J Dev Phys Disabil (2016) 28:735–750
DOI 10.1007/s10882-016-9505-1

ORIGINAL ARTICLE

Correlates of Sibling Relationship Quality and Caregiving Reception of Adults with Disabilities

Meghan M. Burke[1] · Chung Eun Lee[1] · Catherine K. Arnold[2] · Aleksa Owen[2]

Abstract Siblings of individuals with disabilities report close relationships with and a greater likelihood of caregiving for their brothers and sisters with disabilities. However, most research has only relied on siblings without disabilities excluding individuals with disabilities. In this study, we sought to determine the correlates of close sibling relationships and the likelihood of caregiving as reported by individuals with disabilities. To this end, 106 individuals with disabilities responded to a web-based survey. With respect to the sibling relationship, participants who contacted their siblings more frequently and did not have mental health diagnoses were more likely to report closer sibling relationships. Regarding caregiving, participants who were in greater contact with their siblings, had fathers in excellent or good health, were male, and had more siblings were more likely to receive caregiving from their siblings. Implications for future research and practice are discussed.

Keywords Disability · Sibling · Relationship · Family · Caregiving

---

✉ Meghan M. Burke
meghanbm@illinois.edu

Chung Eun Lee
celee@illinois.edu

Catherine K. Arnold
kkeiling@uic.edu

Aleksa Owen
Abolya2@uic.edu

[1] Department of Special Education, University of Illinois at Urbana-Champaign, 1310 S. 6th Street, 288 Education building, Champaign, IL 61820, USA

[2] Department of Disability and Human Development, University of Illinois at Chicago, 1640 W. Roosevelt Road, Chicago, IL 60608, USA

Siblings have the longest familial relationship (Cicirelli 1995). When the relationship includes an individual with a disability, however, the sibling relationship may include roles beyond those expected for siblings of individuals without disabilities. Specifically, siblings of individuals with (versus without) disabilities are more likely to fulfill caregiving (Burke et al. 2012; Heller and Arnold 2010) and supportive roles (Arnold et al. 2012). While these roles are often considered unilateral, with the sibling without a disability providing more support, recent research has found that sibling relationships– wherein a disability is present–are reciprocal (Kramer et al. 2013). Specifically, individuals with disabilities contribute to the sibling relationship by fulfilling family roles (e.g., aunt/uncle), attending medical appointments with their siblings, and assisting with household chores. In return, siblings of individuals with disabilities reported providing daily support, facilitating employment opportunities, and advocating for disability rights.

Yet, most research about sibling relationships only includes samples of siblings without disabilities (Hodapp et al. 2005). Further, most of the sibling research is comprised of primarily White and well-educated sisters who plan to pursue future caregiving for their brothers and sisters with disabilities (Taylor et al. 2016). Given that sibling relationships are reciprocal, it is important to determine whether individuals with disabilities report similar correlates regarding the quality of their sibling relationships and caregiving. The present study identifies the correlates of sibling relationship quality and caregiving as reported by individuals with disabilities.

Sibling Relationships

To date, most research, based on samples of siblings of individuals with disabilities, indicates that siblings have positive relationships with their brothers and sisters with disabilities (Heller and Arnold 2010). Specifically, when an individual has a disability, their siblings report frequent contact, close relationships, and more shared activities. Indeed, many adult siblings report frequent contact (both via the phone and in-person) with their brothers and sisters with disabilities (Krauss et al. 1996), which may facilitate closer relationships.

However, the quality of the sibling relationship may differ in relation to characteristics of the individual with a disability. For example, siblings of individuals with mental health diagnoses (versus other types of disabilities) report worse relationships. Seltzer et al. (1997) compared the perceptions of sibling relationships among individuals with brothers and sisters with mental health diagnoses (versus intellectual disability). Nearly all of the siblings of individuals with intellectual disability reported positive reactions to their sibling relationships whereas more than half of the siblings with mental health diagnoses reported negative reactions. Additionally, gender may relate to the sibling relationship as female (versus male) siblings of individuals with disabilities report closer sibling relationships (Hodapp et al. 2010).

In addition to individual characteristics, family characteristics may influence the quality of sibling relationships. For example, adolescent siblings of individuals with disabilities from larger (versus smaller) families report greater positive affect in their sibling relationships (Orsmond et al. 2009). Such positive affect may continue into adulthood as siblings with multiple brothers and sisters without disabilities (versus lone siblings) report closer relationships with their brothers and sisters with disabilities (Hodapp et al. 2010). Further, sibling closeness may relate to parent health and caregiving ability. In a study of siblings of individuals with intellectual disability (Orsmond and Seltzer 2000), male (versus female) siblings of individuals with intellectual disability reported less positive sibling relationships when their mothers were declining in caregiving abilities. However, sibling relationships were strengthened when their parents were deceased.

Sibling Caregiving

Additionally, caregiving needs of aging individuals with disabilities is a public health crisis (Talley and Crews 2007) as individuals with disabilities are outliving their parents (Bittles et al. 2002) and the adult service delivery system lacks the capacity to meet the needs of aging individuals with disabilities (Braddock et al. 2015). Consequently, family members (e.g., parents and siblings) provide the majority of long-term care to individuals with disabilities (Wolff and Kasper 2006). Most caregiving studies only examine the perspectives of the parents and the siblings excluding individuals with disabilities (Williamson and Perkins 2014). Siblings of individuals with (versus without) disabilities have greater caregiving responsibilities for their brothers and sisters. However, certain siblings are more likely to be caregivers. In a longitudinal study, when siblings had frequent and close contact and the brother or sister did not have a mental health disorder, siblings were more likely to anticipate future caregiving roles (Greenberg et al. 1999). In a national survey of siblings of individuals with disabilities, Burke et al. (2012) found that siblings with closer relationships, worse parent caregiving ability, smaller family size, and female (versus male) siblings, were more likely to anticipate future caregiving roles. In relation to family size, lone siblings (i.e., individuals with no brothers and sisters without disabilities) were more likely than multiple siblings to anticipate future caregiving. However, other studies have indicated that family size may work in the opposite direction. Indeed, during childhood, siblings from large (versus small) families report sharing caregiving responsibilities for their brothers and sisters with disabilities (Howlin 1988). Thus, in spite of less caregiving provided by each sibling, large (versus small) families may provide more overall caregiving (Checkovich and Stern 2002). Notably, however, these caregiving studies were based on samples of siblings of individuals with disabilities. Especially given that the caregiving is for the individual with a disability, it is essential to determine whether the same correlates are reported by individuals with disabilities.

Like family size, the issue of gender and its relation to caregiving may also be complicated. Some studies indicate that female (versus male) siblings are more likely to be closer to, involved with, and provide caregiving for their brothers and sisters with disabilities (e.g., Hodapp et al. 2010; Seltzer et al. 1991). However, other studies indicate that male siblings of individuals with disabilities are more likely to report close relationships (and, perhaps, a greater likelihood of caregiving) with their brothers (versus sisters) with disabilities; for female siblings, the gender of the brother/sister with a disability does not relate to the quality of the sibling relationship (Orsmond and Seltzer 2000). However, it is less clear whether gender relates to caregiving from the perspectives of individuals with disabilities. Further, it is important to understand whether the gender of the individual with a disability (rather than the sibling without a disability) relates to caregiving. By understanding the impact of the gender of the individual with a disability, we can better understand the relation between gender and caregiving status.

Research Questions for this Study

Although sibling relationships are reciprocal, to date, most sibling research relies on samples of siblings of individuals with disabilities. However, given that sibling relationships and caregiving are interpersonal, it is important to determine whether individuals with disabilities report the same correlates with respect to sibling relationship quality and caregiving. Indeed, individuals with disabilities may report different correlates of relationship quality with and reception of caregiving from their siblings without disabilities. Individuals with disabilities have expressed a tension between what their family members want for them and what they want (Mitchell 1997; Beart et al. 2004). Because of this tension, there is a call for increased inclusion of individuals with disabilities in research (Meltzer and Kramer 2016). This study responds to that call by identifying the correlates of sibling relationships and caregiving as reported by individuals with disabilities. Specifically, our research questions were: (1) What are the correlates of sibling relationship quality? And (2) What are the correlates of receiving caregiving from their siblings?

Method

Participants

For this study, 106 individuals with varying types of disabilities responded to a national web-based survey. On average, participants were 40.30 years of age (*SD* = 14.22, range from 19 to 76). Half of the participants did not complete college (*n* = 53) and more than 70 % (*n* = 82) of the participants had annual household incomes below $40,000. Most participants were unmarried (71.7 % or *n* = 76) and participants were primarily White (82.1 % or *n* = 87). The majority of participants (67.0 % or *n* = 71) did not have children. Regarding employment, 46.7 % (*n* = 49) of participants were unemployed. Participants represented 30 of the 50 states in addition to Puerto Rico. More than half (51.9 %) of the participants reported having physical disabilities. Many participants reported having physical health conditions (31.1 %) and mental health disabilities (27.4 %). Less than 20 % of participants reported the following types of disabilities: learning disabilities, cerebral palsy, blind/visual impairment, deaf/hearing impairment, autism, and intellectual disability. See Table 1 for additional participant demographics.

For the survey, participants responded to questions about their sibling relationship and caregiving support in relation to their sibling (without a disability) who was closest in age to them. On average, siblings were 41.69 years of age (*SD* = 15.27, range from 18 to 80 years of age). Of the siblings, 51.9 % were male (*n* = 55). Further, most siblings lived within a 60 min drive from their brothers and sisters (61.32 % or *n* = 65).

Table 1 Participant demographics ($N = 106$)

Characteristic	% (*n*)
Gender	
Female	76.4 % (81)
Educational Background	
Some High school	2.8 % (3)
High school graduate	18.9 % (20)
Some college	28.3 % (30)
College graduate	22.6 % (24)
Some graduate school	6.6 % (7)
Graduate school graduate	20.8 % (22)
Annual Household Income	
Less than \$20,000	52.8 % (56)
Between \$20–40,000	24.5 % (26)
Between \$40–60,000	8.5 % (9)
Between \$60–80,000	5.7 % (6)
More than \$80,000	7.5 % (8)
What is your marital status?	
Single/Divorced/Widowed	71.7 % (76)
Married	28.3 % (30)
What is your ethnicity?	
Caucasian	82.1 % (87)
Latino/Hispanic	7.5 % (8)
African American	6.6 % (7)
Asian	2.8 % (3)
Other	6.6 % (7)
Who do you live with?	
With a significant other	29.2 % (31)
Alone	29.2 % (31)
With parents	23.6 % (25)
With siblings	2.8 % (3)
Other	15.1 % (16)
Which type of disability do you have?[a]	
Physical disability	51.9 % (55)
Physical health condition	31.1 % (33)
Mental health disability	27.4 % (29)
Learning disability	19.8 % (21)
Cerebral palsy	17.9 % (19)
Blind/visual impairment	11.3 % (12)
Deaf/hearing impairment	8.5 % (9)
Autism	8.5 % (9)
Intellectual disability	6.6 % (7)

[a] Percentages do not add up to 100 % as participants could choose multiple types of disabilities

Recruitment

Participants in this study were part of a larger study to examine adult siblings of individuals with disabilities. The larger survey included different questions for: adult siblings of individuals with disabilities, parents of adults with disabilities, professionals who work with adults with disabilities and their families, and adults with disabilities. For this study, the target population and related sample size was 100 individuals with disabilities who had siblings without disabilities.

To attain a diverse national sample, participants were recruited in a variety of ways. E-mails and recruitment flyers were distributed to local, state, and national parent support groups throughout the United States. E-mails and recruitment flyers were also distributed to Centers for Independent Living, state and local chapters of The Arc, the University Centers for Excellence in Developmental Disabilities, and Protection and Advocacy Agencies as well as to the Sibling Leadership Network and state sibling chapters. We also targeted disability-specific agencies (e.g., National Down Syndrome Society, United Cerebral Palsy, National Alliance on Mental Illness). To recruit individuals with disabilities specifically, flyers were shared with self-advocacy groups (e.g., Self Advocates Becoming Empowered) as well as professionals who work with individuals with disabilities (e.g., service provider agencies). Further, social media (e.g., Facebook, Twitter), hard copy mailings, and list servs were used to distribute information about the study. Multiple recruitment e-mails were sent. There was no financial incentive to participate in the survey.

Procedures

In collaboration with professionals, families of adults with disabilities, and adults with disabilities themselves, the survey was developed and revised. The survey was developed based on the literature about adult siblings (e.g., Burke et al. 2012; Heller and Arnold 2010) and adults with disabilities (Kramer et al. 2013). Before launching the survey, we piloted the survey with five adults with varying types of disabilities (e.g., physical disability, Down syndrome, autism spectrum disorder, and mental health disorder).

After piloting the survey, we revised the questions to ensure the questions were accessible to individuals with various types of disabilities. For example, to facilitate access to the survey for individuals with intellectual disability, the questions were short, clear, and included specific examples when appropriate. Additionally, the survey was written at the 5th grade reading level. Also, the survey platform met accessibility standards dictated by Section 508 of the American Rehabilitation Act. The study was submitted to and approved by the University Institutional Review Board. The survey was then put onto a secure survey platform, Qualtrics (2015). Responses were downloaded periodically to guard against computer malfunctions. The study was posted from January 2015 to April 2015. All of the surveys were completed electronically; however, participants were given the option to complete and return paper versions of the survey. For adults with disabilities, the survey took 20–30 min to complete.

Measures

Dependent Variable: Sibling Relationship Quality Participants rated their relationships with their siblings with respect to: understanding, trust, fairness, respect, affection, and closeness (Bengston and Black 1973). Using a six-item scale, responses ranged from *not at all* (1) to *extremely* (6). In previous studies about siblings of individuals with disabilities, Cronbach's alpha for these questions equaled .92 (Burke et al. 2012). In this study, responses were summed ranging from 6 to 36; Cronbach's alpha was .92.

Dependent Variable: Current caregiving We asked participants, "Currently, do you receive support from your brother or sister without a disability?". The question was dichotomous; participants answered *no* (0) or *yes* (1).

Independent Variable: Mental health diagnosis Participants were asked "Do you have a mental health diagnosis?". Participants answered *no* (0) or *yes* (1).

Independent Variable: Gender of the Sibling We asked participants, "What is the gender of your sibling that is closest in age?". Participants answered *male* (0) or *female* (1).

Independent Variable: Gender of the Respondent We asked participants, "What is your gender?". Participants answered *male* (0) or *female* (1).

Independent Variable: Maternal Health We asked one question about the health of the mother of the participant: "What is your mother's general state of health?". Participants responded to a five point Likert scale which, for ease of interpretation, we adapted into three Likert response options: *deceased* (1), *poor/fair* (2), and *good/excellent* (3). In a review of studies which examined self-reported health (Idler and Benyamini 1997), most responses ranged from a three to a five point Likert scale. However, given that the review examined self-health, we had to adapt the scale to include a "deceased" option. Thus, the maternal health scale includes three response options.

Independent Variable: Paternal Health We asked the same question as the health of the mother but with respect to the father. Originally on a five point Likert scale, for ease of interpretation, we reduced the scale to three points: *deceased* (1), *poor/fair* (2), and *good/excellent (3)*.

Independent Variable: Contact between Siblings We asked participants "Considering all forms of contact, how often are you in contact with your brother/sister?". Responses ranged from: *daily* (1), *several times a week* (2), *weekly* (3), *every other week* (4), *once a month* (5), *once every 2–3 months* (6), *once a year* (7), and *less than once a year* (8).

Independent Variable: Family Size We asked participants how many brothers and sisters were in their families. Participants could respond with any numeric answer. We categorized the responses as: two siblings, three siblings, four siblings, and five or more siblings.

Analyses

First, we conducted preliminary analyses. Specifically, we examined the distributions of each variable to determine normality; we proceeded with parametric statistics. Then, we conducted our primary analyses. Regarding our first research question, we conducted univariate statistics (e.g., Pearson correlations, t-tests, and ANOVAs) to determine the relation between the independent variables and the dependent variable (i.e., Sibling Relationship Quality). To determine the effect size, we used Cohen's *d*. We then conducted a correlation matrix with the independent variables. We found no multicollinearity. Further, the Variable Inflation Factor for each independent variable was below 2.5, further indicating that multicollinearity was not a concern (Tabachnick and Fidell 2007). See Table 2. Correspondingly, we included all of the independent variables in the linear regression with Sibling Relationship Quality as the dependent variable. For the second research question, we conducted separate logistic regressions with each independent variable and the dependent variable (i.e., current caregiving). We included all of the independent variables in a logistic regression. For each independent variable, we provided the odds ratio and the corresponding 95 % confidence interval.

Results

Sibling Relationship Quality

Overall, participants reported positive sibling relationships (M = 29.18, SD = 8.93, range from 7 to 42). Of the six item scale, siblings rated each of the following components: respect (M = 4.43, SD = 1.54), fairness (M = 4.38, SD = 1.33), affection (M = 4.34, SD = 1.49), trust (M = 4.23, SD = 1.55), understanding (M = 3.91, SD = 1.32), and closeness (M = 3.80, SD = 1.67) From the univariate analyses, participants without (versus with) mental health diagnoses reported significantly closer sibling relationships with a large (1.06) effect size. Additionally, participants who had more frequent contact with their siblings reported closer sibling relationships ($r = -.58$, $p < .001$). Also, maternal health related to the quality of the sibling relationship. Specifically, participants with mothers in excellent/good health (versus mothers who

Table 2 Correlation matrix

	1	2	3	4	5	6	7
1. Mental health of the respondent	–	–	–	–	–	–	–
2. Sibling contact	.17	–	–	–	–	–	–
3. Gender of the sibling	−.17	−.24*	–	–	–	–	–
4. Family Size	.10	.18	−.08	–	–	–	–
5. Maternal Health	−.21*	−.37**	.32**	−.09	–	–	–
6. Paternal Health	.07	−.24*	−.07	−.01	.44**	–	–
7. Gender of Respondent	.29**	.13	.04	−.04	−.05	−.12	–

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

were deceased) reported significantly closer sibling relationships ($p < .001$, $ES = .59$). See Table 3.

The linear regression model included the eight independent variables and explained 39.3 % of the variance ($F = 9.06$, $p < .0001$). Participants with more frequent contact with their siblings reported closer sibling relationships ($p < .0001$). Also, participants without (versus with) mental health diagnoses reported closer sibling relationships ($p = .02$). See Table 4.

Current Caregiving

From the univariate logistic regressions, there were some significant relations between the independent variables and current caregiving. For example, participants with more contact with their siblings were more likely to report receiving caregiving ($p = .002$). The health of the father also related to sibling caregiver

Table 3 Univariate analyses for sibling relationship quality

	Sibling Relationship	*t*/*F*	*r*	*P*	Follow-up analyses	*ES*
Does the respondent have a mental health diagnosis?		4.24		.001		1.06
Yes	21.63 (7.46)					
No	30.25 (8.75)					
What is the contact between the siblings?			−.58	.001		
How many siblings are in the family?		.72		.54		.35
Two siblings	29.79 (9.08)					
Three siblings	29.58 (9.26)					
Four Siblings	26.55 (9.32)					
Five or more siblings	30.09 (7.96)					
What is the health of the mother?		6.06		.003	Good/Excellent > Deceased ($p < .001$)	.59
Deceased	24.76 (8.35)					
Poor/Fair	28.50 (8.64)					
Good/Excellent	32.02 (8.56)					
What is the health of the father?		1.89		.16		.40
Deceased	28.03 (9.39)					
Poor/Fair	28.03 (9.64)					
Good/Excellent	31.62 (7.32)					
What is the gender of the sibling?		−1.93		.06		.83
Female	25.00 (8.66)					
Male	31.90 (7.87)					
What is the gender of the respondent?		1.40		.16		.32
Female	31.36 (8.17)					
Male	28.51 (9.11)					

Table 4 Linear Regression for sibling relationship quality

	B (SE)	*Beta*	*p*
Contact with sibling	−2.09 (.35)	−.53	.001
Mental health disability	−4.15 (1.74)	−.21	.019
Maternal health	1.34 (1.12)	.12	.23
Family Size	.72 (.65)	.09	.27
Gender of sibling	−1.24 (1.56)	−.07	.43
Paternal Health	−.09 (1.00)	−.01	.92
Gender of Respondent	.16 (1.77)	.01	.93

status. Specifically, compared to participants whose fathers were deceased, participants whose fathers were in good or excellent health were more likely to receive caregiving from their siblings (p = .01). See Tables 5 and 6.

In the multivariate logistic regression, the eight independent variables were included in the model resulting in 30.9 % of the variance explained (F = 26.32, p = .006). Participants with more frequent contact with their siblings were .66 times more likely to receive care from their siblings (p = .003). Additionally, participants whose fathers were in good/excellent health (versus deceased) were more likely to receive caregiving (p = .03). Further, male (versus female) respondents were 4.39 times more likely to receive caregiving from their siblings (p = .04). Finally, compared to participants with two siblings, participants with five or more siblings were .19 times more likely to receive caregiving from their siblings. See Table 6.

Table 5 Independent variables and current caregiving

	B(SE)	*Wald*	*p*	*OR (95 % CI)*
Does the respondent have a mental health diagnosis? (reference: has a mental health diagnosis)	−.21 (.46)	.21	.65	.81 (.33–2.01)
What is the contact between the siblings?	−.34 (.11)	9.78	.01	.71 (.57–.88)
How many siblings are in the family? (reference: More than five siblings)				
2 siblings	−.69 (.60)	1.32	.25	.50 (.15–1.64)
3 siblings	−.11 (.59)	.04	.85	.89 (.28–2.82)
4 siblings	−.36 (.66)	.29	.59	.69 (.19–2.56)
What is the health of the mother? (reference: Good/Excellent)				
Deceased	−.91 (.58)	2.43	.12	.40 (.13–1.26)
Poor/Fair	−.39 (.48)	.69	.41	.67 (.26–1.72)
What is the health of the father? (reference: Good/Excellent)				
Deceased	−1.27 (.52)	5.87	.01	.28 (.10–.78)
Poor/Fair	−.82 (.52)	2.47	.12	.44 (.16–1.23)
What is the gender of the sibling? (reference: Female)	.55 (.42)	1.70	.19	1.74 (.76–3.99)
What is the gender of the respondent? (reference: Female)	.75 (.55)	1.84	.18	2.11 (.72–6.23)

Table 6 Multivariate logistic regression with current caregiving

	B (SE)	*Wald*	*p*	*OR (95 % CI)*
Contact with Sibling	−.41 (.14)	8.77	.003	.66 (.51–.87)
Father Health (reference: Good/Excellent)				
Deceased	−1.54 (.73)	4.49	.03	.21 (.05–.89)
Poor/Fair	−1.23 (.69)	3.21	.07	.29 (.07–1.12)
Gender of respondent (reference: female)	1.48 (.72)	4.22	.04	4.39 (1.07–18.01)
Family Size (reference: 5 or more siblings)				
2 siblings	−1.63 (.74)	4.83	.02	.19 (.04–.84)
3 siblings	−.89 (.69)	1.66	.19	.41 (.11–1.59)
4 siblings	−1.19 (.79)	2.25	.13	.30 (.06–1.44)
Gender of Sibling (reference: female)	−.41 (.56)	.52	.47	.67 (.22–2.02)
Maternal Health (reference: Good/Excellent)				
Deceased	.55 (.84)	.43	.51	1.73 (.33–9.00)
Poor/Fair	.05 (.65)	.01	.94	1.05 (.29–3.77)
Mental health disability (reference: has a mental health disability)	−.15 (.60)	.06	.79	.86 (.26–2.80)

Discussion

Because sibling relationships are reciprocal, it is crucial to including individuals with and without disabilities in sibling research. However, little research has examined the correlates of sibling relationship quality and caregiving as reported by individuals with disabilities. In this study, we had five main findings about sibling relationship quality and caregiving.

First, sibling contact matters. When individuals with disabilities were in more frequent contact with their siblings, the quality of the sibling relationship was stronger and siblings were more likely to provide caregiving (p's < .001 and p < .01, respectively). This finding aligns with research about siblings of individuals with disabilities wherein adult siblings report frequent phone and in-person contact with their brothers and sisters with disabilities (Krauss et al. 1996). Although, compared to adolescent siblings, adult siblings tend to have fewer shared activities with their brothers and sisters with disabilities (Orsmond et al. 2009), this finding illustrates that frequent contact is a strong correlate of close sibling relationships in adulthood. This finding also may support current research (Kramer et al. 2013) suggesting that people with disabilities experience close sibling relationships as a benefit conferred through support or caregiving.

Second, individuals with (versus without) mental health diagnoses reported weaker sibling relationships. Similar to sibling contact, this finding is also consistent with the sibling literature (e.g., Pruchno et al. 1996; Seltzer et al. 1997). Although mental health diagnoses and other types of disabilities (e.g., intellectual disability) are both chronic disabilities, mental health diagnoses have some unique characteristics, which may contribute to the difference in sibling relationship quality. For example, because mental health disorders are diagnosed later in life, siblings of individuals with mental health diagnoses may struggle with accepting and understanding the disability of their brothers and sisters (Seltzer et al. 1997). Another difference is behavior. Mental health disorders are often “episodic”; the behavior associated with mental health diagnoses may be unstable and cyclical (Eyman and Widaman 1987; Greenberg et al. 1999; Seltzer et al. 1997). Such differences may contribute to the varying sibling relationship quality among individuals with (versus without) mental health diagnoses.

Third, gender relates to sibling caregiving; however, the relation between gender and sibling caregiving seems to be nuanced. Some studies have found that female (versus male) siblings are more likely to provide caregiving regardless of the gender of their brothers and sisters with disabilities whereas male siblings are more likely to provide caregiving when they have a brother (versus sister) with a disability (Orsmond and Seltzer 2000). Other studies have found that, compared to male siblings, female siblings provide the majority of caregiving (Burke et al. 2012; Heller and Kramer 2009). Still further, some studies have not found gender to matter (Burbidge and Minnes 2014; Cuskelly 2016). In this study, the gender of the brother or sister with a disability (not the sibling) mattered. Specifically, male (versus female) respondents were 4.39 times more likely to receive caregiving from their siblings. The gender of the sibling with a disability should be studied further particularly in relation to caregiving and supportive contexts.

Fourth, participants whose fathers were in good/excellent health (versus deceased or, marginally, poor/fair health) were more likely to receive caregiving from their siblings. Other research has similarly demonstrated a relation between parent health/caregiving ability and sibling caregiving. In a national study of siblings of individuals with disabilities, siblings were more likely to anticipate future caregiving when their parents were in excellent (versus poor) health (Burke et al. 2012). Other studies have similarly demonstrated that sibling predictions of future caregiving may not be accurate (e.g., Burke et al. 2015; Freedman et al. 1997). This study extends the literature by confirming this inverse relation between parent caregiving ability and sibling caregiving responsibilities.

Finally, family size related to caregiving status with participants from bigger (i.e, families with five or more siblings versus smaller) families reporting receiving more caregiving. Previous research has found that lone (versus multiple) siblings are more likely to provide future caregiving (Burke et al. 2012). However, from the larger literature about siblings, it seems that when individuals with disabilities have more siblings, each brother and sister provides some caregiving, resulting in greater cumulative caregiving for the individual with a disability (Checkovich and Stern 2002). By sharing responsibilities, siblings may experience less caregiving burden and feel more supported in aiding their brothers/sisters with disabilities.

Alternatively, it could be that participants reported receiving caregiving from the closest brother/sister without a disability and that, in larger versus smaller families, the caregiving is not dispersed but rather all falls on one sibling—the sibling closest in age to the individual with a disability. Indeed, instead of sharing caregiving responsibilities, in larger families, only one sibling may assume the primary caregiving role (Suitor and Pillemer 1996). When siblings struggle to share caregiving responsibilities, sibling relationships may strain, leading to weak or even non-existent sibling relationships (Strawbridge and Wallhagen 1991).

Indeed, with respect to caregiving for aging parents, for the sibling assuming the primary caregiving, the most frequent cause of distress may be the inequity in caregiving among siblings (Strawbridge and Wallhagen 1991). Conversely, the less involved siblings may experience guilt for their lack of involvement (Brody et al. 1990).

Implications for Future Research

Future research needs to include the perspectives of individuals with disabilities with respect to sibling relationships and caregiving. Specifically, future research should examine the opinions and perspectives of individuals with disabilities; such research could include interviews with individuals with disabilities. Within such interviews, individuals with disabilities could be asked about their satisfaction with the caregiving/support that they receive from their siblings. Also, individuals with disabilities could be asked the types of supports needed from their siblings along with the barriers and facilitators to receiving such support. Further, future research should include sibling dyads thereby reflecting the perspectives of both siblings and gaining a more holistic understanding of sibling relationships and caregiving.

Although limited, there are a few examples of how to conduct research with individuals with disabilities. Kramer et al. (2013) conducted a study with dyads of siblings with and without disabilities. To include individuals with disabilities, the interviewer established rapport with the participants, rephrased questions, allowed more time for participants to respond, and offered the sibling to choose a support person to facilitate participation in the research (Mactavish et al. 2000). Indeed, dyadic interviewing (i.e., interviewing an individual with an intellectual disability and a support person chosen by the individual with a disability) may be an effective way to include individuals with disabilities in qualitative research (Caldwell 2013). Other ways to facilitate participation of individuals with disabilities in research include: avoiding abstract questions, using simple wording, and reading items aloud; however, most of these methods pertain to qualitative studies (for a review, see Copeland et al. 2014). Methodological research is needed to understand how to facilitate participation of individuals with disabilities in quantitative (e.g., survey) studies.

Additionally, in families of offspring with disabilities, we have only just begun to examine the impact of family size on sibling relationships and caregiving. Specifically, prior studies have not attempted to separate the effects of "lone versus multiple" siblings compared with the number of siblings in a given family. It may be that, with respect to sibling relationships, multiple (versus lone) siblings have closer relationships with their brothers and sisters with disabilities; however, the number of siblings in the family does not affect sibling closeness. In contrast, with respect to future caregiving, lone (versus multiple) siblings are more likely to be future caregivers (Burke et al. 2012). Further, from this study, it seems that the number of siblings (i.e., two versus five or more) does impact caregiving. Thus, future research needs to more closely examine family size.

Implications for Practice

As individuals with disabilities outlive their parents (Fujiura 2014), caregiving increasingly falls on their siblings without disabilities. However, from this study and other studies (e.g., Burke et al. 2012), it seems that siblings are less likely to provide care when their parents are unable to provide caregiving. Thus, practitioners who work with aging individuals with disabilities and their families need to consider that siblings may not be able to fulfill primary caregiving roles. As such, natural supports and formal services need to be in place for individuals with disabilities. Specifically, practitioners should encourage families to seek formal services (Burke and Heller 2016) as well as rely on their own social networks to support individuals with disabilities (Kramer et al. 2013).

Another implication for practitioners is to consider the impact of a mental health diagnosis on sibling relationship quality. Although many siblings of individuals with disabilities report close relationships with their brothers and sisters (Heller and Arnold 2010), both individuals with disabilities (as presented in this study) and siblings of individuals with disabilities (Seltzer et al. 1997), report weaker sibling relationships when an individual has a mental health diagnosis. Practitioners, thus, should be cautious in overgeneralizing that all siblings have close relationships with their brothers and sisters. When working with individuals with mental health diagnoses and their siblings, practitioners may consider how different facets of mental health diagnoses may impact the sibling relationship. Such facets could include maladaptive behavior (Greenberg et al. 1999), the episodic nature and unpredictability of a mental health diagnosis (Greenberg et al. 1999), or stigma associated with mental health (Seltzer et al. 2005).

Although this study provides a jumping off point to examining sibling relationships and caregiving from the perspectives of individuals with disabilities, there are a few limitations. First, while web-based studies tend to be replicated by other methodologies (Birnbaum 2004), individuals with limited access to the internet may not be proportionately represented in this study. Further, the response rate for this study is unknown. Also, individuals with more extensive support needs may have been unable to access or complete this survey—a common problem in research with individuals with disabilities (Copeland et al. 2014). Additionally, our logistic regression only explained 30.9 % of the variance with respect to sibling caregiving; other potential correlates (e.g., severity of the disability, education/training about caregiving) may explain the remaining variance. Finally, this study was based on a convenience sample. Thus, the generalizability of the results, especially with respect to individuals with intellectual disability, may be limited. Future research should examine whether the same correlates exist across samples of individuals with different types of disabilities.

However, this study provides some important insights about the correlates of sibling relationships and caregiving status. As the longest-lasting familial relationship, it is crucial to determine whether individuals with disabilities report the same correlates of relationship quality and caregiving as siblings without disabilities. This study extended the literature by determining the correlates of sibling relationship quality and caregiving as reported by individuals with disabilities.

Compliance with Ethical Standards

Funding Funding for this grant was received by the Pennsylvania Developmental Disabilities Council and the North Carolina Developmental Disabilities Council. However, the manuscript solely reflects the opinions of the authors and not the funding agencies.

Ethical Approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed Consent Informed consent was obtained from all individual participants included in the study.

Conflict of Interest All of the authors (i.e., Meghan Burke, Chung eun Lee, Catherine Arnold and Aleksa Owen) declare no conflict of interest.

References

Arnold, C. K., Heller, T., & Kramer, J. (2012). Support needs of siblings of people with developmental disabilities. *Intellectual and Developmental Disabilities, 50*(5), 373–382.

Beart, S., Hardy, G., & Buchan, L. (2004). Changing selves: A grounded theory account of belonging to a self-advocacy group for people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 17*(2), 91–100.

Bengston, V. L., & Black, K. D. (1973). Intergenerational relations and continuities insocialization. In P. Baltes & W. Schaie (Eds.), *Life-span development psychology: Personality and socialization* (pp. 207–234). New York: Academic Press.

Birnbaum, M. H. (2004). Human research and data collection via the internet. *Annual Review of Psychology, 55*, 803–832.

Bittles, A. H., Petterson, B. A., Sullivan, S. G., Hussain, R., Glasson, E. J., & Montgomery, P. D. (2002). The influence of intellectual disability on life expectancy. *Journal of Gerontology, 57A*, M470–M472.

Braddock, D., Hemp, R., Rizzolo, M. C., Haffer, L., & Wu, J. (2015). *The state of the states in intellectual and developmental disabilities: Emerging from the great recession*. Washington, DC: American Association on Intellectual and Developmental Disabilities (AAIDD).

Brody, E. M., Dempsey, N. P., & Pruchno, R. A. (1990). Mental health of sons and daughters of the institutionalized aged. *The Gerontologist, 30*(2), 212–219.

Burbidge, J., & Minnes, P. (2014). Relationship quality in adult siblings with and without developmental disabilities. *Family Relations, 63*(1), 148–162.

Burke, M. M., & Heller, T. (2016). Individual, parent, and social-environmental correlates of caregiving appraisal among parents of adults with autism spectrum disorder. *Journal of Intellectual Disability Research, 60*, 401–411.

Burke, M. M., Taylor, J. L., Urbano, R., & Hodapp, R. M. (2012). Predictors of future caregiving by adult siblings of individuals with intellectual and developmental disabilities. *American Journal on Intellectual and Developmental Disabilities, 117*(1), 33–47.

Burke, M. M., Fish, T., & Lawton, K. (2015). A comparative analysis of adult siblings' perceptions toward caregiving. *Intellectual and Developmental Disabilities, 53*(2), 143–157.

Caldwell, K. (2013). Dyadic interviewing: A technique valuing interdependence in interviews with individuals with intellectual disabilities. *Qualitative Research, 1,* 0–20.

Checkovich, T. J., & Stern, S. (2002). Shared caregiving responsibilities of adult siblings with elderly parents. *The Journal of Human Resources, 37*(3), 441–478.

Cicirelli, V. G. (1995). *Sibling relationships across the life span*. New York: Plenum Press.

Copeland, S. R., Luckasson, R., & Shauger, R. (2014). Eliciting perceptions of satisfaction with services and supports from persons with intellectual disability and developmental disabilities: A review of the literature. *Journal of Intellectual Disability Research, 58*, 1141–1155.

Cuskelly, M. (2016). Contributors to adult sibling relationships and intention to care of siblings of individuals with down syndrome. *American Journal on Intellectual and Developmental Disabilities, 121*(3), 204–218.

Eyman, R. K., & Widaman, K. F. (1987). Life-span development of institutionalized and community-based mentally retarded persons, revisited. *American Journal of Mental Deficiency, 91*(6), 559–569.

Freedman, R. I., Krauss, M. W., & Seltzer, M. M. (1997). Aging parents' residential plans for adult children with mental retardation. *Mental Retardation, 35*(2), 114–123.

Fujiura, G. T. (2014). The political arithmetic of disability and the American family: A demographic perspective. *Family Relations, 63*(1), 7–19.

Greenberg, J. S., Seltzer, M. M., Orsmond, G. I., & Kraus, M. W. (1999). Siblings of adults with mental illness or mental retardation: Current involvement and expectation of future caregiving. *Psychiatric Services, 50*, 1214–1219.

Heller, T., & Arnold, C. K. (2010). Siblings of adults with developmental disabilities: Psychosocial outcomes, relationships, and future planning. *Journal of Policy and Practice in Intellectual Disabilities, 7*(1), 16–25.

Heller, T., & Kramer, J. (2009). Involvement of adult siblings of persons with developmental disabilities in future planning. *Intellectual and Developmental Disabilities, 47*(3), 208–219.

Hodapp, R. M., Glidden, L. M., & Kaiser, A. P. (2005). Siblings of persons with disabilities: Toward a research agenda. *Mental Retardation, 43*(5), 334–338.

Hodapp, R. M., Urbano, R. C., & Burke, M. M. (2010). Adult female and male siblings of persons with disabilities: Findings from a national survey. *Intellectual and Developmental Disabilities, 48*(1), 52–62.

Howlin, P. (1988). Living with impairment: The effects on children of having an autistic sibling. *Child: Care, Health and Development, 14*, 395–408.

Idler, E. L., & Benyamini, Y. (1997). Self-rated health and mortality: A review of twenty-seven community studies. *Journal of Health and Social Behavior, 38*, 21–37.

Kramer, J., Hall, A., & Heller, T. (2013). Reciprocity and social capital in sibling relationships of people with disabilities. *Intellectual and Developmental Disabilities, 51*(6), 482–495.

Krauss, M. W., Seltzer, M. M., Gordon, R., & Friedman, D. H. (1996). Binding ties: The roles of adult siblings of persons with mental retardation. *Mental Retardation, 34*, 83–93.

Mactavish, J.B., MacKay, K.J., Iwasaki, Y., & Betteridge, D. (2007). Family caregivers of individuals with intellectual disability: Perspectives on life quality and the role of vacations. *Journal of Leisure Research,* 39, 127–155.

Meltzer, A., & Kramer, J. (2016). Siblinghood through disability studies perspectives: Diversifying discourse and knowledge about siblings with and without disabilities. *Disability & Society, 31*(1), 17–32.

Mitchell, P. (1997). The impact of self-advocacy on families. *Disability & Society, 12*(1), 43–56.

Orsmond, G. I., & Seltzer, M. M. (2000). Brothers and sisters of adults with mental retardation: gender nature of sibling relations. *American Journal on Mental Retardation, 105*(6), 486–508.

Orsmond, G. I., Kuo, H.-Y., & Seltxer, M. M. (2009). Siblings of individuals with an autism spectrum disorder: Sibling relationships and wellbeing in adolescence and adulthood. *Autism, 13*(1), 59–80.

Pruchno, R. A., Patrick, J. H., & Burant, C. J. (1996). Aging women and their children with chronic disabilities: Perceptions of sibling involvement and effects on well-being. *Family Relations, 45*, 318–326.

Seltzer, G. B., Begun, A., Seltzer, M. M., & Krauss, M. W. (1991). Adults with mental retardation and their aging mothers: Impacts of siblings. *Family Relations, 40*, 310–317.

Seltzer, M. M., Greenberg, J. S., Krauss, M. W., Gordon, R. M., & Judge, K. (1997). Siblings of adults with mental retardation or mental illness: Effects on lifestyle and psychological well-being. *Family Relations, 46*(4), 395–405.

Seltzer, M. M., Greenberg, J. S., Orsmond, G. I., & Lounds, J. (2005). Life courses studies of siblings of individuals with developmental disabilities. *Mental Retardation, 43*(5), 354–359.

Strawbridge, W. J., & Wallhagen, M. I. (1991). Impact of family conflict on adult child caregivers. *The Gerontologist, 31*(6), 770–777.

Suitor, J. J., & Pillemer, K. (1996). Sources of support and interpersonal stress in the networks of married caregiving daughters findings from a 2-year longitudinal study. *Journal of Gerontology: Psychological Sciences, 51B*(6), 297–306.

Tabachnick, B. G., & Fidell, L. S. (2007). *Using multivariate statistics*. Boston: Pearson/Allyn & Bacon.

Talley, R. C., & Crews, J. E. (2007). Framing the public health of caregiving. *American Journal of Public Health, 97*, 224–228.

Taylor, J. L., Burke, M. M., Smith, L. E., & Hartley, S. L. (2016). Family of adolescents and adults with intellectual and developmental disabilities. *International Review for Research in Developmental Disabilities*. doi:10.1016/bs.irrdd.2016.04.001.

Williamson, H. J., & Perkins, E. A. (2014). Family caregivers of adults with intellectual and developmental disabilities: Outcomes associated with U.S. services and supports. *Intellectual and Developmental Disabilities, 52*, 147–159.

Wolff, J. L., & Kasper, J. D. (2006). Caregivers of frail elders: Updating a national profile. *The Gerontologist, 46*(3), 344–356.