

Self-Reported Guilt among Adult Siblings of Individuals with Intellectual and Developmental
Disabilities

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RUNNING HEAD: Sibling Guilt

Self-Reported Guilt among Adult Siblings of Individuals with Intellectual and
Developmental Disabilities

Abstract: As more siblings become responsible for their aging brothers and sisters with intellectual and developmental disabilities, it becomes increasingly important to understand these siblings' emotional needs, including potential negative emotions such as guilt.

This study examined the presence and correlates of self-reported guilt among 1,021 adult siblings of individuals with intellectual and developmental disabilities. Respondents completed the Adult Sibling Questionnaire, a national survey examining characteristics of adult health, depression, and feelings of guilt. Over 50% of siblings reported feeling increased guilt. Siblings who experienced increased guilt (versus those who did not) experienced less close sibling relationships, more depressive symptoms, and lower levels of well-being. Siblings experiencing more guilt also had brothers/sisters with more severe emotional/behavioral problems.

Keywords: Siblings, guilt, adults, intellectual and developmental disabilities

Although guilt is rarely the subject of formal studies, many early sibling researchers hypothesized that siblings of individuals with intellectual and developmental disabilities (IDD) may experience high levels of guilt. In literature, guilt has been defined as “an individual’s unpleasant emotional state associated with possible objections to his or her actions, inaction, circumstances, or intentions” (Baumeister, Stillwell, & Heatherton, 1994, pp. 245). That is, guilt can arise even in the absence of indicated objections from others – simply the anticipation of possible objection is enough to elicit guilt. Martino and Newman (1974) hypothesized that siblings feel guilty for fulfilling their own goals while their sibling does not have the same opportunity. Featherstone (1980) reported that this population may feel anger toward their parents who pay more attention to their brother or sister with disabilities, at their brother or sister with a disability for being the beneficiaries of this extra attention, or at the world in general for not understanding their experience. They may then feel guilty for these angry feelings, realizing that their brother or sister’s disability is no one’s “fault” (Seligman, 1983). As siblings often have more caregiving responsibilities for their brother or sister, they may also feel guilty and responsible when something happens to that brother or sister (Hayden, 1974).

Qualitative studies examining siblings’ own perceptions of the experience of growing up with a brother or sister with an intellectual or developmental disability (IDD) have found enough mentions of guilt to warrant its inclusion as a theme (Dansby, Turns, Whiting, & Crane, 2017; Opperman & Alant, 2003). Yet despite the frequency of mentions of guilt in the sibling literature, no quantitative studies have measured how many siblings of individuals with intellectual and developmental disabilities (IDD) report feelings of guilt or

the factors that may relate to such feelings. To address this gap, we conducted a preliminary investigation of the frequency and correlates of adult siblings' self-reported guilt as a result of having a brother or sister with a disability. For purposes of distinction, in the present manuscript, all references to "siblings" refer to the person without a disability; "brother or sister" refers to the individuals with IDD.

Beyond its presence per se, differing levels of sibling guilt may relate to personal characteristics of the sibling, of the brother/sister with disabilities, and of the sibling relationship. Starting in adolescence in the general population, females report more intense feelings of guilt than do males (Evans, 1984; Walter & Burnaford, 2006). Similarly, among caregivers of cancer patients, age is significantly correlated with guilt, with younger (versus older) caregivers reporting more guilt (Spillers et al., 2008). Additionally, researchers have hypothesized that siblings who are older than their brother/sister with disabilities may be at risk for negative outcomes (Levy-Wasser & Katz, 2004) due to potentially having more caregiving responsibilities, so birth order may also relate to sibling guilt. Finally, high levels of guilt have been shown to relate to poorer well-being (Diener, Suh, Lucas, & Smith, 1999); therefore, it is possible that siblings who report greater guilt will also report lower levels of various aspects of well-being, including depression and physical health.

Guilt may also be influenced by characteristics of the brother/sister with IDD. When one sibling believes that they are better off than another, the "better-off" sibling can feel guilty about their perceived privileged position (Glenn, 1995). During childhood, for example, negative outcomes among non-disabled siblings were predicted by higher levels of their brother or sister's behavior problems (Hastings, 2007; Neece, Blacher, & Baker,

2010). Similarly, in families of cancer patients, higher levels of family and caregiver stress were predicted by the patient's low levels of physical and mental functioning (Spillers et al., 2008). Thus, both levels of functioning and behavior problems may thus be a salient example of sibling privilege that can trigger guilty feelings. The nature of the brother/sister's disability also affects sibling outcomes, with adult siblings of individuals with Down syndrome reporting better sibling relationship quality than siblings of individuals with autism (Hodapp & Urbano, 2007). As individuals with Down syndrome typically have fewer behavior problems than individuals with other IDD (Griffith, Hastings, Nash, & Hill, 2010), both the low levels of behavior problems and better sibling relationships may contribute to lower levels of guilt among siblings of individuals with Down syndrome, as opposed to other diagnoses.

Characteristics of the sibling relationship might also influence guilt, including involvement with the brother or sister, sibling relationship quality, and amount of sibling contact. Additionally, adult siblings with greater amounts of contact with their brother/sister with disabilities experienced warmer sibling relationships (Doody, Hastings, O'Neill, & Grey, 2010). Close sibling relationships in adulthood, in turn, have been related to higher well being in the non-disabled sibling (Seltzer, Greenberg, Krauss, Gordon, & Judge, 1997), and also potentially to less guilt.

The present study used data from a national study to conduct a preliminary, quantitative examination of self-reported guilt among adult siblings of individuals with IDD. First, we examined how frequently non-disabled siblings reported more guilt. Based on the literature outlined above, we hypothesize that more siblings will report "more guilt" as opposed to "less guilt." Second, we performed bivariate analyses to determine whether

siblings' guilt levels related to characteristics of the non-disabled sibling, brother/sister with IDD, or the sibling relationship. We hypothesize that siblings who report more guilt will have brothers/sisters with lower levels of functioning and physical and emotional health, poorer sibling relationships, and lower levels of well-being themselves.

Methods

Participants

The current sample included 1,021 adult siblings of individuals with IDD. The sample was primarily female (78.9%) and Caucasian (91.7%), and comparatively well-educated (68.9% reported having a bachelors' degree or higher). Full characteristics of the siblings in the present sample and their brother or sister with a disability can be found in Table 1.

Procedures

The present study used data from the Adult Sibling Questionnaire (Blinded for review). A group of sibling researchers (see Acknowledgements) collaborated with the National Sibling Consortium to develop the questionnaire, which was posted on a secure website based out of [Blinded for review] University. Participants were recruited through The Arc, the Association of University Centers of Disability, SibNet, and numerous local and state IDD networks. The ASQ is a collection of existing validated measures, as well as questions designed for the survey to capture variables salient to the experience of adult siblings of individuals with IDD. All variables in the present study were drawn from the measures and questions included in the ASQ.

Measures

Guilt. Using the question 'As a result of having grown up with a brother/sister with

disabilities, do you think that you have less, the same, or more of the following characteristics: Feelings of guilt?', we created 4 categories of sibling guilt. The first category was created by combining the responses of "'somewhat less guilt" and "less guilt" into "less guilt," (=0) due to the small number of individuals endorsing each response. The remaining three categories corresponded directly to possible answers from the survey: same guilt (neither more nor less guilt as the result of having a brother or sister with a disability, =1), slightly more guilt (sibling has somewhat more guilt as the result of having a brother or sister with a disability, =2), and a lot more guilt (sibling has more guilt as the result of having a brother or sister with a disability, =3). Although the comparative aspect of the question was left open to the respondents' interpretation, it is presumed that most siblings judged their guilt in comparison to what they likely would have felt had they not grown up with a brother or sister with IDD or compared themselves to peers who do not have a brother or sister with IDD.

Sibling relationship. Participants responded to questions derived from the Positive Affect Index of relationship quality (Bengston & Black, 1973). Respondents rated the degree to which they understand, trust, respect, love, feel close to and positive towards their brother or sister with disabilities using a 6-point scale, which were summed into a single scale (maximum = 42), with higher scores indicating a more positive sibling relationship (Cronbach's $\alpha=.90$). The PAI has shown sufficient consistency and validity (Bengston & Black, 1973).

Characteristics of the brother/sister. The four most commonly-reported disabilities from the current sample (intellectual disability (ID), Down syndrome, autism, and cerebral palsy) were analyzed to determine if siblings of individuals with these

diagnoses reported different levels of guilt than siblings of individuals without each diagnosis. All brother/sister diagnoses were gleaned strictly from sibling report; that is, there was no independent verification of clinical diagnoses.

Beyond specific disability, functional abilities of the brother/sister with disabilities (e.g. walking, eating, performing household tasks) were measured with the Activities of Daily Living scale (ADL; Seltzer & Li, 1996), with 15 items on a 5-point scale. Higher scores indicated higher levels of functioning. Cronbach's alpha for this sample was .91. Finally, siblings were asked to rate the extent to which their brother or sister has significant health problems and significant emotional/behavior problems. Both questions were scaled from 1 (not a problem) to 5 (very much a problem). The ADL has been used frequently in IDD and caregiving research (e.g., Fisher & Morin, 2017, Shivers & Kozimor, 2017).

Sibling characteristics. Participants were asked to rate the general quality of their physical health by responding to the question "How would you say in general your health is?" Responses ranged from 1 (poor) to 5 (excellent). Self-rated health has been found to be a strong predictor of lifespan (Idler & Benjamini, 1997). Level of depressive symptoms was calculated using five questions taken from the Center for Epidemiological Studies Depression scale or CES-D (Radloff, 1977). Respondents indicated how often in the past week they had experienced the following: felt depressed, had restless sleep, felt lonely, could not 'get going', and had crying spells. Response options were coded from 1 (rarely or none of the time – less than 1 day) to 4 (most or all of the time – 5- 7 days). For this study, Cronbach's alpha for the CES-D equaled .79. Finally, sibling overall well-being was measured using 18 items taken from Ryff's (1989) Psychological Well-Being measure. Cronbach's alpha for this sample equaled .82. Both the CES-D and the Psychological Well-

Being measure have shown adequate reliability and validity (Radloff, 1977; Ryff, 1989).

Analysis

One-way ANOVAs were used to analyze group differences in continuous variables (sibling relationship, brother/sister physical health problems, brother/sister emotional health problems, brother/sister functional abilities, sibling physical health, sibling depression, sibling well-being, and sibling age) based on amount of self-reported guilt. Post-hoc analyses (Tukey's least significant difference test) were used to determine which levels of guilt significantly differed from other levels. For categorical variables (i.e. gender and nature of brother/sister's disability), chi-squares were used to assess group differences in level of guilt reported.

Results

Over half of the sample (54.2%; $n = 553$) reported more guilt as the result of having a brother or sister with disabilities. Only 12.5% ($n=128$) reported less guilt, and a third of the sample (33.3%, $n = 340$) reported the same guilt (e.g. no more or less guilt as the result of having a brother or sister with disabilities). Of those that reported more guilt, 45.0% ($n = 249$) reported "somewhat more guilt," and 55.0% ($n = 304$) reported "a lot more guilt." Self-reported guilt was not significantly related to participant age, but females were more likely to report "a lot more guilt" than males ($\chi^2 = 15.63, p=.001$).

In terms of characteristics of the brother or sister, sibling guilt was not related to a diagnosis of ID, autism, or cerebral palsy; however, siblings of individuals with Down syndrome were less likely to report "a lot more guilt" ($\chi^2 = 10.75, p=.013$). Guilt was not related to the brother or sister's health problems, but was related to reported levels of emotional or behavioral problems ($F(3,1012) = 9.90, p<.001$); siblings that endorsed

having “a lot more guilt” had brothers/sisters with significantly greater emotional problems than those reporting all other levels of guilt. Additionally, sibling guilt was related to the functional ability of the brother or sister ($F(3,1019) = 2.68, p=.046$); siblings who reported “a lot more guilt” had brothers/sisters with lower levels of functional abilities than did siblings who reported the same amount of guilt. For aspects of the sibling relationship, guilt was related to overall quality of the sibling relationship (e.g., siblings who reported more guilt had lower-quality sibling relationships than did siblings who reported less guilt; $F(3,1017) = 8.06, p<.001$). Finally, in relation to sibling outcomes, self-reported guilt was significantly related to both depression ($F(3,1017) = 23.77, p<.001$), with siblings who reported more guilt having greater depressive symptoms than siblings who reported the same or less guilt, and well-being ($F(3,1019) = 17.82, p<.001$), with siblings who reported more guilt reporting lower levels of well-being than siblings who reported the same or less guilt. Guilt was not significantly related to self-reported physical health. Full results for dichotomous variables can be found in Table 2; results for continuous variables can be found in Table 3.

Discussion

Results from the current study provide preliminary, quantitative evidence that the majority of adult siblings report guilt as the result of having a brother or sister with IDD. These results are the first to illustrate just how common feelings of guilt are among IDD-Sibs and provide a snapshot of how such guilt relates to both characteristics of the individual with IDD and the sibling relationship, as well as mental health of the sibling. The present quantitative results support earlier qualitative studies in which siblings discussed feelings of guilt in relation to brothers or sisters with IDD (Dansby et al., 2017; Opperman

& Alant, 2003), suggesting that guilt is a common emotion among IDD-Sibs, one that persists into adulthood.

Reports of “more guilt” were related to characteristics of the brother/sister – in particular, higher levels of sibling guilt were related to poorer brother/sister emotional and adaptive functioning. It is possible that a greater gap in skills contributes to sibling feelings of guilt. That is, the less that a brother or sister is able to do, the more typically-developing siblings are likely to feel guilty for their own abilities or opportunities. Additionally, as found in literature on the general population, high sibling guilt was related to higher levels of depression and lower levels of well-being (e.g. O’Connor, Berry, Weiss, & Gilbert, 2002).

The present results can inform clinicians and families, as well as researchers. When endeavoring to promote healthy development for the entire family, professionals and parents should be aware of potential feelings of guilt among typically-developing siblings. By definition, guilt can be present even in the absence of disapproval from others (Baumeister et al., 1994); therefore, families and support providers should consider discussing potential feelings of guilt with siblings, as they may be unspoken. Addressing feelings of guilt may have particular importance for well-being, as higher levels of guilt in the current study were significantly related to reports of depressive symptoms and well-being. For researchers, future studies should include more comprehensive measures of guilt to allow for more precise statistical analysis of the correlates thereof. Using a continuous measure of guilt would allow for better examination of the subtleties differentiating sibling outcomes. More research is needed to understand, in particular, the development of guilt, in order to create targeted strategies to help siblings manage feelings

of guilt before they become problematic. Although the current study utilized data from an existing survey of adults, adolescents have reported feelings of guilt, also (Opperman & Alant, 2003); therefore, larger-scale studies of guilt in childhood and adolescence are called for. In qualitative studies, siblings have reported feeling guilt over negative feelings toward their brother/sister and guilt for wanting their own support (Dansby et al., 2017). Future studies can expand on these causes and others to better understand the development of guilty feelings.

The current study is preliminary; the original survey was not designed to measure guilt, specifically. Therefore, the single item of guilt is neither standardized nor comprehensive; although the measure specified guilt “as the result of having grown up with a brother/sister with disabilities,” there was no further definition of guilt. On one hand, this phrasing allowed siblings to create their own meaning; however, the lack of standardization prevents any interpretation of the types of guilt or origins of guilt siblings may be feeling. However, the large number of participants allowed for the examination of several factors related to guilt. The proportion of siblings who endorsed “more guilt” suggests that, regardless of definition, guilt is a salient characteristic of the lives of many siblings of individuals with IDD and deserves more consideration.

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Table 1

Sample characteristics

	Mean (SD)	Percentage of Sample (n)
Gender		
Female		78.9 (802)
Male		21.1 (215)
Age	36.85 (13.71)	
Ethnicity		
White non-Hispanic		91.7 (922)
African-American		2.0 (20)
Hispanic		2.9 (29)
Native American		0.1 (1)
Asian or Pacific Islander		1.1 (11)
Other		2.3 (23)
Highest Education Level		
Less than High School		0.9 (9)
High School		23.7 (238)
Some College		6.5 (65)
Bachelors' Degree		39.4 (396)
Masters' Degree		24.2 (243)
Doctorate		5.3 (53)
Marital Status		
Never Married		39.8 (402)
Married		50.5 (511)
Separated		0.9 (9)
Divorced		7.2 (73)
Widowed		1.6 (16)
Brother/Sister Disability*		
ID		53.2 (543)
Down syndrome		27.6 (282)
Autism		17.7 (181)
Cerebral palsy		14.3 (146)
Other		22.5 (230)
Brother/Sister Gender		
Female		41.5 (424)
Male		58.5 (597)
Brother/Sister Age	34.36 (14.44)	

*Note: Participants could endorse more than one disability for their brother/sister; 31.3% of the sample (n=320) indicated more than one disability diagnostic category.

ID = intellectual disability. "Other" disabilities listed in the survey include fragile X syndrome, Prader-Willi syndrome, emotional disturbance or condition, sensory impairment, Williams syndrome, health condition, and unspecified developmental disability

Table 2

Percentage of participants in each category by siblings' level of guilt

	Less Guilt (n=128)	Same Guilt (n=340)	Somewhat More Guilt (n=249)	More Guilt (n=304)	χ^2
Sibling Gender					
Male	13.5%	42.8%	23.3%	20.5%	15.63**
Female	12.3%	30.8%	24.7%	32.3%	
Brother/Sister Diagnosis					
ID -Yes	12.0%	32.4%	24.1%	31.5%	1.75
No	13.2%	34.4%	24.7%	27.8%	
Down syndrome-Yes	14.2%	38.7%	24.5%	22.7%	10.75*
No	11.9%	31.3%	24.4%	32.5%	
Autism-Yes	12.2%	27.6%	26.0%	34.3%	3.86
No	12.6%	34.5%	24.0%	28.8%	
Cerebral Palsy-Yes	12.3%	35.6%	21.2%	30.8%	1.04
No	12.6%	32.9%	24.9%	29.6%	

*p<.05, **p<.01

Note - The diagnosis analyses compared individuals who reported their brother/sister had each diagnosis (Yes) to those not reporting each diagnosis (No - e.g. siblings of individuals with Down syndrome to siblings of individuals without Down syndrome)

ID = intellectual disability

Table 3

Means (SD) of each variable by siblings' level of guilt

	Overall Mean (N = 1021)	1. Less Guilt (n=128)	2. Same Guilt (n=340)	3. Somewhat More Guilt (n=249)	4. More Guilt (n=304)	F-Value	Group Differences
Sibling Relationship	28.94 (5.80)	30.54 (4.68)	29.40 (5.64)	28.91 (5.53)	27.99 (6.18)	6.74***	4<1,2; 3<1
Knowledge of Brother/Sister	26.58 (5.06)	26.86 (5.43)	26.68 (4.74)	26.05 (5.28)	26.39 (5.14)	1.03	
Brother/Sister Health Problems	2.55 (1.32)	2.58 (1.37)	2.41 (1.30)	2.56 (1.29)	2.69 (1.35)	2.45	
Brother/Sister Emotional Problems	2.67 (1.37)	2.47 (1.31)	2.44 (1.30)	2.68 (1.34)	2.99 (1.44)	9.90***	1,2,3<4; 2<3
Brother/Sister Functional Abilities	42.74 (12.20)	43.20 (13.40)	44.05 (12.21)	42.34 (11.81)	41.41 (11.86)	2.68*	4<2
Sibling Physical Health	3.87 (0.96)	3.92 (1.00)	3.92 (.92)	3.82 (.98)	3.84 (.96)	.78	
Sibling Depression	7.63 (2.89)	6.64 (2.03)	7.00 (2.50)	7.78 (2.91)	8.61 (3.27)	23.77***	1,2<3<4
Sibling Well-Being	83.60 (11.62)	87.60 (9.98)	85.56 (10.57)	82.94 (10.76)	80.25 (13.04)	17.82***	4<3<1,2
Sibling Age	36.85 (13.71)	39.59 (15.38)	36.74 (13.52)	36.60 (14.10)	36.03 (12.76)	2.08	

*p<.05, ***p<.001