation between −0.6 and +0.6 between dissimilar constructs on our survey instrument. For younger siblings' survey, the constructs were identified as the summative scores from questions 13, 18, 24, and 25 (positive construct) and questions 16, 19, 23, and 26 (negative construct). The survey met our criteria for discriminant validity ($r = -0.60$, $N = 11$). For the older siblings' survey, the constructs were identified as the summative scores from questions 8 and 14 (positive construct) and questions 13 and 16 (negative construct). The survey met our criteria for discriminant validity ($r = -0.43$, $N = 40$). Reliability was determined by measuring test-retest reliability after the second mailing, which was defined *a priori* as >80% of participants responding ≤ 1 point difference on our Likert scale. Two questions failed to meet this reliability for the younger siblings' survey, and four questions failed for the older siblings' survey. These questions were eliminated from our final survey instrument used for national distribution. The responses from our participants in our validity and reliability testing were not part of our final data analyses. The final survey for the younger brothers and sisters had a Flesch-Kincaid grade level of 4.7; the survey for the older siblings had a grade level of 6.1 Final surveys were also translated into Spanish and checked by another person for accuracy.

Phase III: Study—The final surveys were distributed through non-profit DS organizations in six different states using evidence-based best practices [Edwards et al., 2002; Nakash et al., 2006]: We provided self-addressed stamped envelopes; nonrespondents were mailed a second copy of the questionnaire approximately 6 weeks after receiving the first copy; the questionnaire packet was mailed on university stationery; and the survey was kept purposely short to encourage completion. One younger sibling's survey and one older sibling's survey were included in each packet mailed to the family, with additional copies available for download from a secure, password-protected web site. Both surveys for siblings had a simple introduction stating that they should place their survey in the provided envelope and seal it before returning to their parents for return mailing.

At all times, confidentiality of the families was maintained. The survey packets were mailed only to the non-profit DS organizations, who then forwarded the mailings to their members. Packets written in Spanish were mailed by the non-profit DS organizations to their known members who were exclusively Spanish-speaking. Contact information was received only when the brothers or sisters voluntarily chose to respond to the survey. Upon receipt of the surveys, contact information was separated from the questionnaire and stored in a locked file cabinet. No identifiable information was linked to the responses in our database. One author randomly checked 15% of the data entry by the research assistant, achieving 98% accuracy with differences resolved.

Data Analyses

Our survey collected both quantitative and qualitative responses so mixed methods were used to analyze the data. Means and standard deviations were calculated for each of the close-ended Likert questions. To examine the relationships between the responses, paired Pearson's correlations were calculated with significance designated at p values of .05, .01, and .001. From the linked parent surveys, a composite functional activity score was calculated for each child by summing the 7-point Likert statements of each functional activity (e.g., walking, preparing meals, going on dates). Any response of "not applicable" was assigned a score of "1" with the composite functional activity score ranging between 7–77. Higher scores represented higher levels of parental perceived functionality in the person with DS. To standardize these scores, we divided the composite functional activity score by the age, in years, of the family member with DS. From the same linked parent surveys, we obtained a 7-point health conditions score—"To what extent does your son or daughter with Down syndrome, in your opinion, have significant health problems?"—with "1" being "not a problem" and "7" being "very much of a problem." We also obtained a 7-point educational score—"To what extent does your son or daughter with Down syndrome, in your opinion, have significant educational/learning difficulties?"—with "1" being "not a problem" and "7" being "very much of a problem."

To explore which variables might best predict the attitudinal responses of our sibling participants, we performed mixed stepwise, multivariate regression analyses. Variables were entered at the probability level of .05, and the standardized β and R^2 are reported. To determine significance of our models, ANOVA was performed, and df, F, and p values for the models that achieved significance at .05 level are reported. The independent variables included the parent-reported composite functional activity score divided by the age of the child, parent-reported health conditions score, parent-reported educational challenges score, parent-reported birth order, gender relationship to sibling with DS, age difference from the sibling with DS, biological status of siblings, number of brothers and sisters, number of parents, living situation for sibling with DS, and sociodemographic variables (age, race, gender, state, religion, educational level).

The responses to open-ended questions were coded by the first two authors using the Constant Comparative Method of Qualitative Analysis [Glaser and Strauss, 1967]. Thematic saturation was achieved after reviewing about 40 surveys for each question. *De novo* themes were not subsequently identified. At least one author coded all the surveys for siblings, ages 9–11; approximately 10% were blindly coded by the second author with coding agreement achieved at 96%. At least one author coded 49% of surveys for siblings, ages 12 and older, as the numbers were sufficiently large and results had stabilized; approximately 10% were blindly coded by the second author with coding agreement achieved at 95%. For both surveys, differences were discussed, and mutual agreement was obtained. We report those themes that were mentioned by at least 5% of respondents.

RESULTS

Respondents

We received 822 responses from brothers and sisters. As the DS non-profit organizations do not gather complete and reliable data on the ages of siblings within their family members, we used the 2000 U.S. Census figures to estimate a response rate. Each family with children has about 2.4 children, and given that each of the 4,924 families in our sample population already has a child with DS, we estimate that each of our participating family would have 2.4 − 1.0 or 1.4 additional children. Of all of the children in family households, approximately 49% are over the age of 12 and approximately 14% are between the ages of 9–11 [United States Census Bureau, 2001]. So, therefore, we theoretically invited about 4,924 × 1.4 × (0.49 + 0.14) or 4,343 brothers and sisters. Our 822 responses, we therefore estimate, represent a 19% response rate.

Of the 822 responses, 229 were from individuals completing the younger sibling survey (24% estimated response rate). Of these, 2 were returned indicating no interest in responding. An additional 11 surveys were excluded because they were completed by siblings younger than 9 years old, and 5 surveys were excluded because they were completed by siblings older than 12 years. The remaining 211 surveys were included in our analysis for siblings, ages 9–11 (22% functional response rate).

Of the 822 responses, 593 were from individuals completing the older sibling survey (18% estimated response rate). Of these, 11 were returned indicating no interest in responding. An additional 10 surveys were excluded because they were completed by siblings younger than 12 years. The remaining 572 surveys were included in our analysis for siblings, ages 12 and older (17% functional response rate).

The average age of respondents completing the younger survey was 10.6 years ($SD = 0.8$, $N = 205$). These brothers and sisters had, on average, 2.7 siblings ($SD = 1.6$, $N = 207$) and 2.1 parents ($SD = 0.5$, $N = 208$). The average age of respondents completing the older survey was 21.5 years ($SD = 9.7$, $N = 559$), with ages ranging from 12.0–61.8 years. These brothers and sisters had, on average, 2.6 siblings ($SD = 1.6$, $N = 568$) and 2.1 parents ($SD = 0.5$, $N = 568$).

As can be seen in Table I, slightly more sisters responded to our survey. The majority of respondents were full biological siblings, who were proportionally distributed by geography with diversity among Hispanic origin and religion. The majority of respondents identified themselves as White and lived with their brother or sister. About half of the brothers or sisters had graduated from high school or achieved a higher education at the time of completing the survey.

Feelings Toward Brother or Sister with DS

The vast majority of brothers and sisters, of all ages, love/like their siblings with DS (Tables II and III). Younger siblings were more likely to love if they had a brother with DS and were of the same sex, along with some religious variation (*Love* = 1.9 − 0.1 *sibling with DS is a brother* − 0.1 *same-sex sib with DS* − 0.1 *Catholic, Mormon, Jewish, other religion* + 0.1 *Protestant, atheist* ($R^2 = 0.23$, $F[0.05;4;193] = 15.6$, $p < 0.001$)); for older siblings, there was simply geographic and racial variation (*Like my sibling* = 6.3 − 0.5 *Black* + 0.2 *White, Asian* + 0.1 *other race* − 0.2 *CA* + 0.2 *CO, MA, NC, TX, GA* ($R^2 = 0.06$, $F[0.05;4;420] = 7.95$, $p < 0.001$)). Put another way, younger Catholic boys who have brothers with DS would be expected to respond, on average, with a 1.6 in regards to love for their sibling (with a result of "1" on a scale of 1–4 being maximum expression of love). Older white brothers who were from Massachusetts would be expected to respond, on average, with a 6.7 in regards to liking their sibling (with a result of "7" on a scale of 1–7 being maximum expression of likability). The majority of siblings, especially the older ones, are proud of their sibling with DS. Younger siblings were slightly more likely to have pride if their sibling with DS was of the same sex, along with some other associations (*Proud* = 1.6 + 0.1 *sibling respondent is brother* − 0.2 *same-sex sib with DS* − 0.2 *MA, NC* − 0.7 *TX* − 0.2 *Catholic, Jewish, atheist, other religion* + 0.2 *Protestant, Mormon* ($R^2 = 0.19$, $F[0.05;7;165] = 6.5$, $p < 0.001$)). In contrast, older siblings were slightly more likely to have pride if their sibling with DS was of the opposite sex, along with some other associations (*Proud* = 5.5 − 0.2 *same-sex sibling* + 1.2 *MA, TX* + 1.0 *CA, CO, NC, GA* ($R^2 = 0.07$, $F[0.05;4;549] = 11.7$, $p < 0.001$)). Siblings who expressed love/like were also more likely to feel pride (Tables VI and VII).

A minority of brothers and sisters said that they felt sad or sorry for their sibling with DS (Tables II and III). Sibling respondents, ages 9–11, were more likely to feel sad if their brother or sister with DS had more learning difficulties and were the middle or older child in the family, with some racial and geographic variation (*Sad* = 3.6 − 0.2 *learning difficulties in sibling with DS* + 0.7 *White, Black, Asian* − 0.7 *other race* − 0.5 *CO, MA, NC, TX, GA* + 0.5 *CA* − 0.2 *sibling with DS middle or oldest child* + 0.2 *sibling with DS youngest child* ($R^2 = 0.17$, $F[0.05;4;163] = 9.5$, $p < 0.001$)). They also tended to worry that their brother or sister with DS would be teased by others (*Worry* = 1.8 + 0.1 *number of siblings* ($R^2 = 0.06$, $F[0.05;3;199] = 5.03$, $p < 0.01$)). Older siblings' feeling sorry was associated with many of the same factors (*Feel sorry* = 2.3 + 0.2 *learning difficulties for sib with DS* − 0.4 *sib with DS youngest* + 0.4 *sib with DS middle*, *oldest child* + 0.2 *CA, CO, MA, NC, GA* ($R^2 = 0.09$, $F[0.05;4;443] = 11.6$, $p < 0.001$)).

An even smaller minority of siblings felt embarrassed by their brother or sister with DS when in public (Tables II and III). Embarrassment for the younger siblings was more likely to be associated with having a sibling with DS who was the oldest or middle child, along with some religion and geographic variation (*Embarrassed* = 2.9 + 0.1 *number of siblings* + 0.2 *difference in gender* − 0.2 *sibling with DS is oldest or middle child* + 0.2 *sibling with DS is youngest* − 0.2 *CA, MA, NC, TX, GA* + 0.2 *CO* − 0.5 *Jewish* + 0.5 *Catholic, Protestant, Mormon, Atheist, other religion* ($R^2 = 0.23$, $F[0.05;5;163] = 10.5$, $p < 0.001$)). Older siblings were more likely to feel embarrassed if their sibling with DS was the oldest child, with some other variations in religious and educational levels (*Embarrassed* = 4.1 − 0.1 *number of siblings* − 0.3 *sibling with DS youngest, middle child* + 0.3 *sibling with DS oldest child* + 0.5 *Jewish* − 0.5 *Catholic, Protestant, Mormon, atheist* − 0.2 *high school, college, doctorate* + 0.2 *not graduated 8th grade, graduated 8th grade, masters* + 0.2 *CA* − 0.2 *CO, MA, NC, TX, GA* ($R^2 = 0.11$, $F[0.05;7;420] = 8.60$, $p < 0.001$)).

The vast majority of older siblings feel that their relationship with their brother or sister with DS is a good one (*Good relationship* = 5.9 − 0.2 *same-sex sibling* + 0.3 *CO, MA, NC, GA* +

0.7 *TX* − 0.2 *CA* [R^2 = 0.06, *F*[0.05;4;453] = 8.4, $p < 0.001$), Table III). Younger siblings are sometimes annoyed that their brother or sisters with DS might need more help to learn things (Table II). Yet, the vast majority of siblings, of all ages, would not trade their brother or sister with DS for another sibling who did not have DS (Tables II and III). The small percentage of younger siblings who would desire a trade were more likely to have siblings with more learning difficulties (*Trade your sibling* = 3.6 − 0.1 *learning difficulties in sib with DS* − 0.4 *Black* + 0.4 *White, Asian, other race* − 0.2 *NC* + 0.2 *CA, CO, MA, TX, GA* (R^2 = 0.13, *F*[0.05;3;176] = 10.1, $p < 0.001$), Table II). Older siblings rarely contemplated such a trade (*Trade sibling* = 2.1 − 0.3 *sibling with DS is youngest, middle child* + 0.3 *sibling with DS is oldest* − 0.4 *CO, MA, NC, TX, GA* − 0.1 *CA* (R^2 = 0.08, *F*[0.05;3;448] = 13.4, $p < 0.001$), Table III).

Perceived Impact on Having Brother or Sister with DS

The majority of siblings feel that their friends are comfortable around their brothers/sisters with DS (Tables IV and V). Younger siblings are more likely to indicate this is true when their sibling with DS is the youngest child, along with some religion and geographic variation (*Friends comfortable* = 1.4 − 0.2 *CO* + 0.2 *CA, MA, NC, TX, GA* − 0.2 *Catholic, atheist, other religion* + 0.2 *Protestant, Mormon, Jewish* − 0.2 *sibling with DS youngest* + 0.2 *sibling with DS middle or oldest child* (R^2 = 0.11, *F*[0.05;3;164] = 7.9, $p < 0.001$)). The majority of younger siblings also feel comfortable telling other people that their brother/sister has DS. Geographic location was also associated with whether friends had fun around the sibling with DS (*Friends find sibling fun* = 1.4 + 0.3 *CA, CO, MA, NC, GA* − 0.3 *TX* (R^2 = 0.08, *F*[0.05;2;176] = 8.6, $p < 0.001$)). Older siblings were more likely to feel that their friends were comfortable if their brother/sister with DS had few health concerns, along with some religious and geographic variations (*Friends comfortable* = 6.4 − 0.1 *CA, CO, TX* + 0.1 *MA, NC, GA* − 0.3 *Jewish, other religion* + 0.3 *Catholic, Protestant, Mormon, atheist* − 0.1 *health concerns in sib with DS* (R^2 = 0.08, *F*[0.05;4;419] = 10.1, $p < 0.001$)).

A minority of siblings feels that their parents pay too much attention to their brother/sister with DS and not enough to them (Tables IV and V). Younger siblings who had many brothers and sisters, in general, were less likely to feel this way (*Too much attention to sibling* = 3.0 + 0.1 *number of siblings* (R^2 = 0.04, *F*[0.05;2;198] = 5.49, $p < 0.01$)). Older siblings were more likely to feel the disproportionate attention if they had not yet graduated from 8th grade or were the same sex as their sibling (*Too much time* = 2.7 − 0.5 *doctorate, masters, college, high school* + 0.8 *not graduated 8th grade* + 0.2 *graduated 8th grade* − 0.2 *sibling respondent is a brother* + 0.2 *same-sex sibling* − 0.1 *number of siblings* (R^2 = 0.14, *F*[0.05;6;539] = 15.2, $p < 0.001$)). Still, a vast majority of all siblings felt comfortable asking their parents questions about DS (Younger siblings: *Comfortable asking questions* = 1.0 + 0.1 *health problems in sibling* (R^2 = 0.11, *F*[0.05;2;183] = 1.8, $p < 0.001$); Older Siblings: *Comfortable asking questions* = 5.0 − 0.2 *sibling respondent a brother* + 0.2 *CA, MA, NC, GA* − 0.2 *CO, TX* (R^2 = 0.05, *F*[0.05;3;543] = 11.0, $p < 0.001$)).

The majority of younger brothers and sisters like helping their sibling with DS learn new things (*Like to help sibling* = 1.5 − 0.1 *CA, CO, MA, NC, GA* + 0.5 *TX* (R^2 = 0.08, *F*[0.05;3;175] = 5.83, $p < 0.001$), Table IV). A small percentage, however, feel that their sibling with DS should be held accountable for more chores around the house (*More chores* = 2.1 + 0.4 *number of parents* + 0.1 *number of siblings* − 0.2 *Mormon or atheist* + 0.2 *Protestant, Catholic, Jewish, other religion* (R^2 = 0.08, *F*[0.05;3;192] = 6.4, $p < 0.001$)). A small percentage of older siblings also feel that they are asked to do too much for their brother/sister with DS (Table V). This sentiment was more often associated with sibling respondents who had not yet graduated from 8th grade who were also living at home with their brother/sister with DS (*Do too much* = 2.4 + 0.4 *live with sibling* − 0.2 *high school, college, masters, doctorate* + 0.2 *not graduated from 8th grade or graduated from 8th grade*

($R^2 = 0.11$, $F[0.05;2;549] = 34.9$, $p < 0.001$)). Very few older siblings felt that their social life was worse off by having a brother/sister with DS (*Worse social life* = 1.6 + 0.2 *live with sibling* ($R^2 = 0.01$, $F[0.05;1;551] = 8.25$, $p < 0.01$)).

In general, a vast majority of older brothers and sisters felt that they were better people because of their sibling with DS (Tables V). This impact was associated with sibling respondents who had a high school degree or higher, with some geographic and racial variation (*Better person* = 4.9 − 0.3 *Black, other race* + 0.3 *White, Asian* + 1.2 *CA* + 1.0 *CO, MA, NC, TX, GA* − 0.2 *not graduate from 8th grade, graduated from 8th grade* + 0.2 *high school, college, masters, doctorate* ($R^2 = 0.10$, $F[0.05;4;506] = 15.7$, $p < 0.001$)). A vast majority also plan to be involved in their sibling's life when they both become adults. This desire was associated with sibling respondents who had a high school degree or higher and whose sibling with DS was the younger or middle child, with some religious variation (*Plan to be involved* = 5.6 − 0.1 *not graduated from 8th grade, graduated from 8th grade* + 0.1 *high school, college, masters, doctorate* − 0.2 *sibling respondent a brother* − 0.1 *Mormon, Jewish, atheist* + 0.1 *Catholic, Protestant, other religion* − 0.1 *sibling with DS oldest child* + 0.1 *sibling with DS youngest, middle child* ($R^2 = 0.09$, $F[0.05;5;418] = 9.49$, $p < 0.001$)).

Advice for Expectant Parents

Of the 211 surveys analyzed from brothers and sisters, ages 9–11, 169 siblings (80%) responded to the open-ended question asking for advice that they would offer to a couple expecting a child with DS (Table VIII). Of the 282 surveys analyzed from brothers and sisters, ages 12 and older, 264 siblings (94%) responded to a similar open-ended question (Table IX). The majority of siblings, of all ages, mentioned that having a child with DS was a joy, and the birth would be an event to be congratulated (e.g., "It's the best thing that will ever happen to them"; "The joys and triumphs far outweigh the struggles"; "Although having a child with Down syndrome is unordinary, it will make their lives extraordinary").

The next theme most frequently mentioned was that children with DS could sometimes be hard to raise—that there would be challenging moments (e.g., "I would tell them that raising a child with Down syndrome is more difficult than raising a child without Down syndrome, but that it is, of course, worth the effort"). But, younger brothers and sisters emphasized that everything would be okay (e.g., "It isn't as bad as you think. It's a good thing in your family"; "Don't worry. It takes time but after a while he/she will be almost like a normal child"). The older siblings underscored the lessons about love that would come from a child with DS (e.g., "They are so easy to love"; "Expect to experience the biggest love of your life"; "[My sister] is a wonderful example of true love and trust"). They also mentioned that the expectant parents would become better people in having a child with DS (e.g., "It will open them up to a different way of seeing the world, one that is less judgmental"; "…I was confused and resentful, but now, having grown up with my sister, I am a better person"; "It has changed my life for the better, and I honestly couldn't imagine my life without my sister").

Brothers and sisters of all ages emphasized that more similarities—than differences—exist between people with DS and their typically developing peers (e.g., "She'll be just as good as us"; "They aren't different than me. They just learn slower"; "They have and give just as much love as any other child"). People with DS have a positive personality (e.g., "People with Down syndrome are really fun!"). Some siblings even felt that a person with DS was a blessing (e.g., "It's a blessing because you understand the true meaning of love"; "That it's a gift and they should feel blessed").

Parents were advised to be patient (e.g., "It will take more patience, but you will experience unconditional love"; "Take one day at a time"), supportive (e.g., "He needs lots of attention and care”; “Just give your child all the support you can”), and avoid setting limits (e.g., “Do not limit their opportunities”; “Don’t treat them any different”). Some siblings recommended that parents continue the pregnancy (e.g., “Keep the child. Every day is better having someone different in your life”; “Don’t abort. You’ll like having a kid with Down syndrome”). A few suggested termination (e.g., “I would like to tell them to terminate”; “If they were considering termination, I would support that option”) or adoption (e.g., “In their heart of hearts, if they feel anything other than blessed, there are many out there who would adopt their child”).

Life Lessons

Of the 282 surveys analyzed from brothers and sisters, ages 12 and older, 265 siblings (94%) responded to a similar open-ended question about life lessons that they had learned from their brother or sister with DS (Table X). (This question was not asked of the younger siblings.) The most frequently cited lesson was an enhanced perspective on life—that life was good in many ways (e.g., “Life isn’t perfect, but that’s the best part of life”; “Dance when the music plays”; “I’ve learned from an early age to appreciate the small things and not take for granted anything”).

These older brothers and sisters mentioned that they gained a deeper understanding and appreciation for human differences (e.g., “Being different is better than blending in”; “Everybody’s a little different”; “I am much more tolerant of differences…I am less judgmental because my ideas of progress, achievement and order have been altered”). They learned patience (e.g., “Patience is important”; “He has helped my realize that I shouldn’t push through things every day but take things slower”); and, profoundly, how to love (e.g., “…the biggest things my brother has taught me is a whole new level of love”; “I’ve learned from my brother’s example about love and forgiving. He’s showed me forgiveness when I don’t deserve it, and he shows me love because he shows it to everyone unconditionally”).

They have learned that everyone has talents (e.g., “I’ve learned that a role model does not need to be a superhero, it can be your brother with Down syndrome”; “Everyone in the world has potential”; “He gives me a sense of peace and comfort I could not get anywhere else”). People with DS are more alike than different, in their estimations (e.g., “He can do almost anything I can”; “Life may not deal you the best hand, but you can still be like everyone else”; “They might act different but they are the same as anyone else”). From their brothers and sisters with DS, they also learned that hard work pays off (e.g., “My brother never gives up and never stops trying”; “He showed me how to push yourself to achieve a goal no matter how hard or impossible”).

Yet, siblings also realized that life can be cruel at times (e.g., “I’ve learned that life isn’t fair”; “Words can cut like a sword and also make them feel like they are on top of the world”; “That life is a struggle. That struggling builds character and brings us closer to perfection”). Some cited lessons on humility (e.g., “She has humbled me in ways that nothing else can”; “He has taught me now to be more thankful for everything”; “I guess I’ve tried to be an all-around better person because of him”); others gained deeper understanding about their own faith or beliefs (e.g., “I’ve learned the importance of life—it’s sacredness and need to be protected”; “I’ve kept a bit of a child-like spirit in me”; “Everyone is made in God’s image”).

Many siblings cited lessons on advocacy (e.g., “Always fight for what you want. Never give up”; “Never let anyone intimidate you”; “…stand up for people with Down syndrome or special needs”). Still others mentioned that their career choices were somehow linked to their sibling with DS (e.g., “I believe I am a special education teacher because of my sister…I believe she helped lead me down the path I am on today"; "I have found purpose"; "I have chosen a career of nursing because of my sister").

Brothers-and-Sisters Workshops

Of the 493 surveys analyzed from brothers and sisters, of all ages, 477 siblings (97%) responded to our question about brothers-and-sisters workshops. These are formal opportunities, oftentimes organized by non-profit organizations or healthcare professionals, where siblings gather to learn more about DS and discuss their feelings. Of these brothers and sisters, 27% indicated that they had participated in such an experience in their lifetime. Of those who did, 55% found these workshops helpful (e.g., "I get to meet other kids with siblings with disabilities"; "It made me realize I was not the only one who felt the same or who was going through the same things I was going through"; "I got to see what other children like me feel…"; "I found out how they get Down syndrome"); 10% did not find them useful (e.g., "I didn't benefit much because we just played games and told about how we thought our siblings felt"; "It didn't really help me that much because I have an open relationship with my family about this stuff so I already knew most of what was used in the workshops"); and 34% did not offer an explanation either way.

DISCUSSION

Overall Results

Among those brothers and sisters who responded to our survey, the vast majority of siblings, of all ages, expressed love and pride for their siblings with DS. Most notable, however, was that such feelings were not related to the functional skills of their sibling with DS; nor were they related to the degree of their health conditions or educational challenges. Put simply, the degree to which a sibling with DS had more educational, medical, or functional challenges did not seem to matter when it came to love and pride. Further, birth order, age difference, biological status of the sibling, size of the family, and living situation of the sibling with DS were not associated with these feelings of admiration. With some variation in sociodemographic factors, love and pride were expressed by the vast majority.

As siblings matured, particularly as they entered high school and beyond, they began to identify themselves as better people because of their brother or sister with DS. They felt they had learned important life lessons regardless of the degree to which their sibling had challenges. Many felt their perspective on life was enhanced, with a deeper appreciation for human variation. And, when asked to provide advice for expectant parents, the most popular response was to convey the joy and rewards that would come with having a family member with DS.

Of course, not all brothers and sisters felt so uniformly positive. A minority of the surveyed siblings did feel sorry that their brother or sister had DS, particularly those whose siblings had significant learning disabilities. As many brothers and sisters now share the same school system with their siblings, one explanation could be that they felt bad about non-inclusive educational settings. That is, they might feel some sadness in knowing that their brother or sister attends a substantially separate classroom in the same building or in a separate private school placement, while they are able to attend regular classes in their home schools with their peers. Additionally or alternatively, they might empathize how much harder their sibling with DS has to work to achieve scholastic success. Some brothers and sisters felt embarrassed by their siblings, which is not altogether an atypical finding for any sibling. Those younger brothers and sisters who did feel embarrassed more likely had older siblings with DS; the older siblings, conversely, were more likely to feel that way when their sibling with DS was younger. These patterns are most likely consistent with typical patterns within sibling relationships, but the feelings are likely to be more pronounced, we suspect, when the sibling with DS has behavioral issues. (We asked parents about medical conditions in the child with DS, but not behavioral issues, in particular.) Despite some of these emotions, very few brothers and sisters would ever want to trade their sibling with DS for a different sibling who did not have DS. The person with DS had become a welcomed and valued member within the family unit.

Only a small percentage of siblings in this study felt burdened by the extra chores or caregiving responsibilities that they were asked to perform by their parents. This finding is consistent with previous reports [Cuskelly and Gunn, 2003], but the non-uniformity in our responses could suggest a number of explanations: some parents really do ask their other sons and daughter to assume an unfair or disproportionate amount of work; some siblings assume more burdensome caregiving responsibilities voluntarily; some siblings might feel, like some typical brothers and sisters, that any amount of chores will be unfair; or a combination of any of these. Regardless, the vast majority of older siblings plan to be involved with their brother or sister with DS when they become adults. This feeling could be one of welcomed or resigned commitment, but few siblings reject the notion altogether. In fact, the vast majority feel that their current relationship with their sibling is a good one.

Limitations of Current Study

This study is subject to selection bias. Only brothers and sisters whose families were on the membership lists of non-profit DS organizations were sampled, leaving the possibility that their responses are not fully representative of all brothers and sisters who have siblings with DS in the U.S. Regrettably, no national population-based registry currently exists for people with DS and their families (although efforts are being put in place by the National Down Syndrome Society, www.ndss.org, and other organizations). Until such a time occurs, however, researchers have no other way of sampling families than through the non-profit DS organizations. We purposely invited every family of the sampled non-profit DS organizations to participate in our research, so as not to further restrict the selection bias within the organizations. We also took particular care to invite only those members of the sampled non-profit DS organizations, so as to not allow unfettered selection bias that might have occurred, for example, with an open-invitation web-based survey. In the end, over 800 siblings responded, making the results powerful, if not definitively representative.

This study is also subject to non-response bias. Our response rate of 19%, however, is consistent with research standards, with the nationally respected Pew Research Center citing between 15–25% response rates on their studies [The Pew Research Center for the People & the Press, 2010]. Emerging research shows that while response rates on national surveys have been declining over time, lowered response rates do not necessarily reflect lower survey accuracy [Singer, 2006]. The non-profit DS organizations do not collect the relevant demographics on their members, so we were unable to know how representative our participants were of their members, at large.

Our results are also limited by the lack of diversity of our respondents, which did not include many black/African Americans, Asian, American Indian, or Alaska Native Americans. The results from the parent/guardian respondents (published separately) also showed that their median gross household income of $100,000 was significantly higher than the national median gross household income of $49,777 reported in the last Census income publication in 2009 [DeNavas-Walt et al., 2010]. Until non-profit DS organizations diversify their memberships or until a population-based national registry is created, family epidemiologists are limited to participants with homogenous cultural backgrounds. Our results, however, did include a sizable representation from Spanish/Hispanic/Latino Americans, and we did not observe any statistically significant differences in this sibling population. We purposely chose to oversample in areas of the country with high numbers of Spanish/Hispanic/Latino Americans, and we also made all of our survey materials available in Spanish.

Our question stems might have also biased participants to respond in a particular way. We took particular care, however, to minimize this effect in our survey design by balancing the amount of positively worded questions (e.g., “Do you love your brother or sister with DS?”) and negatively worded questions (e.g,. “Do you feel sad that your brother or sister has DS?”).

Future Research

Geographic differences were significant in some of the multiple regression analyses in this study. Certainly, the non-profit DS organizations differ dramatically in scale, scope, and mission across the country. Additionally or alternatively, there might be regionally specific cultural mores and acceptances that influence particular responses. Future research should expand to additional U.S. states, beyond the ones sampled here, to see if further geographic differences are noted. Ideally, a national population-based assessment of siblings needs would provide the most comprehensive portrait.

About 27% of the siblings in our study had participated in a brothers-and-sisters workshop, which is a specially designed session where siblings can learn more about DS, discuss their feelings, and even learn advocacy skills. Of those who did, a little over a half found the workshops useful. Future research can and should explore what makes these workshops successful and meaningful for sibling. What are the essential components of these opportunities? Which siblings receive the most benefit? How can successful models be replicated throughout the country?

This study purposely did not compare brothers and sisters with DS to matched individuals without DS, so we cannot surmise how similar or dissimilar their attitudes might be to the general population. Future studies might ask siblings from the general population how “proud they are of their brother or sister” and compare the answers to the same question asked of matched siblings who have a brother or sister with DS. Do brothers or sisters who have a sibling with DS “love” their sibling more than matched sibling counterparts? Do they worry more? Such studies would be helpful in better understanding the incremental advantages and challenges of having a brother or sister with DS.

Implications

In previous survey research, medical students admit to getting little training on children with intellectual disabilities [Special Olympics, 2005]. Even more rare, we would imagine, would be training on the impact such people have on their brothers and sisters. This study creates an opportunity to have evidence-based discussions about sibling issues through the coursework on medical, genetic counseling, and nursing students around the country. Further, as national Down syndrome organizations (www.ndss.org and www.ndsccenter.org) begin to mobilize public awareness campaigns about DS, this study creates an opportunity for the voices of brothers and sisters to be part of this public education.

As new noninvasive prenatal diagnostic tests are commercialized, more couples will be expected to receive prenatal diagnoses of DS, and, as a result, they will begin to reflect how such diagnoses might influence their family dynamics. Recently, the non-profit organization, Lettercase, Inc. (www.lettercase.org), created a prenatal informational booklet on DS with representative input from the American College of Obstetricians and Gynecologists, the American College of Medical Genetics, the National Society of Genetic Counselors, the National Down Syndrome Society, and the National Down Syndrome Congress. As this collaboration of organizations keeps the booklet current with each new version, evidence-based data on sibling issues can now be included.

Finally, and perhaps most importantly, health care professionals can share evidence-based statements during their counseling, with the understanding that these statements are based on the sample of respondents:

- The vast majority of brothers and sisters love their siblings with DS and are proud of them.
- The vast majority of brothers and sisters feel that their relationship with their sibling with DS is a good one.
- The vast majority of brothers and sisters would not trade their sibling with DS for another sibling who did not have DS.
- A minority of brothers and sisters feel sorry for their sibling with DS and are embarrassed when among friends or in the public.
- The majority of brothers and sisters gladly are comfortable assuming increased responsibilities, and a vast majority plan to remain involved in their sibling’s life as they both age.
- In general, the vast majority of brothers and sisters feel that they are better people because of their sibling with DS.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table I

Characteristics of the Brothers and Sisters ($N = 783$).

Background Variable	%
Sibling role ($N = 766$)	
Brother	44
Sister	56
Sibling with Down syndrome ($N = 774$)	
Brother	57
Sister	43
Full biologic sibling? ($N = 767$)	
Yes	88
No	12
Age of sibling respondent ($N = 764$)	
≥9 and <12	27
≥12 and <20	46
≥20 and <30	16
≥30 and <40	6
≥40	5
Spanish/Hispanic/Latino ($N = 761$)	
Yes	15
No	85
Race ($N = 749$)	
White	85
Black	3
Indian	1
Other	8
Multiple	3
U.S. State ($N = 770$)	
Massachusetts	22
Colorado	22
California	20
Georgia	13
Texas	6
North Carolina	5
Other	11
Religious Affiliation ($N = 735$)	
Protestant	44
Catholic	36
Atheist	11
Mormon	4
Jewish	3
Other	2

Background Variable	**%**
Living Situation (*N* = 765)	
Lives with sibling with Down syndrome	76
Does not live with sibling with Down syndrome	24
Educational Level of Siblings ≥ 12 years (*N* = 564)	
Not graduated from 8th grade	23
Graduated from 8th grade	30
Graduated from high school	24
Graduated from college/university	17
Received a master’s degree	5
Received a doctorate	1

All percentages might not add up to 100% due to rounding.

Table II

Feelings from Siblings, ages 9–11, Toward Brother or Sister with DS.

Statements	***N***	***M***[*]	***SD***	**% Agree**[†]
Do you love your brother or sister with DS?	210	1.1	0.5	97
Are you proud of your brother or sister with DS?	210	1.5	0.9	87
Do you feel sad that your brother or sister has DS?	208	2.9	1.2	29
Do you feel embarrassed by your brother or sister with DS when you are out?	210	3.6	0.8	9
Do you worry about your brother or sister with DS getting made fun of?	210	2.1	1.2	61
Does it annoy you that your brother or sister with DS might need more help to learn things than you do?	210	3.5	1.0	12
Do you wish you could trade your brother or sister with DS for a brother or sister that did not have DS?	208	3.8	0.6	4

[*] Siblings were asked to rate their level of agreement with the statements on a Likert scale of 1 to 4 with “1” indicating “Yes,” “2” being “Most of the Time,” “3” being “Once in a While,” and “4” indicating “No.”

[†] Percentage of siblings who circled “1” or “2” on Likert scale for that statement.

Table III

Feelings from Siblings, ages 12 and older, Toward Brother or Sister with DS.

Statements	***N***	***M***[*]	***SD***	**% Agree**[†]
I like my brother or sister with DS.	570	6.6	0.8	96
I am proud of my brother or sister with DS.	569	6.6	0.9	94
I often feel sorry for my brother or sister with DS.	570	3.1	1.9	27
I often feel embarrassed to have a brother or sister with DS.	571	1.7	1.4	7
I feel my relationship with my brother or sister with DS is a good one.	570	6.3	1.1	91
I often with I could trade my brother and sister with DS for a different sibling without DS.	570	1.6	1.2	4

[*] Siblings were asked to rate their level of agreement with the statements on a Likert scale of 1 to 7 with “1” indicating “strongly disagree,” “4” being “neutral,” and “7” indicating “strongly agree.”

[†] Percentage of siblings who circled “5,” “6,” or “7” on Likert scale for that statement.

Table IV

Perceived Impact from Siblings, ages 9–11, who have Brother or Sister with DS.

Statements	***N***	***M***[*]	***SD***	**% Agree**[†]
Do you think most of your friends find your brother or sister with DS fun to be with?	208	1.6	0.9	83
Do you feel most of your friends are comfortable around your brother or sister with Down syndrome?	210	1.5	0.9	90
Do you think your brother or sister with DS should have more chores to do?	209	3.5	0.9	14
Do you feel comfortable about telling other people that your brother or sister has DS?	209	1.7	1.0	78
If you have a question about DS, do you ask your mom or dad?	209	1.5	0.8	86
Do you feel your parents pay too much attention to your brother and sister with DS and not enough to you?	209	3.2	1.0	19
Do you like to help your brother or sister with DS to learn new things?	210	1.6	0.8	86

[*] Siblings were asked to rate their level of agreement with the statements on a Likert scale of 1 to 4 with “1” indicating “Yes,” “2” being “Most of the Time,” “3” being “Once in a While,” and “4” indicating “No.”

[†] Percentage of siblings who circled “1” or “2” on Likert scale for that statement.

Table V

Perceived Impact from Siblings, ages 12 and older, who have Brother or Sister with DS.

Statements	***N***	***M***[*]	***SD***	**% Agree**[†]
In general, my friends are comfortable around my brother or sister with DS.	568	6.2	1.2	89
I often feel I am asked to do too much for my brother or sister with DS.	569	2.5	1.6	15
I am a better person because of my brother or sister with DS.	570	6.2	1.3	88
My parents spend too much time with my brother or sister with DS and not enough time with me.	567	2.3	1.6	12
I feel my social life is worse off by having a brother or sister with DS.	570	1.7	1.3	5
I feel comfortable asking my parents questions about my brother or sister with DS.	569	6.3	1.3	88
I plan to be involved with my brother or sister with DS when we are adults.	570	6.5	1.0	93

[*] Siblings were asked to rate their level of agreement with the statements on a Likert scale of 1 to 7 with “1” indicating “strongly disagree,” “4” being “neutral,” and “7” indicating “strongly agree.”

[†] Percentage of siblings who circled “5,” “6,” or “7” on Likert scale for that statement.

Table VI

Correlation Among Responses from Brothers and Sisters, ages 9–11.

	A	B	C	D	E	F	G	H	I	J	K	L	M	N
A	—													
B	$-0.15^{\ddagger}$	—												
C	$0.20^{\dagger}$	$0.18^{\ddagger}$	—											
D	-0.31^{*}	0.32^{*}	0.04	—										
E	-0.26^{*}	0.29^{*}	−0.02	$0.17^{\ddagger}$	—									
F	0.06	-0.25^{*}	$-0.19^{\dagger}$	-0.25^{*}	−0.11	—								
G	-0.39^{*}	0.35^{*}	0.04	0.27^{*}	0.23^{*}	$-0.18^{\dagger}$	—							
H	0.32^{*}	$-0.17^{\ddagger}$	0.02	-0.26^{*}	$-0.19^{\dagger}$	0.08	$-0.20^{\dagger}$	—						
I	$0.17^{\ddagger}$	-0.26^{*}	0.00	-0.25^{*}	-0.25^{*}	0.33^{*}	-0.36^{*}	0.03	—					
J	0.44^{*}	−0.11	0.01	−0.09	$-0.21^{\dagger}$	$0.14^{\ddagger}$	-0.34^{*}	$0.15^{\ddagger}$	0.34^{*}	—				
K	$-0.17^{\ddagger}$	$0.22^{\dagger}$	$0.20^{\dagger}$	0.28^{*}	0.08	-0.38^{*}	0.26^{*}	−0.01	−0.08	$-0.14^{\ddagger}$	—			
L	0.50^{*}	$-0.15^{\ddagger}$	0.10	-0.24^{*}	-0.27^{*}	0.12	-0.42^{*}	0.23^{*}	$0.20^{\dagger}$	0.45^{*}	$-0.16^{\ddagger}$	—		
M	0.52^{*}	−0.13	$0.22^{\dagger}$	$-0.21^{\dagger}$	$-0.15^{\ddagger}$	0.03	-0.33^{*}	0.35^{*}	$0.15^{\ddagger}$	0.35^{*}	−0.05	0.59^{*}	—	
N	-0.48^{*}	0.28^{*}	−0.12	0.23^{*}	0.34^{*}	−0.10	0.34^{*}	-0.24^{*}	$-0.21^{\dagger}$	-0.31^{*}	$0.18^{\dagger}$	-0.51^{*}	-0.62^{*}	—

The statements were as follows: A: Do you like to help your brother or sister with DS to learn things?; B: Do you feel your parents pay too much attention to your brother and sister with DS and not enough to you?; C: Do you worry about your brother or sister with DS getting made fun of?; D: Does it annoy you that your brother or sister with DS might need more help to learn things than you do?; E: Do you think your brother or sister with DS should have more chores to do?; F: Do you feel comfortable about telling other people that your brother or sister has DS?; G: Do you feel embarrassed by your brother or sister with DS when you are out?; H: If you have a questions about DS, do you ask your mom or dad?; I: Do you feel most of your friends are comfortable around your brother or sister with DS?; J: Do you think most of your friends find your brother or sister with DS fun to be with?; K: Do you feel sad that your brother or sister has DS?; L: Are you proud of your brother or sister with DS?; M: Do you love your brother or sister with DS?; N: Do you wish you could trade your brother or sister with DS for a brother or sister than did not have DS?

[*] $p < 0.001$.

[†] $p < 0.01$.

[‡] $p < 0.05$.

Table VII

Correlation Among Responses from Brothers and Sisters, ages 12 and older.

	A	B	C	D	E	F	G	H	I	J	K	L	M
A	—												
B	−0.26*	—											
C	0.35*	−0.16*	—										
D	−0.33*	0.43*	−0.15*	—									
E	0.56*	−0.23*	0.31*	−0.33*	—								
F	−0.38*	0.29*	−0.18*	0.38*	−0.30*	—							
G	0.57*	−0.22*	0.34*	−0.22*	0.48*	−0.39*	—						
H	−0.47*	0.24*	−0.24*	0.30*	−0.37*	0.35*	−0.42*	—					
I	−0.38*	0.20*	−0.19*	0.29*	−0.29*	0.38*	−0.37*	0.44*	—				
J	−0.19*	0.15*	−0.16*	0.17*	−0.19*	0.14*	−0.17*	0.24*	0.27*	—			
K	0.28*	−0.19*	0.28*	−0.16*	0.24*	−0.20*	0.31*	−0.20*	−0.16*	−0.16*	—		
L	0.34*	−0.14*	0.21*	−0.21*	0.32*	−0.26*	0.29*	−0.25*	−0.34*	−0.18*	0.23*	—	
M	0.53*	−0.18*	0.37*	−0.24*	0.49*	−0.37*	0.59*	−0.39*	−0.34*	−0.14*	0.29*	0.33*	—

The statements were as follows: A: I like my brother or sister with DS; B: My parents spend too much time with my brother or sister with DS and not enough time with me; C: I am a better person because of my brother or sister with DS; D: I often feel I am asked to do too much for my brother or sister with DS; E: I feel my relationship with my brother or sister with DS is a good one; F: I feel my social life is worse off by having a brother or sister with DS; G: I am proud of my brother or sister with DS; H: I often wish I could trade my brother and sister with DS for a different sibling without DS; I: I often feel embarrassed to have a brother or sister with DS; J: I often feel sorry for my brother or sister with DS; K: I feel comfortable asking my parents questions about my brother or sisters with DS; L: In general, my friends are comfortable around my brother or sister with DS; M: I plan to be involved with my brother or sister with DS when we are adults.

[*] $p < 0.001$.

Table VIII

If a mom and/or dad were going to have a child with Down syndrome, what would you like to tell them? (*N* =169 brothers and sisters ages 9–11).

Category	**Total**[*]	**%**
be happy, joy, congratulations	83	44
child will be hard to raise/challenge/trouble learning	46	25
don’t worry/it’s okay	43	23
children with DS are more the same than different	26	14
children with DS have positive personality	22	12
love your child	20	11
offered general thoughts on parenting/help	11	6
appreciation for specialness	11	6
you will learn/there will be life lessons	11	6
you might worry/be protective/feel guilty	9	5
offered some facts about DS	9	5

[*] Indicates number of siblings who incorporated this category in their response to this question; percentages will not add to 100%, as responses might contain more than one category.

Table IX

If a couple were expecting to have a child with DS, what would you like to tell them? ($N = 264$ brothers and sisters ages 12 and older).

Category	**Total**[*]	**%**
this will be rewarding/great thing/gift/joy	116	41
there will be challenging moments	103	37
you will learn lessons on love	42	15
become a better person/perspective	41	15
people with DS more alike than different	38	13
This child is a blessing/angel/gift from God	35	12
don’t be afraid	29	10
be patient	27	10
seek support	23	8
don’t abort	19	7
do not set limits for your child/they all have talents	18	6
be supportive/keep child involved/be accepting	18	6
offered advice on medical issues/therapies	13	5

[*] Indicates number of siblings who incorporated this category in their response to this question; percentages will not add to 100%, as responses might contain more than one category.

Table X

What life lessons have you learned from your brother or sister with DS? ($N = 265$ brothers and sisters ages 12 and older).

Category	Total*	%
life is good/rewarding/joy/important perspectives	115	41
understanding of differences	82	29
patience	77	27
how to love	41	15
everyone has talents	24	9
people with DS are more alike than different	21	7
Perseverance/hard work	18	6
don’t let others define you/know thyself	18	6
humility	13	5

[*] Indicates number of siblings who incorporated this category in their response to this question; percentages will not add to 100%, as responses might contain more than one category.