Stress and Coping in Siblings of Individuals with Intellectual and/or Developmental Disabilities

Miles Abney

Department of Psychology: Vanderbilt Peabody College

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Dr. Jessika Boles

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Abstract

Millions of children are living with intellectual and developmental disabilities worldwide, yet little is known about this experience from the vantage point of neurotypical siblings. Therefore, the purpose of this mixed-methods study was to explore the coping mechanisms and stressors of adult siblings of individuals with intellectual and/or developmental disability to identify opportunities for better supporting this population. Twenty-seven adults who identified as a sibling of a person with intellectual and/or developmental disabilities completed a series of electronic instruments including a demographic questionnaire, the Coping Resources Inventory, the Brief Coping Orientation to Problems Experienced Inventory, and the Perceived Stress Scale. Thirteen participants also completed a semi-structured telephone interview following survey completion. Results demonstrated that participants most often used Self-Blame, Instrumental Support, and Acceptance coping mechanisms, and that, overall, emotional and social were the most commonly endorsed coping resources. Interview responses highlighted four major themes: 1) caretaking across the lifespan, 2) negotiating normalcy inside and outside the household, 3) parental transparency about sibling diagnosis and 4) reframing the sibling experience. Taken together, the results of this study suggest that providers and caregivers can better support siblings of individuals with intellectual and/or developmental disabilities by recognizing and supporting them through the negotiation of normalcy that comes with their unique stressors and experiences.

Intellectual and developmental disabilities (IDD) often transpire in infancy and early childhood and can affect an individual's function throughout the lifespan (Cogswell et at., 2022). In the United States alone, approximately one in every six children and adolescents is living with an intellectual and/or developmental disability (Cogswell et al., 2022). Compared to their typically developing peers, individuals with IDD are two to seven times more likely to receive services related to mental health or services from a specialized health care provider, and to take prescription medication. Additionally, they are eighteen times more likely to receive early intervention and special education services compared to their neurotypical peers (Cogswell et al., 2022).

Families of individuals with IDD report experiencing increased stress (Marquis et al., 2020). Impacts of caring for a child with IDD can include increased overall stress and anxiety, adjustment problems, worsened physical health, increased problem behaviors and mental health struggles, financial difficulties, and more. There is particular evidence to support that siblings of children with IDD also experience increased levels of stress and worse mental health outcomes, especially as compared to siblings of neurotypical children. However, the variables that contribute to these outcomes yet remain unclear (Marquis et al., 2020; Leedham et al., 2022). Some research suggests these may be due to intricate interactions between characteristics of neurotypical siblings, characteristics of the child or adolescent with an IDD, and social determinants of health (Marquis et al., 2020). In addition, variables such as the type of IDD, the sex of sibling without IDD, the sex of the individual with IDD, family income, birth order, and characteristics of the neighborhood in which the family lives have all shown to contribute to the outcomes of siblings of children with IDD (Marquis et al., 2020).

Impact on Family Systems and Caregivers

Living with and caring for a child with IDD, in addition to the individual level impacts, also impacts the function and wellbeing of family systems. A small subset of studies has focused on this phenomenon at the family level. For instance, in families with an individual living with autism spectrum disorder (ASD), Critchley et al. (2021) observed both closeness within the family unit as well as adoration for the individual with ASD through interviews with parent-sibling dyads. Additionally, some studies have confirmed that the presence of an individual with IDD yields many benefits for family members and the family unit as they become more united and co-operative as family teamwork is strengthened (Dervishaliaj & Murati, 2014).

At the same time, though, it has been seen that both the parents and siblings of individuals with ASD were somewhat consumed by the individual's diagnosis both at the time of the interview and when discussing the future – which appeared to be related to increased parental sacrifice, increased sibling responsibility, and inadequate support (Critchley et al., 2021). Other studies have demonstrated that the impact on family dynamics differs from country to country as cultural-specific expectations, societal judgment, and the availability of support changes (Rossetti et al., 2020). In short, the presence of a family member with ASD and/or other IDD appears to have significant impacts on the family unit, to be associated with increased responsibility for family members, and to differ in impact in different cultures and countries.

Many studies have explored the effects of intellectual and developmental disability on the individual who is navigating that disability as well as the needs and experiences of their parents. Boulet et al. (2009) demonstrated that children with one or more IDD were 4 to 32 times more likely to experience limitations in movement (6.1%), need assistance with personal care (3.2%), require the use of special equipment (3.5%), take prescription medication on a regular basis

(37.5%), and receive at home health care (1.4%) than children without IDD. Parents of children with IDD serve as caregivers and support systems throughout their lives and, in general, show encouraging patterns of resilience as well as effective coping mechanisms regarding their parenting responsibilities. Although some studies have found that, in midlife, parents of individuals with IDD approximated their counterparts with neurotypical children regarding patterns of attainment, health, and psychological well being, there appears to be a decline in the similarities as the parents age. In addition, many studies have found conflicting results, which demonstrate that parents of children with IDD appear to have greater difficulties in psychosocial functioning compared to the general population (Seltzer et al., 2011).

The role that siblings play in child development and throughout the lifespan is significant. Within existing literature, the influences siblings have on each other emerge both in larger family dynamics and through their interactions with each other. Sibling relationships appear to be shaped by extrafamilial, familial, and individual forces and the roles of siblings vary across time and place. Further, the power of sibling influences appears even when there are other significant relationships taken into consideration (McHale et al., 2012).

Significant differences have been observed between the relationships of two neurotypical siblings and the relationships between one neurotypical sibling and one sibling with IDD. In neurotypical adolescent siblings, opposite sex dyad relationships appear to have a larger presence of warmth, whereas, for adolescents with IDD, more warmth is found between same-sex dyad sibling relationships. Birth order also often impacts status/power differences within neurotypical sibling relationships, but, in relationships between a neurotypical sibling and an adolescent with IDD, status/power differences disappear (Begum & Blacher, 2011). When compared to siblings of children with IDD, siblings of individuals with both ASD and other IDD have shown to have

more emotional problems, demonstrating that the presence of multiple IDD can increase sibling

struggles (Petalas et al., 2009). Additionally, studies have shown higher levels of self-control and

cooperation in siblings of individuals with IDD compared to children without a sibling with IDD

(Mandleco et al., 2003). Overall, emotional and behavioral problems are often seen among

siblings of adolescents with IDD, in addition to positive characteristics such as self-control.

Impacts on and Outcomes of Neurotypical Siblings

The mental health outcomes for siblings of individuals with IDD are often associated

with the type(s) of IDD of the sibling, family dynamics, and characteristics of the neurotypical

sibling. These include factors such as household income, birth order, sex of both the child with

and without IDD, and age. In addition, compared to other developmental disabilities, there is

evidence to support significant positive differences in sibling relationships when the individual

has down-syndrome (Braconnier et al., 2017).

In a 2022 study by Leedham and colleagues, neurotypical siblings of individuals with

ASD generally reported mental health struggles related to the difficulties associated with extra

pressure and responsibility as they are forced to undertake parental and caring roles at times.

They also often described feeling as if they are perceived as secondary to their sibling with ASD

and as if their needs and feelings are overlooked, both of which impact well-being. Neurotypical

siblings of children with aggressive behaviors have also shown increased anxiety related to these

actions (Leedham et al., 2022). In short, while there is little literature regarding the needs and

experiences of siblings of individuals with IDD, many studies have identified common themes

among these siblings related to increased responsibility and feeling overlooked. In addition to

feeling overlooked in the home, it's been documented that siblings get overlooked in the

healthcare setting. Bronson et al. (2022) examined the lack of psychosocial care implementation

for siblings in a variety of healthcare settings through qualitative interviews with psychosocial care providers. Researchers concluded that barriers to providing sibling care occur at multiple levels of the healthcare system and that these barriers often contribute to limited provision of services, which leads to under prioritization of siblings and limited utilization of existing services. This limits sibling service provision and causes siblings to be off the radar entirely in many healthcare settings (Bronson et al., 2022).

Many siblings also report positive impacts of having a sibling with an IDD. The results of Shivers' 2019 study demonstrate that siblings of individuals with ASD often described significantly greater levels of perspective-taking than siblings of neurotypical individuals. Across all sibling relationships, feelings of positive affect towards siblings are significantly related to perspective-taking. Therefore, increased positive affect towards their sibling with IDD could contribute to these increased levels of perspective-taking. When presented with a question regarding their "three magic wishes," siblings of children with ASD have been significantly more likely to report family and sibling related wishes rather than selfish wishes, something that is less common among individuals with only neurotypical siblings (Shivers, 2019). When looking at sibling adjustment, difficulties in sibling adjustment have shown to be negatively correlated with parental satisfaction with their role as caregiver for a child with ASD.

In a study conducted by Hesse et al. in 2013, parental satisfaction was the only significant predictor of sibling adjustment as parental stress, parental self-efficacy, parental educational involvement, and parental therapy involvement were not significant predictors. Further, many siblings often report that they have developed increased compassion and empathy towards their sibling and others due to their life experiences (Marquis et al., 2020). Interestingly, siblings have even been shown to describe their relationship with their sibling with IDD more positively than

their parents or guardians. Parental reports tend to be more critical of the relationship with a focus on argumentation, whereas sibling reports tend to focus on appreciation and are more supportive and caring (Braconnier et al., 2017). Children with IDD also appear to have significant positive effects on feelings and overall mood for the family unit, including teenagers (Dervishaliaj & Murati, 2014).

Overall, although negative impacts of having a sibling with IDD have been observed, just as many positive impacts have been observed, too. In Moss and colleagues' 2019 study assessing the experiences of adult siblings with ASD, 77% of participants described positive benefits, mostly related to their own personality and impact on their own life, and only 14% could not describe any positive aspects. Most participants also described negative and positive emotions and experiences related to current concerns about future, long-term care for their siblings with ASD. As individuals with IDD age, siblings become increasingly more responsible for ensuring the wellbeing of the individuals with IDD, which is overlooked by medical and other services causing siblings to sometimes be excluded in decision-making and care-planning (Moss et al., 2019).

Coping in Caregivers and Siblings

Although distinct from the experiences of siblings of individuals with IDD, caregiver coping appears to influence mechanisms utilized by their children. Glidden et al. (2006) conducted a study to examine how birth and adoptive coping strategies manifest in parents of individuals with IDD. Parents reported the strategy of "Planful Problem-Solving" the most, three to four times more than any other strategy, and the strategy of "Escape-Avoidance" the least. Personality factors, especially neuroticism, predicted coping strategy usage. Additionally, lower

levels of subjective wellbeing were associated with high levels of "Escape-Avoidance" and high levels of subjective wellbeing were associated with "Positive Reappraisal" (Glidden et al., 2006).

In a follow-up study, Glidden and Nacher (2009) found the results of Glidden et al. (2006) to be stable and consistent over a 6-year interval. In a 2017 self-report study conducted by Shivers et al., caregivers described lower levels of subjective strain than objective strain. Unmet service needs and objective and subjective internalized strain were significantly related. Coping styles were strongly correlated with all types of strain. Researchers concluded that the relationship between strain and coping mechanisms appears to be stronger than that of objective and subjective internalized strain and caregiving responsibility (Shivers et al., 2017). With this in mind, it appears that strain and personality are related to coping mechanism usage in parents.

Further, Shivers and Dykens (2017) explored how behavioral problems and level of sibling functioning relate to sibling empathy and emotions as well as how parental optimism and perception of the brother or sister relate to empathy and emotion. Researchers concluded that siblings of individuals without IDD reported lower levels of anxiety towards the target child compared to siblings of individuals with IDD. Further, among the families of individuals with IDD, sibling feelings towards the target child were related to both target child and parental factors, demonstrating the impact of parental and target child behaviors on a neurotypical sibling (Shivers and Dykens, 2017).

Only a smaller subset of studies has addressed how siblings cope with their experiences with their sibling with IDD. Ross & Cuskelly (2006) conducted a study examining adjustment problems and the coping strategies implemented by siblings of children with ASD in response to common stressors. They found that the most reported stressor within sibling interactions was aggressive behavior as 84% of siblings stated this to be a concern. The response to this was

usually anger, which is interesting as emotional regulation was one of the most utilized coping strategies among siblings. Wishful thinking was also commonly utilized in response to anger, and both were reported by 91% of children. Following these were "social withdrawal (86%) distraction (81%), problem solving (71%), social support (62%), resignation (57%), cognitive restructuring (48%), blaming others (24%), and self-criticism (10%)" (Ross & Cuskelly 2006; p.82). When navigating difficulties with their sibling with ASD, siblings in this study did not generally utilize blaming, both of themselves and others, as a coping strategy.

Additionally, the specific problem being faced did not appear to influence the siblings' choice of coping strategy and the use of coping strategies remained similar across syndrome-specific and aggressive incidents. Wishful thinking and emotional regulation were the most common strategies utilized in response to both problem types and self-criticism and blaming others were utilized the least. Although contributing factors are still unknown, it does appear that siblings were at greater risk for developing internalizing behavioral problems (Ross & Cuskelly, 2006).

Although millions of children are living with IDD worldwide, little is known about how neurotypical siblings experience and cope with their sibling's IDD. Building on the current research, the purpose of this study is to explore the coping mechanisms of adult siblings of individuals with intellectual and/or developmental disabilities. Researchers will explore the following three questions:

1. What are the coping mechanisms of adult siblings of individuals with intellectual and/or developmental disabilities?

2. What associations may exist between sociodemographic factors and coping mechanisms in this population?

3. How do adult siblings of individuals with IDD perceive the impact of their

siblings' disability as adults?

Methods

Given the lack of research on this topic, a mixed-methods design was used to generate

quantitative, qualitative, and convergent data. Quantitative data were drawn from participant

demographic questionnaire responses as well as the Coping Resources Inventory (CRI) (Marting

& Hammer, 1988), the Brief COPE (Carver, 1997), and the Perceived Stress Scale (PSS)

(Siqueira Reis et al., 2010). Qualitative data was drawn from optional semi-structured, audio-

recorded interviews with participants who indicated interest. Convergent data emerged from

comparison and integration of these two data sources (Plano Clark & Creswell, 2018).

Participants

To meet the aims of this study, eligible participants included neurotypical adults, eighteen

years of age and older, who 1) had one or more siblings with one or more intellectual and/or

developmental disability, 2) spoke English as their primary language, and 3) provided consent to

participate. Exclusion criteria included being unable to read and write in the English language

and lack of consent to participate. Eligible participants were recruited from a variety of social

media sources: 1) Facebook groups, 2) the Vanderbilt University Medical Center communication

systems, 3) the Organization for Autism Research website, 4) the Vanderbilt University

Psychology Department's Research Sign up System (SONA), and 5) the personal social media

profiles used by the researchers. A study recruitment flier was distributed on these social media

sites, which gave information about the study, eligibility criteria, and linked the survey using a

QR code.

Procedures

Interested participants accessed the study consent form and survey using the REDCap link and QR code provided in the recruitment flier. Upon entering the survey, they were prompted to review and accept an informed consent document. After giving consent, they completed a brief demographic questionnaire, followed by a series of three standardized instruments: the Coping Resources Inventory (CRI) (Marting and Hammer, 1988), the Brief COPE (Carver, 1997), and the Perceived Stress Scale (PSS) (Siqueira Reis et al., 2010). At the end of this section, there was an opportunity for participants to indicate interest in an additional interview about their experiences by providing name and contact information. For those who did not opt into the interview, their participation in the study ended at survey completion.

Participants who indicated interest in the additional semi-structured interview portion were contacted by a member of the research team to schedule a zoom or telephone interview that lasted between 30 and 60 minutes. At the interview, participants elaborated on their experiences in response to the interview guide as facilitated by the researcher. These interviews were audio recorded and transcribed for the purposes of data analysis. At the conclusion of the interview, the participant's involvement in the study ended.

Measures

The demographic questionnaire consisted mainly of multiple choice and open-response questions related to participant and sibling demographics. The Coping Resources Inventory (CRI) is a 60-item questionnaire that measures five basic ways people handle stress (Marting & Hammer, 1988). The 5 scales measured are: Cognitive (COG), Social (SOC), Emotional (EMO), Spiritual/Philosophical (S/P), Physical (PHY). Participants responded to statements according to what best described their experience over the past 6 months by using a four-point Likert-type

scale that ranged from "never or rarely" to "always or almost always." The Brief COPE is a brief form of the Coping Orientation to Problems Experienced Inventory (Carver, 1997; Carver, Scheier, & Weintraub. 1989). The Brief COPE is a 28-item questionnaire that consists of 14 scales with two items each. The 14 scales are: Active Coping, Planning, Positive Refraining, Acceptance, Humor, Religion, Using Emotional Support, Using Instrumental Support, Self-Distraction, Denial, Venting, Substance Use, Behavioral Disengagement, and Self-Blame. Participants responded to statements by rating them from 0 "I haven't been doing this at all" to 3 "I've been doing this a lot." The Perceived Stress Scale (PSS) is a 10-question survey that aims to understand how different situations affect our feelings and our perceived stress (Siqueira Reis et al., 2010). The questions asked about participant thoughts and feelings during the last month and the participants indicated how often they thought or felt a certain way by using a five-point Likert-type scale that ranged from "0 never" to "4 very often." Participant scores were coded into one of the following three categories: low perceived stress, medium perceived stress, and high perceived stress.

Analysis

Participant responses to demographic questionnaires and coping and stress inventories were characterized using measures of central tendency in SPSS. Given the small sample size, it was not possible to do between subject comparisons therefore only descriptive statistics were used. To analyze participant interview responses all interview transcripts were coded using an inductive open coding approach. After all transcripts were coded, codes were combined into categories and themes to describe essential participant experiences.

Results

Demographics

Twenty-seven participants completed the quantitative survey component of this study (see Table 1 below). The majority of participants identified as female (n=21; 77.8%) and ranged from age 18 to 29 (n=22; 81.5%). Almost half of the participants (n = 12; 44.4%) identified that they had more than one sibling with IDD, but only two participants completed the sibling demographic questionnaire for more than one of their siblings. The total number of participant siblings with demographic data is twenty-nine, as two participants reported multiple siblings with IDD.

Almost all participants had never been married (n=22; 81.5%) and a little over half identified as some denomination of Christian (n=14; 51.9%). Sibling age and gender varied slightly from participant demographics as many siblings identified as male (n=17; 58.6%) and ranged from ages 20 to 29 years (n=20; 69%). The majority of siblings had a diagnosis on the Autism Spectrum (n=17; 58.6%). Additionally, although not reported in the table, the majority of siblings were younger than the participants (n=18; 66.7%), with 8 (27.6%)siblings being older than the participant and 3 (10.3%) siblings being the same age/twins. Most siblings lived at home with their parents/guardians (n=21; 72.4%). However, it is notable that some siblings are still high school age or younger as 7 (24.1%) siblings range from ages 10-19 years. One (3.4%) sibling lived in a full-time state funded residential facility and two (6.9%) siblings were living in a full-time, non-state funded residential facility. "Other" was used to describe 5 (17.2%) siblings' living situations and participants further defined this category as living independently or with their partner.

Table 1. *Participant Demographics*

Variables	Variables	Frequency	Percentage (%)
Gender	Male	6	22.2
	Female	21	77.8
Age	18-29	22	81.5
	30-39	4	14.8
	40-49	0	0
	50+	1	3.7
Race	White	22	81.5
	Black/African American	5	18.5
	Asian	4	14.8
	Hispanic/Latino	2	7.4
Education Level	High School/GED	2	7.4
	Some College	7	25.9
	Associate Degree	2	7.4
	Bachelor Degree	10	37
	Graduate Degree	4	14.8
	Post-Graduate Degree	2	7.4
Marital Status	Never Married	22	81.5
	Currently Married	4	14.8
	Living with Partner	1	3.7
Religious Affiliation	No Religion	5	18.5
	Agnostic	2	7.4
	Catholic	2	7.4
	Hindu	1	3.7
	Jewish	1	3.7
	Protestant	6	22.2
	Other	9	33.3
	Prefer to not respond	1	3.7
Sibling Gender*	Male	17	58.6
	Female	12	41.4
Sibling Diagnosis §	ADHD†	5	17.2
	Autism Spectrum Disorders	17	58.6
	Cerebral Palsy	4	13.8
	Downs Syndrome	4	13.8
	Genetic Disorder(s)	1	3.4
	Intellectual Disability	5	17.2
	Learning Disorders	1	3.4
	Other	3	10.3
Sibling Age*	1-9	0	0
	10-19	7	24.1
	20-29	20	69
	30-39	1	3.4
	40+	1	3.4
Sibling Living Situation	At home with parents/guardians	21	72.4
	Full-time, state funded residential facility	1	3.4
	Full-time, non-state funded residential facility	2	6.9
	Other	5	17.3

Note. n=27 for participants; n=29 for siblings of participants (individuals with IDD)
*Some participants had more than one sibling with IDD
†Attention-Deficit/Hyperactivity Disorder
§ Some siblings had more than one diagnosis

Coping Resources

The Coping Resources Inventory measures the five primary ways that people handle stress. For 75% of participants (n=18), using Emotional coping resources was the most prominent method of handling stress. Emotional coping resources, in this context, are understood to encompass an individual's capacity to both express and accept a wide range of emotions as it fosters emotional resilience and is instrumental in mitigating the long-term adverse impacts of stress (Marting & Hammer, 1988). 75% of participants (n=18) demonstrated that Social resources were their second most prominent method of handling stress. Additionally, Social resources were the second most common primary method of handling stress among this sample. Social resources are understood as the extent to which individuals are a part of social networks that provide support during times of stress (Marting & Hammer, 1988). Although no participants named Spiritual/Philosophical resources as their primary resource when coping with stress, more than half of the participants (n=13; 54.17%) cited it as their third most utilized coping resource. Utilization of Spiritual/Philosophical coping resources is understood as the degree to which an individual's actions are guided by personal philosophy or consistent religious, cultural, or familial traditions as they may guide how one interprets the meaning of a stressful event or the strategies they use when responding to the stress. The scope of this scale extends beyond traditional western religious definitions of spirituality (Marting & Hammer, 1988).

Cognitive and Physical coping resources were the least common forms of coping resources reported among participants. Only 13 participants cited one of them as one of their top three coping resources. Cognitive resources encompass the extent to which an individual maintains a sense of positive self-worth, general optimism about life, and a positive outlook towards others in the presence of stress (Marting & Hammer, 1988). Physical coping resources

encompass the degree to which an individual implements health-promoting behaviors that are

believed to contribute to increased physical well-being (Marting & Hammer, 1988). Based on

these results, it appears that Emotional, Social, and Spiritual/Philosophical coping resources are

relatively available to and utilized by siblings of individuals with IDD. However, Cognitive and

Physical resources do not appear to be as available or utilized by siblings. This raises the

questions of whether Cognitive and Physical coping resources and strategies are accessible to

this population and how their access to these resources can be increased.

Table 2. *Coping Resources Inventory*

Coping Type	Primary	Secondary	Tertiary
Cognitive (COG)	0.00% (n=0)	4.17% (n=1)	25.00% (n=6)
Social (SOC)	20.83% (n=5)	75.00% (n=18)	4.17% (n=1)
Emotional (EMO)	75.00% (n=18)	4.17% (n=1)	4.17% (n=1)
Spiritual/Philosophical (S/P)	0.00% (n=0)	4.17% (n=1)	54.17% (n=13)
Physical (PSY)	4.17% (n=1)	8.33% (n=2)	12.50% (n=3)

(n=24)*†
*Some participants had equivalent scores causing more than one category to be their secondary and/or tertiary coping type.
† Three participants are not included here due to equivalent scores that could not produce a ranking.

Coping Mechanisms

The Brief COPE includes 28 items and assesses 14 scales, or coping mechanisms, via two

items per scale. Table 3.1 and Table 3.2 report on the mean, median, and mode for each of the 14

scales as well as the percentages of participant responses for each scale. The three least common

coping mechanisms utilized by participants were Behavioral Disengagement, Denial, and

Substance usage. The three most common coping mechanisms utilized were Self-Blame,

Instrumental Support (a form of social support), and Acceptance. More than half of the

participants demonstrated a regular use of Religion, Humor, Self-Distraction, Planning, Positive

Reframing, Self-Blame, Instrumental Support, and Acceptance by scoring a 2 or higher in those

scales. Overall, more than half of coping mechanisms assessed were utilized by most participants

and more data is needed to better understand which strategies are most used among them.

Table 3.1. *The Brief COPE*

Coping Style	Mode	Mean	Median
Behavioral Disengagement	0	0.5	0
Denial	0	0.62	0
Substance	0	0.72	0
Emotional Support	1	1.5	1.5
Religion	0	1.51	1.75
Active Coping	1	1.51	1.5
Humor	2	1.58	2
Venting	1.5	1.65	1.5
Self-Distraction	2	1.67	2
Planning	2	1.77	2
Positive Reframing	1	1.82	2
Self-Blame	3	1.87	2
Instrumental Support	3	1.87	2
Acceptance	3	1.91	2

Table 3.2. *The Brief COPE*

Coping Style	"I haven't been doing this at all" (0)	(0.5)	"I have been doing this a little bit" (1)	(1.5)	"I have been doing this a moderate amount" (2)	(2.5)	"I've been doing this a lot" (3)
Behavioral Disengagement	73%	0%	12%	0%	8%	0%	8%
Denial	65%	0%	8%	12%	8%	0%	8%
Substance	58%	0%	8%	23%	4%	0%	8%
Emotional Support	4%	8%	31%	19%	27%	4%	8%
Religion	27%	8%	4%	12%	23%	0%	27%
Active Coping	0%	8%	38%	19%	23%	0%	12%
Humor	15%	8%	15%	8%	35%	0%	19%
Venting	12%	12%	4%	35%	12%	0%	27%
Self-Distraction	12%	4%	15%	15%	31%	8%	15%
Planning	8%	0%	23%	8%	42%	0%	19%
Positive Reframing	0%	4%	31%	12%	27%	4%	23%
Self-Blame	8%	4%	12%	23%	23%	0%	31%
Instrumental Support	8%	0%	23%	12%	27%	0%	31%
Acceptance	4%	0%	19%	19%	27%	4%	27%

Perceived Stress

All participants (n=27; 100%) completed the Perceived Stress Scale. Many participants (n=15; 55.56%) demonstrated moderate perceived stress. Around a quarter of participants (n=7; 25.93%) demonstrated high perceived stress and 5 (18.52%) participants demonstrated low levels of perceived stress. The mean for the participants demonstrating low perceived stress was 8.2 and the mean for participants demonstrating high perceived stress was 31. The mean for participants demonstrating moderate perceived stress was 19.4. The overall mean was 22.3,

falling on the higher end of the moderate perceived stress level category. In all three categories,

participants answered with a wide range of scores. In the moderate category the full range, 14-

26, was represented through the participants' answers. Both the low and high categories also

represented a broad range of answers. However, the lowest and highest possible scores were not

represented with the lowest reported score being 3 and the highest reported score being 35.

Table 4. *Perceived Stress Scale*

Perceived Stress Level	Frequency	Proportion	Range	Mean
High	7	25.93%	27-35	31
Moderate	15	55.56%	14-26	19.4
Low	5	18.52%	3-12	8.2

Scores ranging from 0-13 would be considered low stress.
Scores ranging from 14-26 would be considered moderate stress.
Scores ranging from 27-40 would be considered high perceived stress.

Semi-Structured Interview Responses

Throughout the semi-structured interviews regarding neurotypical sibling experiences,

participant responses highlighted 4 major themes: 1) caretaking across the lifespan, 2)

negotiating normalcy inside and outside the household, 3) parental transparency about sibling

diagnosis and 4) reframing the sibling experience.

Caretaking across the Lifespan. The support needs for siblings with IDD are vast given

the variety of diagnoses represented within the participant pool. For some, their sibling with IDD

can successfully live independently with the right supports in place. For others, their sibling

requires more full-time care resources. In both cases, siblings expressed some form of fear and/or

anxiety related to their sibilng's future care. One participant noted that even though her sibling

could live independently with the right supports in place, thinking about her sibling's future care

is scary "mainly because there's just very little information out there" to support individuals with

IDD transitioning into adulthood (participant 34). For many siblings, while fears and worries

were present, parental future planning, the current supports in place, and open communication

regarding future care left them feeling at ease for the time being. However, for siblings who don't have parents or caregivers planning ahead for the future care of their sibling with IDD, the stress is harder to move past. Interestingly, on multiple occasions, female participants noted that they were expected to take on more responsibilities regarding the future of their sibling with IDD in comparison to their neurotypical brothers.

For many participants the care of their sibling was a cause of familial strife. Many participants described instances where parents disagreed on what resources their child with IDD needed, causing feuds about their current and future care. One participant stated that "[her] mom was made to do it alone, everything alone" when speaking about the stress associated with how her father ignored her sibling's struggles associated with their diagnosis (participant 43). Additionally, many siblings noted that they began to disagree with their parents' plans for their sibling with IDD as they personally transitioned into adulthood, causing strife in their relationships with their parents.

Another notable aspect of caretaking across the lifespan comes down to adaptability and adjustment of environmental factors and schedules. Many participants spoke about their families adjusting their schedules by, for example, going to restaurants at less crowded times to ensure the environment was more accessible for their sibling (participant 10). Multiple participants also discussed having to adapt their personal schedules and participation in activities around their sibling and their responsibilities related to taking care of their sibling, especially during childhood and adolescence. One participant noted that they "couldn't do anything because everybody had to take care of [her] brother" (participant 7). However, instances like these appeared to vary based on the sibling with IDD level of independence. Families appeared to often adjust how and where they traveled based on the needs of their family member(s) with IDD

and the resources available. Multiple participants specifically listed airports, TSA screenings, and customs screenings as significant stressors for their families and siblings with IDD when navigating travel.

Negotiating Normalcy Inside and Outside the Household. One common statement by many participants was that they feared judgment from others when in public with their sibling with IDD. Even when participants described a positive relationship with their sibling, they identified struggles related to navigating how others viewed them in public spaces and fearing how people would respond if their sibling had a meltdown. Many appeared to feel guilty about feeling this way as they followed their explanation with something like "but that's more my problem, not really [theirs]" (participant 14). It appeared that navigating what was "normal" in their household vs what other people viewed as "normal" was a consistent struggle for many participants throughout their childhood and adolescent years. Some participants also wrestled with normalcy by feeling confused when their sibling would behave in ways that they were not allowed to and did not receive a punishment. For example, one participant noted that their brother would "run around the house making noises and flapping or clapping his arms… so [she] was confused when [she] was in trouble for doing a cartwheel in the house" (participant 41).

Parental Transparency About Sibling Diagnosis. About half of the interviewed participants could not recall a specific moment when they were told about their sibling's diagnosis. However, they do recall knowing that their sibling was unique and had different needs throughout their childhood. Some even stated that their parents were "a little less focused on [them] per se", but they were not necessarily concerned by this because they understood that their sibling had different needs and sometimes those required more attention to be met (participant 14). However, in the instances where participants coped with this imbalance of

parental attention in an understanding manner, there was always an open dialogue between the participant and their parent(s) about their sibling's needs and diagnosis. For one participant, even though the diagnosis was not fully communicated by their parents, they recall conversations related to their sibling needing a little more support and attention during which their parents assured them that "it [was] not because we don't love you as much" (participant 41).

In contrast, the other half of interviewed participants never received an explanation about their sibling's diagnosis and there was little communication about why their sibling behaved differently or received different treatment than they did. In these instances, participants reported feeling like "it was all my fault… I am the problem" and/or learning about their sibling's IDD because "all my friends and people in our class called him weird" (participant 43, participant 47). While these siblings have more holistic and matured understandings of their siblings now, they more frequently reported "wish[ing they] had a 'normal' older brother… like on Disney channel TV shows" (participant 33). Based on these reflections, it appears that open communication about an individual's IDD and their needs significantly impacted how a neurotypical sibling internalized and coped with navigating life with a sibling with IDD.

Reframing the Sibling Experience. Building on this, many siblings expressed that they, at one point in time, thought about what their life would be like if they did not have a sibling with IDD, but few said it was something they ever actually wished for. The experience of thinking about what life would be like if their sibling was neurotypical appeared to be more common when the participant and sibling with IDD were close in age. For example, one participant with a sibling a year younger than them expressed being "always kind of disappointed" thinking about how their sibling "was old enough to experience everything [they] were] experiencing" (participant 30). Watching their peers' siblings do so, increased this feeling

of disappointment at times, yet participants generally maintained a sentiment of gratitude for their sibling even when discussing this.

Many participants noted that their field of work was influenced by their love for their sibling and their impact on their lives. The majority of interviewed participants expressed that they worked in healthcare fields or in spaces that were passionate about supporting individuals with IDD. One participant noted that they work in healthcare and find that the tangible impacts they have on people at work feels like a coping mechanism for them. They noted that they see many other siblings of individuals with IDD "go into care fields like healthcare or other types of care centered areas of work" (participant 7).

Almost all participants stated that their sibling with IDD broadened their perspective on life and the world, increased their levels of empathy for others, and made them have more respect, care, and concern for others. Participants also often communicated their gratitude for their sibling and frustration with other people who have the perspective that it is a negative thing. In conversation about this, one participant stated "I don't wish everyone had a disabled sister, but I wish people could step into my shoes and see how beautiful their lives are, and how much they teach you. It is really incredible" (participant 48). Another said "as much as I feel like some people view it as a negative thing that makes your life harder… when I think about it as a whole, I think about it as a positive experience way over a negative one" when discussing her takeaways from her relationship with her sibling (participant 14). Overall, almost every interviewed participant expressed gratitude for their sibling and listed positive impacts they have had on them and their life.

Table 5. *Participant Experiences and Stressors by Theme*

Theme 1: Caretaking Across the Lifespan
"It does make me a bit anxious, especially when I think about how my parents are getting older" (participant 47)
"I feel really obligated to take care of him. I realized that not a lot of my friends have that" (participant 7)
"I took care of myself and [my mom] took care of my brother... I definitely felt like there was never really a time I could just be myself" (participant 7)
"[Taking care of my sibling] requires a lot of mental stability... it has a lot of demands emotionally and even physically" (participant 26)
"I do plan on being his full-time caretaker [in the future]" (participant 30)
"I'm a bit worried [about his future care]... I'm also worried for his well-being" (participant 43)
"I don't think it's something my whole family has come together to talk about" (participant 41)
Theme 2: Negotiating Normalcy Inside and Outside the Household
"I don't think I noticed anything was wrong until other people would tell me" (participant 33)
"I only had one sibling, so I never knew any different" (participant 48)
"You see that your lifestyle is maybe different from theirs because they do not have a lot of commitment like you do" (participant 26)
"There was this sense of dreading people judging us" (participant 10)
"It was weird that my friends did not seem to care about their siblings... they're not so intertwined" (participant 34)
"I felt like I needed to give people a warning if they came to my home... [but] he was my only reference to normalness, so I didn't understand what was abnormal" (participant 30)
Theme 3: Parental Transparency About Sibling Diagnosis
"[they] actually never explained it to me" (participant 33)
"I wondered 'why do you love her more than me'" (participant 51)
"I had to be an advocate for myself more, and kind of more independent" (participant 14)
"I saw that the teachers were with her more so I kind of realized that she had an intellectual disability" (participant 14)
"I was confused a little bit because I didn't understand why he did those things" (participant 41)
"I thought it was literally my fault... I am the problem" (participant 43)
Theme 4: Reframing the Sibling Experience
"He had a positive impact on my family... he always makes us laugh" (participant 47)
"I tend to be more affectionate when I say things compared to my peers" (participant 50)
"One thing I've learned from having a sister with downs syndrome and cerebral palsy is how to love everybody, no matter what they have gone through" (participant 48)
"I think it has made me a more patient person and more kind as well" (participant 51)
"It has made us more compassionate people, people who notice when other people need things" (participant 10)
"I do a good job of balancing professionalism and being warm and I think that's because of [my brother]" (participant 10)
"My exposure to disability has made me a much more accepting and empathetic person" (participant 34)

Integrated Results

Throughout participant interviews, it was clear that many participants used positive reframing as an approach to their relationship with their sibling. When comparing their sibling with IDD to a peer's neurotypical sibling, multiple participants expressed being grateful for their sibling rather than jealous of their peers'. Similarly, one participant noted that seeing their sibling navigate challenges "gives [them] the belief that I can get through anything, any hard times" (participant 48). However, this creates a slight discrepancy with the qualitative data where positive reframing fell more in the middle of most utilized coping mechanisms. Additionally, cognitive coping resources did not appear to be utilized by participants very often within the quantitative data.

Similar to the moderate stress levels reported in the PSS, many participants listed aspects of their lived experience with a sibling with IDD that were a source of stress at times. The qualitative data offers more clarity on the cause of this stress and how it changes throughout the lifespan. Specifically, participants report stress that depends on factors such as the independence level of their sibling with IDD, whether the participant lives with the sibling, and how future care for the sibling is being planned, or not planned, in relation to them.

In congruence with the quantitative data, many interviewed participants highlighted the importance of community support when caring for their sibling with IDD. One participant stated that "even if there are places that have better resources for [my sibling's] physical or developmental disability it's hard to get those things accomplished if you don't have a support system… the support system matters more" (participant 7). The qualitative data also highlighted the importance of social resources and support systems as the Brief COPE demonstrated

instrumental support as a common coping mechanism and the CRI noted social coping resources as the second most utilized coping resource.

Discussion

The purpose of this descriptive, mixed-methods study was to explore the coping mechanisms and stressors of adult siblings of individuals with intellectual and/or developmental disabilities. Researchers approached the topic by exploring what coping mechanisms and coping resources are most utilized by adult siblings of individuals with intellectual and/or developmental disabilities. Researchers also explored what associations may exist between sociodemographic factors and coping within this population. Finally, researchers aimed to better understand how adult siblings of individuals with IDD perceive the impact of their siblings' diagnosis throughout their lifetime. Thinking about the limited research on this topic, the implications of the results are impactful as it is one of the few research studies looking specifically at the stressors, coping mechanisms, and experiences of siblings with IDD. In turn, the results provide new avenues for supporting parents and siblings of individuals with IDD.

Responses to the Coping Resources Inventory demonstrated that 75% (n= 18) of participants primarily utilized Emotional coping resources. Additionally, 75% (n=18) of participants demonstrated that Social resources were their second most prominent utilized coping resources. Building on this, the Brief COPE identified that Self-Blame, Instrumental Support, and Acceptance were the most common coping mechanisms utilized by this sample, while Behavioral Disengagement, Denial, and Substance Usage were the least common. Based on the common use of Emotional and Social coping resources, as well as the use of Instrumental Support and Acceptance coping mechanisms, social supports appear to play a prominent role in the coping strategies of siblings of individuals with IDD. This is congruent with the qualitative

data from participant interviews as many spoke to the importance of social support when navigating caring for their sibling.

Responses to the Perceived Stress Scale highlighted that the majority of siblings of individuals with IDD demonstrate moderate levels of perceived stress. Although this study did not compare these results to those of individuals without siblings with IDD, the moderate levels of perceived stress appear to align with previous research regarding increased levels of stress in family members of individuals with IDD (Marquis et al., 2020; Leedham et al., 2022). Qualitative data shed light on what these stressors are and how they change over time, which suggests that things such as increased communication with children about their sibling with IDD, future planning for sibling's care, and skills for navigating familial strife could mitigate the impact of these stressors for siblings.

In 2006 Ross & Cuskelly examined the coping mechanisms utilized by children and adolescent siblings of individuals with IDD and identified wishful thinking and emotional regulation as the most common coping strategies utilized by their participants. These findings correlate with the common use of Emotional coping resources identified by the CRI in the present study, which could suggest a connection between common coping mechanisms used in childhood/adolescence and the coping resources utilized in adulthood. Ross & Cuskelly (2006) also found that the coping mechanisms of self-criticism and blaming others were utilized the least, which contrasts with the present study's finding that Self-Blame was a common coping mechanism utilized by adult siblings. However, based on qualitative data, it is unclear what situational variables impact the use of self-blame among neurotypical siblings, such as parental transparency about the sibling diagnosis. Future research should seek to expand upon this by

examining which specific factors have significant impacts as well as how different factors influence the coping mechanisms utilized by this population.

Although not sibling focused, Glidden et al. (2006) explored parental coping strategies and concluded that parents reported utilizing Planful Problem-Solving coping strategies the most and Escape-Avoidance coping strategies the least. Similarly, the siblings of individuals with IDD in the present study did not appear to utilize denial or behavioral disengagement coping strategies, which supports data that suggests parental influence on siblings (Glidden et al. 2006; Shivers and Dykens, 2017). Based on qualitative data, it appears that parental transparency about a diagnosis with neurotypical siblings influences the coping strategies utilized by siblings as well as how they internalize their emotions.

It is possible that many parents are not aware of how impactful conversations with their neurotypical children can be regarding their child with IDD's diagnosis and needs. Supporting parents by making them more aware of these impacts could yield many positive outcomes for siblings of individuals with IDD. Additionally, many parents may not be aware of how challenging navigating normalcy in the household can be in comparison to normalcy in public and other households. Preparing families for negotiations with normalcy in different settings could help them better navigate stressful situations and support each other. Future research should address both the impact of open communication and transparency with neurotypical siblings as well as the negotiation of normalcy to better understand what intervention strategies can be implemented to support families.

Despite many useful implications, the present study has several limitations. For one, although the sample size was like that of other sibling studies, the small sample size limits the generalizability of the data at large. In addition, the sample was largely female, white, unmarried,

and in the 18-29 age range, which limits the generalizability of the results to the larger

population. In an effort to keep the survey brief, a few potentially important factors and

information were eliminated. For example, researchers chose to use the Brief COPE inventory

rather than the original, much longer COPE inventory due to its shortened length.

Socioeconomic status information was also not collected for participants, which could have been

insightful, especially when considering participant anxiety surrounding long-term housing and

lifestyle plans for the individuals with IDD. Finally, by allowing participants to qualify

regardless of their sibling's specific diagnosis, the results encapsulate a variety of IDD. Although

this has its benefits as it creates a better understanding of a variety of experiences, it also has its

limitations as it is difficult to assert how different diagnoses differently impact the coping

strategies, stressors, and family dynamics.

Conclusions

Having a sibling with an intellectual and or developmental disability comes with a variety

of unique lived experiences. From caretaking responsibilities to unique stressors and increased

life perspectives, this population faces challenges and experiences unique to their relationship

with their sibling. Common stressors include caring for their sibling across the lifespan,

negotiating normalcy inside and outside the household, and parental transparency about sibling

diagnosis. Participants in this study highlighted Self-Blame, Instrumental Support, and

Acceptance as utilized coping mechanisms, with Emotional and Social coping resources most

often used by this population. Additionally, many siblings reported gratitude for their sibling and

all they have learned from them. Thus, healthcare providers, teachers, and other professionals

can better support siblings by recognizing the negotiation of normalcy that siblings experience

and supporting them through their navigation of the variety of "normals" in which they live.

Finally, future research can further explore the implications of siblings utilizing specific coping

strategies as well as the factors that influence which strategies are utilized in order to continue

building resources and interventions to better support siblings and their families.

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